ECONOMIST IMPACT

Advancing breast cancer care in Europe: a roadmap to a women-centric approach

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Contents

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About the report

Advancing breast cancer care in Europe: a roadmap to a women-centric approach is an Economist Impact report sponsored by Daiichi-Sankyo Europe. The report examines the state of breast cancer care for women across Europe and emphasises the need for a more women-centric approach. Although the focus of the report is women with breast cancer—99% of breast cancer cases occur in women—it acknowledges that a small proportion of men and transgender individuals are also affected by the disease.

The roadmap aims to define what truly constitutes women-centric breast cancer care, while identifying the challenges and opportunities for improving care in Europe through effective healthcare policy. **Our assessment of women-centricity in breast cancer care is largely informed by insights from over 75 multi-disciplinary experts, the majority of whom are women, including those with lived experience of breast cancer.** Qualitative insights were gathered through a series of interviews and roundtable discussions conducted in Brussels, France, Germany, Italy, Spain and the UK between May and December 2024.

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Executive summary

Women with breast cancer are now living longer than ever, with over 5.5m survivors across Europe. Despite this progress, women—the primary demographic affected by this disease—continue to face numerous challenges that impact their quality of life both during and after care. The needs and preferences of women with breast cancer, whether in the early or advanced stages of the disease, are often overlooked in both policy and practice. And when women with breast cancer do express their unmet needs, they often feel unheard by healthcare providers.

Enhancing the focus on women-centric care is essential, necessitating a deeper understanding of each woman's physical, emotional and cognitive needs and personal motivations. This approach allows care to be tailored to each woman's evolving life goals as they navigate the disease. However, a clear European roadmap for achieving this more personalised approach to breast cancer care is still lacking.

This report examines the state of women-centric breast cancer care across the five most populous European countries: Germany, France, Italy, Spain and the UK. The key findings from our research are as follows:

- **Significant disparities in access to breast cancer care persist, creating barriers for women across Europe.** Access to breast cancer care is influenced by geographical, ethnic, socioeconomic and age-related factors. Screening guidelines and coverage rates differ across countries. Current practices do not fully address changing demographics, with increasing cases among younger women and a need for more research on managing breast cancer in the ageing population.

- **Survivorship concerns of women are inadequately addressed in both early and advanced stages of the disease.** Women with breast cancer face a range of physical, emotional, financial and work-related challenges from diagnosis onwards, with these issues often intensified for those with metastatic disease. Support in these areas is essential but frequently difficult to access. Sexual and reproductive health needs, including fertility preservation, are often overlooked owing to inconsistent coverage and limited provider knowledge. Meanwhile, psychological support for anxiety and depression is lacking, leaving many women struggling to manage personal and family responsibilities without adequate resources or awareness of available support.
- **The policy landscape for women-centred breast cancer care is progressing, yet significant challenges remain in putting these policies into practice.** Europe's Beating Cancer Plan (EBCP), an EU initiative, emphasises the need for survivorship care and quality of life improvements, along with a cancer inequalities registry to address care disparities. Many countries are now developing national cancer control plans that include a focus on women-centred care, but implementation varies widely across and within countries. For example, breast centres have improved the quality of women-centred care, yet access remains inconsistent, especially in rural areas.
- **Improved public health messaging and better resource allocation are needed to strengthen prevention efforts.** Primary prevention efforts for breast cancer are often insufficient, with limited focus on improving health literacy among women. Modifiable risk factors, such as alcohol use, obesity and inactivity, contribute to about 38% of breast cancers in postmenopausal women, and lifestyle-based strategies could reduce this risk by up to 60%.[1,2] Only 25% of European cancer prevention funders focus on primary prevention, even though such initiatives have the potential to lower overall cancer incidence. By comparison, 52% of funders focus on secondary prevention, such as early detection and screening, while 47% support research into cancer causes.[3]

Economist Impact's assessment of women-centricity in breast cancer care is largely informed by insights from over 75 multi-disciplinary experts, the majority of whom are women, including those with lived experience of breast cancer. Based on these insights and published evidence, we propose a roadmap, validated by our steering committee, to advance the implementation of women-centric breast cancer care in Europe. This roadmap highlights opportunities for improvement at various stages of the care pathway and aims to transform breast cancer care from a survival-focused approach to one that empowers women to thrive. Additionally, this model can serve as a prototype for implementing quality-of-life improvements in other types of cancer care.

To successfully develop and implement this roadmap, we identified the following key actions:

- Adopt a universally recognised definition of women-centric breast cancer care.
- Co-create women-centric solutions for breast cancer care.
- Develop a women-centric care toolkit to help healthcare professionals.
- Invest in high-quality data collection and research cost-effectiveness of the women-centric care model.

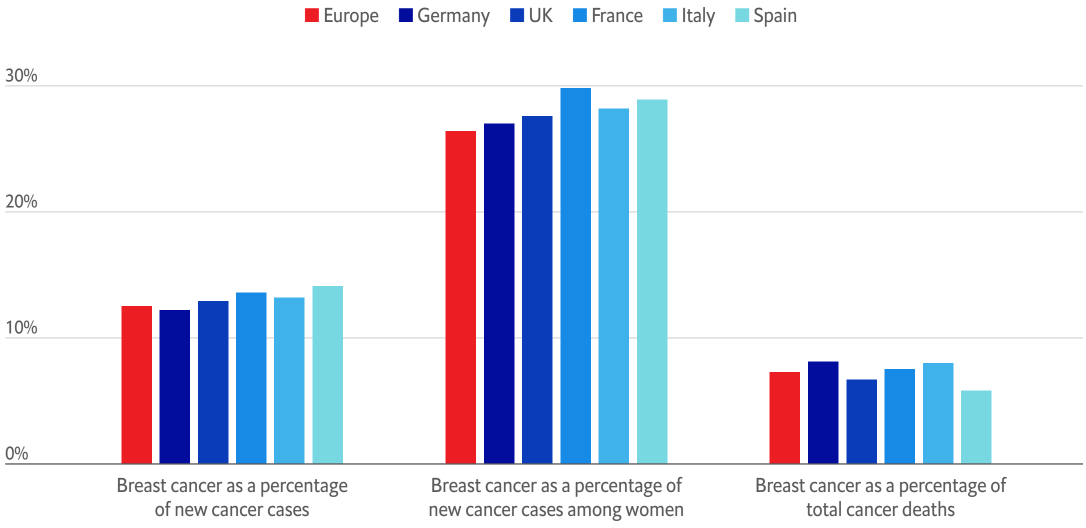
Introduction

Breast cancer is a defining global health challenge, and the toll of the disease weighs heavily on women, societies and economies alike. In Europe, breast cancer is the most prevalent cancer, representing 12.5% of all new cancers and 26.4% of new cancers diagnosed in women (Figure 1).[4] Of all cancers, breast cancer bears the most significant economic costs, accounting for €15bn (US$15.8bn), of which half is attributed to healthcare costs, highlighting the need for robust intervention.[5]

However, the situation is not all doom and gloom for women with breast cancer. As a result of the remarkable advancements in science and medicine, high-quality breast cancer care has led to better survival rates.[12] Europe alone saw a 23.1% reduction in the age-standardised death rate between 1990 and 2019.[13] In 2020, almost 5.5m women in Europe were estimated to be survivors of breast cancer, accounting for a quarter of all cancer survivors across the continent.[14]

Figure 1. Breast cancer incidence and mortality rates in Europe in 2022[6,7,8,9,10,11]

A comparison of breast cancer incidence as a percentage of total incident cancers or women's cancers and mortality as a percentage of total cancers in Europe and EU-4 + UK



> **“Survivorship care not only encompasses medical care, but also includes quality of life concerns including work, social and individual life projects of survivors.”**
>
> Andrés Cervantes, Former President, European Society for Medical Oncology

Although it is encouraging to see that women with breast cancer are now living longer than ever, this does not always equate to a good quality of life, as survivorship and supportive care for women with metastatic breast cancer are often underserved areas on the pathway. “Survivorship care not only encompasses medical care, but also includes quality of life concerns including work, social and individual life projects of survivors,” explains Andrés Cervantes, former president of the European Society for Medical Oncology.

Women can face several challenges as a result of living with breast cancer, including financial hardship, body image issues, and sexual and fertility problems, which can in turn lead to poorer psychosocial outcomes.[15,16] Addressing the challenges of survivorship and improving overall health and wellbeing is now an urgent priority and requires a women-centric approach that considers the needs and preferences of women of all ages and employs a good understanding of their socioeconomic and cultural background.[17,18]

The concept of women-centred cancer care is often used interchangeably with person-centred care, though interpretations vary. Both approaches prioritise considering the individual’s or woman’s unique circumstances and preferences in care. However, women-centred care specifically focuses on addressing the distinct needs and experiences of women in the context of cancer care, including physical, emotional and cognitive requirements and motivations. Although there is no clear definition of women-centric care, various working definitions have been proposed for cancer in general. For instance, the FemTechnology Summit, which focuses on innovations in women’s health, states that “women-centric cancer care improves the lives and health experiences of all women, regardless of where they live, by empowering them to make informed decisions and providing them with evidence-based prevention and integrated health care that is innovative, accessible, affordable, equitable, tailored and holistically delivered.”[19]

Economist Impact consulted with a range of multi-disciplinary experts to gather their insights on the importance of women-centred breast cancer care:

“I believe that our healthcare system primarily aims to treat the diseases patients have. Comprehensive patient care often falls short, such as in providing holistic support that includes not just medical treatments from oncologists and surgeons but also additional services like physical fitness programmes, nutritional guidance and physiotherapy support, which are not as commonly available.”
Eva Carrasco, CEO and scientific director, GEICAM, Spanish Breast Cancer Group (Spain)

“I think empowering women with breast cancer to be more involved and really listening to them, rather than making assumptions on what they would say through the proxy of oncologists is key. Oncologists and researchers have their expertise, but sometimes when you talk to patient advocates and patients themselves, they have a different perspective, and they can help us prioritise.”
Virginie Adam, Scientific Director, Breast International Group (Belgium)

“There’s a clear need for more women-centric, holistic care based not just on the tumour but also on other health conditions.”
Nicolò Battisti, Consultant Medical Oncologist, The Royal Marsden NHS Foundation Trust, Department of Medicine, Breast Unit (UK)

“It is very important to provide a good comprehensive framework for women so they don’t actually have to [explain] things unless they want to—rather the [healthcare] centre just takes care of things for them, including the necessary appointments. This is hugely important, because they can be completely lost and they can’t always rely on the support of family and loved ones and friends. Many women work—and with the elderly, it is usually not the husbands who take care of the wife.”
Birgit Carly, National Representative, Europa Donna Belgium (Belgium)

“They are not just women; they are mothers, they are wives, they are daughters. When a woman falls ill, the mother falls ill, and the whole family structure is shaken up.”
Kerstin Paradies, Chairwoman, Nursing Working Group of the KUK Conference of Oncological Nurses and Paediatric Nurses (UK)

“It is important to consider this from a social-health [perspective], not just [as] a medical problem. Women need support, they deserve it, and if we are able to give them this it is a social advantage, because fewer problems are generated, fewer years of absence from work, for them and for their caregivers. If we organise things in a way that makes their life easier, we will have a social advantage.”
Michelino De Laurentiis, Chief of the Breast Oncology Division at the National Cancer Institute “Fondazione Pascale” (Italy)

“What is special about women with breast cancer? Women are also very strongly involved in their careers, family planning and the like, and affected in these fields. Therefore, when we talk about unmet needs, we need a support system which has a very strong focus on the patient itself. And we need to take the social environment very much into account. If I have breast cancer and I’m the mother of two children, then of course the question arises as to how I can still fulfil my role as a mother. But also, how do my children deal with this diagnosis? How do I communicate this with them?”
Ingo Neupert, Professor, RheinMain University of Applied Sciences (Germany)

Based on the insights of our research and validation by our steering committee, we have devised a working definition of women-centric care in breast cancer:

Working definition: Women-centric breast cancer care addresses the unique preferences, needs, challenges, and experiences of women with breast cancer, providing personalised and holistic support throughout their breast cancer journey and beyond. The aim of women-centric breast cancer care is to improve clinical outcomes, overall experience, and quality of life for women with breast cancer, while empowering them to maintain their vital roles in society.

At the policy level, there have been promising developments, including women-/person-centricity in cancer control at the global level with multi-stakeholder organisations such as the Advanced Breast Cancer (ABC) Global Alliance developing a global charter in 2015, which highlights the need to prioritise multidisciplinary care and quality of life among patients with advanced breast cancer. The alliance advocates for better patient engagement in the co-creation of quality-of-life measurement tools for more women-centric cancer care metrics, another overlooked area in care.[20] "Social sciences should also focus on finding tools or methods of use that can be simplified, better validated and more useful to employ, because Quality of life measurement is an area where we are still not 100%," says Dr Cervantes.

> **"The literature and best practices have not clearly articulated what women-centric care looks like for someone with breast cancer. While the healthcare community has aimed to provide such care in cancer services for decades, without a concrete framework, the concept remains largely aspirational."**
>
> Susanne Cruickshank, Strategic Lead for Applied Health Research, Royal Marsden NHS Foundation

Momentum has also picked up in Europe with Europe's Beating Cancer Plan (EBCP), presented by the European Commission in 2021. The plan provides an overarching strategic vision to turn the tide against cancer by addressing the entire disease pathway and four key action areas: prevention, early detection, diagnosis and treatment, and quality of life of patients and survivors. The plan aims to reduce disparities in care across countries. The EBCP is the first political commitment of the EU in tackling cancer while prioritising the underserved areas of survivorship and quality of life.[21] Following the launch of the EBCP, many European countries (Germany and France, for example) are either developing or have developed national cancer control plans. However, implementation has been a key challenge, particularly when taking into account a women-centric approach in the context of breast cancer care. In part, this is due to the lack of a clear definition and implementation plan.

"The literature and best practices have not clearly articulated what women-centric care looks like for someone with breast cancer," says Susanne Cruickshank, strategic lead for applied health research at the Royal Marsden NHS Foundation. "While the healthcare community has aimed to provide such care in cancer services for decades, without a concrete framework the concept remains largely aspirational."

The World Health Organisation (WHO) Global Breast Cancer Initiative, established in 2021, mobilises stakeholders globally and across sectors towards a shared goal of reducing breast cancer mortality by 2.5% per year, and its framework highlights the need to standardise patient-centred care metrics.[22] These include patient-reported outcome measures (PROM) and patient-reported experience measures (PREM) regarding access to care for women with breast cancer, including those with metastatic disease.[23] Defining and implementing women-centric breast cancer care can help to develop the necessary infrastructure and training, while also serving as a model for applying similar approaches to less-common cancers.

Unmet needs and challenges in delivering breast cancer care

Women with breast cancer face major challenges throughout their care journey, which negatively impact their health and quality of life. Many of these challenges often begin before the disease is diagnosed. Further, disparities in care continue to persist, with many women facing unequal access to quality breast cancer care based on where they live. Referring to the UK, Dr Battisti, consultant medical oncologist at The Royal Marsden Breast Unit, explains: "Unfortunately, when it comes to breast cancer, there is sometimes what we call a 'postcode lottery'... where the availability of services for breast cancer can vary significantly depending on geographic location … this applies to various aspects of care, including access to screening, early diagnosis, local and systemic treatment, multidisciplinary care, research, survivorship care, palliative care and specialist nurse support."

Experts highlight that barriers to women-centric breast cancer care arise from disparities in both access and quality of care. These issues can affect women's overall engagement with breast cancer services and thus lead to poorer health outcomes. The following section outlines the key barriers and challenges to women-centric care across the main pillars of the breast cancer care pathway.

Primary prevention

Many women are not well informed about breast cancer risk factors, a key driver of high incidence rates.[24] "There is no specific prevention plan

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> Nicolò Matteo Luca Battisti, Consultant Medical Oncologist, The Royal Marsden NHS Foundation Trust, Department of Medicine, Breast Unit

for breast cancer," says Emilio Alba, head of the department of medical oncology at the Virgen de la Victoria University Hospital and professor of oncology at the University of Malaga. "You can only really influence two issues, which are being overweight and alcohol consumption. But at an educational level, institutions do not send clear messages about this."

Primary prevention efforts are often inadequate, and there is a lack of emphasis on improving health literacy among women.[25,26] Modifiable risk factors play an important role in the development of breast cancer—for instance, about 38% of breast cancers among postmenopausal women are related to alcohol consumption, obesity and physical inactivity; adherence to lifestyle-based preventive strategies can reduce this risk by up to 60%.[27,28] Furthermore, primary prevention is the least funded area in preventive cancer research in Europe, with only 25% of prevention research funders focusing on primary prevention, compared with 52% for secondary prevention and 47% for causal research.[29]

"In terms of prevention, we are still far from truly preventing [breast cancer] because we clearly see that the incidence continues to rise, particularly among young women in Spain," says Eva Carrasco, CEO and scientific director of GEICAM, the Spanish Breast Cancer Research Group. "In my view, we completely fail in this area. We have not managed to reduce the incidence of breast cancer, and with the knowledge we now possess, we should really start thinking about this reduction."

Italian experts highlight the lack of public health campaigns promoting a healthy lifestyle or discouraging harmful alcohol consumption. "I have never seen a campaign that says that alcohol is a risk factor for breast cancer," says Giampaolo Bianchini, associate professor at the Vita-Salute San Raffael University and head of

> **"As a part of broad civic education, citizens should be taught the importance of prevention and that they are co-responsible, not only for their personal health but for the administration of health resources for everyone."**
>
> Natacha Bolaños, independent expert and Member of the ESMO Patient Advocacy Working Group

breast oncology at the San Raffaele Scientific Institute. “Physical activity reduces the risk of many tumours, including breast cancer, but again, I have never seen a massive, heavy campaign.” Experts also point out an increasingly conflictual relationship between the public and the government, which has driven governmental reluctance to impose directives, resulting in missed opportunities for prevention. “It’s really difficult [to influence] behaviour change, and we need to be focusing on talking to individuals as individuals, not just blanket health messages at a top-down level,” says Simon Vincent, director of research, support and influencing at Breast Cancer Now. “Doctors should be discussing the risks and saying, look, if you carry on like this, then this could happen to you.”

The lack of focus on prevention has led to reduced public awareness of modifiable risk factors for breast cancer. A cross-sectional survey spanning a 14-year period found that awareness of hormone replacement therapy (HRT) as a breast cancer risk factor significantly increased from 36% to 57% among German women, whereas awareness of other reproductive risk factors like age at childbirth (24% to 15%), lack of breastfeeding (37% to 23%) and childlessness (32% to 18%), all decreased within the same timeframe.[30] In this instance, it is likely that the increased awareness of HRT as a breast cancer risk factor was influenced by strong media coverage of the topic: for current HRT users and those who stopped one to four years ago, the risk of being diagnosed with breast cancer increased by 1.023 times for each year of use, reaching 1.35 times higher for women who had used HRT for five years or more.[31]

“As a part of broad civic education, citizens should be taught the importance of prevention and that they are co-responsible, not only for their personal health but for the administration of health resources for everyone,” says Natacha Bolaños, who contributed to this report as an independent expert.

Screening

Although screening guidelines for breast cancer are well-established, national recommendations differ, leading to disparities in coverage within and between European countries (Table 1). The European Commission Initiative on Breast Cancer (ECIBC) recommends organised mammographic screening for women aged 45 to 74 years with an average risk of breast cancer; however, the frequency of screening varies according to age.[32] For instance, triennial or biennial mammography is offered to women aged 45 to 49 years and 70 to 74 years, whereas biennial screening is offered to women aged 50 to 69 years.

The demographic of the disease is changing, as younger women (typically defined as those under 40) are more likely to have aggressive forms of the disease and face higher risks of recurrence at five and ten years post-therapy compared with women over 40.[33] However, current screening eligibility across many European countries excludes this group, as well as other groups that may be more at risk, such as women older than 70 years, preventing early diagnosis.[34] Experts describe how younger women are being diagnosed with breast cancer before they reach the age for screening and patients older than 70 years are not being invited to screening even though they may live 15 years longer.

"Currently, 30-40% of breast cancer patients are over the age of 65, and 70% of breast cancer mortality occurs in this age group," says Dr Battisti. "Unfortunately, we still lack a comprehensive nationwide initiative [in the UK] to address the needs of this very complex patient population. It is important for healthcare systems to discuss what can be done at the policy level to prepare for the 'silver tsunami'."

The Age X trial in the UK is one ongoing study evaluating the benefit of offering an additional screening opportunity to women in the 47-49 and 71-73 age groups, but efforts are few, especially when it comes to other forms of risk-based screening.[35] "There are studies underway focused on stratifying the recommendation according to the risk, but this seems to me to still be very preliminary, and I don't know of any country that really recommends it," says Josep Maria Borràs, director of the Catalan Cancer Strategy. "Everyone is discussing how it can be done, but it does seem that we are still in a situation rather in the field of research than in the field of public policy."

Risk-based screening, though highly effective, is still in its infancy across Europe. "What you'd really like to be able to do is have a screening programme which is much more stratified based on the individual risk that a woman is likely to get breast cancer," says Dr Vincent. "That risk might be due to family history, it might be due to a particular panel of genetic markers, it might be due to lifestyle issues. And the higher the risk, the more frequently you should get a mammogram." However, experts also urge that before pursuing policy efforts to focus on expanding implementation of different models for risk-based screening, it may be more important to increase general coverage rates, reach underserved groups and be more inclusive within the scope of the free screening programmes.

Of the five European countries of focus in this report, France's national screening programme is most aligned with the recommendations of the ECIBC, as it offers biennial screening to a broader age range of women at risk. Conversely, in Italy's decentralised healthcare system, screening eligibility varies by region, with some regions offering screening to women aged 45-74 years and others to women aged 50-69 years.[45]

Table 1. Mammogram screening guidelines by country[36,37,38,39,40,41,42,43,44]

Country	Mammogram screening guidelines
France	Biennial mammograms for women aged 50 and 74 years
Germany	Biennial mammograms for women aged 50 to 69 years
Italy	Varies by region, biennial mammograms for women aged 45 to 74 or 50 to 69 years
Spain	Biennial mammograms for women aged 50 to 69 years
UK	Triennial mammograms for women aged 50 to 71 years

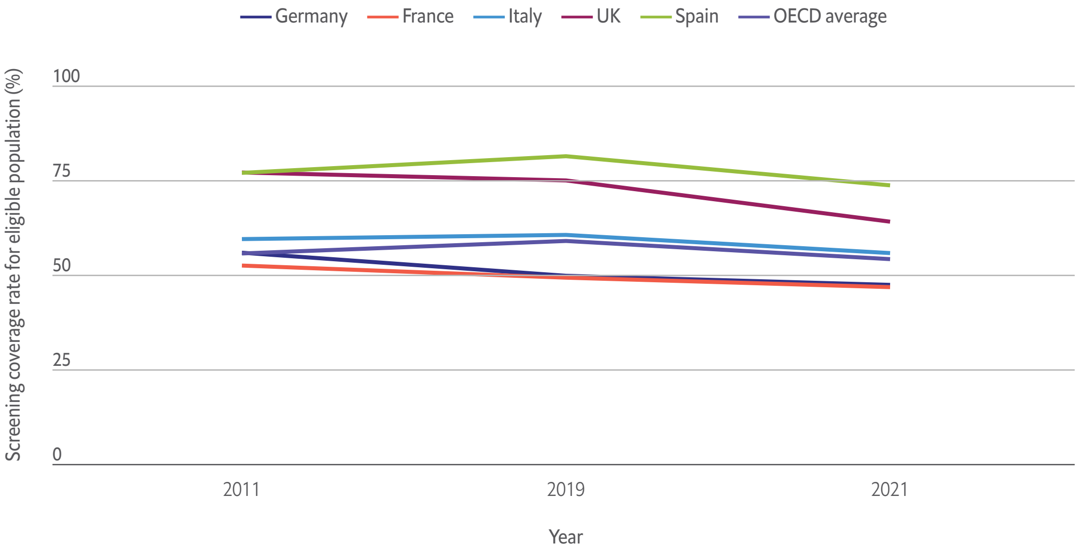
> **“There’s always room for improvement, because there are always patients who don’t go for screening. But in principle, I think breast cancer screening in Spain is a success story.”**
>
> Eva Carrasco, CEO and Scientific Director, GEICAM, Spanish Breast Cancer Research Group

European guidelines recommend a minimum of 70-75% participation rate in screening programmes for effective coverage.[46] Of the countries of focus, Spain is performing better with respect to this recommendation, although all countries have seen a slight decrease in screening coverage since 2011 (see Figure 2). “There’s always room for improvement, because there are always patients who don’t go for screening,” says Dr Carrasco. “But in principle, I think breast cancer screening in Spain is a success story.” One aspect that may be driving greater participation in mammogram screening is the provision of pre-scheduled appointments.[47]

The methods used to invite women to attend screenings greatly affect participation rates, and these methods are not always aligned with recommended practices for effective organised screening. The WHO’s guide to screening programmes suggests that individual invitations are generally more effective than open public invitations, such as mass-media campaigns; other strategies that have been shown to increase participation include telephone reminders and endorsement by primary care doctors.[48]

“It’s 2024, and women are still invited to do mammography screenings through a letter that arrives by post”, says Ylenia Zambito, a senator representing Italy’s Democratic Party. “We should find a more direct way that somehow increases patient engagement. This could include embracing new technologies, along with greater involvement of doctors in general practice.” Experts in our London workshop cautioned about exacerbating the digital divide, a concern that has persisted since the UK began using online services for booking mammogram screenings. In addition, they noted that mammogram screening can exclude certain vulnerable populations who may not be registered with a general practitioner. In France, experts note a regional disparity in that the north of the country has significantly lower screening rates than the rest of the country, resulting in inequities among women. Similarly, inequities are widespread across Italy, where experts note the huge divide between the north

Figure 2. Breast cancer screening coverage rate in Europe (2011 to 2021)[49]



and south of the country, with northern Italy having better screening coverage compared to the rest of the country.

A German study assessing non-attendance in a national mammography screening programme found that among 1,494 women, more than half reported non-attendance due to participation in various private breast cancer prevention and screening programmes that exist outside of the national screening programme.[50] Although the reasons behind the preference for private screening were not explored in this study, possible explanations could be convenient scheduling of appointments, reduced waiting times, better facilities, comfort and high rates of private insurance coverage.

“In Paris, we can have a waiting time that can be less than a week, about a week,” says Myriam Delomenie, a surgical oncologist at the American Hospital of Paris. “If we go outside Paris, I have patients who are in the provinces who can have waiting times of up to three months just to have a mammogram, and then another month to have a biopsy, and then several more months to see a specialist.”

These findings feed into other expert observations that socioeconomic determinants play a significant role in breast cancer outcomes, in that more affluent individuals are more likely to attend screenings, while those from lower-income groups face greater barriers to access. “There is still room for improvement on increasing participation from all of the targeted population,” says Pia Cox, executive director of All.Can Belgium. “When you look at underrepresented populations, for example—either those who are socioeconomically underserved or people from different cultures or ethnicities—there’s still room for improvement to get these people participating in screening initiatives.”

Spain’s breast screening strategy

Spain has made concerted efforts to increase breast cancer screening coverage across the country over the past decade, and screening coverage increased from 77.1% to 81.5% between 2011 and 2019.[51] To enhance breast screening coverage, Spain implemented an organised approach by offering biennial mammography screenings to women aged 50 to 69. Personalised invitation letters were sent to eligible women which included details about the date, time and location of the screening appointment along with information about the importance of screening. “In Spain, when a woman is called to participate in the early diagnosis programme for breast cancer by having a mammography, around 90% of the patients follow the programme,” says Andrés Cervantes, former president of the European Society for Medical Oncology. “That is, they respond positively and undergo the mammography.”

Furthermore, to address disparities, Spain rolled out targeted community outreach programmes to raise awareness and address barriers to screening among women living in rural areas and those from lower socioeconomic backgrounds, who traditionally have lower participation rates. However, in 2020, during the covid-19 pandemic, screening coverage expectedly dropped, declining to 73.8%, as services were suspended or women who feared contracting covid-19 did not attend screening appointments.[52] Since the pandemic, the system for invitations and scheduling appointments has evolved towards a more women-centred approach; a pre-scheduled appointment is still provided but women now have greater flexibility as they have the option to reschedule their appointments through online portals, by phone or text. Longitudinal observations will enable better understanding of the impact of the changes in flexible scheduling practice on screening coverage.[53]

Diagnosis and treatment

Beyond screening, geographical disparities also exist in diagnosis and treatment access across all countries of interest. Experts from our London workshop noted that in some locations, like the Royal Marsden Hospital in Sutton, "one-stop" clinics are provided where patients receive imaging, biopsies and results in a single day, representing a "Rolls-Royce" level of NHS service. Yet other areas—the south-east London borough of Croydon, for example, which is less than five miles from Sutton—lack this efficiency, leading to delays and inconsistent care.

Experts from Italy describe how decentralisation has resulted in the establishment of up to 20 administrative regions, each with varying degrees of healthcare provision, which can exacerbate regional health disparities for women with breast cancer.[54] "This is a huge problem, especially for the southern regions, and may even be leading to medical health migration," says Carmine Pinto, director of medical oncology at the Scientific Research Institute of Reggio-Emilia.

A similar policy environment exists in Spain, where each of the country's 17 different autonomous regions has its own healthcare system. "This creates inequality in the end; not all provide the same services, some cover gender reassignment surgery and others cover breast prostheses, for instance," says Dr Carrasco. "This creates a lot of inequality between regions."

In Germany and France, experts note, specialised breast centres are predominantly located in metropolitan cities, requiring patients to travel long distances and arrange local accommodation to access care. This adds a significant financial burden. In some instances, French patients prefer to travel to centres in cities like Paris, even when care is nearer to their homes, further straining these centres and resulting in increased costs for patients, and sometimes leads to women discontinuing their care. "It's just unthinkable to stop your care because there is no means of transport to go to the care centre," says Delphine Lichte-Choukroun, director of research, innovation and health prevention at PRO BTP Group. A more extensive network of centres of excellence is essential, to ensure that high-quality care is more accessible to women closer to their homes.

Furthermore, certain populations, such as women from ethnic minorities and those from lower socioeconomic groups, face greater inequities in care. Women from ethnic minorities tend to be diagnosed with breast cancer at a later stage, are less likely to have their cancer detected through screening, and often experience more aggressive disease with poorer outcomes; these patterns suggest disparities in disease biology and access to care.[55,56] According to the responses of over 26,030 women in the England National Cancer Patient Experience Survey, women from ethnic minorities, those from lower socioeconomic groups and younger women were more likely to rate their experience of healthcare as less favourable compared to their counterparts.[57] Factors such as a lack of focus on the issues that patients with breast cancer face as mothers, along with racism, stereotyping, language barriers, lack of cultural sensitivity of care and inherent mistrust of the Western approach to medicine, can contribute to poorer healthcare experiences among certain minority groups.[58]

There have been various efforts, often localised, to reach such women. "When I previously worked at Barts Health NHS Trust [in east London], there were significant initiatives to reach out to mosques to educate women about breast cancer, to encourage them to seek medical attention if they found a breast lump," says Rebecca Roylance, consultant medical oncologist at University College London Hospital (UCLH). "Similarly, there are initiatives to engage with schools in Jewish communities to educate the girls, who in turn educate their mothers, especially in groups with a high inherited predisposition risk, such as BRCA mutations… Initiatives must be tailored to reach the local population effectively."

Women from ethnic minority groups are also underrepresented in clinical trials. “We know that with many studies, people from different ethnic groups weren’t included,” says Dr Cruickshank. “Therefore, when we do the meta-analysis and review clinical trials, we see that actually, a significant portion of the population isn’t represented in the trial data. How will this then work when it comes to clinical practice?” As well as a historical lack of inclusion, issues such as patient distrust, complex paperwork and the emotional stress of a recent diagnosis can deter participation, particularly among certain demographics with breast cancer. Concerns around distrust and poor engagement have also been compounded by the underrepresentation of ethnic minorities within the healthcare workforce.[59]

Similarly, women from lower socioeconomic groups have poorer survival rates than their counterparts from higher socioeconomic groups, a gap that persists despite the overall reduction in breast cancer mortality over time.[60] The survival gap in breast cancer is influenced by patient and tumour factors, healthcare system attributes, and social conditions. Even when accounting for diagnosis stage, hormone status, comorbidities and treatment, disparities persist, highlighting the need for further research into healthcare-seeking behaviours and barriers to access.[61] Socioeconomic disparities also impact the quality of life of women with breast cancer. “The health system in Spain is not equipped to tackle the socioeconomic differences that affect the quality of life of patients outside of the care system,” says Dr Borràs. “For example, an 80-year-old patient who lives on the fourth floor without an elevator [who] may not be able to leave their home, or a patient from a rural area who requires support at a time when family support structures are receding… These issues are not addressed by the healthcare system… social care needs to be expanded to improve quality of life.”

Standardisation of frailty assessments to facilitate optimal treatment decisions for older women

Frailty and comorbidities impact the choice of treatment for older women with breast cancer, but there is currently no guidance incorporating these aspects into clinical decision-making. The National Audit of Breast Cancer in Older Patients developed a fitness assessment form for women aged over 70 based on two validated instruments, the Clinical Frailty Scale and the Abbreviated Mental Test Score, along with three screening questions regarding medical and cognitive comorbidities. The form is available in many NHS organisations and should be completed beforehand to enable multidisciplinary team decision-making on the best treatment plan for the individual. The fitness data are also being integrated into the Cancer Outcomes and Services Dataset for NHS England. However, the percentage of women with completed fitness assessment forms was less than 5% in an audit performed between 2020 and 2021, suggesting poor implementation of such tools in clinical practice.[62]

There is a lack of standardisation around treatment decisions for older women with breast cancer, and they are frequently undertreated owing to concerns around frailty and toxicity of treatment. "There is a degree of variation for older patients with breast cancer across different hospitals, and studies have shown significant variation in the rates of surgery and systemic treatment in older patients, even when accounting for patient age, comorbidities, and fitness and health status," says Dr Battisti. "This suggests there are many other factors at play, including perhaps some assumptions we make as clinicians."

In England and Wales, the National Audit of Breast Cancer in Older Patients (NABCOP) 2022, found that the likelihood of receiving surgery for early-invasive breast cancer decreased with older age at diagnosis (97% for women aged 50-69 versus 77% for women over 70), as did the use of radiotherapy (90% for women aged 50-69 versus 81% for women over 70) and chemotherapy (74% for women aged 50-69 versus 31% for women over 70). A similar trend was seen in metastatic disease, with 41% of women aged 50-69 receiving chemotherapy, compared with 13% of those aged over.[63] In women over 70 with early-invasive breast cancer, omission of surgery or adjuvant chemotherapy in those at high risk of recurrence has been associated with poorer outcomes.[64,65]

Strained healthcare resources and lack of adequate workforce can not only impact disease outcomes, but also affect women-centric care. "There are too few doctors and support staff in the clinics," says Sibylle Loibl, chair of the German Breast Group. "This makes women-centric care complex. If I have a complex procedure, an individualised test with an individualised therapy to bring to the patient, but it takes too long because I have to explore how the logistics work first, then I take what I get off the shelf, because it's just quick and I can cover that with my staff."

A lack of time may mean that doctors also have less time to communicate effectively with their patients, and this can sometimes be exacerbated by doctors working in silos. "The system is quite brutal, and it can be quite devastating when doctors don't have time to dedicate to each patient," says Ms Bolaños. "If we want patient-centred systems, there are many elements to put in place. From health literacy, prevention, [to] doctor-patient communication. There has to be interaction between the different levels of care so that they are capable of supplementing each other, but we often work in silos—this is something quite common to all environments and all countries."

The issue of workforce inadequacies extends to different specialties involved in cancer management. However, there are limited data available on the number of pathologists, radiation therapists and allied health professionals, including genetic counsellors, who are key to multidisciplinary care; this is varied across countries (Table 2). "Today there are fewer pathologists, who also need to deal with more tests and interpretations on the same biopsy specimen, like molecular and genetic testing," says Fedro Peccatori, director of the Fertility and Reproduction Unit at the European Institute of Oncology. "This is a big problem—not just an Italian issue but a European issue."

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Table 2. Number of breast cancer specialists per 100,00 population, by country

	Germany	France	Italy	UK	Spain
Physicians (2020)[66]	450	320	400	300	460
Specialist surgical workforce[67]	108 (2015)	59 (2015)	142 (2017)	133 (2015)	80 (2014)
Radiologists[68]	10.3 (2019)	13.3 (2019)	19.7 (2021)	8.5 (England in 2020)	9 (2021)
Medical and clinical oncologists (2018)[69]	115	74	122	131	52
Nurses (2020)[70]	1210	1130	630	850	610

A variety of new and effective treatments including targeted agents and immunotherapy options have been approved for both early-stage and advanced breast cancer by the European Medicines Agency (EMA). Between January 2015 and June 2021, 21 new indications for 14 novel breast cancer therapies were approved by the EMA.[71] However, disparities in access exist both within and between European countries, thereby impacting outcomes. Once EMA grants regulatory approval to new cancer treatments, each European country has its own health technology assessment mechanism for approval. As of January 2024, Germany reimbursed 96% of EMA-approved oncology treatments while other European countries had much lower reimbursement rates (Figure 3). Delayed reimbursement is another barrier to access, creating inequalities between countries and conflicting with the EBCP's goal of ensuring that all cancer patients in the EU receive equal access to treatment, without "first class" or "second class" distinctions.[72] The shortest average time to reimbursement of oncology drugs was in Germany, at 93 days after EMA approval, while in other countries reimbursement was a much longer process, the longest being 725 days in Spain (Figure 4).[73]

Some countries, including Italy, have additional local requirements for reimbursement, which cause further delays in access to treatments. "In Italy, drugs must go through the public tender system to establish a local price in different territories in accordance with legal requirements, just like any other product or service," says Michelino De Laurentiis, chief of the breast oncology division at the National Cancer Institute "Fondazione Pascale". "These processes, though illogical since the price is already fixed at the national level by the Italian Medicines Agency (AIFA), can take months and may result in the loss of human lives."

> **"Testing for biomarkers is necessary to use targeted treatments, but these tests are not included in the regulatory and reimbursement system for drugs. This disconnect creates a situation where a drug may be reimbursed, but the companion diagnostic tests may not, thereby impeding the effective implementation of personalised medicine approaches."**
>
> Giampaolo Bianchini, Associate Professor, Vita-Salute San Raffael University and Head of Breast Oncology, San Raffaele Scientific Institute

Figure 3. Availability of oncology medicines in Europe[74]

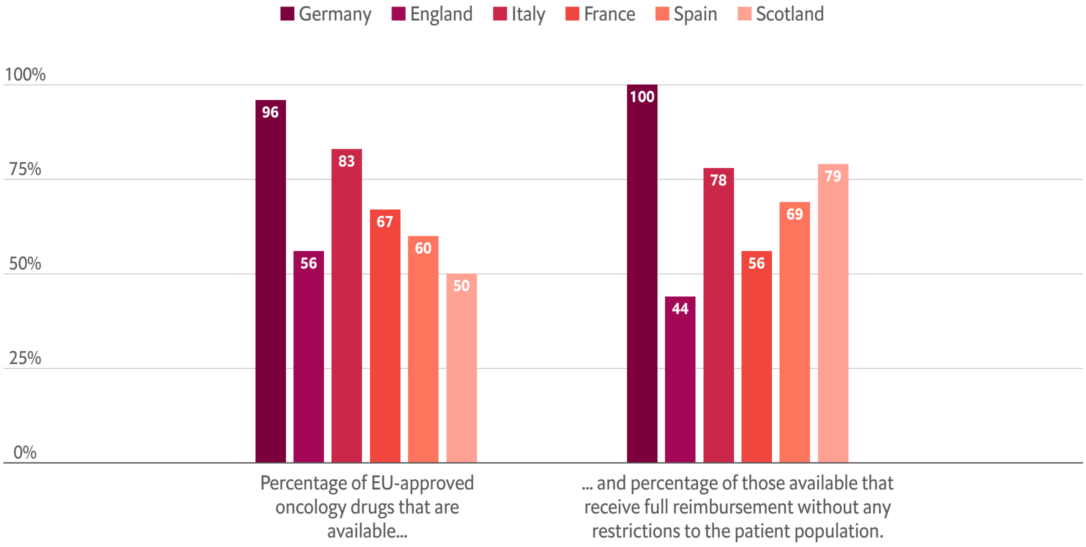
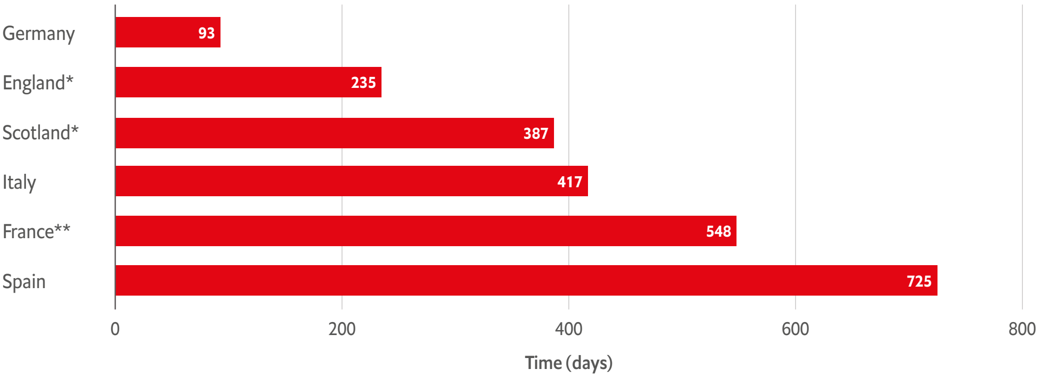


Figure 4. Time to availability of oncology drugs as of January 2024, by country[75]



Personalised oncology care improves patient outcomes by tailoring treatment to individual needs. This approach also offers socioeconomic benefits by reducing productivity loss and supports the health system by optimising the use of resources for testing and treatment.[76] For instance, the use of biomarker testing for breast cancer with targeted treatments has shown improved outcomes in women.[77] However, biomarker testing that is recommended by international guidelines is not fully reimbursed in countries like Italy.[78] "Testing for biomarkers is necessary to use targeted treatments, but these tests are not included in the regulatory and reimbursement system for drugs," says Dr Bianchini. "This disconnect creates a situation where a drug may be reimbursed, but the companion diagnostic tests may not, thereby impeding the effective implementation of personalised medicine approaches." To this point, Dr Loibl adds, "I don't think the knowledge among healthcare professionals is widespread enough. 'Where can I test? How can I test? Who do I need to contact?' Logistical knowledge is limited."

Reimbursement patterns also impact access to safer and/or cost-effective radiotherapy options. For routine postoperative radiation to the breast, the use of hypo-fractionated schedules compared to conventional dosing (15-16 fractions versus 25 fractions) significantly reduces treatment time for patients and is cost-effective for healthcare systems.[79] However, hospitals in France have been slow to adopt this modality, as they are reimbursed based on the number of radiotherapy sessions rather than the total dose of treatment.

"In my opinion, unmet medical needs include access to more targeted radiotherapy," says Frédérique Penault-Llorca, director general of the Centre Jean Perrin and vice-president of UNICANCER, a French federation of cancer centres. "Today, very short radiotherapy courses are available, but unfortunately, some radiotherapy services still offer longer treatments because they are financially more advantageous for them. In most cases, a shorter course of treatment is just as effective as a two-month course. For patients, this improves quality of life, and for society, it reduces healthcare costs."Other forms of safer radiation therapy, including accelerated partial breast irradiation and intraoperative electron radiation therapy, are also not reimbursed in several countries.[80]

Survivorship and aftercare

The physical effects of cancer, such as a mastectomy (breast-removal surgery), can have a huge effect on quality of life, and can lead to psychological effects and issues with body image. "What is really missing is a general approach to patient care, especially in the area of sexual health," says Dr Carrasco. "Breast cancer patients face issues related to the types of surgeries they undergo [that] can make women feel less feminine than before, such as mastectomies."

Effects of treatment such as early menopause can also be a huge challenge for younger women, who may not be expecting these symptoms. "A young woman, a girl who is saved due to the treatments she has undergone, may have a very early menopause, which can make her life very difficult in human and social relationships," says Dr Cervantes. "She may also be at increased risk of deterioration of her bone mass or of having cardiovascular problems in adult life. People who are cured of cancer are not exempt from having health problems throughout their life trajectory."

Besides the risk of premature menopause or concerns of subfertility (difficulty becoming pregnant), waiting for the completion of all treatment for breast cancer before starting a family—which can take five years or more in early-stage disease—can be a major concern for women reaching the end of their reproductive period. Fertility preservation options for women such as egg freezing are funded to varying extents with differing eligibility criteria by European countries.[81,82] However, lack of formal training of oncologists regarding fertility preservation, lack of awareness of facilities offering services and lack of relevant referral pathways result in gaps in care.[83]

Ms Cox emphasises the need to include sexual health needs within breast cancer care. "There is a lack of education and communication on the topic [of sexual health] among healthcare providers, resulting in lots of women being left nowhere, because healthcare providers do not discuss it," she says. "The topic also remains taboo, despite consistent advocacy around this for a long time."

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Sexual dysfunction, including symptoms like decreased sexual desire, dyspareunia (genital pain before, during or after sex) and anorgasmia (delayed, infrequent or absent orgasms), is also common after treatment.[84] A survey of 319 women included in an observational cohort study in southeastern France showed that only 53% of women were satisfied regarding the fertility-related information they received during treatment, while only 43% were satisfied with guidance around sexuality.[85] Similarly, another French study, surveying 517 women aged 43 years and under, found that only 46% were offered specialised cancer-fertility counselling, while just 35% received at least one fertility preservation procedure. With a median follow-up of 27 months after the end of treatment, 133 pregnancies had occurred, including 20 unplanned pregnancies. Women who had unplanned pregnancies reported lower rates of receiving information on the consequences of treatment on fertility, highlighting the gap in sexual and reproductive care and counselling for women with breast cancer.[86]

Survivors of breast cancer experience a range of symptoms as a result of their cancer and side effects of treatment, including shoulder dysfunction, lymphedema (lymph fluid build-up between the skin and muscle), and chemotherapy- and radiotherapy-induced toxicities, that can be addressed by physical rehabilitation.[87] There are increasing efforts to optimise rehabilitation services in Europe, and Germany is leading the charge. “Every patient [in Germany], regardless of the type of tumour, is entitled to follow-up treatment,” says Kerstin Paradies, chair of the Nursing Working Group of the KUK Conference of Oncological Nurses and Paediatric Nurses. “I think that 90% of all women, especially those with breast cancer, take advantage of this opportunity to go into follow-up treatment for two to three weeks, possibly with an extension, with different focuses—one patient wants to do more sport, another needs psycho-oncological support, another wants to get nutritional tips, so it’s very individualised. With cancer, there is a very long trail behind treatment, where patients have to go to a protected space every now and then, to reflect on their expectations and quality of life.”

Although many countries recognise the importance of providing rehabilitative services as part of breast cancer care, survivors often experience a lack of service provision. For instance, the National Cancer Survivorship Initiative in the UK recommends early access to physical rehabilitation for cancer patients with the recommendation to consider “prehabilitation” or rehabilitation in advance of cancer treatment for selected patients.[88] However, implementation has not kept up with this guidance. “To this day, the systems are still not prepared to treat anything but the disease exclusively,” says Natacha Bolaños, an independent expert and member of the ESMO Patient Advocacy Working Group. “There are no rehabilitation programmes to try to bring the person to the best possible physical condition. There are no programmes for physical or psychological rehabilitation. No, the system is not able to address all of this. It’s important to emphasise that the capacity of healthcare systems is extremely limited. Only in exceptional cases can some support be provided, but unfortunately, this is never to the extent truly needed by patients.”

Women with metastatic disease remain invisible

Significant advances in treatment have changed outcomes for metastatic breast cancer (MBC), an advanced stage of the disease where the cancer spreads to another part of the body, most commonly the bones, lungs, brain or liver. Certain subtypes of MBC now have a median overall survival of five years, and some women with MBC now live over ten years and are increasingly being considered as survivors of a chronic disease.[89] However, despite the advancements in treatment, shorter survival and poor quality of life are the realities faced by many women with MBC.[90]

Women with MBC can experience a rapid decline, manifested by pain and physical and psychological disability, but they often lack support to manage their symptoms. “There is insufficient management of oncological pain,” says Nuria Sánchez, founder and CEO of the Oncology Institute of Aesthetics in Spain. “Many patients do not receive adequate and specialised pain control. There is the added problem of waiting lists to be treated in pain units and the lack of pain specialists.” In addition, women with MBC must adjust to living with the disease while managing changes in family dynamics and expectations, which can cause further psychological stress.

Earlier research on cancer survivorship primarily focused on those who had completed curative treatment or transitioned to maintenance therapy. The evolving nature of breast cancer as a chronic disease has broadened the definition of survivorship. Today, a woman is now considered a breast cancer survivor from the moment of diagnosis through the remainder of her life. Despite the broader definition of survivorship and efforts to include patients at all stages of cancer, supportive care remains insufficient, particularly for those with metastatic disease. “Cancer is not pink; positivity does not cure and 20% of patients diagnosed with breast cancer will experience a metastasis either from the beginning of the disease or years later,” says Pilar Fernández Pascual, president of the Spanish Association for Metastatic Breast Cancer. “Palliative care should not be reserved solely for the end of life, but should be integrated throughout the disease process to manage symptoms and side effects.”

> **“Cancer is not pink; positivity does not cure and 20% of patients diagnosed with breast cancer will experience a metastasis either from the beginning of the disease or years later. Palliative care should not be reserved solely for the end of life but should be integrated throughout the disease process to manage symptoms and side effects.”**
>
> Pilar Fernández Pascual, President, Spanish Association for Metastatic Breast Cancer

There are also significant gaps in resource allocation and research for MBC, partly because cancer registries typically track only initial diagnosis, treatment and death, leaving the true prevalence of MBC unknown.[91] This lack of data can lead policymakers to prioritise early breast cancer, and for this reason healthcare providers and even advocacy groups may also pay less attention to women with MBC, leaving them feeling stigmatised, undervalued or under-recognised.[92] “I think we all feel, in the metastatic cancer world, that we are ignored and that our needs are not considered, and that very little research is done on us,” says Siobhan Gaynor, a member of Cancer Trials Ireland (CTI) and BIG against Breast Cancer Patient Partnership Initiative, and a metastatic breast cancer patient. “In fact, the data I’ve looked at suggests that only 5% of research funding available for breast cancer across Europe is directed towards research on metastatic breast cancer.”

Supportive oncology care is also lacking in France. "I think that we need to increase supportive oncology care for patients, and where I think there is a real gap is in the post-cancer period—the support for patients when they have finished treatment," says David Balayssac, professor at the University Clermont Auvergne and hospital practitioner at Clermont-Ferrand University Hospital. "For cancer survivors, the support for patients who may have after-effects, particularly pain, a topic that I am working on, is an important point in my opinion. It is important to be able to provide medical and possibly non-medical care after the end of treatment to allow patients to return to an almost normal life."

> **"Even in countries like the UK where universal health coverage is available, women often drop their income bracket following a cancer diagnosis."**
>
> Stuart McIntosh, Professor of Surgical Oncology, Queen's University Belfast and Consultant Breast Surgeon, Belfast City Hospital

In addition to physical impairments, women with breast cancer often face psychological distress that affects their health and wellbeing. For instance, systematic reviews have found that over a third of breast cancer patients experience depression or anxiety.[93,94] However, the provision of psychological care for survivors of breast cancer remains inadequate across Europe. "There are no psycho-oncologists—usually general psychologists who [for example] treat a person who has had a traffic accident is the same person who treats a cancer patient, and sometimes there might only be one psychologist for an entire hospital," says Ms Fernández Pascual. According to Germany's National Cancer Plan, psychosocial support for cancer patients should be an integral part of multidisciplinary cancer care whenever there is a need for it, and hospitals must inform all patients about the availability of psychosocial services if they are to be certified by the German Cancer Society.[95] However despite this, not all patients receive this information, and few access the services. A German survey of 456 women who received treatment in an accredited breast cancer centre found that the availability of psychosocial services was known to 91% of women, offered to 68% and accessed by just 55%. The availability of social services was known to 86% of women, offered to 65% and used by only 51%.[96] The reasons for low levels of access to these services are unclear and require further investigation, although in some instances cost may be a factor. "Psychological support is important, but sometimes it is not reimbursed," says Dr Bianchini. "If I am told that I have to have a psychologist, but I am not given the resources to pay for it, this makes no sense. But in general, psycho-oncology, for example, is not a service offered to everyone."

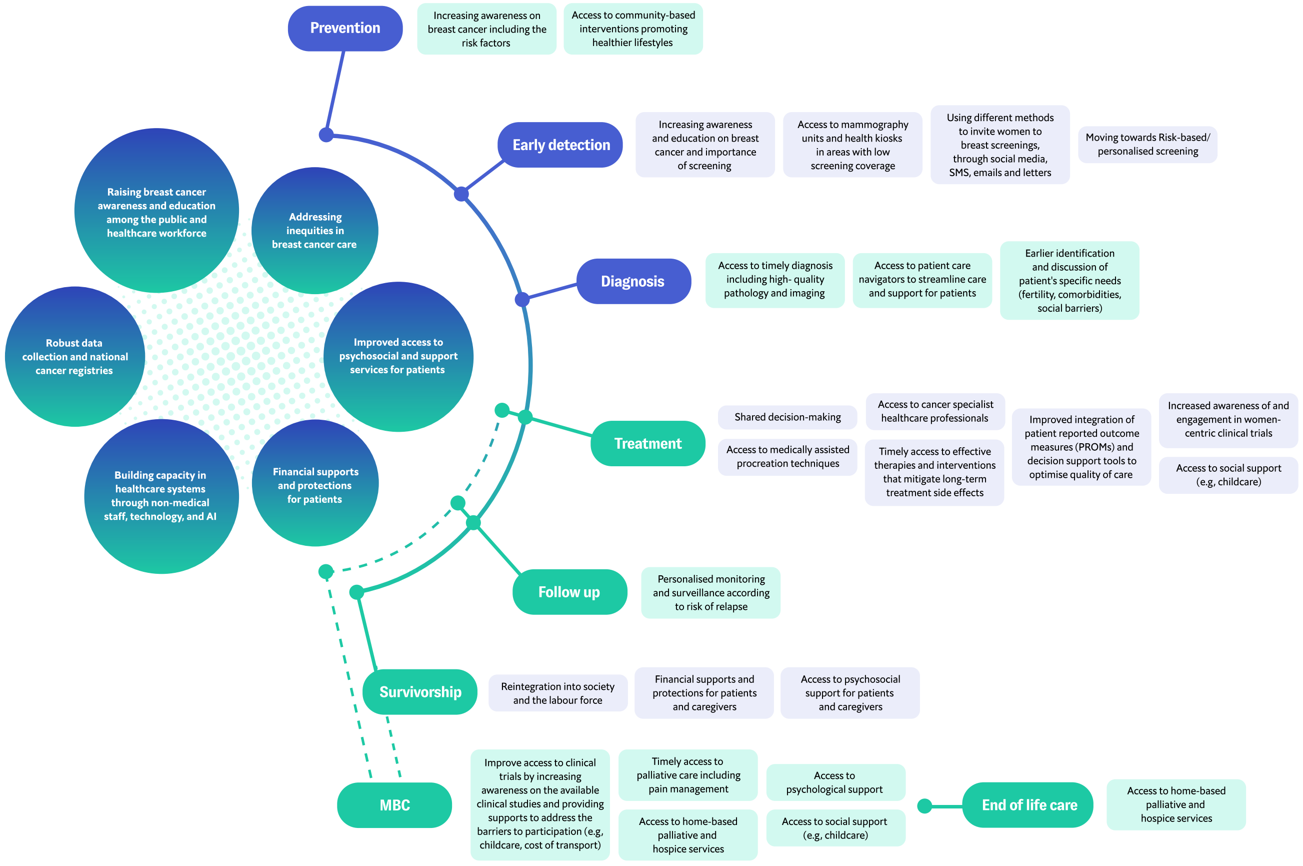
The financial burden of living with breast cancer impacts individuals across all socioeconomic levels. "Even in countries like the UK where universal health coverage is available, women often drop their income bracket following a cancer diagnosis," says Stuart McIntosh, professor of surgical oncology at Queen's University Belfast and consultant breast surgeon at Belfast City Hospital. According to the findings of a UK survey, nearly 16% of respondents with early-stage breast cancer were no longer employed, and 25% experienced a drop in income. For those with MBC, around 39% became unemployed, and 38% saw a decrease in income. Among caregivers, 47% experienced employment changes, with 23% reporting reduced income.[97]

Where some form of financial support is offered, it is often inadequate or not easily accessed by women. Experts from Italy question the need for repeated evaluations of women with incurable metastatic cancers to confirm their eligibility for "legal disability" status. "If you have a metastatic disease that is potentially incurable, once you give me legal disability status, why do you need to see me again?" says Dr Bianchini. "It doesn't make sense, right? I can't get better. These are small things, but there is room for improvement."

In Germany, cancer patients are entitled to six weeks of full pay followed by 1.5 years of sick pay, which is calculated at 70% of their most recent income. "However in practice, we often see that women with breast cancer in particular are also affected by the fact that their health insurance company has to take them off sick pay in accordance with Social Code 5, which means that they no longer even have the chance to take advantage of the 1.5 years of sick pay, but may be forced into early retirement by the health insurance company before then," says Ingo Neupert, professor at RheinMain University of Applied Sciences. "This can lead to a structural downward spiral in their financial situation."

A women-centric approach to revolutionising breast cancer care

Our assessment of women-centricity in breast cancer care is largely informed by insights from over 75 multi-disciplinary experts, the majority of whom are women, including those with lived experience of breast cancer. Based on these insights, Economist Impact proposes a roadmap, validated by our steering committee, to advance the implementation of a women-centric approach to breast cancer care in Europe. This roadmap highlights opportunities to incorporate women-centric at every stage of the breast cancer journey from prevention to early detection, diagnosis and treatment, follow up and survivorship, and end-of-life care.



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Room for improvement: seizing women-centric opportunities

Fostering collaboration among multiple stakeholders—including patients and patient organisations, policymakers, researchers, healthcare professionals, and biopharmaceutical companies—is an effective way to encourage the transition towards women-centric breast cancer care. "There are still too many stakeholders who speak on their own island, and are not necessarily speaking to each other or trying to find a solution together," says Ms Cox. "You have the medical experts, the healthcare providers, the patients, but you also have the industry, and there's still work to do to bring all stakeholders together to find innovative solutions together, particularly when we speak about access."

Co-creating women-centric cancer control plans and guidelines

European countries are at varying stages of developing or having developed their national cancer control plans, with many incorporating the needs and preferences of cancer patients within these plans (Table 3).

Table 3: National cancer control plans and how they currently encompass the needs and preferences of women with breast cancer[98,99,100,101,102,103,104,105,106,107,108,109,110,111]

Cancer control strategy	Stakeholder involvement in co-creation	Focus on the needs and preferences of women
Germany's National Decade Against Cancer (2019)	Federal health agencies, professional associations, research centres, patient organisations and pharmaceutical companies	Primary focus is cancer research. Some patient-centric aims include: • Raising awareness about cancer and primary prevention • Active participation of patient organisations in developing the oncology research strategy
England's Long Term Plan (2019)	National Health Service (NHS) leaders, patient groups, clinicians, nurses, allied health professionals and local government representatives	England does not currently have a standalone cancer control plan. Instead, England adopts a whole-person, whole-pathway approach for major health problems including cancer. A package of interventions for patient-centric care has been proposed including: • Holistic needs assessment and care planning • Providing a treatment summary to patients • Arranging health and wellbeing events • Performing a cancer care review. The review is completed by a GP or nurse and provides post-treatment support, financial support services, information regarding cancer treatment, early and late complications of therapy, and self-management
NHS Wales Cancer Improvement Plan (2023-2026)	Unclear	Improving patient experience, reducing waiting times and compliance with national optimal pathways are key aims. The national optimal pathway for breast cancer care in women highlights patient-centred care, and includes: • Holistic needs assessment and an associated care plan • Provision of a key contact for queries • Focus on overall health optimising prehabilitation, rehabilitation, and the collection of PROMs and PREMs.
Scottish National Cancer Action Plan (2023-2026)	Developed through consultation with the public, engagement with focus groups, and the input of national, regional and local clinical and management representatives	Patient-centric care is emphasised with attention to rehabilitation, palliative care and mental health services.
A Cancer Strategy for Northern Ireland (2022-2032)	Co-created with the participation of people living with cancer. Staff providing clinical care for patients and government representatives	Emphasises patient-centric care with a sustained focus on enabling, informing and supporting people to make decisions on their treatment and self-manage in the long term. There are recommendations for holistic survivorship care.
National Cancer Control Strategy of France (2021-2030)	The plan was put together by the National French Cancer Institute, the French cancer community and French citizens through a national consultation.	Prioritises survivorship as one of the key objectives and is focused on reducing after-effects of treatment, improving the quality of life of patients, guaranteeing access to high-quality supportive care throughout the treatment pathway, promoting the right to be forgotten, adapting education during illness, and ensuring job retention and caregiver support. The plan recommends shared decision-making with patients and the development of personalised treatment plans.
Italian National Oncology Plan (2023-2027)	The working group included patient organisations and professional organisations.	The plan recommends involvement of patient organisations in streamlining the patient pathway. The inclusion of a satisfaction evaluation system for patients attending the public health system is recommended. There are recommendations to improve training for providers in care models, technology, communication, and essential aspects of humanisation and respect for individuals. The significance of raising awareness and empowering patients is underscored.
Spain's National Cancer Control Strategy (2021)	Unclear	The plan focuses on improving multidisciplinary care and survivorship.

Many country plans have been co-created by a diverse range of stakeholders including patient representatives, who can be instrumental in amplifying the patients' voice in cancer care at the policy level. However, there should also be caution to avoid overburdening patients with issues that should be addressed by policymakers. "I think we have to be careful not to burden patients with this," says Ms Cox. "Although they can be an important voice, the responsibility should not be with them. I think there are ways to include the patient voice along the whole pathway, and that's something that should be done systematically—that's where policy can help."

Patient-centricity of the National Cancer Control Strategy of France (2021-2030)

The National Cancer Control Strategy of France (2021-2030) is exemplary in its focus on patient-centred care. The main goals of the plan are to improve prevention and quality of life, address cancers with poor prognoses, and ensure that progress in cancer care benefits all by reducing disparities. The plan aims to achieve a breast cancer screening rate of over 70% by improving screening awareness, encouraging opportunistic screening, streamlining the referral process and addressing the barriers to access. In addition, risk-adapted precision screening (a personalised approach to breast cancer screening that considers an individual's risk factors to determine the best screening options) and the early adoption of innovative technologies are also recommended. Breast reconstructive surgery is prioritised with recommendations to organise a reconstruction access pathway, integrate reconstruction into practice guidelines and increase psychological support for women.

Survivorship care is also a key area of focus within the plan, aiming to address issues around the after-effects of treatment, quality of life, access to high-quality supportive care throughout the care pathway, financial hardship, and vocational and caregiver support. The plan highlights the importance of shared decision-making with the development of personalised treatment plans. It comes with an implementation framework and flags stakeholders responsible for ensuring effective delivery.[112,113]

From policy to practice: measures to support effective implementation

Although breast cancer policies are well-developed, their implementation remains slow. "We know what the priorities for policy are—we have spent so many years defining them," says Fatima Cardoso, president of Advanced Breast Cancer (ABC) Global Alliance. "The problem is in the implementation, which varies between countries and regions and depends on so many factors, including the knowledge of the person seeking care."

In the UK, Dr Battisti notes some important collaborations: "The Joint Collegiate Council for Oncology in collaboration with the International Society of Geriatric Oncology, Macmillan Cancer Support and the British Geriatrics Society, has developed guidance on implementation, assessment and management of cancer services. We hope it will boost more activity and initiatives around this at the national level." However, he also notes that more is needed. "What we're missing is a larger programme that, like in other countries, supports a broader set of initiatives for this large and increasing patient population" he says. "These initiatives should combine not just clinical implementation or provision of clinical services, but also importantly, education and research."

> **"We know what the priorities for policy are—we have spent so many years defining them," says Fatima Cardoso, president of Advanced Breast Cancer (ABC) Global Alliance. "The problem is in the implementation, which varies between countries and regions and depends on so many factors, including the knowledge of the person seeking care."**
>
> Fatima Cardoso, President, Advanced Breast Cancer (ABC) Global Alliance

An important pillar of implementation is the development and funding of relevant programmes and care models. The French National Cancer Plan has been successfully funding the development and integration of a geriatric-oncology care model over the past two decades for a more inclusive approach. In this plan, all regions of France have developed one or more regional units offering integrated care that encompasses both oncology and geriatric specialties for cancer patients aged over 75 years.[114]

Alain Toledano, medical director of the Hartmann Cancer Institute in Paris and president of the Institut Rafael, describes the work of his institute in co-creating solutions with women to improve their experience of breast cancer care and support them towards achieving their life goals. Integrated care with a personalised care pathway is offered by the institute, with access to 40 different disciplines, encouraging active engagement of women with breast cancer and their caregivers with a dedicated care coordinator.[115] "The idea is to offer support to all patients during their treatment, to show that taking care of every dimension overall is better than taking care of the illness alone," says Dr Toledano. "We have shown that we can reduce the rate of depression, the rate of isolation and sleep disorders by taking care of the people."

Many of the experts involved in our study agree that establishing an extensive network of certified breast centres is essential for providing quality care. Further, they highlight the importance of adhering to quality indicators at these centres, which can be monitored, audited and replicated to improve outcomes."It may not be realistic that each hospital and province in Spain has specialised [breast] centres," says Ms Sánchez, but she emphasises the importance of referring women with breast cancer to appropriate community services, especially for those with metastases who often rely on novel clinical trials for treatment.

Although there should be some scope for national differences in implementation, experts agree that it is also important to increase alignment to address regional disparities—for example, when it comes to price-setting for drugs. "I think that there could definitely be improvements and it would be a lot more effective if prices could be negotiated at a European level, and if regulatory bodies imposed certain requirements," says Virginie Adam, scientific director of Breast International Group. "Maybe also [needed are] requirements that ensure that a drug demonstrates benefits not just in terms of its efficacy, but also in terms of quality of life."

Leveraging women-centric prevention and early diagnosis for breast cancer control

Despite our understanding of the breast cancer risk factors and the potential of prevention, current efforts in this area remain notably insufficient across the entire care continuum. "Prevention is very important because more than a third of all cancers can be prevented," says Dr Cervantes. "They could be avoided through a series of important actions, and for me the first and most important is health culture. Society suffers from a kind of health illiteracy, and this results, for example, in problems such as smoking, alcoholism, air pollution, environmental pollution, which clearly are related to cancer. [This is] something that doctors cannot solve alone; society must tackle it."

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>
> Andrés Cervantes, Former President, European Society for Medical Oncology

Some risk factors have emerged owing to societal changes such as later first pregnancies, and some such as alcohol consumption and weight gain can be more easily addressed through preventable measures. For change to happen, education is important. "We could start working earlier, for example, in schools when people are younger, before an adult has stabilised their habits and change becomes more complex," says Dr Alba. Awareness campaigns are also key, and can be effective if they are designed in a way that ensures they reach their desired audience. "In groups like ours, we continuously emphasise this, and many of our awareness campaigns revolve around this issue, about what preventative measures can be attempted," says Dr Carrasco. "We even conduct workshops at the corporate level and such where we explain these things."

According to many of the experts involved in our study, current age-based criteria for screening inclusion are considered outdated. "Age should not be the only factor in determining a need to participate in screenings," says Dr Peccatori. "What you'd really like to be able to do is have a screening programme which is much more stratified based on the individual risk that a woman is likely to get breast cancer; and that risk might be due to a range of risk factors such as family history, a panel of genetic markers, lifestyle issues, etc. And so we need to screen you more frequently so the higher the risk you are of getting breast cancer, the more frequently you get a mammogram … This [approach] will detect more cancers earlier, which means that you're likely to have better outcomes," he explains.

Although research demonstrates the benefits of risk-stratified screening, which uses individualised risk assessments to guide screening intensity, interval, starting age, imaging modality and even the decision not to screen, there is a reluctance for those at a lower risk to participate.[116] "It might even be possible that actually some people need less screening, if they're at really low risk, we could say to a woman, we only need to see you every four years rather than every three," says Dr Vincent. "There is some delicate health-economic balancing, but I think that's one really good example of where a person-centred approach could have a massive impact on early detection." For low-risk women who show low acceptance of risk-stratified screening, it is essential to provide tailored information about the approach and outcomes to support better shared decision-making and participation. This is particularly important, as factors influencing acceptability often arise from knowledge gaps, cultural norms, and emotional concerns.[117]

Furthermore, the use of decision aids, which provide information on a risk-stratified screening approach, has been shown to positively impact acceptability and uptake of lower-frequency screening.[118] A qualitative study in France involving 40 semi-structured interviews of 13 women and 27 healthcare professionals assessed the use of breast cancer screening decision aids. Both groups found decision aids useful, with healthcare providers noting that these could improve their knowledge of screening and standardise discussions on the screening process. All women preferred a user-friendly, graphic, interactive, computer-based decision aid. Concerns included lack of knowledge regarding shared decision-making, unbalanced positive information about screening and the potential misuse of the decision aid to promote screening rather than provide opportunities for shared decision-making.[119] Patient decision aids can also be useful in increasing patient involvement in decision-making, reducing decisional conflict and lowering fear associated with risk of cancer recurrence.[120] France's DEDICADES project is currently evaluating a decision aid in breast cancer care, while regional cancer centres in Germany send decision aids with invitations for mammographic screening, offering balanced, evidence-based information on risks and benefits.[121,122]

Risk stratification has shown potential in offering a comprehensive women-centric approach to screening, but additional data is needed to confirm its effectiveness in improving outcomes and cost-efficiency before it can be adopted into routine practice. Expert opinion suggests that this approach could be cost-saving in the long term, as it will detect more cancer earlier. “It should be cost-effective, because there will be people where you are detecting it earlier, which means the treatment costs in the long run are not as great because you’re treating that cancer earlier,” says Dr Peccatori.

There are also additional economic benefits to be gained from risk stratification as a result of increased workforce participation. “When discussing chemotherapy, radiotherapy or surgical options, it’s important to consider the impact of prolonged treatment on a patient’s ability to work and fulfil caring responsibilities, whether that’s for children or for elderly parents,” says Dr McIntosh. “And I think if we had better discussions about the risks and benefits to enable people to make individualised choices about their treatment, that might mitigate some of those expenses or financial tolls—although not all of them.”

Although Spain has the highest screening coverage rate among the five countries studied, it is also advancing personalised, risk-based breast cancer screening by assessing individual risk and offering a tailored approach. This strategy will provide personalised recommendations on the best screening method, the optimal starting and ending age, and the ideal screening frequency, while involving patients in a shared decision-making process.[123] International research is underway to study the effectiveness of risk-stratified screening. My Personalised Breast Screening, an EU-funded randomised-control study of 85,000 women aged 40 to 70 years, aims to investigate whether a personalised risk-based breast cancer screening approach could be better than standard screening.[124] The project will also assess whether the economic resources spent on a personalised, risk-based screening strategy are justified by the outcomes and will propose general recommendations for more effective breast cancer screening in Europe.

> **“In Germany, health kiosks enable us to approach and talk to people about barriers and make access easier. We create space for discourse at their doorstep, and ideally women will then come to a mobile clinic and then we can do mammograms.”**
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> Ingo Neupert, Professor at RheinMain University of Applied Sciences

To address inequities in current breast cancer screening, many countries are striving to bring care closer to home. In France, the “Mammobus”, a mobile breast screening unit, has been rolled out to drive screening rates in working-class Paris suburbs, aiming to boost screening coverage among women with low awareness.[125] Germany has adopted a comparable strategy by introducing health kiosks in its most disadvantaged communities; consultations are offered in German as well as six other languages. These initiatives have demonstrated considerable success. An evaluation of a pilot health kiosk programme in Hamburg, implemented in 2017, revealed a 19% reduction in preventable deaths through more effective treatment, compared to neighbouring districts without such kiosks.[126] As a result, national expansion of the programme has been recommended, offering significant benefits to diverse populations, including women with breast cancer. “Particularly in the case of preventive services such as early detection through mammography, it is important that women who are not reached by regular services are specifically addressed. This requires access and dialogue spaces to break down individual barriers,” says Dr Neupert. “These structures should be flexibly tailored to specific population groups and be low-threshold. In Germany, the first interesting approaches and experiences in this area have been made by health kiosks, which also offer programmes to promote health literacy in social spaces." These initiatives offer an innovative approach to healthcare delivery by addressing structural barriers to access for hard-to-reach populations. By adopting a community-based model, they also help to relieve pressure on healthcare systems, boost efficiency and improve care outcomes.

Building capacity and efficiency in the healthcare workforce: a multipronged workforce strategy

Given that one in three people will be diagnosed with cancer in their lifetime, a comprehensive workforce strategy is essential to address the rising demand for cancer care.[127] This surge impacts not only the general population but also healthcare providers, who are themselves part of this growing statistic. Ensuring sufficient, well-trained staff is crucial for managing the increasing burden on the healthcare system.

> **"One of the most important issues in the UK at present is capacity. We lack oncologists and radiologists. With a new government, policymakers need to highlight the importance of a comprehensive cancer workforce strategy. This strategy should assess what's needed, what we're lacking and what needs to happen going forward."**
>
> Rebecca Roylance, Consultant Medical Oncologist, University College London Hospital

A key factor in the successful delivery of women-centric care is the development of a healthcare workforce that is both adequately staffed and appropriately trained to meet the specific needs of women. Developing a robust specialist nurse programme can enhance and complement the work of physicians, increasing both the focus on women's needs and preferences, and overall efficiency of care delivery. "I am responsible for 60,000 nurses in oncology in Germany, and I can say that these are colleagues who are really committed to making everything possible for their patients," says Ms Paradies. In breast cancer care, specialist nurses play a multidimensional role across the entire care continuum, significantly improving the care experience for women and their families. Specialist nurse care is also cost-effective, as it reduces the time required for physician consultations, improves patient self-management skills, and reduces emergency room visits and hospital admissions.[128] In addition, care quality is improved through better communication between healthcare professionals, early detection and management of symptoms, and timely referral to end-of-life and palliative care.[129]

"There has been an increased move in recent years towards the use and deployment of what's called non-medical prescribers for patients, including those with cancer, specifically breast cancer," says Dr Battisti. "These include advanced nurse practitioners and senior pharmacists who are able to essentially fill the gaps in the availability of medics around the country. I would argue this is also a good opportunity to provide patients with more holistic care, because nurses and pharmacists often have a more comprehensive view of patients. This is a specific trend that, while not being pushed at a national level, is developing in specific areas and institutions."

The European Society of Breast Cancer Specialists (EUSOMA), a non-profit society, has established a set of quality indicators for breast cancer care. These guidelines specify that at least 85% of women diagnosed with breast cancer should receive counselling from a breast cancer nurse specialist at the time of diagnosis, and 95% must have direct access to breast cancer nursing support throughout their treatment.[130] Although certified breast units in Europe have successfully incorporated the specialist nurse model into

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>
> Simon Vincent, Director of Research, Support and Influencing, Breast Cancer Now

their care frameworks, significant gaps still remain in its widespread implementation. A self-assessment performed at the Functional Breast Unit of the Institut Català d’Oncologia in Spain demonstrated that specialist nurse support for patients with advanced breast cancer was suboptimal. Only 58% of women with advanced disease had contact with a specialist nurse during the first year of their illness, highlighting a critical gap in care for this vulnerable population.[131]

Similar issues are experienced by women with advanced breast cancer in the UK. “We have campaigned for a long time that every woman who has metastatic breast cancer should have the right to access a specialist nurse,” says Dr Vincent. “And yet those nurses do not exist in many places in the UK.”

Besides specialist nurses, other healthcare staff can also support the delivery of women-centred breast cancer care. Patient navigators can support women with breast cancer by identifying a defined period of cancer care, assessing the health services required to provide care, identifying individual patient-level barriers to accessing care, and supporting efforts to overcome these barriers for access to timely care.[132] An assessment of 61 systematic reviews found that patient navigator programmes are effective in improving participation in screening, reducing time to diagnosis and treatment initiation, and reducing hospital admissions, especially during the active treatment phase.[133] In the UK, social prescribing link-workers engage with patients to understand what really matters to them, help them connect with community services and activities that can improve their health and wellbeing, and develop personalised support plans that can be integrated into their medical care plan.[134] Furthermore, the Holistic Needs Assessment devised by Macmillan Cancer Care, a charity, has also been effectively rolled out across hospitals in the UK to identify a patient’s needs and concerns and develop a Personalised Care and Support Plan, as well as signposting to relevant services, addressing the broader issues around care.[135]

Increasing automation of diagnostic procedures through collaboration with AI, particularly in pathology and radiology, can further alleviate strain on the healthcare workforce.[136,137,138] By streamlining tasks such as image analysis and pattern recognition, AI integration can enable faster, more accurate diagnoses, allowing healthcare professionals to focus on complex decision-making and deliver women-centric care. “Automating certain diagnostic processes to increase efficiency can prevent system implosion by adapting to workforce constraints while maintaining diagnostic accuracy and treatment efficacy,” says Dr Peccatori. This approach can optimise resource allocation and improve efficiency in breast cancer care.

In addition, the use of mobile apps can improve health literacy by providing education and support around breast cancer, including when and where to seek care, while reducing dependence on the healthcare workforce. For example, Owise, an app developed in the UK in collaboration with patients, provides personalised information on breast cancer and patient-specific treatment pathways, a tailored list of questions to discuss with the oncology team, a diary function, data sharing options, and a secure audio-recording function to record and replay clinical consultations. The data from the app can be integrated into NHS electronic health record systems, providing access to a dimension of data beyond what is captured within the walls of clinical settings. Although further research is needed to fully assess the effectiveness of Owise, innovations like these represent a positive step toward empowering patients to integrate healthy behaviours into their daily lives. "Digital health is beginning to appear and we have huge spaces and opportunities for its implementation as an improvement in quality of life," says Dr Bianchini. However, caution should be exercised, especially with apps that lack regulatory certification.[139]

A major obstacle to successfully implementing women-centric breast cancer care is the lack of healthcare provider awareness around the preferences and needs of women. "The main obstacle to delivering women-centric care is cultural, and therefore we need to improve training for healthcare professionals," says Dr Toledano. "We must relearn how to look at the person and not just the illness."

At the European level, projects like INTERACT-EUROPE 100 aim to improve cancer care by breaking down medical silos and providing professionals from different specialties with the skills to communicate with each other more effectively for better patient care.[140] Under this initiative, the Inter-Specialty Cancer Training Programme aims to bring together 44 partners across 17 European countries to deliver a multispecialty training programme focused on improving patient-centric care. Relevant competencies for the programme were co-developed with patient-advisory stakeholders such as the European Cancer Organisation, showcasing a proactive approach in amplifying the patient's voice in both policy and programme development.[141] Healthcare professionals should also be aware of the need to retrain themselves in some respects, to be able to deliver the best care. "I believe that we have to take matters into our own hands, and learn to deal with the changing conditions—to have the freedom to look for solutions ourselves," says Dr Loibl.

> **"The main obstacle to women-centric care is cultural, and therefore we need to improve training for healthcare professionals. We must relearn how to look at the person and not just the illness."**
>
> Alain Toledano, Medical Director, Hartmann Cancer Institute in Paris and President, Institut Rafael

Supporting women to survive and thrive

Simply surviving is not enough for women with breast cancer. To help women thrive, a holistic approach to survivorship care is required, encompassing physical, psychological, vocational and financial needs. "Whereas in the past we used to take a very strong biomedical view, the system is opening up more to the psychosocial perspectives, and that gives me hope that we can take this topic further and also push it forward," says Dr Neupert.

There is an urgent need to fill the gap in the management of sexual, reproductive and fertility consequences of breast cancer care. France is conducting a clinical trial to assess how training and education for oncologists affect the delivery of onco-fertility counselling. The study will develop training materials using existing information tools and participatory methods, test these materials at six centres, and evaluate their impact on counselling rates, with a focus on identifying key elements for broader application across the country.[142] Reimbursement for fertility preservation techniques is variable and needs to be harmonised to mitigate inequities. In England, although there is universal coverage for gamete and embryo cryopreservation for patients with cancer, there is regional variability in the eligibility criteria and duration of storage—coverage is typically better in regions with better socioeconomic status. In Scotland, Northern Ireland and Wales, there is a national policy for equitable reimbursement for cryopreservation of embryos and gametes for people with benign or malignant conditions undergoing treatments that can impair fertility. Scotland also offers cryopreservation of ovarian and testicular tissue.[143] More uniform reimbursement will mitigate inequities and improve access. "These services are in demand and positively valued by the patients themselves and should be part of the hospital's healing process," says Ms Sánchez. "I firmly believe that these types of treatments should be financed by the same laboratories and pharmaceutical companies that are responsible for the production of antitumor medications."

Women with breast cancer experience various challenges with returning to work and reintegration into society. Europe's Beating Cancer plan emphasises the importance of vocational rehabilitation and social integration for these women.[144] A longitudinal mixed methods study in Germany called B-CARE is studying breast cancer survivors five to six years after diagnosis to understand determinants of rehabilitation use, return to work, employment patterns, and voluntariness and satisfaction with job changes.[145] German experts describe a return-to-work counselling programme where a case manager accompanies the patient throughout the process of professional reintegration, offering both digital and in-person support. "Person-centred care to combat the economic impacts as well, is very important," says Frances Fitzgerald, a former member of the European Parliament and chair of Transforming Breast Cancer Together. "We at Transforming Breast Cancer Together work with an organisation, Working with Cancer in the UK, to talk to individuals who do have cancer about what they might need from their workplace, and to talk to workplaces about how to adapt."

Women with breast cancer are disadvantaged regarding social and financial rights. "More rights should be given to post-cancer patients: the right to adoption, the right to mutual health insurance and the right to private health insurance that is equal to those who have not had cancer before," says Dr Peccatori. The right to be forgotten, meaning that the person will not be penalised on an ongoing basis by health insurance for having been a cancer patient at some point, is currently implemented among some countries in Europe. These include the Netherlands, Italy, France, Cyprus, Spain, Portugal and Romania, though Ms Fitzgerald notes that broader implementation across all countries is necessary.

"The right to be forgotten is particularly important for breast cancer patients, who may have high chances of cure compared to other cancer types," says Dr Battisti. "However, they may still face questions about their cancer history or struggle to access insurance or specific benefits due to a cancer diagnosis from

> **“Currently, most European countries have national cancer registries that collect information upon diagnosis, including tumour markers and treatments. However, often, the only subsequent data point collected is death. This makes researching the treatment journey difficult.”**
>
> Siobhan Gaynor, Member, Cancer Trials Ireland (CTI) and Breast International Group (BIG) against Breast Cancer Patient Partnership Initiative and a metastatic breast cancer patient

five, ten or fifteen years ago, despite it being very curable. This issue feeds into the broader challenge of reintegrating cancer patients into normal life after their treatment journey.”

The European parliament has laid the foundation for broader implementation by adopting the EU consumer credits directive in September 2023. This is a non-binding code of conduct, according to which EU countries are advised not to allow the use of oncological disease data to determine health insurance coverage after a particular time period has passed following the end of medical treatment. There is flexibility for countries to determine the time frame, but the directive recommends not exceeding 15 years.[146] France applies a time frame of five years after the end of treatment for the “right to be forgotten” and the European cancer community calls for this to become the norm across Europe.[147] In 2023 Italy followed suit by passing the “Oncological Oblivion Law”, which allows patients with cancer to not share their oncological history with banks, insurance companies or adoption agencies, provided five to ten years have passed since the successful end of their treatment.[148]

Opportunities for adopting data-driven change

There is a need to develop robust cancer registries that capture comprehensive women-centric data across European countries. “Currently, most European countries have national cancer registries that collect information upon diagnosis, including tumour markers and treatments,” says Ms Gaynor. “However, often, the only subsequent data point collected is death. This makes researching the treatment journey difficult.”

To better understand the person-centredness of care being provided in breast cancer centres, EUSOMA recommends the routine use of validated patient-reported outcomes (PRO) questionnaires at baseline and follow-up, with a minimum completion standard of 20% and a target of 40% in specialist breast centres.[149] Only a few countries in Europe routinely collect patient-reported outcomes measures (PROMs). Of our countries of focus, only Wales routinely collects PROMs data as part of the cancer care pathway.[150] Belgium, Denmark, Finland, Netherlands and Norway have integrated PROMs into their registry data. Elsewhere, regions of Spain are making headway by rolling out e-forms to collect PROMs. “In Catalonia we are creating a repository of PROMs so that all clinicians can have an electronic folder that all citizens can access,” says Dr Borràs. However, PROMs data collection needs to be harmonised, and questions should be included that accurately reflect the concerns and needs of women with breast cancer. Additionally, to encourage patient engagement, providers should explain the purpose of completing PROMs forms and how completing them will enhance the patient’s care. Several concerns at the provider level also need to be addressed to engage the workforce in data collection, including the need for additional time spent by providers to collect and analyse data, reduced face-to-face time with patients that impacts physician-patient relationships, redundant work, and lack of trust and confidence in the utility of PROMs.[151]

Experts note that clinical research is heavily focused on evaluating treatment response and survival, whereas issues important to women such as side effects, toxicity, safety and quality of life considerations with treatment are under-researched, highlighting a data gap. “Clinical trials have developed extraordinarily because now both the professional world and the patient community are very involved,” says Dr Cervantes. “However, I think there are still useful tools to be developed to help patients live longer and better, to consider aspects that are priorities for patients. For example, there are very few cases of regulatory approvals because there was a benefit exclusively for parameters measured by patients. And this is something that needs to be extended."

Dr McIntosh agrees: "Research is often driven by what researchers think is interesting, rather than by what patients think is important, and I think that's something that we really do need to get around. And we need to ensure that our patients, our patient advocates, our patient partners are involved in the design and development of clinical trials, so that they are actually meaningful and looking at questions which are important to patients, rather than to researchers or pharmaceutical companies."

Between 2020 and 2022, the UK Association of Breast Surgery and the James Lind Alliance, a non-profit organisation, undertook a priority-setting exercise to identify a set of questions related to breast cancer care that were deemed important to healthcare professionals, women with breast cancer and their caregivers. Women with breast cancer and those at high risk of the disease prioritised questions relating to support and informed decision-making, whereas healthcare professionals focused on treatment-related questions like de-escalation of surgery for low-risk lesions. The top identified questions from this exercise for both patients and healthcare professionals were included as research questions that will inform future research strategies for breast cancer surgery in the UK.[152]

Other initiatives also exist. "At Breast International Group [BIG], we have set up the Patient Partnership Initiative, which is a group of patient advocates who have had or currently have breast cancer, some of whom have metastatic breast cancer," says Ms Adam. "We involve our patient partners at all stages of the trials that we conduct at BIG, so we ask them for their input when we design new concepts; we ask them, do you think that this question is relevant to patients, is there something about the proposed trial design that you would change? We involved them throughout the trial, and once the results are reported, we ask them to help us make the results more understandable for other patients."

There can also be significant gaps in patient awareness and participation in clinical trials, with widespread stigma and lack of information on alternative treatments. "It can be difficult for patients to know what trials are available—they get diagnosed and then, within their hospital, if there are trials running, they get offered those clinical trials," says Dr Cruickshank. "Sometimes I'm not sure they fully understand what they're signing up for. Cancer Research UK excels here, with their directory on their website, where you can input information about your tumour and find clinical trials registered in the UK."

Dr De Laurentiis also describes the challenges in explaining to patients the potential benefits of participating in randomised trials, which he terms "advantageous uncertainty." BIG is one organisation that has been developing videos and educational material for patients that explains the study design in a simple, straightforward fashion to support informed consent.[153]

Conclusion: a call to action

Breast cancer serves as an example of how advances in care have significantly improved disease outcomes. However, women-centricity in breast cancer care is still a relatively new concept, and the needs and preferences of women relating to quality of life remain largely unaddressed. Although the policy landscape across Europe has begun to incorporate a women-centric approach, gaps are seen in implementation. Our research defines women-centricity in breast cancer care and proposes a roadmap to facilitate its implementation within healthcare systems and the treatment journey. The refining of this roadmap and successful implementation would require four key actions.

Adopt a universally recognised definition of women-centric breast cancer care

An important impediment to effective women-centric breast cancer care is the absence of a unified definition. Although working definitions have been proposed, there is a need for a more widely accepted and unified definition such as the one proposed in this report, and for this definition to be used in both policy and practice. Key national and international societies need to adopt such a definition and include it in their breast cancer treatment guidelines to increase visibility of women-centricity among healthcare providers.

Co-create women-centric solutions for breast cancer care

Women should play a key role in designing women-centric solutions. The involvement of breast cancer patient organisations in co-creating cancer control plans, co-designing implementation programmes, and developing personalised management strategies, educational materials, decision aids and healthcare provider training programmes for improving women-centricity will ensure that women are heard throughout the care pathway. Such involvement needs to be balanced against an over-reliance on patient organisations and the understanding that these women may not be representative of the entire cohort of women or people with breast cancer. Greater efforts must be made to seek opinions from women of disadvantaged or minority backgrounds to ensure inclusivity.

Develop a women-centric care toolkit for healthcare professionals

“To be able to provide women-centric care, healthcare professionals need the tools to do that,” says Sara Cerdas, a former member of the European Parliament. Our roadmap proposes interventions along the care pathway that can be deployed to enhance women-centricity, and suitable tools should be designed to support this roadmap. Such tools could include: 1) easily accessible guidelines for managing survivorship issues such as sexual, reproductive and psychological concerns; 2) clearly defined referral pathways for psychosocial, rehabilitative and reproductive care; 3) easily accessible programmes for supporting vocational rehabilitation; 4) provision of approved apps for raising awareness among women and offering support during treatment; 5) electronic and paper options for collecting PROM and PREM data; and 6) regular training programmes for providers regarding communication, shared decision-making and women-centric care.

Invest in high-quality data collection and research cost-effectiveness of the women-centric care model

Risk-adapted and personalised screening and surveillance strategies could further enhance the women-centricity of care. More research is needed regarding their impact on outcomes, cost-effectiveness and acceptability among women before wider implementation. Therefore, greater investments need to be made to enhance complete data collection for registries that not only record findings at diagnosis and mortality, but also capture the various stages of the care pathway in between. Improving electronic capability to collect PROM and PREM data, with subsequent integration into cancer registries, can offer more robust information on women’s experiences. Eventually, the development of complete and unbiased data sets will support harnessing AI for further analysis to support recommendations.

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