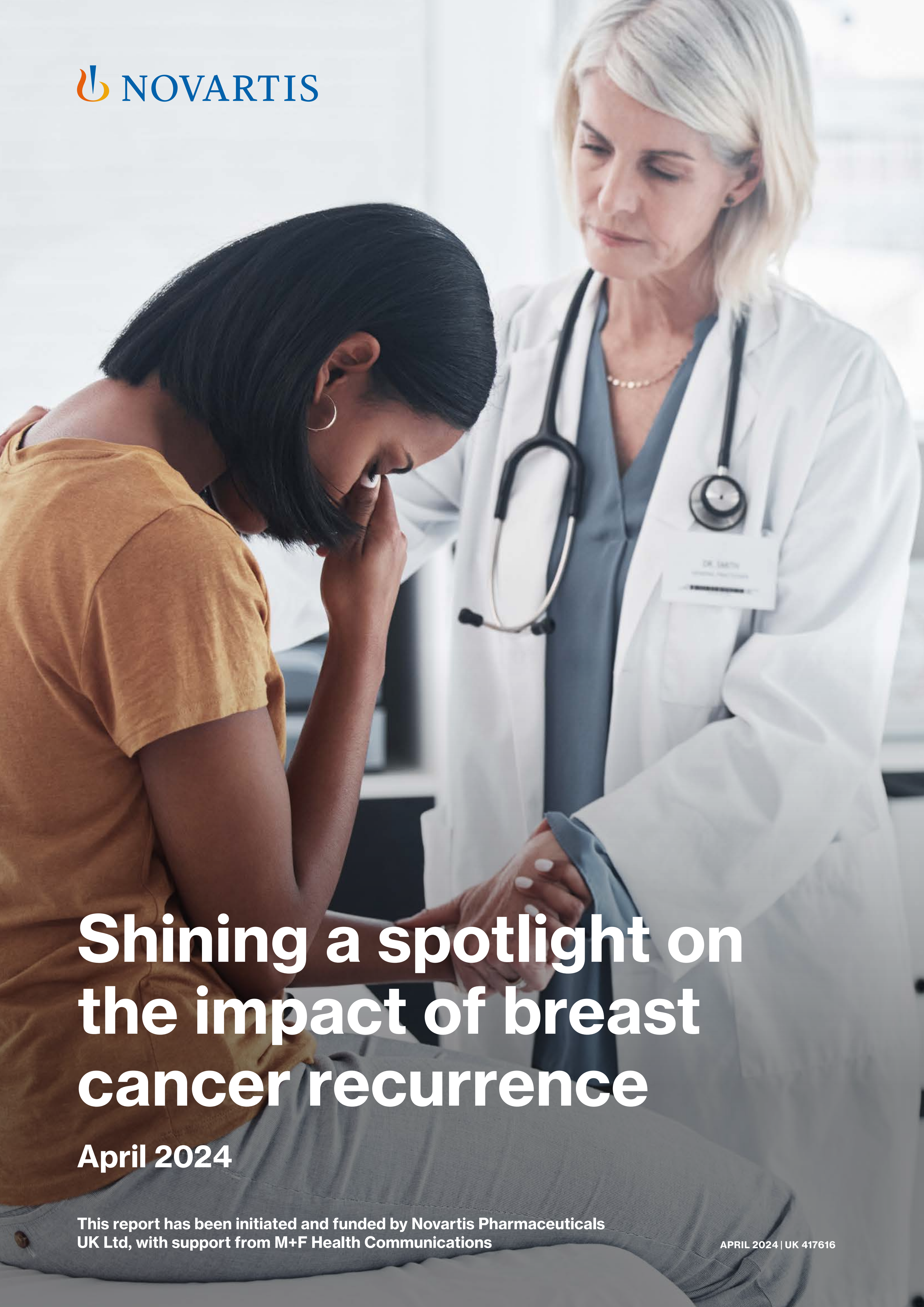

Shining a spotlight on the impact of breast cancer recurrence

April 2024

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Contents

Executive Summary

Whilst breast cancer outcomes have improved considerably in recent years, driven largely by the focus on early diagnosis and the wider availability of new and innovative treatment options, there is a growing recognition of the need for greater emphasis on the later stages of the disease pathway if this improvement is to continue in the coming years. This particularly applies to the prevention, treatment and management of recurrent breast cancer.

This area requires significantly greater attention due to its growing and profound impact on patients, their families and carers, and NHS services more widely. As well as the devastating and at times terminal impact of a diagnosis of recurrent breast cancer, particularly when this has progressed to incurable metastatic breast cancer, women who have been treated for primary breast cancer typically face a lifelong risk of disease recurrence, which imposes a significant, yet often ignored impact upon their mental well-being.

As we look to improve patient care and outcomes for all patients with breast cancer, at whatever stage of the disease, it is vital that sufficient consideration is also given to breast cancer recurrence, to help better understand its true burden, as well as the steps that are needed to reduce this.

The following report, informed by input from leading stakeholders from across the breast cancer care community, including nurses, consultants, and patient group representatives, seeks to shine a spotlight on this burden and set out key areas for improvement. The recommendations it lists can help to inform the development of a more comprehensive national vision for the prevention, diagnosis, and treatment of breast cancer recurrence.

Recommendations

1. The overall emphasis of breast cancer policy needs to expand beyond early diagnosis and incorporate a greater focus on the later stages of the disease pathway, including the management of breast cancer recurrence.

2. Joined-up action across breast cancer stakeholders is needed to accelerate the adoption of solutions to the system anti-cancer therapy (SACT) capacity challenges to ensure that patients can maximise the benefits of therapies that reduce the risk of recurrence or treat recurrent breast cancer.

3. There needs to be improved access to tailored mental health support for patients who are in the later stages of the breast cancer pathway to help them manage both the fear and a diagnosis of recurrence.

4. Conversations about the risk of recurrence between patients and healthcare professionals should be given sufficient time and attention, and incorporate the following core elements:
    - take-away information about the risk of recurrence.
    - guidance on adherence to therapies and lifestyle advice that can reduce a patient’s risk of recurrence.
    - information to empower patients to recognise the signs and symptoms of recurrence

5. Ongoing evaluation of Patient-Initiated Follow-up (PIFU) approaches is needed to assess their suitability for patients who are at high risk of breast cancer recurrence.

6. There needs to be improved data collection across the pathway to better understand the true burden of recurrent breast cancer with appropriate incentives in place to ensure that this is consistent across local areas

Chapter 1

What is breast cancer recurrence and how does it impact patients and the NHS?

What: When primary breast cancer is successfully treated, patients are considered 'in remission' or 'all clear'. However, it is possible for the cancer to come back; this is breast cancer recurrence.[1]

When: The risk of recurrent breast cancer peaks within the first few years after treatment, however, this risk remains significant up to 20 years post diagnosis and never completely goes away.[2,3,4] The signs of cancer recurrence depend on where the cancer resurfaces, but common symptoms include changes to the breast/chest area, weight loss, breathlessness, pain in the bones, headaches, or feeling more tired than usual.[5]

Where: There are three main types of breast cancer recurrence, depending on where the cancer returns, including:

- **Local:** The cancer returns in the same area as the original tumour
- **Regional:** The cancer returns near to the original tumour, such as in the lymph nodes of the armpit or in the collarbone area
- **Metastatic:** The cancer returns in a part of the body away from the breast, such as the liver, bones or brain

Why: All breast cancer patients will face a different risk of recurrence dependent on the size, type, grade and features of the cancer. Specific characteristics than can increase your risk include lymph node involvement, large tumours, and being aged under 35.[4] Strategies to reduce this risk include lifestyle changes and certain medications known as 'adjuvant' treatment.

How: Some breast cancer cells manage to evade the initial treatment cycle and enter a state of dormancy. They may grow and divide during this time but remain stagnant, meaning they are difficult to detect. These dormant cells can then reawaken and lead to the development of new tumours in the same or a different part of the body.[6]

Impact on patients and the NHS

Despite improvements to outcomes in recent years, breast cancer continues to impose a **significant burden** on both the individual and the NHS and it remains the **biggest killer of women under 50.**[7] A substantial if often unconsidered part of this burden relates to the incidence of **breast cancer recurrence**.

Impact of breast cancer

10mins

Breast cancer is the most common form of cancer in the UK with one woman diagnosed **every 10 minutes.**[8]

70,000

Around **55,000 people** are diagnosed with breast cancer each year, expected to **rise to nearly 70,000 by 2040**[8]

24%

Incidence rates have **increased by 24%** since the early 1990s.[6]

14% → 5%

The risk of dying from early breast cancer within **5 years is currently estimated to be around 5%**, compared to 14% in the 1990s.[9]

Impact of recurrence

Breast cancer recurrence is a growing but under appreciated part of the overall breast cancer disease burden, with shortfalls in national data collection creating challenges when it comes to reaching an accurate figure of the number of people who experience a recurrence.

According to the latest estimates, just over **1 in 5 women** diagnosed with breast cancer will experience a recurrence of their cancer.[10]

27%

Patients who relapse with distant metastases face a terminal diagnosis, and within this cohort the five-year **survival rate is just 27%.**[11]

60,000

In the UK there are estimated to be nearly **60,000 patients** living patients with metastatic breast cancer, many of whom will have developed this following a recurrence.[12]

Impact on the economy

£2.6 – £2.8 bn

In 2024, it is predicted that breast cancer will cost the UK economy **£2.6 – £2.8 billion**.[13]

2034

£3.6bn

In line with current trajectories and if nothing is done to reduce the impact of the disease, this could **rise to £3.6bn** per year by 2034.

£17.5bn

The wider wellbeing costs attributed to patients' illness and early mortality in breast cancer are estimated to **£17.5bn.**[14]

£££

There is a similar lack of data on the specific costs associated with the treatment of recurrence, however these patients will typically require **more costly care** due to the likely progression to later stage disease.[14]

£400 – £800

Indeed, it is estimated that the treatment of advanced forms of breast cancer incurs between **c.£400-800 additional costs** per patient per month, compared to stable disease that has not spread to other parts of the body.[15]

Impact on mental health

81%

The risk of recurrence also has a significant mental health burden and according to recent Novartis polling, **81% of breast cancer patients** experience a fear of recurrence.[16]

1 in 5 say that the fear of recurrence impacts both relationships with their partner and leisure time, hobbies, and travel plans.[17]

69%

Personalised and in-depth conversations between patients and healthcare professionals can help to overcome the fear of recurrence, and **69% of patients** would like to receive more takeaway information on this risk.[17]

Chapter 2
The current policy landscape

A focus on early diagnosis

The current cancer policy landscape is dominated by initiatives focused on improving early diagnosis. This was most clearly defined in the NHS Long Term Plan, which established the ambitious target of diagnosing 75% of cancers at stage 1 or 2 by 2028.[17] Whilst performance against this target has not increased at the required rate, with just over 50% of all cancer diagnoses currently coming at the earliest and most survivable stages, NHS leaders have repeatedly reiterated their commitment to it and it continues to sit at the heart of national cancer policy.[18]

This focus on early diagnosis was further embedded following the recent changes to cancer waiting time standards. Since October 2023, there are now just 3 core measures, reduced from 10, to assess cancer performance including:[19]

- **The 28-day Faster Diagnosis Standard**
- **The 62-day Referral to Treatment Standard**
- **The 31-day Decision to Treatment Standard**

This streamlining was justified on the grounds that it will enable more patients to be referred 'straight to test pathways', particularly due to the removal of the two-week wait target for suspected cancer in favour of the faster diagnosis standard.[19] The changes notably saw the removal of the one specific target for breast cancer, with systems no longer expected to meet the maximum two-week wait for breast cancer patients to be seen by a specialist.[20]

The Government's forthcoming Major Conditions Strategy, due for publication in the coming months, is expected to be largely complimentary of these existing initiatives. Indeed, the recently published Major Conditions Strategy framework emphasised the importance of NHS England's 'comprehensive early diagnosis strategy' alongside wider work targeted at the key risk factors for the disease and enabling people to live well with cancer.

Implications for breast cancer

This focus on early diagnosis has naturally been at the heart of recent breast cancer policy initiatives, namely the NHS Breast Cancer Screening Programme and the parallel efforts to increase breast cancer symptom awareness.

The current scope of the Breast Cancer Screening Programme includes all women aged between 50-70 and women are invited to take part every three years.[21] Women over 70 women can continue to be screened every 3 years but they won't be automatically invited and need to contact their local screening service, although in Scotland this offer ends at 75.[20] Uptake in 2021/22 was around 65%, compared to 72% in 2019/20, with coverage beginning to increase again after the disruption during the pandemic.[22] Operational since 1988, the screening programme is estimated to save around 1,300 lives each year, with one life saved for every 200 women who are screened.[22] As a result of the screening programme, breast cancer is one of the better performing cancers (behind testicular and skin) when it comes to early diagnosis across the UK, with 70% of cases being diagnosed at stage 1 or 2.[21]

Alongside efforts to increase uptake of the screening programme, there has also been a concerted effort to increase awareness of the signs and symptoms of breast cancer. Breast Cancer Now's 'Touch, Look, Check' campaign has been particularly effective, encouraging people to report anything new or unusual to their GP.[23] The NHS also recently announced a first of its kind partnership with Morrisons to put advice on underwear labels around the symptoms of breast cancer.[24]

The Government's 2022 Women's Health Strategy reinforced this prioritisation, with a further £10 million allocated to the breast cancer screening programme to provide 25 additional mobile screening units. These units have been set up in the areas with the greatest challenges around uptake and coverage, as part of a broader approach to tackling the health disparities associated with breast cancer. The strategy also brought welcome investment in new ultrasound and x-ray technologies to improve the detection of breast cancer.[25]

Despite the Government's recent transition away from more bespoke health strategies, the commitment to the Women's Health Strategy appears to be secure with a number of relevant measures announced in July last year as part of a one-year progress update. This included the launch of a new women's health area on the NHS website, funding for Integrated Care Systems (ICSs) to establish women's health hubs, and the establishment of a new network of women's health champions, led by the Women's Health Ambassador for England, Professor Dame Lesley Regan.[26]

Due to this focus on early diagnosis, combined with the impact of research and the availability of new treatments for the disease, breast cancer outcomes have improved significantly in recent years.[27] Indeed, the average risk of dying from breast cancer in the five years following a diagnosis has fallen from 14% in the 1990s to around 5% by 2020.[28] Women are therefore now 66% less likely to die from the disease within the first 5 years than they were 30 years ago.[9]

However, it is important to acknowledge the need for further progress, particularly given breast cancer's ongoing status as the biggest killer of women under 50 in the UK.[28] 11,500 women die from breast cancer each year, with 1 in 7 women being diagnosed with the disease at some point in their lifetime.[29]

What about recurrence?

The recurrence of breast cancer is a significant contributor to this overall disease burden from an economic, health system and quality of life perspective. The risk of recurrence typically peaks within the first few years after treatment, but remains significant up to at least 20 years post diagnosis and never completely goes away.[2,3,4] Around 1/5th of women with breast cancer are likely to experience this devastating news and within this cohort, the five-year survival rate is just 27%.[8,9]

Many patients who develop a recurrence will progress to metastatic breast cancer which still represents the 'poor relation' of the disease, when compared to primary breast cancer, according to stakeholders who were consulted during the development of this report.[8,9] Recent campaigning led by Breast Cancer Now and METUPUK has highlighted how these patients do not have access to the same level of support and information as those with primary breast cancer.

As a result, there is a real need to consider initiatives that could help to improve the prevention, diagnosis, and treatment of breast cancer recurrence, as part of the wider strategy for tackling the disease. Enhanced secondary prevention strategies have a particularly key role to play, as although patients are never completely free from the risk of recurrence, steps can be taken to reduce this risk and ensure that patients are identified early to prevent progression to metastatic forms of the disease. There is an opportunity to do this through defining a more comprehensive vision for breast cancer recurrence that can be applied to all different stages of the breast cancer pathway.

Recommendation

1. **The overall emphasis of breast cancer policy needs to expand beyond early diagnosis and incorporate a greater focus on the later stages of the disease pathway, including the management of breast cancer recurrence.**

Chapter 3
The current treatment landscape

In recent years a growing number of breast cancer treatments have become available that have demonstrated their potential to improve both the prevention and management of breast cancer recurrence. Many metastatic breast cancer patients, who are still presented with an incurable and life-limiting diagnosis are now able to live well with the disease for several years whilst there are several treatments that can actively reduce a patient's risk of developing a recurrence.[30]

Adjuvant endocrine therapy, for example, is associated with a 50% reduction in the risk of breast cancer recurrence and is now widely used across the NHS, with around 45,000 breast cancer patients benefitting from this treatment every year.[31,32] In the case of metastatic breast cancer, combination therapies are playing an increasingly important role in enabling patients to lead a relatively normal life.

The greater availability of these new treatments, combined with their impact on improving outcomes, is however placing growing pressure on already stretched oncology departments. Since 2017, 20 new drugs for breast cancer have been approved with 7 approved in 2022 alone.[33] The number of breast cancer treatment courses increased to over 300,000 during 2021/22, compared to around 250,000 during 2018/19.[32] Many of these new treatments are also more complex, with various additional delivery, monitoring and follow-up requirements that further add to staff workloads. Representatives from the nursing sector, who were consulted as part of the report, also highlighted how due to these pressures there are limited opportunities to learn about the application of new treatments, undermining their potential benefits.

Taken together, this has contributed to a system-wide SACT capacity crisis, which has the potential to be especially acute across breast cancer services with 46% of breast clinical oncologists due to retire within the next 10 years.[32] Indeed, there were reports from the frontline last year that this decline in consultant numbers was already starting to have an impact leading to delays in the implementation of NICE-approved treatments for breast cancer. To mitigate against these delays patients are often being forced to travel much further for treatment with knock on effects on both patient and staff wellbeing.[38]

Hospitals and oncology departments are facing particular challenges when it comes to the treatment of patients with recurrent breast cancer that has progressed to metastatic disease. The number of hospital episodes from the disease doubled from 500,000 – 1m between 2016-21, whilst there are estimated to be 57,215 women living with metastatic breast cancer alone, far higher than the previous assumption.[32] Going forward, stakeholders involved in the development of this report emphasised how more traditional models of breast cancer care are proving to be increasingly unsuitable for this growing patient population, particularly as many will be living with the disease for several years and therefore require a different kind of support. It was suggested that this could involve shifting to a more community-based approach that empowers patients to take a more active role in their care. This could also take advantage of recent innovations, such as electronic patient reported outcomes measures (e-PROMS), to enable more self-administration and self-reporting of treatments.

Concerted efforts are being made by NHS England and the broader cancer stakeholder community to address these pressures and as part of this work it is vital that specific attention is directed towards the later stages of the SACT pathway.

More broadly, all future drug approvals need to be accompanied by capacity reviews to assess the additional workforce and infrastructure that will be required to deliver a treatment to a specific patient population. This will ensure that we can continue to capitalise on the benefits of new innovations and their potential to lead to a further improvement in breast cancer outcomes.

Recommendation

2. **Joined-up action across breast cancer stakeholders is needed to accelerate the adoption of solutions to the system anti-cancer therapy (SACT) capacity challenges to ensure that patients can maximise the benefits of therapies that reduce the risk of recurrence or treat recurrent breast cancer.**

Chapter 4

The significant mental health burden of recurrence

Breast cancer survivors can experience feelings of uncertainty and psychosocial issues, which has a significant impact on their quality of life. Breast cancer survivorship is often associated with 'raised risks of anxiety, depression, fatigue, sleep disorders, pain, and sexual dysfunction, persisting well into the survivorship period'.[35] Understandably, some of this anxiety is driven by the fear of recurrence.

For those patients who are then assessed as being at high risk of, or who have received a diagnosis of, recurrent breast cancer, the impact on their quality of life and mental health can be substantial. Understanding both the changing physical and mental health needs of these patients is therefore needed to offer timely, targeted interventions at this point of the breast cancer care pathway, where there remains considerable unmet need.

Mental health and anxiety around the fear of recurrent breast cancer

As NICE notes, the 'initial diagnosis [of breast cancer] is distressing and the fear of the cancer returning is a common cause of stress and anxiety for patients and their families. This is because of the need to have further treatment or the possibility of progression to non-curable metastatic disease.'[36] For breast cancer survivors, support is therefore needed to help manage the fear and anxiety that their cancer will return.

According to a recent YouGov survey, commissioned by Novartis, 81% of breast cancer patients in the UK experience some fear of recurrence and for 1 in 5 women, this fear impacts both relationships with their partner and leisure time, hobbies, and travel plans.[16] Other studies have highlighted how this fear is often particularly pronounced amongst younger women, leading to a higher frequency of unscheduled visits to the GP, higher frequency of breast self-examination, and heightened feelings of anxiety around not having mammograms, ultrasounds or other forms of cancer screening in the past year.[37,38] There is also evidence that mothers, regardless of their ages or the ages of their children, experience greater fear of cancer recurrence and intrusiveness into their intimate life.[37,38]

Building Resilience in Breast Cancer (BRIC), hosted by the University of Reading, leads research on 'discovering new and better ways to practice resilience in women with either a primary or metastatic breast cancer diagnosis.' Hosting regular discussions with those who have received primary and metastatic breast cancer diagnoses, it provides a platform for conversations around anxiety, mental health, and the quality of life impact following a cancer diagnosis. On fear of recurrence, participants have shared on BRIC's blog that:[39]

- Although the fear of recurrence never goes away fully, the longer the period of time that has elapsed from a primary breast cancer diagnosis, the frequency of how often thoughts turn to recurrence and progression diminishes. However, it was also acknowledged that often fear and anxiety creeps up without warning after periods of time when they have had respite from it.
- Even when active treatment for primary breast cancer has finished, individuals have to manage a loss of confidence in their previously healthy body, creating anxiety and fear about the future.
- Family and friends want to think of them as being 'fine now', because they may not possess the insight into recurrence that patients do. This may also be due, in part, to active treatment regimens finishing resulting in the individual's physical appearance generally looking well.

Novartis' own research shows that the area where the greatest number of patients who have received a diagnosis of early breast cancer feel that they are not getting as good a level of care / service as they should, was with regards to access to mental health support.[40] In fact, 58% rated the level of support offered as 'insufficient'.[40] This is despite evidence showing that at the point of diagnosis, the resource / type of support most wanted by patients with early breast cancer was mental health support and counselling (65%).[40]

Our interviewees told us that for the patient, moving between treatment for breast cancer to self-management is often where the worry and anxiety starts to emerge, as they miss the safety net of regular contact with their oncologist. It is at this point that they can have trouble finding the right balance between moving on and retaining hypervigilance about symptoms of recurrence. They also told us that there is significant variation in access to mental health support, with clinical nurse specialists often required to provide much of this pyschological support.

UK patient advocacy groups provide much-needed support to patients to help them move forward after breast cancer and help address their mental health needs at each stage of the care and treatment pathway. One good example of this is Breast Cancer Now's BECCA app. In addition, the charity's forum allows individuals to share their concerns with others in a similar situation.

Based on a sample of thirty-one patients with a diagnosis of early breast cancer, 90% said that they would want to know how likely it would be that their cancer might come back. Only 3% said that they would not want to know.

Novartis research[40]

Mental health and anxiety around diagnosis of recurrent breast cancer

Diagnosis with breast cancer recurrence can be devastating, often bringing high levels of stress. When breast cancer recurs, the feelings experienced after the first diagnosis can resurface, sometimes even stronger than before.[42] As it can be a shock to find out that the cancer has come back, individuals need to be allowed the time to deal with and understand the information given to them by healthcare professionals.[43]

All individuals with recurrent breast cancer need tailored interventions to support them with the severe effects of the disease on their quality of life. Interventions may vary owing to the type of recurrence, for example, an individual who has progressed to metastatic breast cancer will have unique needs in comparison to someone with local breast cancer recurrence. One of our interviewees told us that receiving a diagnosis of recurrent breast cancer is a ‘very different experience’ to the initial diagnosis, particularly when this has progressed to being metastatic. At this point it can feel that there is no escaping the endless cycle of more treatments and varying side effects, alongside a decline in quality of life with the introduction of each more aggressive line of therapy.

Our interviewees also reported that people with metastatic breast cancer often do not have the support of a clinical nurse specialist, despite it being particularly important for this patient group. These individuals will be on lifelong treatment and often have very complex emotional and supportive care needs.

Recommendation

3. **There needs to be improved access to tailored mental health support for patients who are in the later stages of the breast cancer pathway to help them manage both the fear and a diagnosis of recurrence.**

Chapter 5

Opportunities for better conversations between patients and healthcare professionals

Honest, open and thoughtful conversations between patients and healthcare professionals about the risk of recurrence can play a key role in helping patients to overcome this fear.

Getting the balance right

Novartis research has shown that patients with a diagnosis of early breast cancer are often focused on the immediate treatment steps and returning to their normal lives, sometimes unaware of the possibility of cancer recurrence after completing initial treatment.[44] Ensuring a greater understanding that they are at high risk of recurrence and specifically what the treatment options are, could empower more patients to make informed decisions about their healthcare.

For healthcare professionals, it is therefore important to identify who is high risk and be thoughtful in how and when the information is communicated to patients and caregivers. This is particularly important as the research showed that understanding and perception of the risk of recurrence varies for each patient and is based on a number of factors, including age, diagnosis, and level of health literacy.[43]

The conversation is undoubtedly challenging as healthcare professionals are typically presented with the difficult balancing act of raising awareness sufficiently so that patients are able to monitor for the signs and symptoms of recurrence, but not contributing to prolonged anxiety that can hold people back and prevent them from moving on. Despite this anxiety, patients would generally rather receive more information than less with 69% of patients reportedly keen to receive more takeaway information about the possibility of their cancer coming back.[16] The point at which this information is delivered is also crucial, with the discussion around the risk of recurrence often being brought up quite early meaning it can get lost amongst the information being given regarding immediate treatment. Resuming this conversation at a later stage in a patient's journey can help to ensure that it is afforded sufficient time and attention.

Stakeholders who were consulted during the development of this report highlighted how there has been significant progress in recent years to ensure that patients are aware of the risk of recurrence, but that there is still widespread variation in the quality of information that is dispensed during these conversations.

More broadly, there is a seemingly significant gap between patients and healthcare professionals in the perception of the degree to which quality of life is being discussed during appointments. A recent European study, which included data from NHS trusts, found that 34% patients were never asked about their quality of life during follow-up appointments with oncologists, increasing to 56% during appointments with nurses.[45] This is despite 88% of oncologists and 92% of nurses believing that this topic is addressed.[44]

Ultimately, more needs to be done to embed this in national cancer strategies and guidelines on breast cancer care.

Delivering more standardised lifestyle, symptom and adherence advice

Whist all conversations about the risk of recurrence should be personalised to individual patients, there are certain elements that must be incorporated including guidance on the signs and symptoms of recurrence, support with treatment adherence, and advice on the specific lifestyle changes that patients can make to reduce their risk. The more widespread dissemination of this information could play a key role in both reducing the incidence of recurrence and enabling rapid diagnosis following symptom emergence.

Work led by Breast Cancer Now has highlighted some of the shortfalls in this area, with just 13% of patients receiving sufficient information on the signs and symptoms of metastatic breast cancer. Similarly, according to the 2022 National Cancer Patient Experience Survey, only 57.5% of breast cancer patients are given information about the possibility and signs of their cancer coming back, the lowest amongst major tumor groups.[47]

For this reason, the signs and symptoms of recurrence would benefit from a more prominent place within NICE's guideline for 'early and locally advanced breast cancer: diagnosis and management' whilst patients should be equipped with better guidance on who to contact if they have any concerns.[48]

Another important aspect of these conversations relates to the provision of guidance on treatment adherence to ensure patients maximise the benefits of treatments that lower the risk of recurrence. This is particularly relevant given that non-completion of adjuvant treatment courses (<90% compliance) is associated with a 61% increase in the risk of recurrence over the next 8 years.[50] During these conversations, the impact of treatment discontinuation should be emphasised with enhanced monitoring put in place for patients who are more likely to be non-adherent. The side-effects of treatment should also be clearly explained to help mitigate against instances where these are particularly severe.

The signs of breast cancer recurrence can be divided according to two areas:[47]

1. **Changes to the breast or chest area such as:**
    - Swelling in the chest, armpit or collarbone
    - Changes in the size or skin texture of the breast
    - Emergence of a rash or lump
    - Liquid discharge
    - Nipple has become inverted
2. **Symptoms elsewhere in the body such as:**
    - Unexpected weight loss
    - Severe ongoing headaches
    - Dry cough
    - Fatigue
    - Pain in the bones

Lifestyle advice is the final key element and should be further embedded into the patient pathway. Regular physical activity, a healthy diet that is high in fibre and low in saturated fats, limiting alcohol, and maintaining a healthy weight all have the potential to reduce a person's risk of recurrence and can work alongside existing therapies.[51] Consultants involved in the development of this report lamented how across the system, there can be a lack of effort put into lifestyle advice following cancer care despite it being a relatively low cost intervention. In the context of breast cancer, patients should be provided with personalised wellbeing plans at the completion of their treatment. Where staff have insufficient bandwidth to support the development of these plans, patients should be directed to third sector organisations, such as Breast Cancer Now and Macmillan.

More broadly these conversations also need to emphasise that the risk of recurrence never completely goes away.

Patient initiated follow-up approaches

Having these personalised and in-depth conversations will also be crucial in the context of the broader system-wide shift towards patient-initiated follow-up approaches (PIFU).

These approaches are reliant on patients self-reporting any worrying symptoms and requesting to see their oncologist when they need them, rather than attending a regular set of follow-up appointments. PIFU approaches are increasingly being rolled out for breast cancer survivors to monitor for the signs and symptoms of a recurrence.

PIFU's are already conferring several benefits for patients, clinicians, and systems.[52] For patients, they will often feel more in control as services are better able to respond to their needs, whilst clinicians can benefit from more productive and meaningful appointments. At a system level, PIFU has demonstrated its potential to reduce waiting lists and the number of 'did not attends'.[46]

However, stakeholders referenced how these approaches may not always be appropriate, particularly for high-risk patients, and that they are reliant on patients knowing what to look out for and prompt onward referral following the emergence of symptoms. This prompt onward referral becomes challenging given the generally low awareness of the symptoms of recurrent breast cancer in primary care. Over half of GPs and practice nurses have difficulty linking non-specific symptoms with recurrent breast cancer, whilst over a quarter of patients have to see their GP three times or more before a getting a diagnosis of metastatic breast cancer.[53]

More work needs to be done to raise awareness of these symptoms, including directing healthcare professionals to the GatewayC programme, an educational platform which equips staff with tailored information to enable early cancer detection.[54] The platform now includes a specific module on breast cancer recurrence, providing guidance for HCPs on when to refer former breast cancer patients for further tests.

More research is also needed to assess the overall effectiveness of PIFU, particularly around whether it ensures that patients are presenting in the right setting. Stakeholders who contributed to this report raised some concerns that it has potentially led to an increase in the number of patients who are discovering that they have recurrent breast cancer following an emergency hospital admission.

Recommendations

4. **Conversations about the risk of recurrence between patients and healthcare professionals should be given sufficient time and attention, and incorporate the following core elements:**

- **take-away information about the risk of recurrence.**
- **guidance on adherence to therapies and lifestyle advice that can reduce a patient's risk of recurrence.**
- **information to empower patients to recognise the signs and symptoms of recurrence**

5. **Ongoing evaluation of Patient-Initiated Follow-up (PIFU) approaches is needed to assess their suitability for patients who are at high risk of breast cancer recurrence.**

Chapter 6

The urgent need for better data collection

Noteworthy progress has been made in developing accessible datasets that provide a clearer picture of cancer trends and performance against key targets.

These include:

- National cancer registries in Scotland, Wales, Northern Ireland and in England
- Hospital Episode Statistics (HES)
- the National Cancer Registration and Analysis Service (NCRAS)
- National Cancer Patient Experience Survey (CPES) datasets
- NHS Digital information on Cancer Waiting Times.

However, as recently noted by Cancer Research UK, whilst 'the data collected across the UK for cancer patients is world leading', there remain key differences across the four countries in terms of comprehensiveness and reporting timelines.[55] This suggests that there is still some way to go towards reaching a fully comprehensive picture of cancer in the UK.

With regards to breast cancer specifically, while good quality data is captured for primary breast cancer patients, data on recurrence and metastatic breast cancer has historically been lacking, particularly as these patients are not automatically recorded on the national cancer registries.[56,57]

For example, a 2016 report by Breast Cancer Care found that, at the time, 'two thirds of Hospital Trusts in England were not collecting data in full on their metastatic breast cancer patients', despite it being a mandatory requirement.[58] In addition, the report highlighted how recurrence of primary breast cancer and metastatic breast cancer were often grouped together in these local datasets, 'despite having clear and distinct differences.[57] This is a key challenge, as the needs of these patient cohorts differ hugely, with the potential for those living with recurrent primary breast cancer being overlooked. NCRAS therefore provides clear guidance for the recording of recurrence in cancer via Trusts' Cancer Outcomes and Services Data set (COSD) submissions.

> **"It is hugely important for many audits and national benchmarking projects that recurrent cancers are recorded correctly through COSD".[59]**
>
> National Audit of Breast Cancer in Older People, November 2021

However, interviewees told us that data collection remains variable and a long running issue, and that these limitations on collection have presented challenges for commissioners and healthcare providers alike in understanding their local patient populations, what their needs are, and how to plan services and support to meet these needs.

Indeed, for many years, the prevalence of metastatic breast cancer was thought to be around 35,000, until Professor Carlo Palmieri's paper, published at the end of 2022, put this figure at just below 60,000.[12] Interviewees referenced the possibility that this figure could still be an underestimation in line with the impact of new drugs which are enabling people to live longer with metastatic breast cancer.

Complete and up to date information and patient data is essential to identify where improvements can be made throughout the pathway, as well as to understand regional variation. An announcement in October 2022 was therefore welcomed that preparations were underway to commence two new national breast cancer audits, as the work of the National Audit of Breast Cancer in Older Patients (NABCOP) closed. The National Cancer Audit Collaborating Centre (NATCAN), run by the Clinical Effectiveness Unit (CEU) at the Royal College of Surgeons of England, has been tasked with developing these - the first will look at primary breast cancer, while the second will focus on metastatic breast cancer, for women and men of all ages.[60]

The National Audit of Primary Breast Cancer (NAoPri) will seek to bring together currently siloed information to support a 'comprehensive analysis of all aspects of breast cancer care' in England and Wales.[60] The second audit should, for the first time, provide accurate figures around the number of people in England living with breast cancer that has metastatised. The data captured through the audit will also provide insight into the experiences and needs of metastatic breast cancer patients and therefore support the NHS to design and plan improved, patient-centric services. Recognising the challenges that have gone before, the National Audit of Metastatic Breast Cancer (NaoME) audit will seek to collect data in a more systematic and comprehensive way.[60] Outputs from this audit are expected soon and stakeholders emphasised the importance of thinking about how this data will be applied in clinical practice.

In addition to this prevalence data, there are also hopes that the audit will improve understanding around how and where breast cancer patients are presenting following a recurrence, quality of life outcomes, and the effectiveness and complexities associated with different treatments. This presentation data will be particularly important when it comes to assessing the overall effectiveness of the PIFU model, and whether it is enabling effective diagnosis and onward referral following symptom emergence.

There have also been developments aimed at improving data collection in the devolved nations. Last year saw the publication of the Scottish Government's Cancer Action Plan for 2023-2026, which includes a commitment to improve data collection on metastatic cancers, with an initial focus on metastatic breast cancer.[61] In Northern Ireland, an audit on metastatic breast cancer is currently being conducted by the Northern Ireland Cancer Registry, funded by the charity Cancer Focus NI. [62]

Treatments datasets: are they keeping up with innovation within the breast cancer care pathway?

The SACT dataset, managed by the National Disease Registration Service (NDRS), collects SACT activity from all NHS England providers.[63] It has been designed to: provide a clear picture of patterns of systemic anti-cancer therapy use across England; understand resources required for service provision and support commissioning decisions; and link to other data sources, to provide a complete picture of the cancer patient pathway.[63] The data items cover: patient and tumour characteristics; trust and consultant details; treatment characteristics including drug names and drug combinations (regimens); and outcome fields.[63]

This collection of this data has significant implications for breast cancer care and could support the NHS to plan more effectively for new treatments and increase service capacity for adjuvant care accordingly. However, concerns from the Royal College of Radiologists have been raised around the dataset needing greater investment to ensure high quality data is collected.[34] The College recommends specific investment in SACT waiting time data, as well as the need for more granular data collection ‘for instance, breaking down curative and palliative treatment, and reporting time from surgery to SACT for adjuvant therapy.[34]

Recommendations

6. **There needs to be improved data collection across the pathway to better understand the true burden of recurrent breast cancer with appropriate incentives in place to ensure that this is consistent across local areas.**

Chapter 7
Glossary of terms

Early breast cancer - The cancer is small and only located in the breast tissue.

Primary breast cancer - Breast cancer that has not spread beyond the breast or the lymph nodes close to the breast, under the arm.

Secondary or Metastatic breast cancer - Breast cancer that has spread beyond the breast or proximal lymph nodes to other parts of the body. The common places for breast cancer to spread are the bones, lungs, liver, and brain.

Recurrent breast cancer - Breast cancer that has returned after a period of dormancy; whereby a collection of cancerous cells evaded initial rounds of treatment and survived, before multiplying exponentially to reform the cancer. Recurrent breast cancer may occur months or years after your initial treatment. The cancer may come back in the same place as the original cancer (local recurrence), or it may spread to other areas of your body (metastatic recurrence).

Local recurrence – Breast cancer that has returned in the same region of the body as initial the cancer, namely the breast or in the skin near scar tissue if a mastectomy or other breast surgery conducted.

Regional recurrence - Breast cancer that has returned in the areas close to the breast tissue, such as the chest wall, skin of the breast, or the lymph nodes around the chest, neck and under the breastbone, but has not yet spread to other areas of the body.

Distant (metastatic) recurrence – Dormant breast cancer cells have travelled to other areas of the body and proliferated leading to metastatic disease.

Remission – A reduction in or the disappearance of signs and symptoms associated with breast cancer.

Endocrine (hormone) therapy – Treatment regimens that slow or stop the growth of hormone-sensitive tumours by blocking the body’s ability to produce hormones or by interfering with effects of hormones on breast cancer cells.

Adjuvant therapy – Treatment given concurrent to or after main treatment to reduce the chance of cancer coming back by destroying any remaining cancer cells. It usually refers to chemotherapy, radiation therapy, hormone therapy, and/or immunotherapy given after surgery.

Combination therapy – Treatment regimens that combine two or more therapy types, such as chemotherapy and surgery.

Patient Initiated Follow Up (PIFU) – A patient initiates an appointment when they need one, based on their symptoms and individual circumstances.

Systemic anti-cancer therapy (SACT) – SACT is medication given to treat cancer. It is taken orally (swallowed) and comes as tablets or capsules. SACT can be taken at home, meaning patients don’t have to come into hospital to receive treatment.

Health literacy – Patients having the knowledge, understanding, skills and confidence to use health information, to be active partners in their care, and to navigate health care systems and treatment pathways.

Secondary prevention – Aims to reduce the impact of a disease that has already occurred through early detection and access to treatment, action to reduce the risk of recurrence and long-term management to enable people to return to their original health and function.

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