



## Review

## Breast cancer follow-up after a primary diagnosis: A confused picture

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## ABSTRACT

The follow-up care of people diagnosed with early breast cancer varies across the world. In the UK, services have evolved in an *ad hoc* way, with no standardized approach nationally. Some people are seen face to face at regular intervals, others are discharged at two years, while others are followed up over the telephone. This is creating confusion for patients as to what is best practice. The lack of evidence to support intensive surveillance is frequently cited as the main reason to reduce or indeed review the benefits of face to face clinical consultations in the hospital/community setting. In addition, a lack of specific recommendations in current guidelines compounds this. Although primary disease stage and treatment are strong indicators of survival, and time to recurrence (both local and distant) is extending, patterns of follow-up care in the UK differ depending on where you live. Yet, European and American guidelines, where survival is frequently reported as being better than the UK, continue to recommend follow-up at regular intervals as part of their overall management approach; to ensure new and changing ways of treating early breast cancer are initiated, managed and monitored accordingly. Indeed their guidelines are increasing rather than decreasing follow-up. While their health systems may differ, survival outcome reporting is not adjusted to reflect these differences.

This paper provides an overview of breast cancer follow-up guidance across the world and opens up a debate about whether patterns of follow up care will affect survival outcomes into the future.

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## 1. Introduction

Survival is a key metric of overall progress in cancer control [1] and female breast cancer survival is better than most cancers, with 78% predicted to survive their disease for ten years or more [2]. It is estimated [3] that 550,000–570,000 women are alive in the UK who have had a diagnosis of cancer. This figure is set to increase

further as the use of endocrine therapies are extended or switched between groups of drugs up to 10 years [4] and treatment for recurrent advanced disease becomes more targeted.

Improving survival through treatment, and, reducing the risk of the breast cancer recurring still remains the main goal of treatment but increasingly clinicians have to balance risk of the cancer recurring and risk of persistent and debilitating toxicities [5]. Risks associated with the cancer recurring are often difficult to quantify, or indeed explain as; “a risk is something that might happen in the future” [6], p.1] and predicting risk in breast cancer is not an exact science. Research on patterns and risks associated with recurrence

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are beginning to characterise this risk by breast cancer subtypes such as oestrogen receptor (ER), progesterone receptor (PR), HER2/ ErbB2 receptor (HER2), the absence or all three or triple negative breast cancer (TNBC). ER negative breast cancers are associated with a higher risk of recurrence during the initial five years but the risk of recurrence risk increases in ER positive for the next 10 years, and at 15 years the risk equals across the subtypes [7]. This risk unfortunately can continue up to and beyond 20 years [8,9].

Detecting early local recurrences or contralateral breast cancer, evaluating and treating therapy-related complications, motivating patients to continue hormonal treatments and providing psychological support and information in order to enable a return to normal life, whatever the new normal is, is consistently reported as the main purpose of follow-up care [10]. However, some would argue this is “aftercare” an essential part of patient care after treatment of cancer where the primary goal is to reduce disease burden by extending and improving quality of life [11]. The interchangeable use of the terms “follow-up” and “aftercare” is a source of confusion and conceptual understanding is unclear. While aftercare suggests a clear delineation at which treatment ends and care begins, it appears primarily focused during the intense period of recovery after primary treatment [12]. Follow-up suggests a more systematic approach whereby a continuation or observation of an individual is provided through contact between the patient and his/her treating clinicians in relation to the treated cancer.

The treatment of breast cancer is more complex than ever. Combining surgery±reconstruction, radiotherapy, chemotherapy, endocrine therapy or biological agents are common [13], and in most other areas of medicine, each would be eligible for follow-up in their own right. Commonly the aftercare of one treatment used in breast cancer overlaps with the active treatment of another, and physical and psychosocial problems are not isolated events after any one treatment but occur from the moment breast cancer is suspected, through treatment and beyond. Determining the beginning and end of follow-up is therefore difficult and may reflect the reason why follow up practices have become so variable across the UK.

Previous guidelines in the UK included substantial guidance about how follow-up care should be provided [14–16], but updated versions have been rather vague [17,18], leading to ambiguity about what is recommended practice, and therefore deemed best practice. While this may reflect a positive trend in overall survival, it has also left patients with breast cancer receiving very different follow-

up care, depending on the hospital or region where they live across the UK. Although NICE is widely respected, and often cited when difficult decisions in health and social care must be made, their guidance on follow-up is open to wide interpretation.

### 1.1. Review of breast cancer guidelines

The author reviewed breast cancer guidelines from across the world to understand how each country recommends follow-up surveillance. Guidelines for the management of early breast cancer were sourced from the following organisations: The National Institute for Clinical Excellence (UK) [18], Scottish Intercollegiate Guidelines Network (SIGN) [17], Cancer Care Ontario (CMA) [19], and National Comprehensive Cancer Network (NCCN, USA) [20,21], Comprehensive Cancer Centre the Netherlands (DF) [22]; European Society of Medical Oncology (ESMO) [10]; Australian National Breast and Cancer Centre (NHMRC) [23] and The Association of Breast Surgery (UK) [24].

## 2. Results

Table 1 shows the fifteen recommendations identified for action within the guidelines.

By mapping against these, the authors have established a picture of the range of guidance provided by different organisations across the world (Table 2).

The only consensus globally is the continuation of mammography. However, while the majority recommend annual mammography, BASO [24], based on research by Kaas et al. [25] and Kokko et al. [26] concludes that this could be either annual or bi-annual up to 10 years. The different conclusion based on the same evidence is unhelpful. No reference is made to the specific follow-up needs of women following bilateral mastectomy.

Four organisations recommend switching and/or extending endocrine therapy [10,18,20,24]. However in most cases this is not linked to any detail about appointments, and/or whose responsibility it is to enable it to happen. It is unusual for treatments to be changed or altered in other areas of medicine such as happens in asthma, cardiac, diabetic or respiratory conditions without a follow-up review built in to assess for efficacy, toxicity or adherence. However, it seems that patients with breast cancer don't receive the same service when changes are made. Although some may argue that being less prescriptive is more patient centred,

**Table 1**  
Categories associated with follow-up practice recommendations.

Category	Explanation
1. Clinical History	Assessment of factors affecting a patient's health status
2. Physical examination	Includes examination of the breast (s) or chest wall, regional lymph nodes and the arm on the treated side
3. Mammography	Specialized medical imaging that uses a low-dose x-ray system to see inside the breasts.
4. Pelvic examination	Gynaecological assessment
5. Patient education about recurrence	Specifically about the signs and symptoms of recurrence
6. Rehabilitation	Care that focuses on the functional, physical, psychological and social problems associated with cancer
7. Review new signs and symptoms/stratifying follow-up according to risk	A mechanism to refer new symptoms, primarily those associated with a local or regional recurrence
8. Preferred method described	By who, and in what setting (hospital/primary care)
9. Schedule stated	Frequency of appointments stated
10. Length of time to be followed up	Number of years or indefinitely
11. Endocrine switching/extending	An opportunity for Patients with ER positive disease to have endocrine therapy reviewed.
12. Data gathering of long-term conditions	Processes recommended to gather on-going data associated with outcomes
13. Referral system back to breast unit from primary care	Specific instructions about the process
14. Lifestyle factors	This includes active lifestyle, healthy diet, limited alcohol intake, achieving and maintaining ideal body weight
15. Bone density evaluation	This refers specifically to women on an aromatase inhibitor

**Table 2**  
Guidelines mapped against categories.

Guidance*	Clinical history	Physical exam	Mammography exam	Pelvic exam	Patient education about recurrence	Rehabilitation	Review signs and symptoms	Preferred method described	Schedule stated	Length of time to be followed up	Endocrine switching/ extending	Data gathering long term conditions	Referral system back to breast unit from primary care	Lifestyle factors	Bone density evaluation
BASO 2009			x			x	x		x	x	x		x		
NHMRC 2010	x	x		x	x	x		x	x	x				x	
DF 2010	x		x			x	x		x	x			x		
CMA 2012	x	x		x	x	x		x	x	x					
SIGN 2013			x												
ESMO 2015	x	x		x	x	x		x	x	n/a	x		x		x
NCCN 2016	x	x		x	x	x		x	x	n/a	x			x	x
NICE 2018													x		

BASO, British Association of Surgical Oncology (UK) (2009); NHMRC, National Health and Medical Research Council of Australia (Cancer Australia, 2010); DF, Dutch Breast Cancer Federation (2012); CMA, Canadian Medical Association (2005); SIGN, Scottish Intercollegiate Guidelines Network, (2013); ESMO, European Society for Medical Oncology (2007); NCCN, National Comprehensive Cancer Network (USA) (2014); NICE, National Institute of Clinical Excellence (England and Wales) (2018).

assumptions are being made that after a short consultation, woman and men fully understand the details of their new medication, possible toxicities, benefits and reporting.

A broad range of endocrine therapies are in use currently [27], In a review of survival data by McCowan et al. [28], those with low adherence to tamoxifen had a shorter time to recurrence, increased medical costs and worse quality of life. In addition, a review of endocrine therapies by Palmieri et al. [4] concluded that the extension of endocrine therapies beyond 5 years, including switching between groups of drugs up to 10 years will have implications for overall survival but also managing long-term adverse events. There is no standard practice for how people affected by breast cancer can expect these changes to be implemented, and in the absence of follow-up care, access to expert guidance may not be forthcoming.

### 3. Discussion

This guideline review highlighted marked differences between the follow-up recommendations provided in the UK by SIGN [17] and NICE [18] and the more recent guidance provided by Europe [10] and the USA [20,21]. While accepting that the quality of data is sometimes weak in this area, it is still concerning that the recommendations in the UK appear so lacking in any detail. This is particularly so in light of new data published by Allemani et al. [1] who suggest survival outcomes in the UK still lag behind many parts of the world. While some would argue, follow-up surveillance is all about detecting recurrence, evidence suggests that compliance with treatments to extend survival [29] is improved when engagement continues through face to face consultations.

In practice, the arguments for and against the continuation of follow-up surveillance are robustly argued on both sides, and personal preference appears to be driving the decisions within the same networks and regions across the UK. Can it be right that in one area patients are seen regularly and in another region they are discharged at 2 years – where is the evidence for this approach? The introduction of the recovery package [30], a holistic approach to improve overall co-ordination and management to help people recover, and live well with cancer within the UK, should not be viewed as a substitute for follow-up, or aftercare when treatment changes, rather it should be viewed as complementary.

The 13th St Gallen International Breast Cancer Conference expert panel [31], a highly regarded expert body in collating and disseminating up to date evidence about breast cancer believes that the provision of regular follow-up surveillance at the completion of primary treatment is appropriate and should continue. They support nurse specialists undertaking this care, but recommend it continues to be done in person rather than over the telephone. While telephone follow-up may be an excellent approach to provide psychological support, it cannot confirm or deny local or distant recurrence and this should be made clear to patients.

In conclusion, many of the advances gained in breast cancer survival was as a direct result of data gathered, and or clinical observations during follow-up clinics. Breast cancer is entering some uncharted territory with the widespread use of biological agents, patients receiving several lines of treatment and the switching of endocrine agents over long periods of time. There are new risks; unknown short and long term side effects and some complicated decisions to be made by patients and their families. If follow-up practices continue to be variable, and not necessarily based on known risks [7], patients may miss out on the optimal treatment approach to extend survival benefit.

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