

Working with Service User Representatives to provide accessible information about Secondary Breast Cancer (SBC) to patients and GPs within a Personalised Stratified Follow-Up Pathway

Greater Manchester Cancer

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Introduction

NHS England recommends the use of 'Personalised Stratified Follow Up (PSFU) for cancer patients. This patient-led aftercare pathway requires patients and GPs to be able to identify symptoms and signs of local and distant recurrence.

National surveys suggest that breast cancer patients are not provided with adequate information to identify the signs and symptoms of secondary breast cancer (SCB):

58% of patients stated that they did not know the signs and symptoms of SBC¹

20% of patients thought they knew the signs and symptoms of SBC, but did not have the correct information¹

Only **13%** of people with SBC felt they were given enough information about SBC signs and symptoms²

Studies show that patient recall of verbal medical information is significantly improved with the addition of visual cues, such as infographics^{3,4}

Method

The Greater Manchester Cancer Alliance worked with service user representatives, and abcdiagnosis, a breast cancer CIC, to develop a standardised patient information document that would ensure all people diagnosed with primary breast cancer have access to SBC information, in an accessible format, and provided at the right time in their pathway.

Results

An infographic developed by a service user representative, that provides clear, concise, accessible information about SBC signs and symptoms, was embedded within the regional PSFU standardised treatment summary. As per national guidelines, the treatment summary is provided to all patients at their End-of-Treatment appointment and copied to the GP. Seven breast services, supporting approximately 3000 new diagnoses of breast cancer per year, agreed to use the standardised treatment summary that includes the SBC signs and symptoms infographic.

Secondary Breast Cancer
Also known as metastatic or advanced breast cancer

If you have had breast cancer be aware of these **RED flags*** for secondary breast cancer.
There are 5 main areas that secondary breast cancer can appear.

- BRAIN**
Frequent headaches, vomiting (first thing in the am), dizzy, visual disturbance, fits, impaired intellectual function, mood swings, balance, fatigue. Family members and friends may say you are not your normal self.
- BONE**
Pain in bones — commonly thigh, arm ribs and back. Can be dull ache or sharp shooting pain. Bone pain with no obvious cause or haven't fallen over, report any new, unusual and increasing pain.
- LYMPH NODES**
Swelling or lumps and pressure in chest/armpit/neck areas, dry cough.
- LUNG**
Sharp pain on breathing in chest and back area, non productive cough, fatigue, blood clots can also cause shortness of breath.
- LIVER**
Bloating, affected appetite, weight loss, fatigue, weak, pain near ribs on right hand side.

Please visit: abcdiagnosis.co.uk
Twitter: @abcdiagnosis
Facebook: [facebook.com/abcdiagnosis](https://www.facebook.com/abcdiagnosis)

***RED FLAG SYMPTOMS NEED TO BE REPORTED TO YOUR BREAST CARE NURSE**

abcd
After Breast Cancer Diagnosis

'7 years after my primary diagnosis I was diagnosed with secondary breast cancer and there was a lack of information available for clinicians and patients regarding the signs and symptoms of SBC.

I created the infographic to empower patients to recognise the "red flags" and to encourage GPs to make earlier referrals for investigations'

Jo Taylor, founder of ABCDiagnosis and MET UP UK and patient living with secondary breast cancer

Conclusions

An infographic, embedded within a standardised treatment summary, has ensured accessible information about SBC is delivered to all breast cancer patients in Greater Manchester.

The infographic is available on the NHS England PSFU webpage ([click here](#)).

Other cancer alliances may wish to consider using the infographic within their own PSFU patient information resources.

References

1. Breast Cancer Now (2016). Secondary. Not Second Rate. Available at: https://breastcancer.org/sites/default/files/the_case_for_change_summary_report.pdf
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3. Houts, P., Witmer, J., Egeth, H. E., et al. (2011). Using pictographs to enhance recall of spoken medical instructions II. Patient Educ Couns. 43:231-42
- 4.5 Kessels R. P. C. Patients' memory for medical information. Journal of the Royal Society of Medicine, 2003. 96(5):219-222.

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