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 SBC 20% of patients thought they knew the signs and symptoms of SBC, but did not have the correct information 2
Only 13% of people with SBC felt they were given enough information about SBC signs and symptoms 2

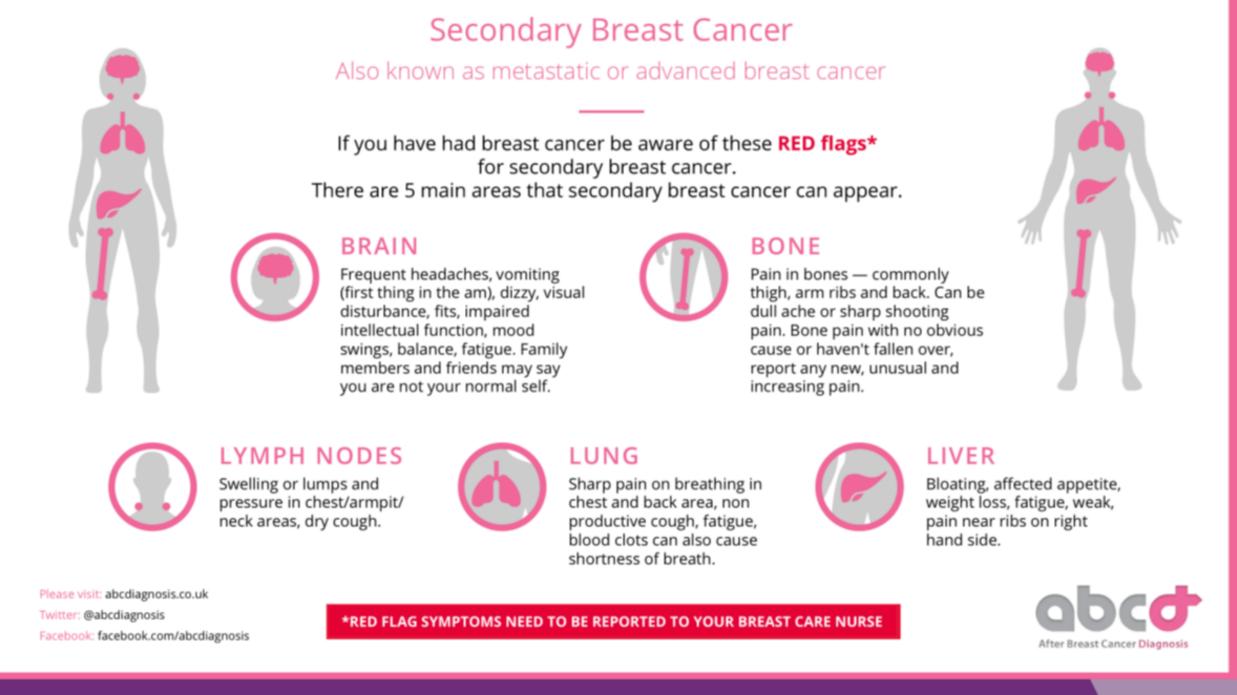
Studies show that patient recall of verbal medical information is significantly improved with the addition of visual cues, such as infographics^{3,4}

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.



'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

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- 4.5 Kessels R. P. C. Patients' memory for medical information. Journal of the Royal Society of Medicine, 2003. 96(5):219-222.

For further information.

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