

The voluntary sector perspective in secondary breast cancers

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Secondary Breast Cancer Taskforce

- A two-year initiative, set up in 2006 by Breast Cancer Care in recognition that people with metastatic breast cancer were not receiving the best possible standard of care.
- A national coalition of healthcare professionals (NHS, RCN), charities, policy-makers and people with metastatic breast cancer, the Taskforce identified gaps in treatment, care and support.



- User led, guided by a User Advisory Group and Reference Panel made up of people living with metastatic breast cancer.
- Examined patient experience and identified areas for improvement.

Invisibility

No-one was there to offer support or advice after my diagnosis

I felt very alone and uncared for, I thought I had been written off

Many metastatic breast cancer patients do not have access to a CNS as they did at primary diagnosis.

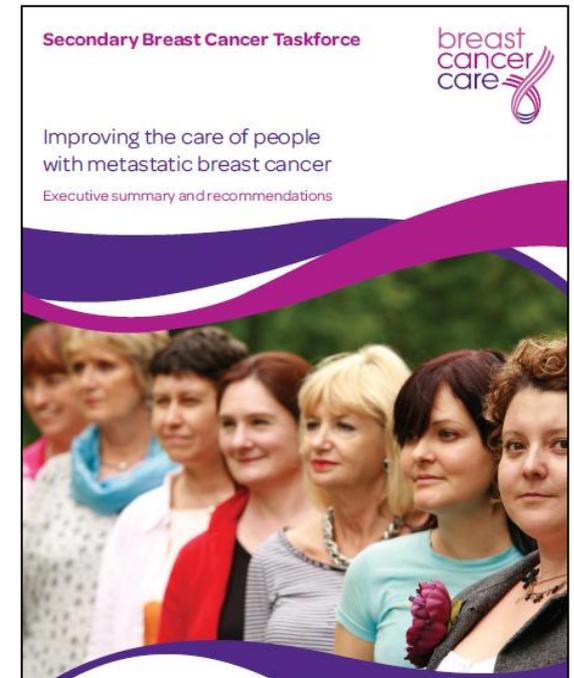
I wanted a breast care nurse specialising in secondaries... (but) I was just sent home to cope with my family



Breast Cancer Care leads on the National Secondary Breast Cancer Awareness Day in the UK. 13 October seeks to make everyone living with breast cancer metastases feel acknowledged and that they have a voice.

Key aims of the Spotlight campaign

- Data routinely collected on the number of people living with sbc in the UK and sites of disease and treatment
- Access to a clinical nurse specialist with training in secondary breast cancer
- Continuity of care for all patients
- Patients receive an MDT approach to their care
- Patients given timely information & a care plan to be clear on treatments & side effects



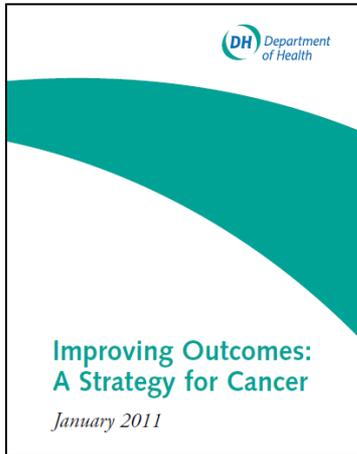
Data collection

I feel like the lack of statistics and information is equivalent to being written off, “you’ll be dead soon anyway, so you don’t count.”



Meeting with the PM and Chairs of the All Party Parliamentary group on Breast Cancer to discuss data collection.

- Breast Cancer care has been lobbying for data to be collected on the number of people living with secondary breast cancer for a number of years
- For services to be accurately planned, it is essential to know the number of patients affected.



- A great step forward in England, *Improving outcomes: A strategy for cancer* (published 12th Jan) contained a commitment to begin collecting data in April 2011 (pilot) with full collection from April 2012.
- MBC patients will now have their case reviewed in a MDM at least once (usually at diagnosis)
- Breast Cancer Care is on the steering group overseeing the pilot project



Users celebrated achieving this milestone with us

Still work to be done

- We are now lobbying the devolved countries to follow suit
- Advantage of being an independent lobbying voice
- Partnerships with HCPs critical to us
- Standards of Care and Service Pledge



Thank you

We owe a big thank you to all the women with secondary breast cancer who worked on the Secondary Breast Cancer Taskforce and the subsequent Spotlight campaign. A number of them are no longer with us, but were intrinsic in shaping our campaigns and achieving the progress we have so far made.



Many inspirational women and men affected by sbc continue to be involved and play a key role in developing our work in this area.