

Who's Counting?

Breast Cancer Care's campaign on secondary (metastatic) breast cancer data collection in England

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Why data matters for secondary breast cancer

- People tell us that the care they receive is inadequate (especially when compared to primary diagnosis)
- People with secondary breast cancer often do not have access to a dedicated secondary Breast Cancer Nurse
- No data means it is difficult to plan services that effectively meets patient need
- The long term effectiveness of treatments and outcomes for primary breast cancer is also unknown



'Who's Counting?' Our campaign

Our map shows each Hospital Trust in England and whether they are recording the number of people diagnosed with secondary breast cancer. This is important as without this data, it is difficult for hospitals to plan their services to meet their patients' needs. Click on the pink button to explore the map.



The map shows the information we've received from Hospital Trusts that manage several hospitals, so you may not see your individual hospital listed.

www.breastcancercare.org.uk/secondary

Findings

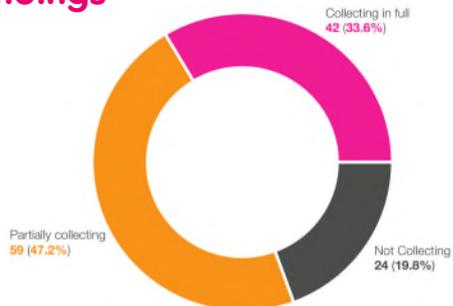


Figure 1: How many Hospital Trusts are collecting data?

Barriers and enablers to data collection

Barriers

- Lack of resources e.g. administrative support
- Confusion over the definition of secondary breast cancer
- Lack of awareness of what data should be collected/how to record secondary breast cancer
- Lack of buy-in and leadership

Enablers

- Infrastructure in place
- Dedicated secondary breast cancer MDT
- Buy-in and involvement of all relevant staff

Case study

There is a dedicated MDT meeting for secondary breast cancer where all patients are discussed. The data has been used to highlight that patients at the Trust are living longer and that questions around sustainability of services will need to be addressed. Furthermore, the information was used to secure external funding for a new administrative post, to free up the time of the nurse in future.

Next steps

Report released in Sept 2016, which makes recommendations to improve data collection

Working with NCRAS to improve COSD v.8

Continuing to monitor progress in this area, and work with Trusts to share best practice

Continue to link people living with secondary breast cancer with this issue, giving them a voice on something that they feel extremely passionate about.



Questions?

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