Case Study - Patient Advocate Stories

Jo Taylor
Patient Advocate, use MY data

I'm Jo Taylor, and I live in the hills near Saddleworth in the Northwest of England.

Thirteen years ago, I was diagnosed with a primary breast cancer whilst I was on maternity leave. It was a huge shock, but as with thousands of others I got through all the treatments over a number of years. But unfortunately, seven years later I was diagnosed with secondary breast cancer in other parts of my body.

I got on with the treatment, did exercise, and started a website about life after a breast cancer diagnosis.

I also developed an infographic about secondary breast cancer, including the signs and symptoms, which is something I wasn't made aware of when I was initially diagnosed with a primary cancer.

Finding statistics about secondary breast cancer is difficult. The charities have general numbers of people dying with secondary breast cancer – around 11,500 people are dying each year. About 35,000 are living with secondary breast cancer, but these are estimates, and the real problem is that people aren't counted properly.

There have been pilots back in 2012, including by the national cancer registry, to try to collect and count secondary breast cancers, which was supported by patients, charities and ministers. But sadly, nothing seems to have happened after that point.

Several charities have continued to lobby in this area, and more reports produced, but nothing has happened to actually collect or report reliable data on secondary breast cancer. I've been told that data has been collected, but after all these years it still isn't reliable enough to produce reliable statistics.

Changes to national datasets will help to better define the data that needs to be collected, but still, it depends on who is collecting and inputting the data at the hospitals. And that doesn't seem important enough to be a priority. But it is for me, and for 11,000 other people who die from secondary breast cancer every year.

Data needs to be collected robustly so that we can use it to understand what is going on. Without data, how can we make any progress?

We are building an online library, where the patient voice is heard direct, talking about the rewards of using their data

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"The only source of data is the patient"

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