Frimley Health
Frimley Health NHS Foundation Trust is routinely collecting data on their secondary breast cancer patients.

Since 2013, it has been compulsory for data to be collected by NHS Trusts on people diagnosed with secondary breast cancer. However, capturing and recording this data is still a challenge within many hospitals.

Frimley Health NHS Foundation Trust believes there are a few key factors that help them to achieve this.

- Taking a team approach- Ensuring that data capture is not a responsibility of just one person.
- Effective Communication- Close working relationships between the CNS and MDT Coordinator helps to ensure that all patients are discussed.
- Clear system- Use of one clear data collection system, in this case, the Somerset Cancer Register.
- MDT- Ensuring patients are discussed within MDT meetings.

The Trust understands the value of collecting and analysing data, particularly on patient outcomes. It helps to identify patients’ needs and ensure that there are adequate resources to meet them. It is used to justify current positions and to build cases for new posts.

Taking a Team Approach

The team that is responsible for the collation of the data includes an analyst, a team leader, a performance lead, the Cancer Manager, and a dedicated MDT Co-ordinator. The trust feels that working in this way alleviates pressure on CNS’s and other clinical staff who otherwise would be left managing data collection on top of other responsibilities.

The MDT Co-ordinator is responsible for updating the Somerset Cancer Register, the system that the trust have chosen to use to record data. It is therefore vital that there are clear routes for the information to reach the coordinator.

Further support is provided by a Support Worker whose role is to support living with and beyond cancer and to help with data collection. The Support Worker works closely with the CNS, recording their activity with patients. Using a spreadsheet, new diagnosis and details of any face to face or telephone contact is recorded. This information is then shared with the MDT coordinator, who ensures all data is recorded.

One of the most important reasons the Trust attributes to how it is able to collect data is the links between clinical and administrative staff. In particular, effective communication between the CNS and the MDT Co-ordinator is paramount to their success. Patient data can be sorted and monitored informally using the expertise of both roles.

Capturing Data

Given the role of the MDT Co-ordinator in recording the information it is vital to have clear referral routes to MDT.

Patients who are diagnosed with secondary breast cancer as their first diagnosis are captured via histology\(^1\) or radiology\(^2\) reports, which are then recorded on a weekly basis. For those who have previously had a diagnosis and treatment for primary breast cancer, the relevant data are captured when the patient is referred to either the CNS or Breast MDT.

This referral system is helped by good working relationships across the different MDTs and departments. The trust are confident that data on the majority of patients are being recorded. However, it is worth noting

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\(^1\) Histology reports at the Trust include a code that determines the type of cancer. There is a specific number within this code that indicates metastatic disease, meaning that these reports can be used to quickly identify patient numbers.

\(^2\) Radiology reports are sorted manually, unlike histology reports. It is hoped that this will soon become an automated process but, in the meantime, it is possible that some secondary breast cancer patients slip through the net.
that some patients may slip through the net, particularly if they were treated for breast cancer previously at a different trust. But the Trust is relatively confident that data on most patients are being recorded as they should be through one of these routes. The data is then submitted to the national datasets, including COSD every month.

**Somerset Cancer Register**

The Somerset Cancer Register (SCR) is a software application developed by the NHS, designed to collect relevant data throughout a patient’s cancer journey. For more information please see- https://www.somersetscr.nhs.uk/about

The Trust uses the SCR to record patient data. There are several ways that the data can be found using SCR, including a new code that is specific to any patient with metastatic breast cancer and a ‘date of diagnosis’ indicator.

**Learnings and Future Improvements**

The Trust has an MDT for breast cancer but not one that is specific to secondary breast cancer. However, there is a regular slot for Oncology, which includes any metastatic breast cancer patients. The CNS ensures that all new metastatic breast cancer patients are discussed at that point in the meeting. However, the MDT meetings are under a lot of time pressure. It is also less focused on registration and more on performance, such as meeting Cancer Waiting Time targets. For these reasons, it is possible that not every patient with secondary breast cancer is discussed or adequately recorded in this meeting.

However, the Trust has recognised a challenge with regards to lack of knowledge among some clinical staff in regard to recording key information about their patients, unless it is related to cancer waiting times and targets. There is information which would aid the collection of data on secondary breast cancer and other metastatic cancers. In order to rectify this, training is planned for staff working across all cancers, particularly as one issue may be a lack of awareness of what should be recorded and why it is important. It is hoped that this will further improve the quality of data on secondary breast cancer that the Trust is able to produce.