

Reference:	FOI.16699.25
Subject:	Breast cancer care
Date of Request:	26 February 2025

Requested:

By a diagnosis of metastatic breast cancer, I mean breast cancer that has spread to other parts of the body, such as the bones, lungs, liver or brain. Metastatic breast cancer is also referred to as 'secondary' or 'advanced' or 'stage 4' breast cancer.

Patients

1. How many patients in your Health Board with a diagnosis of metastatic breast cancer are currently being treated?
2. Are Metastatic breast patients discussed at MDT?
3. How does Hywel Dda UHB breast cancer MDT record and track metastatic breast cancer on the Welsh Clinical Portal and the Welsh Patient Administration System? If precise numbers are unavailable, what steps have been taken to improve data collection on metastatic breast cancer patients?

Nurses

1. How many dedicated metastatic breast cancer nurses are currently in post at Hywel Dda UHB?
2. Do all patients at Hywel Dda UHB with metastatic breast cancer have access to a dedicated Metastatic CNS with the appropriate skills, knowledge and experience of metastatic breast cancer?
3. Do all Metastatic patients receive a Holistic Needs assessment?
4. How are Metastatic patients supported in the HB?

Treatment Summaries and Red Flags

1. Does Hywel Dda UHB inform all primary breast cancer patients at end of treatment of the red flag symptoms to be aware of?
2. What red flag infographic do you use?
3. How many patients with primary breast cancer in the past year received treatment summaries?
4. Does Hywel Dda UHB have a formal policy in place to ensure all metastatic breast cancer patients receive treatment summaries?
5. What is the formal system to ensure GPs are aware of the red flags for their patients who have had breast cancer?

Response:

Patients

1. Hywel Dda University Health Board (UHB) has (50) fifty patients diagnosed with metastatic breast cancer currently being treated.
2. The UHB confirms that metastatic breast cancer patients are discussed at Multi-disciplinary Team (MDT) meetings.
3. The presence of metastatic disease at diagnosis is recorded on the Welsh Clinical Portal (WCP). Tumour, Node, Metastasis (TNM) Cancer Staging is recorded at diagnosis, which clarifies the 'stage' of the cancer at diagnosis.

Since the introduction of Breast Audit recording on the WCP in January 2023, there has been functionality and an additional audit requirement to identify and record metastatic or recurrent disease. The UHB does not hold this data and therefore, any information in relation to this would have to be requested from Digital Health and Care Wales (DHCW). For ease, the UHB provides contact details for the Freedom of Information Team at DHCW below:

Digital Health and Care Wales
Freedom of Information Team
Ty Glan-yr-Afon,
21 Cowbridge Road East,
Cardiff
CF11 9AD
Email: DHCW.FOI@wales.nhs.uk

Nurses

1. The UHB has (3) three oncology clinical nurse specialists (CNS). Their role is to support patients requiring systemic treatment for metastatic breast cancer. The main focus for two (2) out of the three (3) nurses is to support patients diagnosed with metastatic breast cancer.
2. All patients requiring systemic anti-cancer therapy that is managed by an oncologist have access to a Metastatic Breast Oncology CNS, who has experience in working with this patient group.
3. The UHB can confirm that not all metastatic patients receive a Holistic Needs assessment.
4. The way in which metastatic patients are supported will depend on treatment decisions. Patients who have chosen to have systemic anti-cancer therapy are supported by an oncology CNS as their cancer keyworker.

A CNS will tailor support according to the needs of individuals. Support typically includes education, contact outside of clinic appointments and signposting to other services, as well as engaging with local and national patient support events.

Treatment Summaries and Red Flags

1. The UHB can confirm that all primary breast cancer patients are informed of the red flag symptoms to be aware of at the end of treatment clinic.
2. Patients are informed of the following signs and symptoms to look out for and seek advice on:

In relation to the breast and chest area:

- Change in shape or size.
- Lumpy area or thickening on scar line that feels different.
- Lumpy area in axilla/arm pit or around your collarbone.
- Redness or rash on the skin and/or around the nipple.
- Weepy ulcer on treated breast.
- Dry crusty area/itchy.
- Nipple discharge.

Other symptoms to seek advice about:

- Pain that does not improve with pain relief.
- Dry cough that persists.
- Feeling breathless.
- Feeling constantly tired.
- Constant feeling of nausea/sickness.
- Sudden weight loss without trying to lose weight.
- Loss of appetite.
- Severe headaches.
- Altered vision or dizziness.

3. The UHB is unable to provide you with all of the information requested, as it is estimated that the cost of answering your request would exceed the “appropriate limit” as stated in the Freedom of Information Act 2000 and the Data Protection (Appropriate Limit and Fees) Regulations 2004. The “appropriate limit” represents the estimated cost of one person spending 18 hours (or 2½ working days) in determining whether the UHB holds the information, and locating, retrieving and extracting the information.

In order to provide you with the number of primary breast cancer patients that received treatment summaries in the past year, the UHB would need to undertake a manual trawl of all primary breast cancer patients to identify how many received a treatment summary, or identify any information that may fulfil your request, as this information is not recorded centrally.

The UHB is therefore applying an exemption under Section 12 of the Freedom of Information Act 2000 (FoIA), which provides an exemption from a public authority’s obligation to comply with a request for information where the cost of compliance is estimated to exceed the appropriate limit.

However, under Section 16 of the FoIA, the UHB has a duty to provide advice and assistance. Therefore, the UHB provides the accessible information it holds below.

The UHB offers end of treatment summaries to all Pembrokeshire based patients and has recently introduced end of treatment summaries to all Carmarthenshire based patients. The UHB does not currently offer Ceredigion based patients end of treatment summaries due to

staffing pressures the service is currently experiencing. However, the service is working to rectify this.

4. The UHB does not have a policy in place to ensure all metastatic breast cancer patients receive treatment summaries.
5. The UHB confirms that patients within the Pembrokeshire area receive a copy of an end of treatment summary and care plan, which is routinely copied to the GP. However, this has only recently been implemented within the Ceredigion and Carmarthenshire areas.