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|-------------------------|--------------------|
| <b>Reference:</b>       | FOI.15692.24       |
| <b>Subject:</b>         | Breast cancer care |
| <b>Date of Request:</b> | 10 October 2024    |

**Your request and our response**

**Key Relevant Documents**

1. Does your Health Board have a protocol document that sets out what follow up primary breast cancer patients should be offered when they complete their hospital-based treatment and the details of how this process works?

|            |   |
|------------|---|
| Yes        | X |
| No         |   |
| Don't Know |   |

**If yes, please share your current, or most recent, version of this protocol.**

Hywel Dda University Health Board (UHB) provides the 'Nurse Led End of Treatment Clinic for Patients Completing the Main Phase of Their Treatment for Early Breast Cancer Guideline' at Attachment 1. Please note that this procedure is currently under review pending approval.

2. Are all hospitals that form part of your Health Board following the processes set out in the protocol document for primary breast cancer?

|            |   |
|------------|---|
| Yes        |   |
| No         | X |
| Don't Know |   |

**If no, please send the primary breast cancer related protocols of each hospital covered by the Health Board?**

The End of Treatment for Patient Breast Care Clinic Procedure is a Health Board wide policy. However, due to Clinical Nurse Specialist (CNS) workloads and staff capacity, end of treatment clinics are not established in Ceredigion.

**Information provided about breast cancer signs and symptoms**

This section relates to the information given to women about signs and symptoms of primary breast cancer and signs and symptoms of secondary breast cancer.

3. & 4. At the end of hospital-based treatment do you provide primary breast cancer patients with information about the signs and symptoms of **primary** and **Secondary** breast cancer?

|                            |   |
|----------------------------|---|
| Yes - for all patients     |   |
| Yes – but not consistently | X |
| No                         |   |

**If yes-** please provide a copy of the information provided or a link to the information if it is available online. If this information is part of a longer document please provide the full document.

**If yes**, please indicate whether patients are signposted to further services/sources of support for this information and if they are, please provide details for these services/sources of information.

**If no**, please indicate whether patients are signposted to further services/sources of support for this information and if they are, please provide details for these services/sources of information.

After completion of treatment, patients are offered an end of treatment review with their Breast Care Nurse and a Holistic Needs Assessment (eHNA). Signs and symptoms of what to look out for are discussed and documented on a care plan.

Patients are also signposted to further resources and services/sources of support as follows:

- <https://padlet.com/breastsupport/5j7qzmvqg7slkfvw>
- [www.macmillan.org.uk](http://www.macmillan.org.uk)
- [www.lymphoedema.org](http://www.lymphoedema.org)
- [www.breastcancernow.org](http://www.breastcancernow.org)
- [www.breastcancerhaven.org.uk](http://www.breastcancerhaven.org.uk)
- [www.angor.org.uk](http://www.angor.org.uk)
- [www.breastcancerhaven.org.uk](http://www.breastcancerhaven.org.uk)
- [www.maggies.org](http://www.maggies.org)
- [www.lgfb.co.uk](http://www.lgfb.co.uk)
- [www.mind.org.uk](http://www.mind.org.uk)
- The Hywel Dda Breast Cancer Support Group

#### Number of patients

5. How many patients did you treat for primary breast cancer that finished their hospital-based treatment in each of the Financial Years 2022-23 and 2023- 2024?

The UHB provides within the table below the number of patients treated for primary breast cancer that finished their hospital-based treatment during the financial years 2022/23 and 2023/2024.

| Year      | Number of Patients |
|-----------|--------------------|
| 2022/2023 | 453                |
| 2023/2024 | 490                |

6. For the Financial Years 2022-23 and 2023-24, of the primary breast cancer patients that completed hospital-based treatment, please provide an estimate of what proportion were initially stratified to each follow up pathway?

- a) A Patient Initiated Follow Up (PIFU) pathway
- b) A pathway with routine, annual outpatient appointments

If you can provide the figures spilt between the age under 45 category and age 45 and over category that would be useful but if the information is not readily available by age, please provide for all ages combined.

The UHB provides within the table below the total number of primary breast cancer patients by **all** ages that were referred to either PIFU or a routine follow up pathway following the completion of their hospital-based treatment during the financial years 2022/23 and 2023/2024.

| Year                      | 2022/2023 | 2023/2024 |
|---------------------------|-----------|-----------|
| PIFU                      | 53        | 81        |
| Routine follow up Pathway | N/A       | N/A       |

7. At the end of hospital-based treatment, do all primary breast cancer patients covered by your Health Board receive routine follow up for a set period of time before a decision is made about whether they are placed on PIFU?

|  |   |
|--|---|
| Yes- all patients receive routine follow up for a set period of time at the end of hospital- based treatment | X |
| No- patients could immediately be placed on PIFU   |   |

**If yes**, which hospitals offer this and for each hospital how long is the set period of time?

I can inform you that patients are on a 5-year follow up across all hospital sites in the UHB.

All patients are on mammographically led follow up for 5 years.

High risk patients have an annual mammogram and are seen after one year by the consultant and follow up is determined after that.

Mastectomy patients are reviewed by the Consultant and given an ultrasound scan annually.

Patients over the age of 50 that complete the 5-year follow up and that can have a mammogram will be discharged back to the screening programme. For those patients under the age for screening, they will continue to be seen by the UHB until the age of 50 years. Thereafter, they will transition to the screening programme after the age of 50 years old.

Description of the PIFU pathway

We are hoping to understand in more detail how the primary breast cancer PIFU pathway works and how people are able to make contact when they have a concern. If you are providing a protocol document as part of your response, you only need to respond to questions 8, 9, 10 and 11 if the answers to these questions are not fully available in the document.

8. If a patient wants to raise a concern about a breast cancer sign or symptom (either primary breast cancer or secondary breast cancer) while on a PIFU pathway, what are the options for them to do so (please tick all that apply):

|                     |   |
|---------------------|---|
| A telephone service | X |
| Email contact       |   |

|                      |  |
|----------------------|--|
| Drop in clinics      |  |
| Other- please detail |  |

Patients can call the breast CNS.

Monitoring of the pathway

9. Are all breast cancer patients on a PIFU pathway logged and tracked on the organisation's IT system?

|                             |   |
|-----------------------------|---|
| All are logged and tracked  | X |
| All are logged              |   |
| Some are logged and tracked |   |
| Some are logged             |   |
| No                          |   |

PIFU patients are logged on the Welsh Patient Administration System (WPAS). These patients are tracked and flagged to the service when a patient has been on the pathway for 12 months.

10. Is there a standard time limit on how long PIFU is available to breast cancer patients e.g. 5 years?

|     |   |
|-----|---|
| Yes | X |
| No  |   |

**If yes**, what is the standard time limit?

Patients are always placed on the PIFU pathway for 5 years.

**If yes**, how frequently is the standard time limit applied

|                  |   |
|------------------|---|
| Always           | X |
| Most of the time |   |
| Sometimes        |   |
| Rarely           |   |

If any patients have a difference to the standard time limit, please detail and explain in what circumstances this occurs and the range of time limits?

11. When it is time for a breast cancer patient to be discharged from PIFU, are they notified, e.g. by letter or phone?

|            |   |
|------------|---|
| Yes        | X |
| No         |   |
| Don't Know |   |

If yes, please explain how they receive this notification and provide a copy of the standardised information they would receive at that point, if it is in written form.

The UHB will write to the patient and their GP, informing them that they are discharged from the PIFU.