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Bwrdd Iechyd Prifysgol
Cwm Taf Morgannwg
University Health Board



Freedom of Information Request: Our Reference CTMUHB_511_24

You asked:

I am undertaking work on behalf of Breast Cancer Now. They are keen to understand more about the experiences and support offered to primary breast cancer patients when they come to the end of their hospital-based treatment.

At the end of their hospital-based treatment, all primary breast cancer patients used to be offered - in addition to yearly mammograms for suitable patients - an annual clinical appointment for a period of five years, this may have been referred to as routine follow up. In recent years this annual follow up outpatient appointment has for many patients been replaced by Patient Initiated follow-up (PIFU), though some may still be on routine follow up- with both pathways continuing to offer annual mammograms for suitable patients. Note that sometimes other terms are used instead of PIFU, e.g. supported self-management follow up, see on symptoms, stratified follow up or open access follow up.

In accordance with the Freedom of Information Act 2000, I would appreciate it if you could respond to the below questions. *Please use an X in the boxes to indicate your answer when required or provide numerical data where requested. Note that some questions are open questions and some ask for copies of documents*

The questions in this request all relate to the pathway for primary breast cancer patients who have completed their hospital-based treatment. When we refer to 'patient' or 'breast cancer patient' we are referring to primary breast cancer patients.

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	We follow National Optimal Pathway for Breast Cancer (2024) provided by Cancer Network
No	
Don't Know	

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

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	Centralised Breast Care at Royal Glamorgan Hospital site.
No	
Don't Know	

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

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

Yes - for all patients	Breast Cancer Now, After Breast Cancer Treatment, What Now leaflet. Patients are also informed verbally of red flag symptoms and patient group therapy is provided confirming this information. Download and order publications Breast Cancer Now
Yes – but not consistently	
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.

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

Yes - for all patients	Yes, during post op consultation and leaflet as highlighted above.
Yes – but not consistently	
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 to get 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.

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?

	Number of Patients
2022-2023	569
2023-2024	509

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 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.

	% of patients					
	2022-2023			2023-24		
	Under 45	45 and over	All ages	Under 45	45 and over	All ages
PIFU	0	2	2	18	1	2
Routine follow up	100	98	98	82	99	98

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	Yearly mammographic surveillance for 5 years. If patients are under aged 45 they receive yearly surveillance until 50. If patients have undergone bilateral Mastectomy, they are offered clinical surveillance. Also seen on symptom within 5 years from diagnosis.
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? Centralised Breast Care at Royal Glamorgan Hospital site.

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	Yes
Email contact	Yes
Drop in clinics	
Other- please detail	These would be triaged and given clinical appointments if necessary.

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	Yes
All are logged	
Some are logged and tracked	
Some are logged	
No	

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

Yes	5 years, however after this period patients require a G.P. referral and are advised to contact us to fast track
No	

If yes, what is the standard time limit?

If yes, how frequently is the standard time limit applied

Always	Yes
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	They are given a care plan yearly, with the last care plan confirmed they have been discharged back to routine screening where appropriate (<70)
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.
