

## BREAST CARE SURVEY 2007

Breast Test Wales is responsible for women up to the point of diagnosis and then, if they are found to have breast cancer, they are transferred to the hospital services for treatment. This questionnaire looks at the period from being diagnosed with breast cancer to surgical treatment.

We ask about the care and support our breast care nurses offer around this time. The nurses tell women in advance that we might send them a questionnaire in a few months, as we don't wish to alarm them unnecessarily.

We sent out 100 questionnaires in early 2007:

- 25 in north Wales - 16 (64%) were returned
- 25 in west Wales - 16 (64%) were returned
- 50 in south east Wales - 36 (72%) were returned.

68 women (68%) replied in total.

### 1. Where do you live?

There was a good spread of replies from across the whole of Wales.

The next questions were about the service we offer in Breast Test Wales.

### 2. When we gave you your test results, was a nurse there?

66 said a nurse was there. Two did not answer.

#### What could have been done better at that time?

33 replied:

- 28 said "nothing" or that everything was fine e.g.:
  - everyone was very professional and very thoughtful
  - the support was 100 percent
  - the consultant was excellent ..... very kind and gentle
  - sensitive caring attitude
- Two recommended that a friend or family member should be with them
- One would have liked more information on the effects of surgery
- One would have liked the same nurse from the beginning.

One reported that the doctor who took the biopsy had been very abrupt.

**Action:** The nurses will review their procedures to ensure woman are advised or offered the opportunity to bring a friend or family member.

**3. Did the breast care nurse see you before you had treatment?**

64 said yes. Three said no.

**If later, where were you at the time?**

22 replied "at home" and seven "at BTW". (Five of these said both.) 37 did not answer.

*In retrospect, this question may have been confusing.*

**4. If you were visited at home, was this useful?**

Some had declined the offer. One had asked to talk over the phone and found it helpful. One who had been visited at home said it was not helpful. 58 said it was.

**What was most helpful?**

56 replied, all with positive comments. Women liked the individual and personal support and:

- the home environment being more relaxing and "no pressure"
- having time to talk, ask questions, discuss worries and fears, understand the options for treatment and what would happen afterwards
- being given tips and leaflets
- having other family members there
- feeling reassured

**What could have been done better at that time?**

28 women replied. One wanted more reassurance, one to have contact with other patients and one said the nurse was not very accessible due to other commitments. 25 said "nothing" - the service was "excellent", "couldn't have been bettered" etc.

**5. Did we give you any leaflets or booklets?**

One said she had not been given anything. 66 said they had.

**If so, did you read them?**

63 had read them and one was not sure.

**What was most helpful?**

50 replied. Many women found them all helpful and informative and some commented that they were clear and easy to read. One found it difficult to concentrate at the time and one liked having the information there but found it made her more worried.

**What could have been done better at that time?**

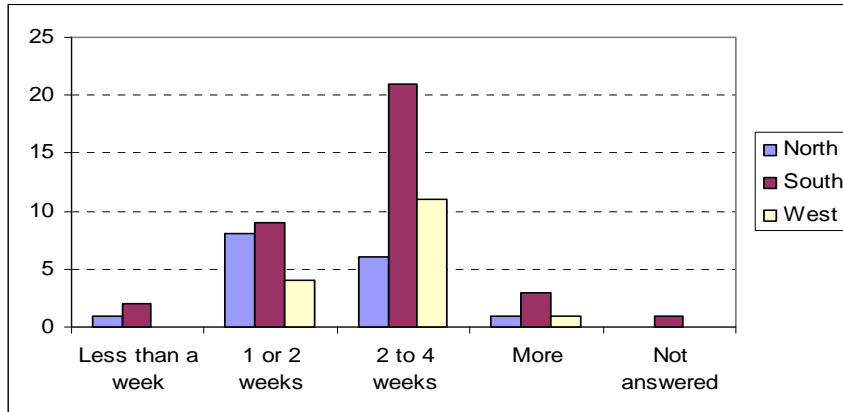
25 replied. 22 said "nothing". One wanted more on breast cancer grade and treatment, one on medication and how it was chosen and one would have preferred more personal contact and reassurance and less reading.

**We work closely with our colleagues in the hospital services and sometimes collaborate by seeing patients there, so we asked about this time too.**

**6. In which hospital did you have your surgery?**

Most NHS major hospitals across Wales were included, also one in England and two private hospitals.

**7. How long did you wait before going into hospital?**



**Was this length of time acceptable?**

63 said it was acceptable. Three, all of whom waited 2 to 4 weeks, said this was too long.

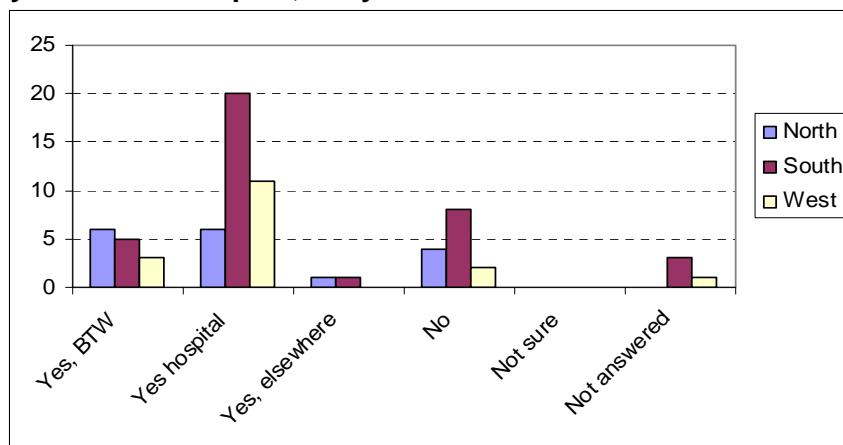
**8. Did you contact us again before you went into hospital?**

51 said no. Four were not sure. 11 said yes.

**If yes, why?**

13 replied. Four wanted information on their admission dates. Four wanted more information about their treatment or to talk about their feelings.

**9. While you were in hospital, did you see a breast care nurse?**



(Some ticked more than one.)

**10. Did you have enough support from the breast care nurse before your operation?**

59 said yes. Three said no.

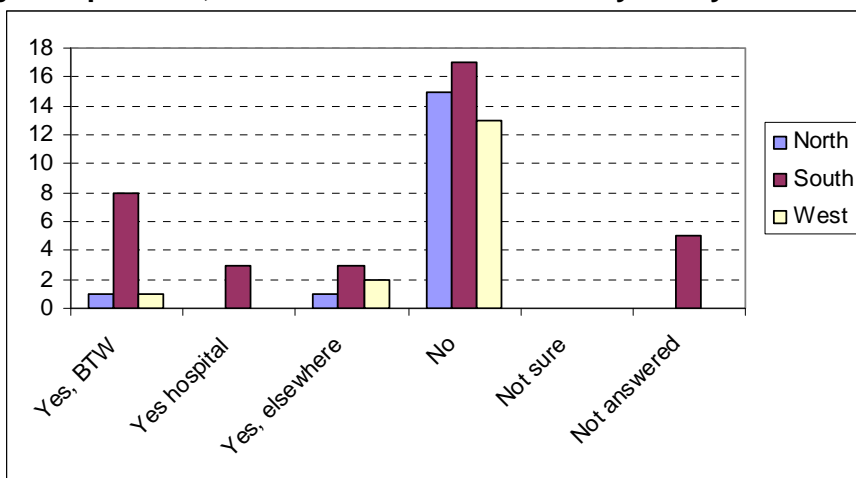
**What could have been done better at that time?**

29 said it was all fine:

- “everyone was really marvellous”
- “everything was done with care and consideration”
- “couldn’t fault it”.

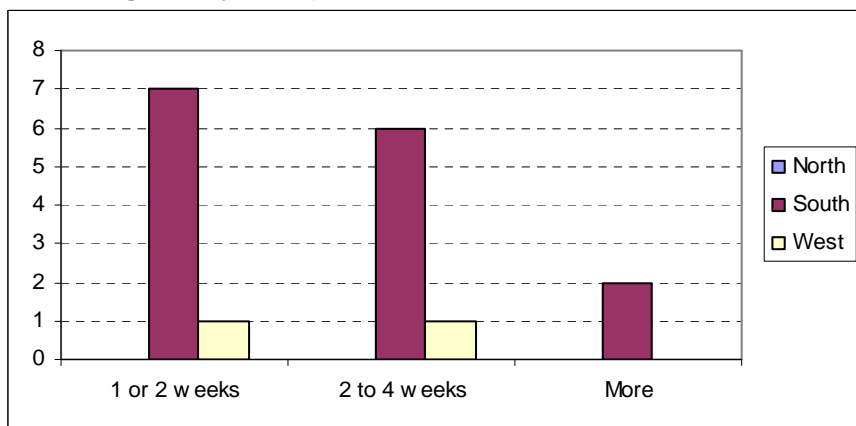
One would have appreciated information about financial help and one on what to do about her existing medication.

**11. After your operation, did a breast care nurse visit you in your home?**

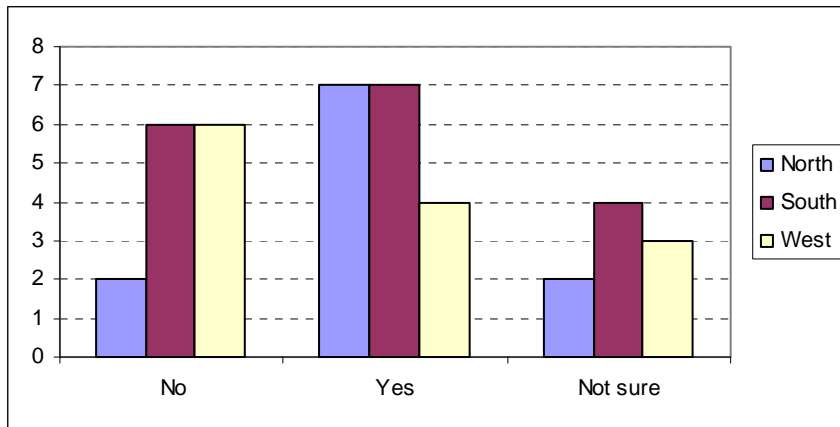


19 said yes. 45 said no.

**12. If yes, how long after your operation did the breast care nurse visit you?**



**13. If no, would you have liked a visit?**



18 said yes.

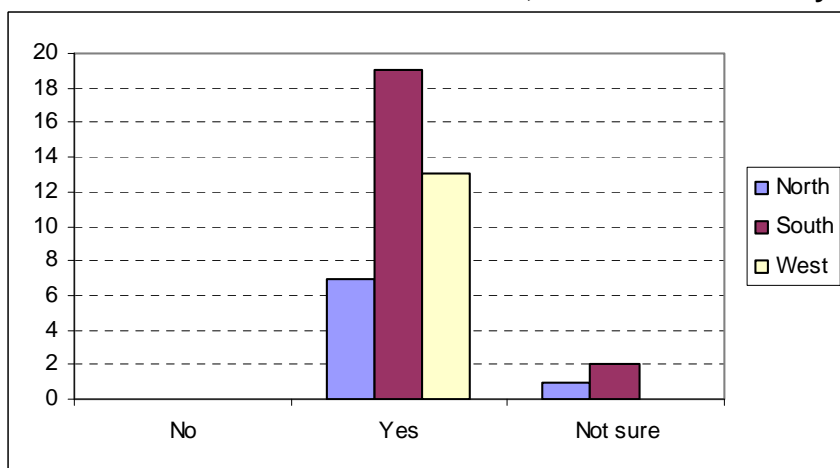
**14. What could have been done better at that time?**

38 replied. One said her hospital experience was very poor. Several reported post operative infections and two experienced prolonged post-operative problems.

- 15 were entirely happy or said “nothing” could have been done better
- Eight would have appreciated more support after their operation, either by a home visit or a phone call
- 12 said the Breast Test Wales and/or the hospital nurses had rung them, some on several occasions. This was very much appreciated by all. One however, had been promised a call but not received it.
- Two had the nurses’ contact phone numbers but didn’t need to use them.

**Action:** The Breast Test Wales breast care nurses will share best practice in contacting women after the operation.

**15. If you saw more than one breast care nurse, was this satisfactory?**



**If not, what was the problem?**

Nobody said “no” to the above and there were no replies to this question.

## Finally we asked:

### 16. Would you like to make any other comments or suggestions?

49 replied. 15 made comments that showed that all their needs had not been met.

- Three said their hospital experience was less than good, quoting bed waits and inattentive staff. One said the wait in the initial BTW assessment clinic between having further tests and seeing the surgeon was too long.
- Five would have appreciated more personal support after their surgical treatment. Three of these specifically mentioned living alone.
  - "... felt emotionally fragile for a time. Phone numbers don't replace contact."
  - "Reading doesn't help when some human support is needed".At least three had ongoing physical problems.

There were helpful suggestions as to how the service could be improved:

- One would have liked to have been able to purchase a bra at the hospital
- Six would have liked more information at an earlier stage, on:
  - suspected diagnosis
  - treatment choices
  - what would happen in the hospital between arrival and surgery
  - post operative care (especially regarding wound drains)
  - radiotherapy and its effects.

27 were happy with their whole experience and a further ten praised either the hospital or BTW.

- I cannot fault the care I had ..... A big big thank you.
- Happy with all Breast Care Nurses and their support.
- I would like to thank everyone for the kindness, caring and support I received which helped me enormously through this difficult time.
- Everyone was most helpful - nurses - consultants - radiographers and hospital staff. They were very kind and answered all my questions clearly. I do not think that I could have received better care and support elsewhere. Many thanks.
- I feel a lucky woman
- I can honestly state that my contact with all staff from the time I was diagnosed with breast cancer to my final radiology treatment was a very humbling experience, I was totally aware that I was in the hands of truly professional people who made it their business to get me back to good health. Their care and commitment was total and I thank them from the bottom of my heart.
- ..... staff were brilliant, you would not receive better care at a private clinic.
- I have been looked after extremely well, and I found all the nursing staff to be friendly and helpful, which in itself is very reassuring. I can't really think of any aspect of my treatment that I could criticise. .... Thank you all.
- The help, advice and support I received from BTW was excellent and made a worrying time so much easier to manage. I would like to take this opportunity to thank everyone for an outstanding service.
- You were very helpful and supportive. Thank you very much.
- I have praise only for all concerned in my pre & post operative treatment. Many thanks to all concerned. Long may Breast Test Wales continue.

**Action:** It is recognised that there are different approaches across Wales to the level of support given and/or offered, both within Breast Test Wales and in the hospitals. Although in general women were very satisfied with the support given, Breast Test Wales' breast care nurses will review their practice and discuss the overall service with their hospital colleagues.