

**PATIENT STAKEHOLDERS' MEETING 2<sup>nd</sup> JUNE 2008 – REQUIREMENTS FOR FUTURE BREAST SERVICE**

<b>SUBJECT</b>	<b>REQUIREMENT</b>
1. Cancer Reform Strategy	All PCTs have received a Government funding settlement for implementing the Cancer Reform Strategy. Please will BNSSG (Bristol, North Somerset, South Gloucestershire PCTs) inform Stakeholders what proportion of this is set aside for breast cancer and how it will be spent, including the schedule to roll out Digital Mammography ?
2. Screening/Symptomatic Radiology	We would like to understand the latest developments in breast screening and how we can benefit from them now and in the future. What could replace/complement mammography? We want less discomfort, less radiation, more accuracy, more technology suitable for dense tissue.
3. Referral	All referrals (both urgent and non urgent) to be seen by Breast Specialist within 2 weeks. GP guidance for referrals to be clear, to cover younger women and men and to be followed by all GPs,
4. Diagnosis	Maintain and improve One Stop Clinics. We understand that many appointments for further tests are scheduled immediately, but we want a future where all tests (e.g. Stereotactic Core Biopsy, MRI) are done in One Stop Clinic and results given same day. All Patients confirm that waiting for test results is extremely upsetting and stressful. We want to reduce even further the time they spend waiting to find out if they have cancer.
	We would like to understand timescales for delivery of results of all diagnostic tests (e.g. CT, Bone Scans), and whether they can be reduced as a goal of the Review.
	We wish to understand best practice for MRI and to ensure that this is implemented. Some patients are very concerned that mammograms do not identify some cancers, particularly those behind the nipple and/or where breast tissue is dense.
5. Surgery	We would like patients to have a realistic understanding what further surgery they may require following histopathology results. We have had feedback from a few patients that they were not aware that they might need a mastectomy following wide local excision.
	Ensure all patients receive full information about reconstruction options, including procedures performed by Plastic Surgeons. Increase opportunities for new patients to meet patients who have had reconstruction to see the cosmetic result and discuss experiences. May require help from patient groups to compile a register of volunteers.
	Ensure that Frozen Section Sentinel Node Biopsy or Gene Assay analysis is used so that patients do not require a second operation to remove more lymph nodes.
	Operation on same day as admission – no waiting overnight on a hospital ward.
	All pre-operative procedures done on same site as surgery (wire localisations, radioactive injections pre-Sentinel Node Biopsy)

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6. Histopathology	<p>All Histopathology to be double reported, performed by specialist breast pathologists and meets and exceeds UK Quality Standards – e.g. CPA, EPA, UK NEQAS</p> <p>FISH/HER2 testing for all patients and high quality, prompt implementation of new diagnostic tests as they emerge.</p> <p>Histopathology to be performed on same site as outpatients/surgery so no requirement to transport specimens between sites and to enable fastest possible results.</p>
7. Day Case Care	<p>Maintain and increase day case surgery – provided patient has proper support at home</p>
8. Inpatient Care	<p>Dedicated breast surgery wards (including reconstructive breast plastic surgery)</p> <p>Specialist nurses who know how to deal with emotional effects of mastectomy, how to lift breast surgery patients, how to remove drains, and to avoid injections, blood pressure monitoring on patient's affected side.</p> <p>Care of male patients needs research to ensure that their needs and the needs of women patients are respected. Some men may prefer to be cared for on a breast surgery ward, some may not.</p> <p>Care of patients with primary breast cancer and those with secondary cancer (including palliative care patients) requires careful consideration. NICE Improving Outcomes Guidance suggests that it may be best to care for them separately.</p> <p>We regard having an Intensive Care Unit on same site as breast and plastic surgery as a requirement.</p>
9. Hygiene	<p>Patients to be screened for infection before hospital admission.</p> <p>Staff hand washing to meet required standards. Soap, alcohol gel dispensers to be accessible and regularly filled.</p> <p>Clean wards.</p>
10. Physiotherapy	<p>To be provided pre and post operatively. Needs good planning and adequate time. No good just before patient goes to theatre.</p>
11. Follow up after surgery	<p>Easily understood process for patients to report and obtain assistance for problems (e.g. Seroma, Haematoma, infection). Clear information on out of hours assistance. Patients need to know when they should get expert advice and whether they should contact GP, member of breast team, the ward that treated them. For Frenchay patients, are the Frenchay GPs experienced at treating breast post op. complications?</p>
12. Lymphoedema	<p>Early and regular monitoring for Lymphoedema. Treatment to be available quickly and accessibly. We have had feedback that patients have found it difficult to get appointments and patients have to go to Weston for treatment.</p>
13. Oncology (Chemotherapy)	<p>More continuity of care and access to a breast care nurse. The Oncology Centre staff are good, but unsatisfactory to see a different doctor each time.</p> <p>Less waiting at appointments and more time for discussion during consultations.</p> <p>More chemotherapy at home or closer to home. Already working well for Herceptin.</p> <p>Improvements to access &amp; parking at Oncology Centre (same applies for patients having radiotherapy)</p>

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14. Oncology (Radiotherapy)	Less waiting at appointments and more reliable equipment.
	More continuity of care – same radiographer at appointments – someone who knows the patient/case notes.
15. Hormone Therapies	Perception of some patients that not enough information is given.
16. Wigs/Prostheses	More information on wig choices. Better timing for wigs – appointment needs to be before patient loses hair.
17. Follow up & after care	Patients to understand the follow up they will receive and how long it continues (There is controversy as to whether NICE Guidance provides sufficiently long follow up). Processes to be in place/info provided to support patients psychologically when they have finished treatment – a lonely and unsettling time for many.
	Clear advice on symptoms to look out for that may indicate recurrence/metastatic disease, but also whether patients can regard themselves as “all clear”.
	GPs to demonstrate vigilance in identifying possible recurrence, metastatic symptoms and refer for specialist opinion, when necessary.
18. Diet & Exercise	Better nutritional and exercise advice during and after treatment, especially as people are constantly told by the Department of Health that good diet and sufficient exercise reduce the risk of breast cancer.
19. Complementary Therapies	What is offered is good, but needs to be more consistent, easily available. Referrals to Homeopathic Hospital to be sorted – inconsistent referral policy by Bristol & S Glos PCTs. Oncology Centre can refer, but this is not well known.
20. Buildings & Facilities	Modern, clean buildings, pleasant surroundings – gardens
	Private rooms for breast patients – beds that can be raised/lowered, modern, clean showering, bathing, washing facilities. Tasty, nutritious food.
	Outpatients – clean, comfortable, airy waiting rooms. Discreet exit for patients who have received bad news. Resource rooms with the latest information, well equipped offices and consulting rooms. Comfortable, quiet rooms for support groups, counselling and complementary therapy.
	If it is proposed to relocate any services as a result of this Review, the prospective provider of the service must demonstrate satisfactory investment in staff, specialist equipment and facilities to deliver high quality, safe services that meet and exceed national standards. This information must be available to patients and the public during Public Consultation.

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21. Improved Outcomes	<p>From a patient perspective, improved cancer outcomes are :</p> <p>Cure. Improved survival rates. Reduced risk of new primary, recurrence, metastatic disease. Less invasive surgery. Reduced complications after surgery – pain, seroma, haematoma, infection, Lymphoedema, less need for further surgery. High standards of reconstruction – comfortable, good cosmetic result, meets surgeons’ and patients’ expectations. Minimise short and long term side effects of chemotherapy, radiotherapy, hormonal treatments. Best possible quality of life following cancer treatment – physical, psychological wellbeing. For metastatic disease – improved survival rates, good quality of life. Palliative Care – access to best practice palliative care.</p> <p>During the course of the Review, we would like to understand how each proposal meets the improved outcomes listed above, as well as meeting NICE Improved Outcomes Guidance, National Quality Standards (e.g BASO – British Association for Surgical Oncology) and Breakthrough Breast Cancer’s Rights and Realities Campaign aims for improvement of breast care services (see link at end of document)</p>
22. Hub & Spoke	<p>We would like the Breast Care Review to follow these two basic principles of the Cancer Reform strategy : 1. <b>localise where possible (spoke)</b> – Chemotherapy at home or closer to where people live. Weston provides some Oncology, we believe chemotherapy is now available at a centre in Whitchurch. Can some be provided at the Frenchay Community Hospital ?</p> <p>2. <b>Centralise where necessary to improve outcomes (hub)</b>. This is a good principle, but there is a risk that centralisation can mean longer waits and impersonal service. This must be avoided. Centre to be easily accessible by car and public transport for all patients regardless of where they live. Must be adequate, inexpensive parking for patients and staff. The NHS, Local Authorities and private companies must invest and work together to achieve this. Patients and their families are tired of it being left as their problem.</p>
23. Modern Equipment	<p>Latest equipment for diagnosis and treatment of breast disease. Plans must be developed to ensure that it is regularly replaced to remain up to date. The NHS must invest in equipment without depending on charities to fund new technology. The role of charity funding should be to complement NHS funding, not be a substitute for it.</p>

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24. Equality	Proposals from the Review must provide overall benefit to all breast patients, regardless of whether they live in Bristol, North Somerset, South Gloucestershire. Nobody stands still or loses out. There must be no postcode lottery for drugs and treatment.
25. Continuity of Care	Patients want to see the same doctors and nurses throughout referral, treatment and follow up as far as possible. Perception of patients in trials is that they get better continuity of care and more time at appointments. Need to ensure that patients not in trials do not feel 'second class'.
26. Clinical cover, succession plans	Effective emergency and out of hours cover. Excellent training for future breast clinicians and breast care nurses to ensure succession plan. Strategy required to recruit the best people for Bristol and Weston.
27. Family History Clinic	Maintain and build on the good work currently done in Bristol.
28. Clinical Trials/Research	Maintain current success in trial recruitment so that Bristol & Weston are leaders in the UK. See whether the Breast Care Review provides opportunities to strengthen this. Look at involving patient groups in publicising trials and contributing to patient information.
29. Administration, Medical Records	Ensure that high quality patient administration and prompt access to medical records is maintained and improved, if necessary.
30. Best in the UK and among the best internationally.	We want the best Breast Care Services in the UK for Bristol, North Somerset and South Gloucestershire in a realistic and achievable timescale. We want to keep it that way for the future. Sir Ian Carruthers' advice to Patient Stakeholders about the Breast Review is to tell the NHS what we want to improve the service and ask it to deliver it. As part of the Review, we would like to have a clear understanding and agreement on what standards have to be met, equipment purchased and infrastructure renovated or built to achieve the best breast services. Longer term, we want our service to be among the best internationally.
31. Future Proofing	The Breast Care Services Review needs to take into consideration not only current requirements, but those for the future. We must ensure that local services remain among the best in the UK as populations increase and more women and men are diagnosed with breast problems.

Breakthrough Breast Cancer Rights and Realities Campaign :

[http://www.breakthrough.org.uk/what\\_we\\_do/campaigning\\_old/our\\_key\\_campaigning\\_activities/index.html](http://www.breakthrough.org.uk/what_we_do/campaigning_old/our_key_campaigning_activities/index.html)