BREAST CANCER
This working paper has been prepared by Dr Elizabeth Roberts, Director of Breast Test Wales, a member of the Cancer Services Expert Group (CSEG). Material used in the report has been drawn from published guidelines and the results of a small survey of health professionals in Wales involved in the provision of services for patients with breast cancer. Their advice and comments on early drafts have been incorporated wherever possible. The recommendations in this report have been agreed by CSEG.

Further information, regarding recommendation priorities and mechanisms for monitoring their implementation, is available from the Project Office.
CONTENTS

1. INTRODUCTION AND BACKGROUND ................................................................. 50

2. SUMMARY OF RECOMMENDATIONS .............................................................. 50

3. EPIDEMIOLOGY ............................................................................................... 51

4. RISK FACTORS ............................................................................................... 53
   Age ..................................................................................................................... 53
   Geography ......................................................................................................... 53
   Hormonal and Reproductive Factors ............................................................. 53
   Family History .................................................................................................. 54
   Previous Breast Disease .................................................................................. 54
   Lifestyle: Diet: Obesity: Alcohol Consumption ........................................... 54
   Socio-economic Group .................................................................................... 54
   Exposure to Ionising Radiation ...................................................................... 54

5. VARIATIONS IN THE MANAGEMENT OF BREAST CANCER ..................... 54
   Wales: Pattern and Trends in Services .......................................................... 55

6. EXPECTED HEALTH GAIN FROM REORGANISING SERVICES .............. 56

7. CHARACTERISTICS OF A HIGH QUALITY SERVICE .................................. 57
   Breast Health Promotion ............................................................................... 57
   Breast Screening ............................................................................................ 57
   Primary Care Services .................................................................................... 58
   Referral to Specialist Breast Service ............................................................ 58
   The Specialist Breast Unit .............................................................................. 59
   Diagnostic Service .......................................................................................... 60
   Treatment ........................................................................................................ 61
   Follow-up ........................................................................................................ 62
   Palliative Care ................................................................................................ 63

8. SPECIALIST CLINICAL GENETICS ............................................................... 63

9. PSYCHO-SOCIAL SUPPORT AND PATIENT SATISFACTION .................. 64

10. COMMUNICATION AND INFORMATION NEEDS ..................................... 64

11. AUDIT, RESEARCH AND PROFESSIONAL DEVELOPMENT .................... 64

12. ORGANISATION, ROLES AND FUNCTIONS TO DELIVER SERVICES ...... 65
    Principal Personnel ....................................................................................... 66
    Surgeon .......................................................................................................... 66
    Radiologist ..................................................................................................... 66
    Pathologist ..................................................................................................... 66
    Clinical and Medical Oncologists ............................................................... 66
    Breast Care Nurse .......................................................................................... 66
    Affiliated Personnel Required ...................................................................... 66

13. MONITORING PROGRESS AND PERFORMANCE .................................... 67
    Minimum Data Set .......................................................................................... 67
    Quality Assurance .......................................................................................... 67
    Cancer Registration and Intelligence ........................................................... 67

14. CONCLUSIONS .............................................................................................. 67

15. REFERENCES .................................................................................................. 68

16. ACKNOWLEDGEMENTS ............................................................................. 69

APPENDIX 1 - EXAMPLE FLOWCHART FOR MANAGING MOST BREAST CANCERS
1. INTRODUCTION AND BACKGROUND

1.1 This report is intended to provide guidance to purchasers on commissioning breast cancer services within the framework proposed by the Cancer Services Expert Group (CSEG) for the implementation of the Calman/Hine Report, ‘A Policy Framework for Commissioning Cancer Services’, recommendations in Wales. As in the rest of the UK, breast cancer is the commonest form of cancer to affect women in Wales and a major public health concern causing more than 700 deaths each year. However, national statistics show an encouraging reduction in breast cancer mortality over recent years and this trend is also present in data for Wales alone. The report presents an epidemiological overview of breast cancer with particular emphasis on data from Wales, describes the breast services currently available, and summarises published guidelines on good practice within the context of a comprehensive breast service for Wales.

1.2 In recent years attention has been focused on breast cancer for a variety of reasons. Despite developments in diagnosis and treatment over the past twenty years, services for women with breast cancer in the UK have been described as fragmented and of variable quality. There is evidence of poorer survival among women diagnosed with breast cancer in the UK compared with other European countries and among women with breast cancer in different parts of the UK. There has been a growing demand from both lay and professional groups for services that are more specialised. The introduction, from 1988/89, of a national programme of breast screening based on specialist teams, quality assurance, and professional and managerial co-ordination, has also contributed to the high profile which breast cancer attracts. The screening programme has undoubtedly influenced the move towards increasingly specialist breast services in many parts of the UK. This is certainly the case in Wales.

1.3 As part of the ‘follow-on’ in England to the Calman Hine Report, the NHS Executive commissioned a report from the Cancer Guidance Sub-Group of the Clinical Outcomes Group (COG). The COG report ‘Improving Outcomes in Breast Cancer’ is now published. The report reflects a considerable investment of time and expertise in compiling evidence to support recommendations for the organisation of breast cancer services and is relevant to commissioning clinically effective and patient centred breast cancer services in Wales. It is hoped, therefore, that the report herewith will be regarded as both complementary and compatible with the work of COG. Both reports draw on the substantial body of guidance published in recent years reflecting the level of concern and interest in ensuring that women with breast cancer receive optimal treatment and care through high quality services which are characterised by co-ordination, effectiveness, acceptability and involvement in continuing research and education.

2. SUMMARY OF RECOMMENDATIONS

2.1 Specialist breast services for the diagnosis and treatment of breast cancer in Wales should be provided by a network of multidisciplinary specialist breast teams. Specialist teams should co-ordinate diagnosis, treatment - primary, adjuvant and for recurrent disease, and follow-up for patients including specialist palliative care. Diagnosis of breast cancer should be by triple assessment carried out in dedicated clinics accessible both quickly and simply. Specialist breast teams should work within written clinical guidelines based on evidence of effectiveness and in line with published national standards and produce written information about their service including advice on access. Specialist teams should audit their work regularly, monitor outcomes and participate in research, continuing education, and professional and team development.

2.2 Primary care services are essential to a comprehensive breast service. The role of GPs and other primary care team members extends from promoting breast awareness and, in collaboration with Breast Test Wales (BTW), encouraging appropriate attendance of women for breast screening, to referring patients with symptoms for specialist diagnosis, and supporting patients undergoing diagnosis, treatment and follow-up leading to cure or eventual death. The specialist breast team should establish good links with primary care teams and share with them clinical guidelines and other operational procedures used in the service. To ensure that patients receive appropriate and prompt attention clear referral policies and guidelines that meet national standards should be agreed, used and audited.
2.3 Good communications are essential to the delivery of a high quality breast service both internally within specialist breast teams and externally between teams and GPs, other primary care workers, BTW, patients and their families and across the network of specialist services. For this reason a specialist breast team should use appropriate written and verbal information and have in place a strategy for ensuring appropriate distribution. It is particularly important that there is good communication between breast specialists and patients to support as full an involvement as possible in decisions about treatment and follow-up. Breast care nurses have a key role in ensuring that patients’ information needs are co-ordinated before, during and after treatment.

2.4 Good quality data are essential to monitor outcomes and evaluate services. Consideration should be given to using a standard minimum data set across Wales for clinical audit at local level and, collaboratively, involving wider groups. At the all Wales level effective cancer registration and population based epidemiological cancer analysis are essential for monitoring trends in cancer incidence and survival. Consideration should be given to establishing an additional all Wales resource to support expert commissioning and the network of specialist breast services. This resource centre could effectively co-ordinate guidelines work, facilitate professional training and quality assurance, liaise with or become a trials office and develop professional collaboration and expert commissioning.

2.5 To be effective specialist breast services should have appropriately trained and experienced specialists with sufficient time dedicated to the management of breast disease. Specialist breast teams require adequate support services, facilities and staff to provide care to patients and monitor compliance with standards, outcomes and patients’ views. A critical mass of patients is needed to maintain expertise, support specialist training programmes and justify the necessary infrastructure. Suggestion for the minimum throughput of new cases of breast cancer each year range from 50 to over 150. The COG report suggests that teams are likely to be effective and cost-effective when dealing with 100 new cases each year. These factors will need to be taken into account in developing a network of specialist services capable of achieving uniformly high standards for all breast cancer patients in Wales.

| Evidence base: | a. NHSBSP/CRC Publications |
|               | b. BTW Business Plan 1995-98 |
|               | c. British Breast Group Publications |
|               | d. BASO Publications |
|               | f. Report of the Joint Council for Clinical Oncology (JCCO) 1993 |
|               | h. Published Papers |

3. EPIDEMIOLOGY

3.1 Breast cancer is the commonest cancer in women in the UK. It accounts for 20% of cancer incidence and 20% of cancer mortality in women. Most breast cancers occur in older women with 80% of new cases arising over the age of 50. Nevertheless, breast cancer is the leading cause of death in women aged 35-54. The incidence of 10/100,000 in women under 30 rises steeply to 150/100,000 by the age of 50 and 300/100,000 in women aged 85 and over. Breast cancer is rare in men. Welsh data are included in Volume 1 and are summarised as follows:

- Average yearly (1984-88) registrations: 1,665
- Registrations in 1990: 1,770
- Projected new registrations in the year 2000: 2,140
- Deaths from 1985 - 1994: 8,014
- 5 year Survival: 66%
- Years of Life Lost for death under 70 years (1985-94): 53,166

Survival data are from the West Midlands Cancer Registry. For other data sources and ICD9 coded see CSEG Report, Volume 1

204 Breast Cancer Task Group Report
3.2 Globally there are marked differences in incidence and mortality rates, with less breast cancer occurring in Asia and Africa. The UK has the highest breast cancer mortality world wide, although reported incidence is lower than in the US and some European countries(1). The poorer survival experienced by British women is difficult to explain but may be due, in part, to less than optimal treatment(2).

3.3 Time trends show increases in reported incidence and mortality over the last 30 years particularly in older age groups. An increase in incidence has been observed in most countries. However recently published OPCS data for England and Wales show a fall in breast cancer mortality from the mid 1980s onwards, observed initially in younger women and subsequently across all age groups(3). The reduction may be attributable to women presenting with earlier stage disease through better breast awareness, improved treatment or both. Until then and despite technical advances in diagnosis and treatment only modest improvements in survival had been achieved.

3.4 There are geographical variations in incidence and mortality in the UK. Incidence is higher in the south than the north reflecting, in part, lifestyle differences between different populations and the increased risk among women of higher socio-economic status(4).

3.5 Routinely reported statistics (OPCS, WCR) suggest that the incidence of breast cancer in Wales may be higher than elsewhere in the UK. In 1990, the most recent year for which data are available, 1763 new cases were registered in Wales. Incidence appears to vary between different areas of Wales with higher rates in parts of north and west Wales than elsewhere. Table 1 shows the average annual frequency and incidence of invasive breast cancer for residents of former Welsh DHAs for the 5 year period to 1988, the most recent period for which the routine statistics are published by WCR.

<table>
<thead>
<tr>
<th>District Of Residence</th>
<th>Average Annual Registrations</th>
<th>Average Annual Registration Rates/100,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clwyd</td>
<td>254</td>
<td>122.6</td>
</tr>
<tr>
<td>East Dyfed</td>
<td>165</td>
<td>138.8</td>
</tr>
<tr>
<td>Gwent</td>
<td>244</td>
<td>107.7</td>
</tr>
<tr>
<td>Gwynedd</td>
<td>167</td>
<td>136.9</td>
</tr>
<tr>
<td>Mid Glamorgan</td>
<td>264</td>
<td>103.8</td>
</tr>
<tr>
<td>Pembrokeshire</td>
<td>67</td>
<td>117.8</td>
</tr>
<tr>
<td>Powys</td>
<td>59</td>
<td>104.7</td>
</tr>
<tr>
<td>South Glamorgan</td>
<td>200</td>
<td>97.8</td>
</tr>
<tr>
<td>West Glamorgan</td>
<td>224</td>
<td>119.3</td>
</tr>
<tr>
<td><strong>Wales</strong></td>
<td><strong>1,665</strong></td>
<td><strong>114.4</strong></td>
</tr>
</tbody>
</table>

Source: Wales Cancer Registry

3.6 The fall in mortality reported nationally by OPCS(3) is also apparent in the data for Wales (personal communication HIU). In 1994 there were 783 deaths from breast cancer in Wales (OPCS VS3). Possible reasons for the reported improvement include earlier reporting of symptoms by women or improvements in treatment or a combination of factors.

3.7 Work currently in progress to establish accurate baseline incidence and underlying trends by identifying cancers from pathology records and cross checking against WCR data suggests that there may be under registration of cases as shown in Figure 1.
3.8 Age specific rates for 1984-88 and 1988-91 show a difference of up to 15% over the age of 50. Screening, introduced in 1989, would be expected to result in an excess of cancer registrations in women aged 50-64. However, during the period shown less than 20% of the population had been covered by the screening programme. Screening is therefore unlikely to account for all of the difference shown and certainly not for women over 65 years.

4. RISK FACTORS

4.01 At present the cause of breast cancer is not understood. A number of risk factors and associations have been identified and others are under investigation. Unfortunately none offers a prospect for primary prevention in the immediate future. The known risk factors have been described by McPherson and co-authors and are summarised below:

Age
4.02 Incidence increases with age, doubling about every 10 years until the menopause.
4.03 The rate of increase in age specific incidence decreases after the menopause.

Geography
4.04 Seven-fold difference in incidence and mortality between different countries.
4.05 Difference between Western and Far Eastern countries diminishing, but still five-fold.
4.06 Migrant studies indicate environmental factors more important than genetic factors.

Hormonal and Reproductive Factors
4.07 Incidence higher among women who have early menarche or late menopause.
4.08 Incidence lower among women who undergo bilateral oopherectomy before the age of 35.
4.09 Incidence higher among women who have no children or their first child later in life.
4.7 No increase in risk in women who have used oral contraceptives in their late 20s for spacing pregnancies.
4.8 Risk increases if oral contraceptives used for four years or more by younger women before their first term pregnancy.
4.9 Risk is increased after 10 to 15 years use of unopposed oestrogen.
Family History
4.13 Up to 10% of breast cancer in Western countries is due to genetic predisposition.
4.14 Some families with an increased incidence of breast cancer also show excess ovarian, colon, prostatic and other cancers.

Previous Breast Disease
4.15 Women are at a higher risk, about 1% per year, of developing a new cancer in the contra-lateral breast if they have already had breast cancer.
4.16 Incidence higher among women with history of severe atypical epithelial hyperplasia
4.17 Incidence slightly higher when there is history of palpable cysts, duct papillomas, sclerosing adenosis or moderate epithelial hyperplasia.

Lifestyle: Diet: Obesity: Alcohol Consumption
4.18 Close correlation between incidence of breast cancer and dietary fat intake in populations, but direct relation between fat intake and breast cancer does not appear to be strong or consistent.
4.19 Obesity associated with a twofold increase in the risk of breast cancer in post menopausal women whereas in pre menopausal women incidence lower.
4.20 Weak link with alcohol consumption.

Socio-economic Group
4.21 Women in socio-economic groups 1 and 2 are at higher risk.

Exposure to Ionising Radiation
4.22 Exposure to ionising radiation increases risk, particularly when exposure is during period of rapid breast development.
4.23 The effect of such exposure through mammography on young women remains unclear.

5. VARIATIONS IN THE MANAGEMENT OF BREAST CANCER
5.01 The British Breast Group (BBG), reporting on breast services\(^6\), noted a wide variation in the provision of services in the UK with some hospitals seeing very few cases per year and others more than 100. Some were described as fragmented with delays in access and poor co-ordination despite recommendations that services should be grouped together with one surgeon encouraged to take primary responsibility for service delivery and audit\(^7\). There is evidence that not all women receive either an appropriate level of diagnosis or optimal treatment\(^8\). Since the introduction of the national screening programme there has been concern that patients presenting symptomatically to hospitals not involved in the delivery of screening may receive an inferior quality of service.

5.02 Pressures for change have occurred with well publicised campaigns aimed at improving the availability of specialist services for all women with breast cancer, irrespective of where they live, by the Cancer Relief Macmillan Fund and, more recently, the Breast Cancer Coalition and a campaign for better information and help for women with radiation induced damage following radiotherapy was mounted by RAGE. A special interest group has campaigned for better information for women entered into trials. In 1995 the House of Commons Health Committee published a report on breast cancer services with 42 conclusions and recommendations for improvements in the organisation and delivery of services including screening. Media and public interest remains high.

5.03 In Wales, diagnosis and treatment of breast cancer have in the past been provided as part of general surgical services in Wales, with tertiary referrals to specialist centres in South Wales and England. However, the pattern of care is changing and the introduction of screening from 1989 on has been influential in the move towards increasingly specialised services for women with breast disease. BTW has eight multi-disciplinary teams of specialist radiologists, surgeons and pathologists who assess women with screen detected abnormalities. BTW’s specialists also provide local symptomatic services provided in 7 NHS Trusts across Wales. A number of combined treatment and follow-up clinics with surgeon, clinical oncologist and breast care nurse working together are in place or, alternatively, clinics running in parallel. Data collected on breast cancer cases from 1988 onwards show that between 1988 and 1991 the number of surgeons treating more than 50 cases per year increased from 2 to 5 whilst there was a slight fall in the number treating less than 10 cases per year.
PEDW data for 1993/94 and 1994/95 show that approximately 60% of all admissions of patients to Welsh hospitals with a primary diagnosis of breast cancer were to hospitals with specialist medical staff who also work in the screening programme. It should be noted that PEDW data are incomplete, episode rather than person based and relate only to admissions to hospitals in Wales. They therefore provide only a partial picture, particularly for districts such as the former Powys, where women are referred to several hospitals for breast services including some in England.

Wales: Pattern and Trends in Services

For the purposes of the CSEG report information was obtained from health professionals in Wales who currently provide services for patients with breast cancer.

Consultant surgeons known to have a significant input into the management of breast cancer were asked to complete a questionnaire about services in their Trust. 15 responses were received out of a total of 16 sent out. The responses suggest there has been a change in the pattern of hospital services available for women with breast diseases towards breast services which are more focused in nature. The results are available from the Project Office.

None of the 15 respondents thought that fewer than 50 new cases of breast cancers were seen in their own Trust in 1994/95 and half of them thought that more than 100 were seen. In volume terms, therefore, the majority of the Trusts surveyed appear to be dealing with enough cases to justify an expectation that they will be recognised as specialist breast units in the future and it is clear that they aspire to be so designated.

The majority, 14 out of 15, were able to name a lead clinician for their breast service and most claimed a dedicated input from radiologists, pathologists, non surgical oncologists, breast care nurses, radiographers and access to other services and facilities required for patients. With regard to the number of surgeons involved in the management of breast cancer 12 respondents stated that 1 or 2 consultant surgeons dealt with all breast referrals in their local service and a further one reported 4 surgeons working together in a specialist breast team spanning more than one Trust. Clearly there are manpower problems and 4 respondents stated that additional surgeons with a breast interest were required. At least two Trusts lacked a radiologist with a special interest and time commitment to breast imaging and there was a shortfall in pathology, particularly cytology.

Frequent comments related to the lack of clear access to a named psychiatrist or clinical psychologist and the need for additional clinical geneticist time. All 15 respondents identified that one or more breast care nurses were available. All but two teams included at least 10 sessions per week of specialist nurse time. All had a prosthesis fitting service. All 15 respondents confirmed that at least one radiographer in their Trust held the Certificate of Competence in Mammography.

When asked about facilities, most respondents felt they had access to suitable clinic accommodation including a quiet room for counselling, access to beds although not necessarily designated, day case and operating theatre time. There were few comments about the need for better accommodation.

When asked about the organisation of services, all reported weekly breast clinics for new cases. 10 respondents indicated that they held regular team meetings to review radiological, clinical and pathology results. Most respondents, 9, held weekly meetings although regular clinical audit was reported from only 6.

The most frequently mentioned perceived deficiencies were information technology, information systems and data collection capacity. The lack of clinical audit was linked by some to the lack of systematically collected data.

The responses indicate that there has been a move towards specialist team working during the recent past although, clearly, there are resource and organisational implications for Trusts in developing the scope of service recommended by the BBG. The importance of having in place systems for recording key items of clinical data for planning treatment, monitoring standards and auditing outcomes together with appropriate support emerges clearly from the responses.

Good quality mammography is a key component of triple assessment in the diagnosis of breast cancer. Superintendent radiographers in Wales were asked about the volume of mammography work undertaken in their Trust and reported an overall increase in workload over the past 4 years from about 400 in 1992 to about 600 currently. The same survey showed that a total of 41 radiographers held the Certificate of Competence in Mammography. The number of mammograms taken per week varied from 10 to 100 per unit with a range per trained radiographers of 8 to 50. The results of this survey are available from the Project Office.
5.15 A survey of the medical physics aspects of symptomatic mammography in Wales gathered information on the performance of equipment, level of medical physics services available and local quality control systems across hospitals in Wales. Of the 20 mammography X-ray units used in the symptomatic services all but 2 were capable of meeting the key NHSBSP technical requirements for image quality and dose, provided that they are used in conjunction with appropriate films, screens and processors although this may not be workable in units carrying out relatively small numbers of mammograms. At the time of the survey, however, most departments used general processors. To meet NHSBSP guidelines, the frequency of testing and, in some, the range of tests performed would have to be increased. This would have resource implications mainly in terms of staffing. Most departments have in place local QC programmes. To meet NHSBSP guidelines there would be some resource implications in terms of additional QC equipment.

5.16 Data on pathology reporting of breast cancer cases between 1988 and 1991 are collected across Wales by the BTW R&E unit for QA and programme monitoring purposes. These data show that over the 4 years the percentage of cancers with size, grade and sampled nodes reported rose from 74-77%, 43-56% and 53-70% respectively. These improvements were recorded in all parts of Wales and not only in those departments which from 1989 onwards had an input into the screening programme as shown in Figure 2.

5.17 FIGURE 2: Completeness of Pathological Reporting of Invasive Breast Cancers 1988-91

![Graph showing completeness of pathological reporting]

Source: Breast Test Wales Research & Evaluation Unit (UWCM)

6. EXPECTED HEALTH GAIN FROM REORGANISING SERVICES

6.1 Screening is expected to result in a reduction in breast cancer mortality of up to 25% in the population included in the national screening programme. Further improvements in survival and reduction in breast cancer deaths can be expected to follow for women presenting symptomatically to specialist services where there is accurate diagnosis using triple assessment which informs treatment planning decisions. The COG report identifies fairly strong evidence that specialisation of providers is associated with improved 5 year survival(9). In addition a number of clinical trials have shown benefits in survival for women appropriately selected for adjuvant systemic chemotherapy and hormone therapy(10).

6.2 Quality of life and patient satisfaction should be increased significantly as a direct consequence of services based on a multidisciplinary team and specialist approach. The COG report suggests that a team based approach in a specialist breast unit setting that responds to the information and support needs of patients could improve patient satisfaction by 50%(9).

6.3 Monitoring the quality of services and the effects of service improvements will present a challenge particularly for small populations in rural parts of Wales where services may be widely dispersed.
7. CHARACTERISTICS OF A HIGH QUALITY SERVICE

7.1 Most women do not develop breast cancer although many experience breast symptoms at some stage in their life. Clearly, therefore, a high quality service needs to be first of all broadly based and meet a range of needs.

7.2 A comprehensive breast service should encompass:

- Health promotion
- Breast screening
- Primary care services
- Specialist breast unit providing:
  - diagnosis and treatment
  - follow-up and palliative care
  - audit, quality assurance, training, research
- Cancer registration and intelligence

Breast Health Promotion

7.3 Many women find the subject of breast cancer extremely worrying. Their perception of risk of developing the disease may be exaggerated particularly among younger age groups. There is constant media interest in breast cancer and treatment services which are often negatively portrayed. The introduction of the national breast screening programme has raised awareness of a broad range of breast cancer issues although it is clear that women do not always receive accurate information even in relation to screening. For example, the majority of women older than the age group automatically invited for screening, when surveyed by Age Concern, thought they were not in a particularly high risk group.

7.4 Clear and factual information is needed to:

- increase awareness of the risk of developing breast cancer and the benefit of early detection.
- convey sensible advice and guidance on breast awareness.
- encourage women to report breast symptoms and concerns early to their GPs.
- encourage a high uptake of screening among women aged 50 and over.
- encourage confidence in the specialist breast services.

7.5 Appropriate breast health promotion is relevant at community level and through the specialist services. At community level clear, consistent and accurate information should be conveyed using a variety of methods appropriate for different cultural and ethnic groups. The primary care team has opportunities, through contacts with women attending well woman services and general primary care consultations, to provide breast health information and advice. Other sources in the community are employers, health promotion departments, voluntary groups and cancer charities and women’s organisations. BTW works collaboratively with local health promotion departments and women’s groups to increase breast awareness and knowledge about screening. BTW has regular contacts with every general practice. BTW’s methods could be further utilised and the scope broadened to improve the transfer of information between primary care, community groups and specialist services.

Breast Screening

7.6 A national population based breast screening programme was introduced across the UK following the acceptance, by health ministers, of the recommendations of the Forrest working group\(^{11}\). Evidence from screening trials in the US and Europe suggested that breast cancer mortality might be reduced by up to 30% in women aged 50 and over by routine mammographic screening. BTW was established as an all Wales service to deliver the programme to women in Wales. Since 1989, women aged 50-64 have been invited systematically to attend for mammographic screening at 3 yearly intervals, the service also being available to older women on request.
7.7 The recently reported fall in breast cancer mortality has occurred too early to be due to direct effects of screening. It is likely, however, that the introduction of screening has had an influence on public awareness of breast cancer issues. Screening has also had an impact on professional and organisational aspects of services for women presenting symptomatically, not the least of which is the development of increasing levels of specialisation among the medical disciplines involved in screening. BTW employs around 80 WTE staff including radiologists, surgeons, pathologists, breast care nurses, medical physicist, radiographers and helpers, administrative, secretarial and clerical staff. Some 80,000 women are invited to attend for screening each year. The service includes:

- Computerised call and recall system
- Public relations and health education for health professionals and women
- Screening mammography
- Multidisciplinary specialist assessment, including the purchase of open diagnostic biopsies
- Training and professional development including the Certificate of Competence in Mammography
- Quality Assurance
- Programme evaluation and research
- Participation in national screening trials

7.8 It is important that women who are found to have breast cancer as a result of screening receive appropriate and prompt treatment. The key interface between BTW and specialist treatment services is therefore monitored as part of screening QA and evaluation. Any shortfall in breast specialist skills either in BTW or in breast services provided by secondary and tertiary specialist services have major implications for screening. Particular worrying for screening is the shortage of radiologists with an interest and expertise in screening. The problems will be exacerbated if the volume of screening work increases, either as a result of pressure from groups such as Age Concern to invite older women for screening or if national screening policy changes in response to ongoing trials of screening age and frequency.

7.9 For the period required to evaluate the Welsh programme it is intended that screening will continue as an all Wales managed service. It is essential that appropriate links are established between BTW and the specialist breast services designated as part of implementing the Calman/Hine recommendations in Wales, particularly those teams that do not have a direct involvement in screening.

**Primary Care Services**

7.10 The Primary Health Care Team (PHCT) should be actively involved in the breast screening programme and has a key role in ensuring its success. The PHCT can help to improve the quality of the programme, increase uptake and provide information and counselling to women. It is the responsibility of BTW to keep the PHCT informed about the programme and to feedback information and results relating to the practice population. BTW depends on the active participation of the PHCT to ensure that women eligible for screening are identified and invited.

7.11 For women with breast cancer presenting to their GP symptomatically and for those with screen detected cancer the GP will be the focus of breast cancer care with an important and continuing role in all aspects of their patients management. Breast cancer is a relatively unusual occurrence at the level of the individual GP who sees, on average, one new case of breast cancer each year. Most women who present with breast symptoms will not have breast cancer, but should have the opportunity to discuss their risks and the advisability of further investigation.

**Referral to Specialist Breast Service**

7.12 Guidelines advising GPs on which patients with breast problems should be referred and which patients can be dealt with safely by the GP have been published and distributed to all GPs in England and Wales. They set out protocols for the referral and management of breast lumps, breast pain and nipple discharge. A randomised controlled trial is currently evaluating the use of the national guidelines, but in the meantime they can be usefully incorporated into local policy guidelines between GPs and the specialist breast team.
Women with significant breast signs or symptoms, e.g. a lump, nipple discharge, eczema or tethering should be referred to the specialist breast service. Current guidance suggests that referral should be to a surgeon within the district with a specific interest and training in breast disease who works with a multidisciplinary breast team in a unit which is properly staffed and equipped\(^6\). Whether referral is to the surgeon or the team, GPs should have well established links with their local specialist breast service with written guidance about the services including advice on obtaining rapid access for women for whom referral is indicated, prompt communication about diagnosis and proposed management.

- The breast unit should send details to GPs of the arrangements for getting patients seen and particularly for obtaining rapid access to the specialist diagnostic service. The guidance should include the arrangements for new patients and also women with established breast cancer already under the care of the breast team who may need to be seen quickly during the follow up period\(^14\).
- The breast unit should develop standards for referral, audit and provide information about waiting times for urgent referrals and all breast referrals.

Local guidelines should also provide advice on areas of particular concern to GPs including:

- Aspiration of breast lumps by GPs which should only be performed by appropriately trained GPs if they are as certain as possible that the lump is a cyst.
- Open access for mammography which is not recommended and is not necessary in a modern breast service using triple assessment\(^7\)
- Referral of women with a family history of breast cancer for whom there are no nationally agreed guidelines published and further research is needed. Until evidence is available regarding appropriate services interim arrangements should be agreed and incorporated into local policies.
- Women on HRT, for whom there is no evidence that a baseline mammogram is required or, for those aged 50 and over, that mammograms should be carried out more frequently than every 3 years.

### The Specialist Breast Unit

#### 7.14

A number of reports either published or in preparation contain guidelines on the organisation of specialist breast services\(^{14-22}\). The report of the BBG defined the following characteristics for a high quality breast service.

- Accurate and timely diagnosis
- Appropriate treatment and follow up
- Effective communication
- Skilled psycho social support
- Access to other specialist facilities as required
- Collection of data on outcome measures

#### 7.15

The BBG states that ‘the provision of a high quality service requires close co-operation between specialists from several disciplines’ and ‘it is essential that care is provided by a multidisciplinary team working together in a specialist breast unit. Women with breast symptoms that warrant further investigation should be referred to a specialist breast unit for triple assessment (clinical examination, breast imaging and needle biopsy as appropriate). The recommendations which appear in the following sections of this report are based mainly on the British Association of Surgical Oncologists (BASO) guidelines\(^{14}\).’

#### 7.16

All breast units should use written policies and guidelines. Clearly, national guidelines should be adapted and owned locally to meet local needs and circumstances. What matters is that they are used and reviewed regularly. Joint management protocols should be developed between specialist breast units and the cancer centre with which they are linked. The BBG suggests that the specialist breast oncologist, who is a core member of the multidisciplinary team, takes on a key role in the development of common protocols for the service. The opportunities for co-ordinating guidelines and protocol development between multidisciplinary teams across a network of specialist services should be considered in Wales. Such work has already been initiated in South East Wales with the production of a breast cancer management guidelines document by a multidisciplinary South East Wales breast group of clinicians who treat breast cancer in Velindre NHS Trust and acute hospital Trusts in the former Mid Glamorgan, South Glamorgan and Gwent Health Authorities\(^{14}\).
7.17 A flow chart providing a summarised framework for the specialist breast service is attached at Appendix 1, with the kind permission of Dr Peter Barrett-Lee who chaired the South East Wales group. Further thought should be given to supporting the development, dissemination and monitoring of guidelines at an all Wales level.

**Diagnostic Service**

7.18 A dedicated diagnostic service is a key element of the specialist breast service and requires expertise, equipment and facilities for the accurate and timely diagnosis of primary breast cancer, distant metastatic disease and recurrence. The diagnostic services should deliver a co-ordinated and patient centred service with the following characteristics:

- Be organised as a dedicated multidisciplinary breast clinic held frequently enough, and at least weekly, to allow rapid access of women referred with significant symptoms or signs.
- Patients should be seen by the consultant breast surgeon, at the very least, for their first consultation.
- Have a core diagnostic team of named specialist staff including a surgeon, radiologist, breast care nurse and pathologist. Larger teams may have more than one specialist from each discipline with the additional advantage of providing cover during periods of leave. Team members, irrespective of the size of the team, should work together effectively.
- Use written protocols based on triple assessment (clinical examination, imaging using mammography and ultrasound, cyto- and histo-pathology) aimed at achieving a pre-operative diagnosis with minimum delay and number of visits and minimum requirement for repeated diagnostic procedures.
- Formally review the results of triple assessment at a weekly meeting of the multidisciplinary team arranged specifically for this purpose with suitable meetings facilities and equipment.
- Have access to image guided core biopsy and/or diagnostic open biopsy for those cases where triple assessment does not result in a definitive diagnosis.
- Obtain histological node status on all invasive tumours either by sampling of at least 4 lymph nodes or axillary clearance.
- Lead to treatment planning which involves the members of the therapeutic team including the surgeon and clinical oncologist.
- Have access to treatment services and facilities.
- Communicates effectively with patients and GPs.
- Have available:
  - A supporting breast radiology service with access to dedicated X-ray mammographic equipment which meets the standards required by the national screening programme, subject to rigorous quality control and carried out by radiographers with appropriate training and expertise and holding the Certificate of Competence in Mammography.
  - Ultrasound equipment appropriate for breast diagnosis and performed under the direct supervision of the team radiologist.
  - Radiology equipment sited conveniently for the clinic and the service organised so that imaging is carried out without delay during the initial visit.
  - Equipment for image guided biopsy available for the diagnosis of impalpable lesions prior to excision.
  - Facilities for specimen radiology to identify impalpable lesions removed at surgery.
- Have available:
  - A supporting breast pathology service with appropriate technical support for the team pathologist(s).
  - Adequate trained staff to report FNA or needle core specimens.
  - Recorded data on excised lesions including histological size and grade, tumour type, nodal status if nodes included, excision margins and vascular invasion assessment.
  - Reporting which should follow guidelines developed nationally for screening.
  - Pathologists who participate in EQA schemes.
  - Have written protocols, quality standards and clinical audits of each aspect of the diagnostic procedures which are in line with national guidelines and published evidence.
Treatment

7.19 The management of breast cancer is complex and has changed markedly over recent years. Evidence for improved survival and better quality of life is available from clinical trials of adjuvant systemic therapy, including tamoxifen for primary operable breast cancer and presented in the COG report\(^9\). The use of tamoxifen may decrease the incidence or may simply slow the appearance of a second primary breast cancer. Trials are taking place to assess the secondary prevention of recurrences following primary treatment, primary prevention for women known to be at high risk and, particularly in relation to screen detected tumours, the optimum management of impalpable cancers and DCIS\(^15\). In addition several chemotherapy trials are ongoing, e.g. ABC, high dose adjuvant chemotherapy for advanced disease.

7.20 Treatment of breast cancer usually involves some form of surgery with adjuvant systemic treatment either chemotherapy, endocrine therapy or radiotherapy according to patient and tumour characteristics including stage. Treatment should be carried out by a team of specialists working together in the specialist breast unit. The BBG recommend that, with the exception of having to receive radiotherapy, the care of patients with breast cancer should be centred on the specialist breast unit.

Treatment Plan

- Treatment of primary breast cancer should follow written protocols agreed by the breast team encompassing surgery, radiotherapy and chemotherapy and including guidelines to determine tumours suitable for conservation therapy or mastectomy. Where neo-adjuvant chemotherapy is planned before surgery, breast imaging plays an important part in the ongoing management\(^16\).

- There should be a defined time for the breast team to meet to discuss treatment plans for individual women attended by the surgeon, pathologist, clinical oncologist and breast care nurse.

- Treatment plans should be discussed with the patient who must be given enough time, information and support to make a fully informed decision about the available options for treatment including its timing and opportunities for entering trials. To achieve this, patients need to have time to discuss their diagnosis and the treatment options particularly with the surgeon and breast care nurse but also with their family and to have access to the nurse for continuing information, support and counseling. It may be appropriate for other members of the team such as the clinical oncologist to be available to discuss specific aspects of treatment and there are occasions when the consultant in palliative care will be involved at an early stage.

- Close communication should continue between surgeon, clinical and medical oncologist to monitor primary treatment and facilitate adjuvant therapies taking into account factors predictive of survival, recurrence and patient characteristics and preferences. Planning should allow for reconstructive surgery where this is appropriate and wanted by the patient.

- Individual patient management plans should be shared with the GP and the patient.

Surgery

- Surgical treatment should be carried out by consultant surgeons who are named members of the specialist breast unit team and who have a special interest and training in breast disease, or specialist trainees with sufficient experience under the direct supervision of the breast surgeon.

- Where mastectomy is carried out there should be the opportunity for patients to receive advice on reconstructive surgery which may be available either in the breast unit or via a recognised line of referral to a surgeon with particular expertise.

- There should be adequate facilities for inpatients, day patient care and theatre sessions.

- To reduce anxiety the date for operation should be agreed with the patient. Patients should not be placed on waiting lists. The breast team should produce written standards for the time between the decision to operate and proposed admission date which are recorded and audited by the team. It is good practice for the operation date to be within 2 weeks with a maximum acceptable wait of 4 weeks, except where treatment is to be delayed, e.g. to follow primary cytotoxic treatment\(^10\).

- BASO guidelines suggest that there is no evidence that a pre-operative search for occult metastases, e.g. chest X-ray, bone or liver scan is useful for women with primary operable breast cancer. However, the Royal College of Radiologists guidelines allow for pre-operative chest X-ray if the patient has malignant disease.

- There should be written standards for surgery relating to tumour margins, number of repeat therapeutic procedures, histological node sampling and clearance which are recorded and audited.
Patients should be supported by the breast care nurse on the team who liaises effectively with ward nursing staff. Subsequent support may be given at follow up visits or in the home and will include advice on clothing, care of the arm and assessment of anxiety or depression so that appropriate referral for specialist help can be made.

Following mastectomy a prosthesis fitting service should be available.

 Patients should have sufficient information about the range of services available to them during and following their primary treatment including their planned follow-up with the team, and self help groups. The breast care nurse has a key role in ensuring that the patient has the information that she needs and that her questions can be addressed.

The breast team should ensure that GPs receive prompt and clear information regarding the diagnosis and care plan including the toxicity profile of any proposed systemic therapy.

Radiotherapy

- The clinical oncologist should have a special expertise in the management of breast cancer, be a member of the multidisciplinary therapeutic team and be involved in treatment planning for individual patients.
- Patients should be reviewed by the clinical oncologist regularly throughout their radiation therapy.
- There should be an agreed standard for the time lapse between surgery and post-operative radiotherapy for early breast cancers treated by wide local excision. Other than for clinical reasons the time should not exceed 4 weeks although it should be determined by clinical assessment and take into account time needed for wound healing\(^\text{(17)}\).
- Where treatment requires both radiotherapy and chemotherapy, phasing of the treatments should be decided for clinical reasons and the planned intervals should be strictly adhered to.
- Prophylactic axillary radiotherapy is inappropriate in cases in which adequate numbers of lymph nodes have been examined and shown to be histologically negative and is contra-indicated in node positive patients who have had axillary clearance.

Chemotherapy

- Cytotoxic chemotherapy should be carried out under the clinical supervision of a consultant with a special expertise in anti-cancer drug therapy in breast cancer.
- The consultant oncologist, either clinical or medical, should be a member of the specialist breast team.
- Treatment can be administered in the specialist breast unit in a designated area which complies with cytotoxic drug regulations and where there are appropriately trained staff and supervision.
- There should be adequate pharmacy support.
- There should be adequate facilities and medical cover for the management of any complications which may arise. Hospital staff and GPs must be given details of how to access this cover.
- In cases in which adjuvant chemotherapy is required, BASO guidelines suggest that the time interval between the decision to give chemotherapy and the start of chemotherapy itself should not exceed 3 weeks.

Follow-up

7.21 Despite improvements in diagnosis and treatment many patients will develop some form of recurrence, the majority within the first 5 years of treatment. However, the benefits of routine follow up hospital visits for women following treatment for operable breast cancer and who are in remission is not proven and requires further research\(^\text{(18)}\). The COG report highlights the lack of evidence and the potential for change as one of five key recommendations. Until evidence becomes available written protocols for follow up should be agreed by the team and monitored with clear advice given to the patient and GP. Arrangements for follow up should include the following:

- Routine follow-up should take place in dedicated clinic space by the surgeon who carried out the treatment with other members of the diagnostic breast team and the breast care nurse, working to standards that are the same as for the diagnosis of primary breast cancer.
- For patients who have had radiotherapy or chemotherapy it is good practice for the surgeon and clinical oncologist to work together in a combined clinic. This is possible where the oncologist has defined sessions as a member of the specialist breast team.
Women at high risk of developing distant, local or regional recurrence should be seen at more frequent intervals. Such patients should be identified from the prognostic factors available and more frequent follow-up arranged for them.

Women who have undergone treatment for primary breast cancer should have open access to a follow-up clinic, should they be worried about any sign or symptom during the period before an appointment is due.

Procedures for the detection of local recurrence following conservation surgery require the same approach as the detection of a primary breast cancer.

Patients at high risk of flap recurrence following mastectomy should be identified and offered prophylactic radiotherapy.

Annual mammography is recommended where conservation surgery has been performed.

Because of the increased risk of developing a second primary cancer the contra lateral breast should be examined by mammography following treatment. However, the optimum frequency for mammography is unknown and should be assessed. Until the evidence is available, women should receive mammograms as agreed in their local guidelines.

If a GP detects recurrence referral should wherever possible be back to the breast unit where the patient was treated initially and not to a different surgeon or oncologist. This implies that there must be a clear mechanism for the GP to have access to the breast unit when problems arise.

It is important that advice about the use of adjuvant endocrine therapy is available for the patient and GP with a requirement that any proposal to prescribe by the GP is shared with the specialist team.

**Palliative Care**

7.22 Centres offering breast cancer treatment should ensure that there are adequate palliative and, where appropriate, terminal care facilities to support the primary care team. Patients who develop metastatic disease have an average survival of about 2 years. The aims of treatment during this time are to relieve symptoms and to maintain the highest possible quality of life. Palliative care is part of the specialist service available for patients and may be of benefit at a number of stages:

- Once a patient develops symptoms from distant metastases she should remain under the care of the specialist breast team and the local unit responsible for her treatment.
- The surgeon and clinical oncologist should help in the management of women with advanced disease together with other members such as the breast care nurse.
- The palliative care team should be involved at the appropriate stage according to the patient’s physical, psychological and spiritual needs.
- There should be a consultant in palliative medicine who is a named member of the specialist breast team.
- There should be protocols for palliative treatment available to members of the team and the GP aimed at the relief of symptoms and promoting the patient’s psychological, social and spiritual well being.
- Palliative care teams should be available in the hospital and the community.

**8. SPECIALIST CLINICAL GENETICS**

8.1 The need for clinical geneticists to assess and counsel women regarding their risk of breast cancer is likely to increase substantially over the next few years. Specific genes have been identified in which mutations are linked to a clearly increased risk of developing breast cancer. Whilst there is no simple test available to identify individuals in the general population at increased risk, genetic testing may benefit individuals from families where a mutation is well documented. With the development of suitable tests possibly available to greater numbers of people, demand for advice is likely to grow quickly.

8.2 Women who feel they are at increased risk are anxious to obtain either screening or surveillance. Women with established disease will ask about the risks for their daughters. Close links between the specialist breast team and clinical geneticists will be essential although further research is needed to identify what constitutes an appropriate service for women at increased genetic risk including continuing surveillance and the role of screening. The trial of a specialist genetics service currently being undertaken in Wales (TRACE) with MRC and Welsh Office funding is intended to address these important questions. At present women who meet the criteria may be offered entry into the tamoxifen prevention trial through the regional trialist in Cardiff.
9. **PSYCHO-SOCIAL SUPPORT AND PATIENT SATISFACTION**

9.1 It is estimated that at least 30% of breast cancer patients suffer psycho-social problems including anxiety and depression, irrespective of whether they undergo mastectomy or breast conserving treatment. There is evidence that patients who are able to choose their treatment suffer less than those in a more prescriptive environment.

9.2 Patients’ quality of life and satisfaction with the services available to them are likely to be enhanced in a well co-ordinated service with a multidisciplinary breast team which is better placed to communicate and inform. The COG report has indicated that there is major scope for improving women’s experience and confidence through the development of specialist units and teams.

9.3 Key persons to improve patient satisfaction and psycho-social support are the surgeon, clinical oncologist, breast care nurse and the palliative care consultant and team, the latter particularly with respect to the control of pain and other symptoms.

9.4 Support from family, GP, other members of the PHCT, and community and self-help groups is crucial. Studies have shown benefits for breast cancer patients from a wide range of supportive interventions for patients and their families.

9.5 To be effective the supportive network should be co-ordinated across Trust boundaries. The breast care nurse has the key role in ensuring that support is co-ordinated and not fragmented.

9.6 Breast care nurses should be adequately trained in interviewing and providing psychological support and should have regular supervision and help from appropriate personnel, either psychiatrists or psychologists. Following surgery for breast cancer, all patients should be observed for signs of anxiety and depression and referred, where appropriate, for specialist psychiatric help.

10. **COMMUNICATION AND INFORMATION NEEDS**

10.1 Effective communication with patients improves their understanding of breast cancer and its treatment, compliance with treatment and quality of life. Women are increasingly concerned with the quality and timeliness of information and the way that specialists and GPs communicate. Several women’s organisations such as Europa Donna and the Breast Cancer Coalition have been established partly for the purpose of improving the information available to individuals. All members of the team should be able to communicate with individual patients although the breast care nurse can make a particularly important contribution.

10.2 Good communication is easier if the environment is appropriate. The breast care nurse should have access to a suitably private room. Because the patient may be emotionally upset and may not take in everything she is told, the presence of a companion, either husband or friend, should be encouraged. A telephone contact number and a further appointment may be made to discuss treatment again and answer any questions. Patients should be informed about the range of services available to them and provided with literature to take home, including details of further follow-up treatment and information about local self-help groups.

10.3 The specialist breast team should be in direct contact with GPs so that they gain a clear understanding of the diagnosis, care plan and toxicity profile of any proposed systemic treatment. Such communications should certainly be sent at the first post-operative review and at the time of any change of treatment.

10.4 It should be possible to assess whether the patient believes that she has been given appropriate information to make a choice of treatment and that after counselling she feels confident about the choice that she has made. It is important that issues such as the patient’s perception of altered self image, her ability to function to her satisfaction within her own lifestyle including family relationships are addressed.

11. **AUDIT, RESEARCH AND PROFESSIONAL DEVELOPMENT**

11.1 Clinical audit should involve all members of the specialist team and each aspect of the specialist service. National guidelines and quality standards already in place for the screening programme can be adapted for use with patients presenting with symptomatic disease. Others have been developed and documented by BASO and RCR specifically for use in symptomatic services. The specialist breast team should document their clinical guidelines and protocols basing them on nationally published standards which are evidence based or, at least, represent a consensus. These will provide an excellent basis against which to audit performance.
11.2 It is imperative that accurate records are kept in which are recorded diagnostic, staging, treatment and follow-up data. Long term outcome measures such as loco-regional recurrence, treatment morbidity, distant metastases and overall survival should be collected and published. A lead clinician on the breast team should have overall responsibility for the production of data by the Unit.

11.3 Participation in research including multi-centre trials should be expected from each specialist team. Whilst it is only through properly conducted research that further improvements in treatment can be identified, only a minority of patients are currently entered into trials of national importance. There is evidence that patients treated in centres where research is carried out do better in terms of survival[22].

11.4 The main breast trials include the following:
- UKCCCR DCIS Trial, by January 1996 43 women in Wales entered.
- CRC over 50s Adjuvant Tamoxifen Trial.
- aTTom, prolonging adjuvant tamoxifen treatment in women with operable cancer.
- BASO 2 Trial, small cancers.
- ABC, UKCCCR adjuvant trial.
- Screening Trials, Age, Frequency.

11.5 Specialist breast team members should be encouraged and have the time to update their knowledge and skills. Specialist breast units including BTW should be closely linked with their respective cancer centre and accredited by the appropriate SACs to be part of co-ordinated formal training programmes for surgical and other medical trainees intending to specialise in the management of breast disease and to contribute to CCSTs. The specialist breast service should also support CME and equivalent activities for team members and for others including PHCT members.

12. ORGANISATION, ROLES AND FUNCTIONS TO DELIVER SERVICES

12.1 The BBG state that access to specialist facilities needs to be balanced against the critical volume of patients required to ensure that a specialist unit is viable and able to maintain the necessary levels of expertise. Studies show that in the past there were large numbers of surgeons and hospitals involved in treating breast cancer. Outcomes may be better in those treating more patients[23]. The BBG recommend an absolute minimum of 50 new patients with breast cancer per year but that, in general, specialist units should manage at least 75-100 new patients per year. The BASO guidelines state that to be cost effective the number should be 100-150. The COG report recommends 100.

12.2 On average a unit seeing 100 new cases per year will receive referrals from a population of 200,000. These rates applied to Wales suggest about 14 such units. Clearly commissioners need to have regard to the geography and rural nature of many parts of Wales as well as the current level of services available and their links with BTW in deciding the pattern for the future. Other constraining factors are:
- The requirement for an oncologist specialising in breast cancer treatment to be a member of each specialist breast team, approximating to 0.5 WTE per team.
- The possible development of a specialist cancer genetics service may also determine how many units can be supported.
- The supply of specialist trained consultants in radiology and surgery, almost certain to pose difficulties for the immediate future.
- The medical staff issues need to be addressed urgently by the Department of Health and the Royal Colleges and remedial measures identified.
- The development of information systems with appropriate staff for data collection and analysis which will require considerable investment for each site.

The key components of a specialist breast unit as defined by the BBG are:
- core named personnel (e.g. surgeon, radiologist, pathologist, oncologist and clinical nurse specialist).
- regular combined review meetings to confirm the diagnosis of cancer and plan treatment.
- adequate facilities (e.g. for imaging, pathology and surgery).
- locally agreed protocols and guidelines covering all aspects of care.
- close liaison with general practitioners and other primary care services and with other specialists involved in a patient’s care.
Principal Personnel

Surgeon
12.3 The breast surgeon should devote a minimum of 3-4 sessions per week to the management of breast disease (i.e. 1 new patient clinic, 1 operating session, 1 follow-up clinic and 1 review/audit session). Larger units probably require 2 surgeons working together, each with 3 to 4 sessions.

Radiologist
12.4 Breast imaging should be reported by radiologists experienced in mammography and breast ultrasound. The radiologist should also have expertise in image guided fine needle aspiration cytology and biopsy techniques. Minimum standards for radiologists involved in the NHS Breast Cancer Screening Programme have been published and The Royal College of Radiologists Breast Group has produced guidelines for Radiologists involved in symptomatic mammography\(^{(21)}\).

Pathologist
12.5 The Breast Team must include a pathologist or pathologists with special expertise in breast pathology and cytology with designated time for breast cancer work. Guidelines for pathology reporting in breast cancer screening have been published\(^{(22)}\).

Clinical and Medical Oncologists
12.6 Radiotherapy and chemotherapy should be carried out by clinical oncologists and medical oncologists who have opted to specialise in breast cancer. They should have special training and interest in breast cancer with expertise in the use of radiotherapy and systematic treatments (hormonal or cytotoxic) in breast cancer and the relief of symptoms associated with metastatic breast disease. Oncologists should have sessions identified for multidisciplinary review and joint follow-up of patients at the specialist unit.
12.7 As with surgery there is evidence that outcomes are better if treatment is prescribed by and supervised by a medical or clinical oncologist with an interest in breast cancer. The RCR has recommended that a safe limit on the workload for a consultant clinical oncologist should be 350 new patients per annum. For Wales this would equate to 5.0 WTE consultants solely devoted to breast cancer and assuming possibly fewer than the 14 specialist units suggested by the population figures.

Breast Care Nurse
12.8 Guidelines for nurses in breast cancer screening have been published\(^{(18)}\). Ideally breast units need two breast care nurses, working together but with one working mainly at the primary stage and one for help in advanced disease. The breast care nurse should:
- be available for all patients undergoing treatment for breast disease, particularly at the time of diagnosis, when any options for treatment are discussed.
- be available to see patients pre- and post-operatively on the ward, e.g. to discuss arm exercises, minor operative complications or personal problems worrying the patient, can be discussed together with any personal problems.
- fit temporary prostheses before discharge and advise on bras, swimwear and choice of permanent prosthesis, where appropriate.
- keep up to date with knowledge of breast disease and help with research.
- be involved in the education of nursing staff on breast disease, both in the hospital setting and elsewhere.

Affiliated Personnel Required

12.9 A number of other specialists may at times become involved in the management of a patient with breast cancer including:
- Liaison psychiatrist and/or clinical psychologist for advising and treating patients and also supporting team members particularly with regard to the continuing development and training of breast care nurses.
- Palliative care specialists and teams, although the South East Wales breast group suggests that a consultant in palliative care should be a member of the core team.
- Physiotherapists and occupational therapists.
- Clinical genetics as discussed in section 8 above.
- Surgeon experienced in breast reconstruction.
- Pharmacist.
13. MONITORING PROGRESS AND PERFORMANCE

Minimum Data Set

13.1 Clearly, accurate and complete data to support audit and performance review are essential. For the future, consideration should be given to agreeing a minimum data set with all specialist teams in Wales which could support useful prospective audits across the whole population\(^{(24)}\). Monitoring performance will be important across a number of areas:

- Written policies, guidelines and information produced for patients and GPs.
- Staffing levels, facilities, equipment.
- Frequency of multidisciplinary team meetings for clinico-pathological review and clinical audit
- Results of audit and compliance with national standards and local guidelines.
- Workload, particularly number of new cases of breast cancer managed.
- Evidence of patient satisfaction.
- Quality of life, anxiety and depression measures.
- Measures of time periods between different stages from referral on.
- Completeness of data collection and reports of results.
- Number of complaints received and dealt with within defined time.
- Number of patients entered into clinical trials.
- Outcomes measures, 1 and 5 year survival, recurrence rates, wound infection and lymphoedema rates.

Quality Assurance

13.2 Quality assurance was considered an essential part of the national breast screening programme and was identified by the House of Commons Health Committee in 1995 as one of its most successful features. The QA approach used in screening could be extended to the specialist breast units and multidisciplinary teams. There would be resource implications in setting up QA teams and systems.

Cancer Registration and Intelligence

13.3 Timely, accurate and complete cancer statistics are essential to improve understanding of the pattern and the characteristics of breast cancer in Wales and the impact at population level of screening and treatment on survival.

13.4 An effective linked network of intelligence gathering and interpretation including cancer registry, public health and clinical information systems should be developed. A breast cancer ‘community’ for Wales might then include further developments such as a national trials office, training centre, meetings organising and reference centre. Existing models for such organisations include the Yorkshire Regional Cancer Organisation and the Scottish Cancer Therapy Network\(^{(25,26)}\).

14. CONCLUSIONS

14.1 The outcome and well-being of women with breast cancer will be improved if the specialist services are organised to facilitate modern best practice. The modern management of breast disease must be based on a multidisciplinary team approach and be evidence based. Services need to be networked so that communications are good within and between units, between BTW and units and cancer centres and extend to involve primary care. Screening and symptomatic services should inter-relate. For women, care must be seamless which depends on communication and collaboration. Continued research is an absolute requirement for this complex and distressing disease and training and professional development programmes are also essential. An effective means of monitoring breast cancer epidemiology and treatment outcomes is required to underpin the service in Wales and to inform the commissioning process.
15. REFERENCES


15. QA Guidelines for Radiologists. NHS Breast Screening Programme 1990


17. Royal College of Nursing of the United Kingdom, Breast Care Nursing Society. Standards of Care for Breast Care Nursing. London: Royal College of Nursing 1994


16. ACKNOWLEDGEMENTS

Consultant Surgeons who see women with breast cancer in NHS Trusts in Wales
Professor RE Mansel, Professor of Surgery, University of Wales College of Medicine
Dr PJ Barrett-Lee, Consultant Clinical Oncologist, Velindre NHS Trust
Breast Care Nurses including Mrs T Cotton at Breast Test Wales
Superintendent Radiographers including Mrs D Winstone at Breast Test Wales
Medical Physicists including Ms A Burch at Breast Test Wales
Ms L Branston from the Breast Test Wales Research & Evaluation Unit
Dr D Shickle, Lecturer in Public Health, University of Wales College of Medicine
Miss E Van Os, Breast Test Wales for secretarial support
APPENDIX I – EXAMPLE FLOWCHART FOR MANAGING MOST BREAST CANCERS

SYMPTOMATIC: Woman with a breast lump or other breast symptoms

Refer to specialist breast unit at Cancer Centre or DGH

ASYMPTOMATIC: Woman aged 50-64 years attending for routine breast screening or older on request with BTW

BTW screening assessment centre

TRIPLE ASSESSMENT: Clinical examination, breast imaging and FNA cytology

REGISTER with clinical information system

Benign disease

Discharge

Screening 3 yearly (age 50-64 years)

BREAST CANCER

Specialist breast multidisciplinary team

Surgery in breast unit

ADJUVANT THERAPY

Potential Entry into Clinical Trials

Radiotherapy

Chemotherapy

Hormones

Follow-up + Annual Mammography

No Recurrence

Recurrence

No adjuvant therapy

Follow up + Annual Mammography

Palliation

Surgery

Continued follow-up