

# Annual Report



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## Foreword

In her Foreword to the first Annual Report of the Director of Breast Test Wales, Dame Deidre Hine, then Chief Medical Officer for Wales, praised the service for achievements made during the first seven years. These were noteworthy not only because Breast Test Wales, clearly, was providing a high quality service to women in Wales but also because it was coping with organisational changes which culminated in its transfer to Velindre NHS Trust in October 1995.

Although no longer with Breast Test Wales, I am nevertheless very pleased to be involved with the production of the Annual Report for the year 1996/97. The screening data presented are once again good, consistent with high standards and provide further evidence that screening will result in fewer deaths from breast cancer in Wales. It is immensely satisfying for staff that they constantly achieve high standards and, particularly, that the service is accepted and valued by women in Wales. The results and evaluation chapters show the critical importance of accurate data and careful analysis in monitoring progress. They also demonstrate a degree of dependence on external sources for data and the opportunities for collaborative work including joint research. In this context, the establishment of the Wales Cancer Intelligence and Surveillance Unit with responsibilities for cancer registration in Wales is welcomed.

For the first time the screening programme seemed to be at a steady state, having covered all general practices in Wales at least once. However, as the Report suggest, Breast Test Wales faces demographic and possible policy changes which, for the immediate future, indicate a greater volume of service provision. The challenge for Breast Test Wales and, indeed, those responsible for commissioning will be to keep pace with change whilst ensuring that the current programme is not impeded, that quality is maintained, evaluation is rigorous and resources are available.

The chapter on quality refers to the strategy to improve cancer services in Wales following the publication of the Calman/Hine Report for England and Wales. There are exciting opportunities for Breast Test Wales to forge partnerships with the developing specialist service for women with symptomatic breast disease across Wales and, indeed, to provide leadership in areas of training, quality assurance and evaluation. In the meantime, Breast Test Wales will build on the existing effective links resulting from good public relations work to establish even closer partnerships with primary health care teams and links within Welsh communities.

I am indebted to Breast Test Wales staff for their hard work and dedication and wish them and the new Director, Dr Cerilan Rogers, success.

***Dr R Elizabeth Roberts***

# Introduction

## Background

This is the second Annual Report of the Director of Breast Test Wales. The first reported on the year 1995/96 and also on the development and performance of Breast Test Wales (BTW) since it was established in 1988.

This years report contains information about Breast Test Wales' performance and achievements during 1996/97, as well as providing more detailed information about particular aspects of the programme. The report also considers challenges facing Breast Test Wales in the future.

## Breast Cancer

Breast cancer is the most common form of cancer amongst women in the United Kingdom and, although the mortality rate has been falling for a decade, it is still the highest in the world. In 1995, the latest year for which full figure are available, there were 1,882\* new cases and 745 deaths in Wales.

\* provisional data

## Breast Test Wales

Breast Test Wales was established in 1988 to:

- provide the national breast screening programme throughout Wales
- carry out quality assurance of the programme
- train staff to the standards required to deliver the programme
- evaluate the programme and carry out research

**Breast Test Wales aims to reduce deaths from breast cancer, in women invited for screening, by 25%, by early next century.**

Breast Test Wales has three divisions, served by centres in Cardiff, Swansea and Llandudno, and six mobile units providing screening in over 80 locations. Since 1995, Breast Test Wales has been part of Velindre NHS Trust.

## The Breast Screening Programme

Every three years each woman in Wales aged 50-64 years and registered with a GP is invited for screening. Women aged 65 and over are screened on request, at intervals of no less than three years. Women attending for screening are offered mammography. If mammography reveals a possible abnormality, the woman is invited to attend a specialist assessment clinic for further tests leading to a definitive diagnosis.

# Quality

## Quality Assurance in the Breast Screening Programme

It was recognised from the inception of the breast screening programme in the UK that its success would depend, to a great extent, on quality assurance (QA). As a result, the National Health Service Breast Screening Programme (NHSBSP) in England put structures into place to support QA, including a number of specialist committees. Breast Test Wales benefits from its strong links with NHSBSP, and contributes to the development of UK wide standards through relevant NHSBSP committees.

Responsibility for service delivery in England rests with individual NHS Trusts and lines of management accountability differ in many respects from those of QA accountability. However, from its establishment, Breast Test Wales adopted a structure which fully integrated management and QA arrangements.

## Quality Assurance in Breast Test Wales

All Breast Test Wales staff are responsible for delivering a high quality service. Designated staff also have an additional responsibility for quality assurance.

The Director is responsible for the overall quality of the screening programme and each staff group has an adviser responsible for QA. Each adviser is accountable to the Director. For non-medical staff this accountability follows the line management structure. An individual radiologist, surgeon and pathologist are each responsible for screening performance within the relevant medical disciplines.

QA is organised by these advisers through multi-disciplinary groups, which monitor, audit and review the quality of the service. The advisers also feed back information and recommend action to colleagues. The QA advisers represent Breast Test Wales on relevant NHSBSP committees.

The advisers review and update the Breast Test Wales Quality Manual and Physical Quality Manual, which together contain full details of objectives, standards, policies, procedures, tests, controls and audits.

## QUALITY IMPROVEMENTS

Breast Test Wales staff are continually seeking ways to improve efficiency whilst maintaining or improving the quality of the service. Examples of achievements during 1996/97 are:

- The administrators' group developed a set of operational standards for the computerised appointment system and the work of the medical secretaries. These are being used to audit the standards and support the recognition and dissemination of good practice.
- Radiographers and administrative staff introduced improved screening appointment systems which even out the workload for staff and minimise waiting times for women.
- Radiographers and helpers introduced revised systems and procedures to reduce film wastage with no reduction in quality.

## Training

As part of Breast Test Wales' commitment to Total Quality Management, staff continue to receive training in communication skills, problem solving and team working.

The Breast Test Wales National Mammography Training Centre provides training for radiographers from both inside and outside Breast Test Wales. During 1996/97, twelve radiographers trained for the College of Radiographers Certificate of Competence in Mammography at the Centre; due to the very low turnover of staff, just one was a Breast Test Wales radiographer. The remainder work in symptomatic departments - nine in Wales and two in England. Twenty-four Breast Test Wales radiographers underwent further clinical training as part of their continuing professional development programme during 1996/97.

## The Multi-disciplinary Approach

In 1994, the Government accepted the recommendations of the Expert Advisory Group on Cancer (EAGC) established by the Chief Medical Officers of England and Wales in their report (known as the 'Calman/Hine Report')<sup>1</sup>. In Wales, the Cancer Services Expert Group (CSEG) was established, under the chairmanship of Professor Ian Cameron, Provost of the University of Wales College of Medicine, to advise Welsh Office and health authorities in Wales on the implementation of the report. The Director of Breast Test Wales was a member of this expert group. The report, 'Cancer Services in Wales – A Report by the Cancer Services Expert Group' (known as the 'Cameron Report')<sup>2</sup>, was published in November 1996.

The recommendations for the management of breast cancer, which were derived from experience within breast screening, focused on the need for specialist multi-disciplinary teams using 'triple assessment' and on good verbal and written communication with patients. Triple assessment is based on a combination of three categories of investigation – imaging, clinical examination and pathology.

In Breast Test Wales, a key part of triple assessment is the multi-disciplinary meeting, known as the Clinico-Pathological Conference of CPC. These meetings bring together surgeons, radiologists and pathologists, along with breast care nurses, and are held weekly in Cardiff, Swansea and Llandudno.

At each meeting, teams consider the cases of all women assessed in the previous week. Each woman's case is discussed in turn, with the clinical members of her team reporting their findings:

- The radiologist presents the screening and assessment mammograms. The area of abnormality is reviewed and a consensus decision is reached.
- The clinical findings are presented by the surgeon.
- The pathological findings, resulting from fine needle aspiration, core biopsy or open biopsy, are presented by the pathologist.

An open multi-disciplinary discussion follows, concluding in a decision on the diagnosis, based on all available information. In some cases, further tests may be required before a definitive diagnosis can be confirmed.

The cases of women who have undergone surgical procedures are also reviewed at the meeting.

Through their participation in the meeting, the breast care nurses are well informed and able to give women appropriate information subsequently and to discuss the implications of the diagnosis.

# 96/97 Screening Results

During 1996/97, women invited for screening fell into the following categories:

- Women who had not previously been screened, usually because they were too young or because they had not accepted an earlier invitation.
- Women who had previously been screened

Additionally, a further group of women, mainly aged 65 and over, referred themselves for screening.

Table 1 shows summarised results for women in each category.

<b>Table 1 – 1996/97 Results</b>				
	<b>Invited women Total</b>	<b>Not previously screened (including previous non- attendees)</b>	<b>Previously screened</b>	<b>Self-Referrals</b>
<b>Invited</b>	79,717	31,239	48,478	Not applicable
<b>Screened</b>	61,934	18,674	43,260	4,474
<b>Referred for Assessment</b>	2,835	1,174	1,661	227
<b>Cancers Detected</b>	312	119	193	48
<b>Invasive Cancers</b>	237	91	146	38

Table 2 shows Breast Test Wales' performance against UK quality standards. As the unscreened population has different characteristics from the screened population, some standards differ for the two groups.

**Uptake** is the percentage of women sent an invitation who consequently attend for screening. Meeting the UK uptake standard of 70% is essential if the breast screening programme is to reduce mortality by 25%. Uptake improved slightly over 1995/96 and continues to meet the standard.

**Assessment Rate** is the percentage of screened women who are called back for further tests. Breast Test Wales aims to call back those women who have cancer, whilst minimising the number called back who do not. The assessment rate has improved since 1995/96 and continues to meet the standard.

**Benign Biopsy Rate** is the rate of women screened who undergo a surgical biopsy, but who do not have cancer diagnosed. Breast Test Wales aims to minimise the number of unnecessary procedures carried out. The rates are similar to 1995/96 and within the standards.

<b>Table 2 – Breast Test Wales Performance against UK Quality Standards – 1996/97</b>		
	<b>Standards (1996 Revision)</b>	<b>BTW Performance</b>
<b>Uptake</b>	>=70%	77.7%
<b>Assessment Rate</b>	<7%	4.6%
<b>Benign Biopsy Rate</b> (not previously screened)	<3.6 per 1,000 women screened	2.8 per 1,000
<b>Benign Biopsy Rate</b> (previously screened)	<4.0 per 1,000 women screened	0.7 per 1,000
<b>Invasive Cancer Detection Rate</b> (not previously screened)	>3.6 per 1,000 women screened	4.9 per 1,000
<b>Invasive Cancer Detection Rate</b> (previously screened)	>4.0 per 1,000 women screened	3.4 per 1,000
<b>Small Cancer Detection Rate</b> (<15mm)	>=50% of all invasive tumours	59% (170 of 288*)
<b>Expected rate of Ductal Carcinoma in situ (DCIS)</b>	Within the range 10%-20% of all cancers diagnosed	23% (87 of 380*)

\* includes cases put on short-term recall

**Invasive Cancer Detection Rate** is reported on separately. The early detection of invasive cancers is more important for reducing mortality than finding non invasive (in situ) cancers. As in 1995/96 Breast Test Wales' results exceeded the standard set for women screened for the first time. However, Breast Test Wales did not meet the standard for women screened for a second or subsequent time. This apparent 'failure' may be due, paradoxically, to a first round effect where the yield of cancers was particularly high<sup>3,4</sup>.

**Small Invasive Cancer Detection Rate** is a key component of the Invasive Cancer Detection Rate. Small cancers are more likely to be treated successfully than large cancers. Their detection, therefore, should have the greatest impact on mortality. Breast Test Wales again met the standard.

**Expected Rate of Ductal Carcinoma in Situ (DCIS)** is reported separately. Since all in situ cancers do not go on to become invasive, their detection is less useful as a predictor of mortality reduction. Nevertheless, DCIS is an important finding in screening and should be monitored against a rate considered acceptable. Breast Test Wales detected a greater proportion of DCIS than expected, although with an improvement on the previous year.

## PERFORMANCE AGAINST TECHNICAL STANDARDS 1996/97

High quality mammograms are essential if Breast Test Wales is to meet the cancer detection standards. The Breast Test Wales Technical Team aims to optimise the quality of the mammograms whilst restricting the radiation dose, and the number of repeat films that are required.

	<b>Standard</b>	<b>BTW</b>
<b>Image Quality</b>		
▪ Spatial resolution	>=10	13.4
▪ Minimum detectable contrast (6mm)	<=1%	1.0%
▪ Minimum detectable contrast (0.5mm)	<=5%	3.3%
<b>Radiation Dose</b>		
▪ Mean glandular dose per film to standard breast (milligray)	<2	1.4
<b>Percentage of women requiring a repeat film</b>	<3%	1.1%

## BASO AUDIT OF 1995/96 DATA

The British Association of Surgical Oncology (BASO) Breast Group undertakes annual audits of surgical data for the entire UK Breast Screening Programme. Breast Test Wales presented all-Wales data to the 1996/97 audit. Some of the topics covered by the audit were:

### **Surgical caseload and number of operations**

Breast Test Wales surgeons are all breast specialists, each treating over 30 screen-detected cases of cancer per year, in addition to symptomatic cases.

Breast Test Wales met the BASO standard of more than 90% of cancers, with a pre-operative diagnosis, being treated with only one therapeutic operation. No screen-detected cases in Wales required more than two therapeutic operations.

### **Pre-operative diagnosis**

Pre-operative diagnosis is a definitive diagnosis of cancer confirmed either by fine needle aspiration (FNA) cytology or core biopsy. Wales was one of two regions to meet the target for pre-operative diagnoses of 70% or more.

### **Open surgical biopsies**

Although Wales had the highest proportion of open biopsies which proved not to be cancer on histology, this is the inevitable consequence of a high pre-operative diagnosis rate, since the remaining lesions are those where the pre-operative signs are more equivocal. Wales also had the lowest average weight for benign biopsies and thus, the use of open biopsy was to some extent mitigated by the small amounts of tissue removed to establish a benign diagnosis. In Wales, all open biopsies with localisation had the tumour correctly found at the first operation.

**Lymph node status and number of nodes sampled**

Histological axillary lymph node status for invasive cancers was obtained for 98% of women with invasive cancer, the highest rate in the UK. In only 6% of cases were less than four nodes found in the sample, one of the better results nationally.

**Variation in treatment with tumour size**

Wales had a lower rate of breast conservation surgery for small tumours compared with many of the other regions. This may reflect patient choice, different clinical practice or different prognostic indicators. This issue is under investigation.

**Waiting times**

Wales was amongst the few regions approaching the standard of at least 90% of cases being admitted within two weeks for biopsy (81% in Wales) or three weeks for therapeutic surgery (89% in Wales). BTW monitors waiting times and follows up problems when they occur .

# Evaluation

## Introduction

The Welsh Breast Cancer Screening Evaluation Unit monitors BTW's performance against national outcome measures. Its core work has been the collection of accurate information about breast cancer in Wales. The Unit also reports on the organisational and resource effectiveness of the model for providing the screening service in Wales. The Evaluation Unit is part of Breast Test Wales and the University of Wales College of Medicine (UWCM) Division of Public Health and staff are accountable to the Director of Breast Test Wales.

An evaluation of the benefits and costs of the breast screening programme provided by BTW is necessary to ascertain whether the effectiveness of screening provided as a routine service matches that under trial conditions. The results of monitoring activities carried out by BTW staff as part of providing a quality service are also reported in this section, particularly under the heading of Acceptability, Coverage and Uptake.

## Evaluation Measures

The anticipated 25% reduction in breast cancer mortality due to screening is expected to take 10 years or more from the introduction of the programme to become evident in reported rates. A number of shorter-term measures are, therefore, necessary to predict the impact on mortality .

BTW reports on the screening measures identified below annually at an all-Wales level.

Table 3 – Key Evaluation Measures – Predictors of Mortality Reduction		
KEY AREA	MONITOR	WHY MEASURED
<b>1 Acceptability</b>	<ul style="list-style-type: none"> <li>▪ acceptability measures</li> <li>▪ coverage</li> <li>▪ uptake</li> </ul>	To indicate the potential for effectiveness of the programme
<b>2 Incidence of Breast Cancer</b>	<ul style="list-style-type: none"> <li>▪ rate of invasive and in situ cancers arising in the population</li> </ul>	To identify the increase in the recorded incidence of breast cancer during the first screening round
<b>3 Characteristics of Cancers</b>	<ul style="list-style-type: none"> <li>▪ Size, grade, type and node status of all cancers (screen detected and symptomatic)</li> <li>▪ Rate of screen-detected cancers in first round</li> <li>▪ Rate of interval cancers</li> </ul>	To quantify the reduction in the incidence rate of advance cancers  To provide a comparative measure of programme performance For radiological quality assurance
<b>4 Mortality</b>	<ul style="list-style-type: none"> <li>▪ Rate of breast cancer deaths</li> </ul>	To quantify the reduction in the death rate of women invited for screening

## Participation in National Screening Trials

Since the establishment of breast screening in the UK, the frequency of screening, target age group and number of views at each screen have been the subject of national multi-centre trials. BTW has participated in the frequency trial, which is now due to report in 1998, and is

currently involved in the age trial. The Unit provides information on all breast cancers in the study populations for both trials.

## KEY AREA 1: ACCEPTABILITY, COVERAGE & UPTAKE

**BTW monitors: coverage, uptake, consumer satisfaction issues**

### Acceptability

*the availability, accessibility and quality of the service as perceived by the population, particularly women eligible for screening*

## CONSUMER SATISFACTION SURVEYS

All women attending for breast screening are given the opportunity to comment on the service provided by Breast Test Wales using bilingual comment sheets. In addition, Breast Test Wales carries out regular in-depth consumer satisfaction surveys. During each survey, 500 women attending for screening are given a questionnaire to complete, together with a reply paid envelope. A survey was carried out in each of the three Breast Test Wales divisions during 1996/97.

The results of each survey have been consistent, and all have demonstrated very high levels of satisfaction. Selected results, derived by combining the results of all three surveys, are shown below:

▪ Questionnaires returned:	74%
▪ Women satisfied with the service provided:	100%
▪ Women finding it easy to change an appointment:	96%
▪ Women happy with screening location:	97%
▪ Women finding the screening location easy to get to:	98%
▪ Women finding the journey time acceptable:	99%
▪ Women seen at or before their appointment time:	89%
▪ Women waiting more than 30 minutes beyond their appointment time:	0%
▪ Average rating of the service provided (on a scale of 1 to 10):	9.66

Breast Test Wales is always seeking to improve its methods of obtaining feedback from service users. As a result, revised consumer satisfaction questionnaires for women attending for screening will be introduced during 1997/98. Also, a new questionnaire will be used to obtain the views of those women recalled to assessment.

## PAIN AND DISCOMFORT DURING MAMMOGRAPHY

Many women find mammography uncomfortable and some find it painful. The radiographer is seeking to obtain a clear image of the maximum area of each woman's breasts, using a minimal radiation dose. This means that the woman is asked to adopt an unnatural position whilst the radiographer operates the X-ray machine to apply firm pressure on each breast. It is surprising that some women do **not** find this a particularly uncomfortable experience!

Of the 1114 women who responded to Breast test Wales Consumer Satisfaction Surveys carried out in 1996/97:

- 82% found the examination “no problem” or “a little uncomfortable”
- 10% found the examination “very uncomfortable”
- 7% found the examination “painful” and
- 0.3% found the examination “very painful”

These percentages are very much in line with those reported elsewhere and demonstrate that there is a small, but significant, minority of women who have an unpleasant experience. Existing published work tends to concentrate on pain resulting from compression of the breast. Researchers have measured the percentage of women who report problems and related it to, for example, anxiety, menstrual status, race, age and breast size. Some results are contradictory or not directly relevant to Breast Test Wales and are not very helpful in predicting which women will find the experience unpleasant nor in suggesting ways of reducing the numbers.

From January 1997 a new question was introduced into the Breast Test Wales Consumer Satisfaction Survey:

If there was a problem, please tell us where you felt the pain  
 .....

Ninety one women gave information on the site or sites of their discomfort and/or pain. The responses were grouped into anatomical areas as listed below.

	a little uncomfortable	very uncomfortable/ painful/very painful	pre-existing condition
arm/neck/shoulder/back/head	10	13	5
chest/side/armpit/ribs/breast bone	7	13	2
non specific	1	1	2
breast side/top/under/between	6	4	0
breast pressure	25	32	1
<b>Total</b>	<b>49</b>	<b>63</b>	<b>10</b>

As expected, the single “problem” most commonly described was pressure on and around the breast and a total of 36 women found this to be very uncomfortable, painful or very painful. However, 27 reported significant problems elsewhere. Ten women volunteered information on a pre-existing condition such as arthritis, which they presumably felt contributed to their pain and/or discomfort.

This analysis will be taken forward in 1997/98, through more extensive research. Whilst for some women undergoing mammography, a degree of pain and/or discomfort may be unavoidable, it is hoped such information might help to inform the radiographic training and thus anticipate problems and minimise distress.

**Coverage**

***the proportion of the eligible population which is invited and attends for screening***

Inviting the maximum number of eligible women depends on accurate and complete patient registration data being held by health authorities. As at 31 December 1996, 70% of eligible

women in Wales had attended for screening as a result of a breast screening invitation in the previous three years<sup>6</sup>.

Coverage and uptake are distinct. Over a three year period new women continue to enter the screening age group, but are not invited until BTW reaches their general practice. As a result, coverage can never be as high as uptake.

The screening programme can only identify women as eligible if they are registered with a GP. BTW is, therefore, unable to establish actual coverage. During 1996/97 BTW and the Multicultural Health Resources and Information Centre in Cardiff completed a project, which used community link workers to identify eligible women in inner city areas who were not registered with a GP and had therefore not been invited for screening. Initial indications are that link workers were not able to identify significant numbers of additional eligible women.

## **Uptake**

### ***the proportion of women invited who attend for screening***

Uptake continued to increase steadily and rose from 76.8% in 1995/96 to 77.7% in 1996/97. This year Wales again exceeded the uptake target of 70%, although rates continued to vary by general practice. For example in areas of Cardiff, uptake was significantly lower than elsewhere with rates for some practices as low as 41%.

The factors associated with low uptake are the subject of research. The BTW Acceptability Group continued to meet and monitored the outputs of ongoing projects:

### **Increasing Uptake**

A GP recommendation is more effective in improving the uptake of screening than intensive health education interventions<sup>7,8</sup>. BTW therefore started a trial to assess the effectiveness of sending non-attenders a personalised letter of encouragement from their GP. Initial results suggest that not enough women respond to the GP letter to justify implementing the intervention in routine screening. The research will be submitted for publication during 1997/98.

### **Uptake in Practices with a High Proportion of Ethnic Minority Women**

Information leaflets and letters of invitation were produced in five ethnic minority languages. These are to be used in a pilot project to improve uptake in selected general practices in Bro Taf Health Authority during 1997/98.

### **Non Attenders Survey**

In 1997/98 BTW will begin a survey amongst non-attenders to find out their reasons for not attending.

## **KEY AREA 2: INCIDENCE OF BREAST CANCER**

**BTW monitors: annual age specific incidence rates in five-year age bands, increase in incidence during the first screening round**

### **Incidence of Breast Cancer in Wales and the Impact of Screening**

***Incidence is the rate at which new breast cancers are diagnosed in the female population***

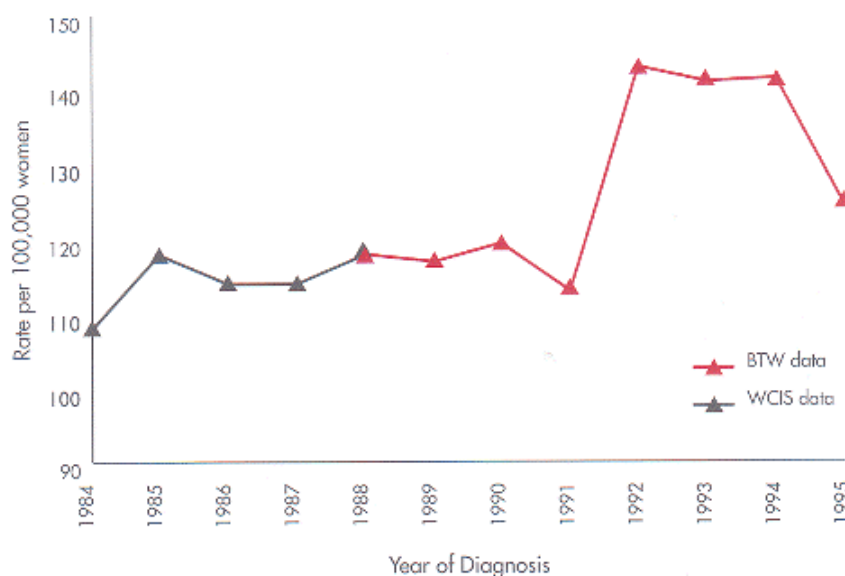
Breast cancer is the most common cancer occurring in women, accounting for 23% of all cancers registered for women in Wales in 1990. The incidence of breast cancer is over twice that of large bowel cancer, the second commonest cancer in women, which accounted for just over 10% of all registrations that year .

<b>Table 4 – Numbers of Invasive &amp; In situ Breast Cancers (ICD 10 C50 &amp; DO5) Wales 1985 - 1995</b>											
	1985	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995
New Cases Invasive	1,724	1,646	1,650	1,680	1,725	1,767	1,689	2,129	2,098	2,108	1,882
New Cases In situ	11	18	13	37	64	64	90	123	130	185	157

Source: BTW Evaluation Unit (Wales Cancer Registry published data 1985-87<sup>10</sup>)

As a result of increased detection, recorded incidence in the age group screened is expected to increase during the first round of screening. Table 4 shows that the overall crude numbers of both invasive and in situ breast cancers have risen in Wales since the introduction of screening in 1989. These figures will be subject to revision as data are further checked and updated.

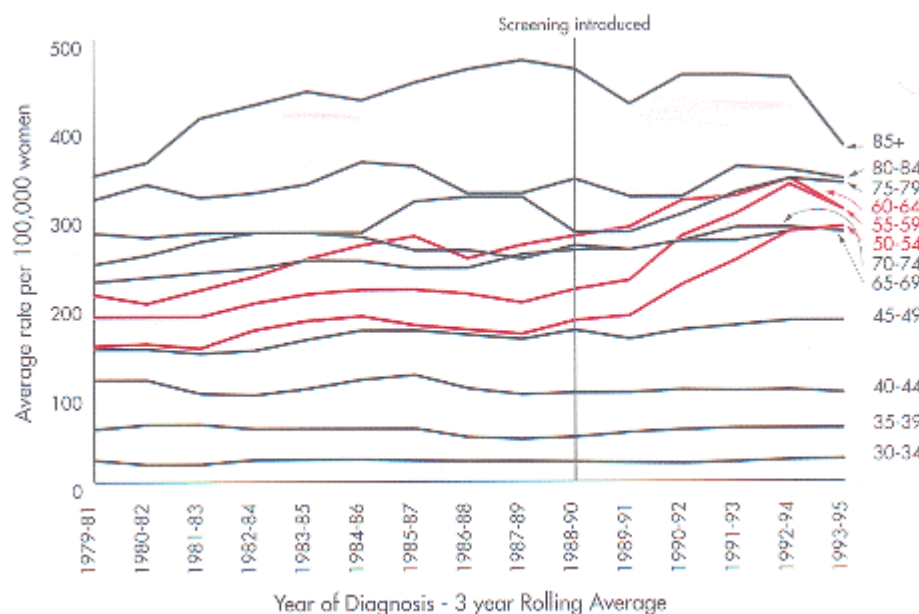
**Figure 1: Annual Registration Rate of Breast Cancer (ICD10 C50) all ages, Wales 1984-95**



The effects of screening were becoming apparent in total breast cancer incidence rates in Wales by 1992, as shown in Figure 1. By this time all three BTW divisions had started screening.

Figure 1 also shows that by 1995 rates were beginning to fall towards pre-screening levels following the completion of the prevalent round. Similar transient increases in breast cancer incidence following the introduction of screening programmes have been observed in other countries.

**Figure 2: Age Specific Incidence of Breast Cancer, Wales 1979-95**



Analysing age specific breast cancer rates suggests that these increases in overall incidence correspond to increases in the 50-64 screening age group during the first round of screening as shown in Figure 2. It is expected that incidence in women aged 50-52, who are being screened for the first time, will remain higher than would be the case in the absence of screening.

Since 1989 the recorded rates in the screened age groups (50-54, 55-59 and 60-64) show sustained increases. Data from 1992-94 onwards show the average rate in 50-54 year olds show the average rate in 50-54 year olds was as high as that for 70-74 year olds and similarly, the rates for 60-64 year olds resemble those for 75-79 year olds from 1981-91 to 1992-94. In younger age groups the rates have fluctuated less markedly. Similar effects have been reported for England and Wales combined data<sup>11</sup>.

Projections using historical data from UK cancer registries have estimated the average annual increase in the registration rate of breast cancer as 1.6% per annum across all age groups, independent of screening<sup>12</sup>. Applying this model to Welsh data, using the 1988 rate of 205 per 100,000 women as a baseline, gives an expected rate of breast cancer of 228 per 100,000 women aged 50-64 by the year 1995 in the absence of screening. The observed rate for 1995 is 263 per 100,000. This difference between the observed and expected rates is statistically significant and demonstrates the impact of screening over and above the underlying trend.

### Variations in Cancer Detection Rates Between Health Authorities

In the first round of screening the cancer detection rates in different HAs, particularly between the former health authorities of Gwynedd and Clwyd, showed variations of up to 40%. The Unit investigated these variations in collaboration with the North Wales Health Authority Department of Public Health Medicine. It was found that standardising the detection rates by age made the variations statistically insignificant. Variations were due to real differences between the age structures of the two populations rather than any difference in screening quality or underlying incidence rates. Because the risk of developing breast cancer increases with age, more breast cancers are likely to be detected in populations containing a higher proportion of older women.

## **TRACE Trial**

BTW continued to collaborate in the TRACE trial and the Cardiff centre held clinics for women with a family history of breast cancer recruited into the trial. TRACE is a three year randomised trial to evaluate the addition of individualised genetic assessment and possible DNA testing to the standard management of women with familial breast cancer, and to compare this with care currently provided through the NHS in Wales.

By March 1997 TRACE had recruited 800 women with a family history of breast cancer. It is unclear what the psychosocial consequences of communicating genetic risk information to these women are and whether this knowledge alters subsequent decision making about participation in surveillance and clinical trials. The TRACE team has set up a service for familial breast cancer and on the basis of the randomised trial will evaluate its effectiveness in psychosocial, economic and service delivery terms. The trial is supported by MRC, Welsh Office, NHS Wales R&D and the Imperial Cancer Research Fund. Preliminary results are expected at the end of 1998.

## **BREAST CANCER DATA VALIDATION**

New cases of cancer are recorded by the Welsh Cancer Registry (now the Welsh Cancer Intelligence and Surveillance Unit (WCISU)). More timely data were required for QA and evaluation than the Registry had historically been able to provide. The Evaluation Unit therefore collects breast cancer data from cytology and histology laboratories to complement Registry incidence data and to add prognostic information to the dataset.

Comparing Evaluation Unit and Registry data for 1988-1991 identified difference. There were over 400 cases per year (approximately 23%) where no match between pathology and Registry data could be established. The Unit is currently validating 1988-1991 incidence data for women aged <80 using medical records and has traced over 40% of these query cases. Of the query cases found to date, 14% have been deleted from the Evaluation Unit database because of:

- miscoding
- duplicate registrations
- cases of recurrent breast cancer (not true incident cases)

This medical records project has encountered issues which, whilst they may be in line with current practice guidelines, could cause difficulties for other retrospective notes studies of this kind. The Unit found:

- destruction of medical notes for live patients at 8 years after last appointment
- destruction of medical notes at 3 years after death
- problems finding notes transferred between hospitals
- failures of note tracking systems within hospitals
- examples of archives being inaccessible or unsafe

These problems have caused some delays but with the continued support of medical records staff, the Unit aims to complete the checking of 1992-95 data during 1998.

## KEY AREA 3: CHARACTERISTICS OF CANCERS

**BTW monitors: the reduction in the rate of advanced cancers, the rate of screen detected cancers in the first screening round, the rate of interval cancers**

### **Prognostic Indicators**

#### ***size, grade, type and node status of screen detected and symptomatic cancers***

Evaluation outcome objectives for the NHS breast screening programme suggest that Wales should aim for a minimum 70% ascertainment of size, grade, type and node status for all breast cancers. The Unit is working towards this target but relies on breast cancers being reported in detail by treating clinicians.

#### **Rate of advanced cancers**

Tumour diameter is an acceptable surrogate for stage of cancer<sup>5</sup> and the Unit monitors the annual incidence of large cancers >20mm. In order for BTW to achieve the predicted mortality reduction, screening should reduce the rate of advanced cancers.

The reporting of size has become more complete over recent years. In 1988 the size of 43% of invasive breast cancers in women aged 50-64 was unknown. This had decreased to 17% by 1995. Such a change in reporting patterns, although welcome, makes it difficult for the Unit to report trends in the incidence rate of >20mm cancers with any confidence. The process of verifying cases in medical records should make the data more complete, but until report completeness reaches a steady state, changes in the distribution of large cancers over time will be difficult to demonstrate.

#### **Histological grade of breast cancers**

Grade is a further indicator of tumour prognosis. Screening is expected to reduce the rate of Grade 3, or poor prognosis, tumours arising in the target population. A similar picture is seen in the reporting of grade as in the reporting of size. The percentage of ungraded ductal invasive tumours in women aged 50-64 decreased from 38% in 1988 to 9% in 1995. This change masks any trends in the incidence of poor grade tumours in Wales.

#### **Trends in histological types**

The reporting of specimen type (not ductal or lobular) cancers increased slightly from 4% of invasive tumours in women aged 50-64 in 1988 to 8% in 1995. These tumours have a better prognosis than non special type cancers. Screening is likely to have increased the incidence of these cancers, but increases may also reflect changes in pathological reporting of breast cancers.

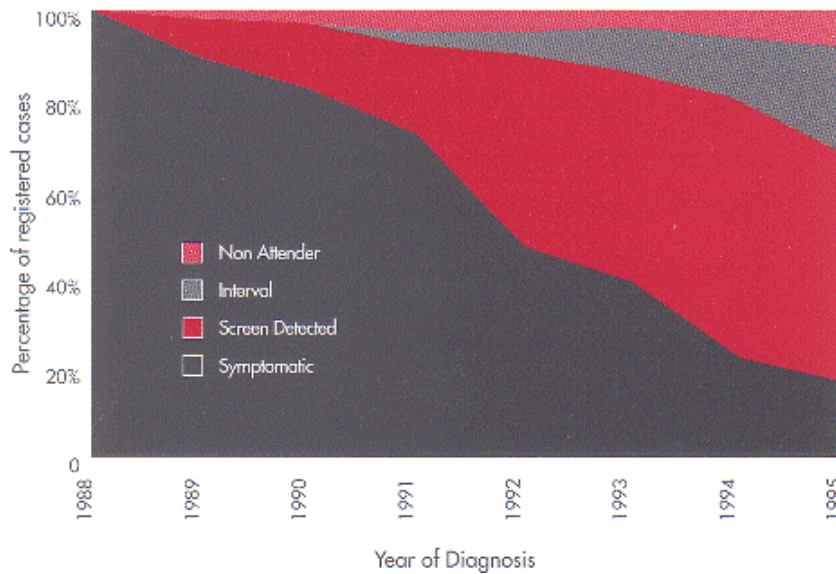
#### **Proportion of node positive cancers**

The presence of nodal metastases has an impact on the staging of breast cancers and indicates a poorer prognosis. The numbers of women with invasive breast cancer who had their nodes examined increased from 44% of all invasive tumours in the 50-64 age group in 1988 to 84% in 1995.

This reflects significant changes in the management of breast cancer during this period with multidisciplinary teams requiring more complete staging of diseases before deciding on a course of treatment. Again, the data suggest that over this period, trends in node positive tumours are confounded by increased sampling and reporting.

## Screening Status of Cancers

**Figure 3: Breast Cancers by Screening Category – Women Aged 50-64, Wales 1988-95**



In evaluating screening, breast cancers are categorised according to their screening history.

Figure 3 shows the relative proportions of different screening histories amongst women aged 50-64 in Wales from 1989 to 1995. By 1995 screen detected cancers accounted for over 49% of all cancers incident in that year and interval cancers for 24%.

### Screen Detected Cancers

#### *cancers identified by screening*

The standardised detection ratio (SDR) provides a measure of the performance of programmes in detecting invasive cancers, whilst taking into account differing age structures, background incidence rates and statistical variations in the cancer detection rate between years<sup>13</sup>. The method incorporates comparative measures in the form of expected rates derived from the Swedish Two Counties trial. The Swedish trial SDR of 1.0 is defined as a reference point. Where a programme has an SDR higher than 1.0 it is performing better than the Swedish trial.

The SDR for all cancers detected at first screens in Wales for 1996/97 was **1.22** and the SDR for small invasive cancers <15mm was **1.56**.

The SDR at routine rescreens in 1996/97 was **0.86** and for small invasive cancers <15mm detected at routine rescreens was **0.91**.

The Welsh results for first screens compare favourably with other UK programmes. The SDR for rescreens in Wales is lower than some UK programmes, but this may be expected if a programme performs well in the first round. The problem of accounting for first round performance in the calculation of second screen SDRs is recognised within UK screening programmes, but following meeting of the UK Interval Cancer Group during 1996/97, the current rates used in SDR calculations have been retained.

### Interval Cancers

#### *cancers diagnosed between screens, no cancer having been detected at the first of these screens*

Interval cancers are of great relevance to the success of screening because the relative proportions and prognostic characteristics of interval and screen-detected cancers will determine the mortality reduction achieved.

Radiological audit is used to distinguish five categories of interval cancer:

- **Unclassified.** Mammography was not performed at the time of diagnosis and therefore the presence of mammographic signs of malignancy cannot be verified.
- **True interval cancer.** The screening mammograms are normal while mammography performed at the time of diagnosis clearly demonstrates features consistent with malignancy
- **Occult interval cancer.** Neither the screening mammogram nor the mammograms performed at the time of diagnosis demonstrate any abnormality that could be interpreted as representing malignancy
- **False negative interval cancer.** On 'blind' review an abnormality is present on the screening mammograms at the site of the malignancy demonstrated on the mammograms performed at the time of diagnosis and these signs would normally be considered sufficient to recall the woman for further assessment.

Revised Radiological QA guidelines (in press) have added a fifth category:

- **Interval cancer with minimal signs.** These may be of two types:
  - 1 Identified on 'blind' review – on 'blind' review an abnormality is present on the screening mammograms at the site of the malignancy demonstrated on the mammograms performed at the time of diagnosis, but these signs would not, according to current radiological practice, be considered sufficient to recall the woman for further assessment.
  - 2 Identified on retrospective review – on informed review of the screening mammograms (after review of the mammograms taken at the time of diagnosis) a subtle sign is recognised at the site where a cancer developed.

The proportion of occult interval cancers in a screening programme is largely dependent on the age of the population screened and the proportion of true interval cancers is primarily decided by the screening interval. False negative and minimal signs interval cancers are of particular relevance to radiologists as these are the subgroups that radiological practice may directly influence.

A radiological review of the proportions of interval cancers in each category in Wales is underway and 300 interval cancers were reviewed by each BTW radiologist during 1996/97. The first results of the review will be reported during 1997/98.

The Unit monitors interval cancers on an ongoing basis. The rates for Wales, shown in Tables 5 and 6, are comparable with those reported from other UK screening programmes.

<b>Table 5 – All-Wales Prevalent Screen Interval Cancer Rates &amp; Comparisons</b>		
	<b>Presenting 1-24 months after a negative screen</b>	<b>Presenting 25-36 months after a negative screen</b>
Interval cancers	266	167
Number of women screened	181718	136265
<b>Expected rate</b>	<b>12 per 10,000</b>	<b>13 per 10,000</b>
<b>BTW Interval Cancer Rate</b> (95% Confidence Interval)	<b>14.6 per 10,000</b> (13.0 – 16.5)	<b>12.3 per 10,000</b> (10.5 – 14.3)
<i>North Western Region</i> <sup>14</sup>	<i>15.8 per 10,000</i>	
<i>Nijmegen Trial</i> <sup>15</sup>	<i>15.7 per 10,000</i>	
<i>Swedish Two County Trial</i> <sup>16</sup>	<i>9.4 per 10,000</i>	

Data to March 1997

<b>Table 6 – All-Wales Incident Screen Interval Cancer Rates</b>		
	<b>Presenting 1-24 months after a negative screen</b>	<b>Presenting 25-36 months after a negative screen</b>
Interval Cancers	66	17
Number of Women Screened	42768	23851
<b>Expected Rate</b>	<b>12 per 10,000</b>	<b>13 per 10,000</b>
<b>BTW Interval Cancer Rate</b> (95% Confidence Interval)	<b>15.4 per 10,000</b> (12.1 – 19.6)	<b>7.1 per 10,000</b> (4.4 – 11.5)

Data to March 1997

(Data include women aged 49 and women screened in the frequency trial. They exclude in situ disease, contralateral tumours and cases of recurrent breast cancer)

#### **Non-Attender Cancers**

***cancers diagnosed in women who have been sent one or more invitations for screening but have always failed to attend***

In 1995 there were 56 cancers in non-attenders which accounted for 8.8% of all cancers incident in that year in the 50-64 age group in Wales. Screening trials have reported poorer survival rates for non-attenders due in part to late presentation. BTW is analysing the prognostic characteristics and relative survival of non-attenders and will report results in 1998.

#### **Symptomatic Cancers**

***cancers diagnosed in women who are not eligible for screening or who are eligible for screening but have not yet been invited***

Prior to screening, all breast cancers in the 50-64 age group were symptomatic. By 1995, 17.5% of cancers (112) in the age group were diagnosed symptomatically in women who had not been invited for screening. As each GP practice is screened in turn every three years, women reaching their fiftieth birthday are not invited immediately. However, all women should receive their first invitation before their fifty-third birthday.

In 1995, 54 (50%) of the symptomatic cancers arising in women aged 50-64 were detected in women aged 50-52 who had not yet been invited. The remainder, in women aged 53 and over, have been audited and consist of two types of cases:

- women who were ceased from screening by their GP because of terminal illness, bilateral mastectomy or because they had been screened recently elsewhere;
- women who had moved into an area or GP practice after it had been screened.

Since 1996, BTW has operated additional fail-safe procedures to identify and invite eligible women who move between areas and would otherwise have a lengthened screening interval. Guidelines for ceasing women from the screening programme have also been revised since 1989.

### **Cancer Registration through On-line Pathology Systems – CROPS Project**

In 1995 the Evaluation Unit, together with WCISU, received funding from NHS Wales Office of Research and Development to evaluate the effect of introducing pathology reporting guidelines and a computerised proforma on the completeness of cancer data available to the Registry. The potential contribution of pathology data to population databases is significant and complete pathology data are essential for monitoring the impact of screening programmes.

Every pathologist in Wales is participating in the trial and two tumour sites are being evaluated – breast and colorectal. Each hospital completes proforma pathology reports for one tumour site, whilst the routine reports for the other cancer site are collected and used as controls.

There has been widespread interest in the project from other organisations in the UK, which are awaiting the results of CROPS when the project finishes in Autumn 1998.

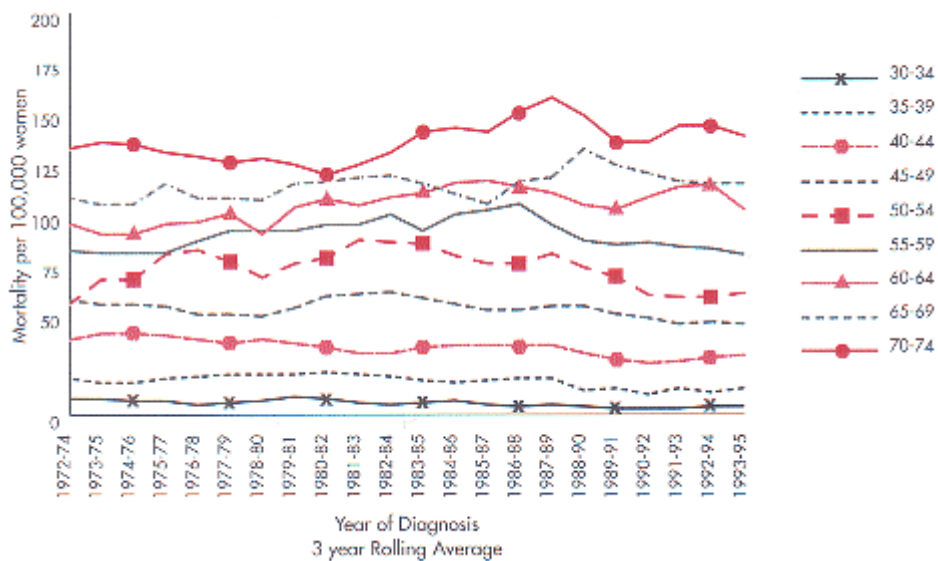
## **KEY AREA 4: MORTALITY**

### **BTW monitors: mortality in five-year age bands for women aged 30 and over**

The primary measure of the success of screening is a reduction in breast cancer mortality in the cohort of women invited for screening. The expected screening effect is likely to be most apparent in the 55-59 age group. Mortality in younger age groups is also of interest, as it helps identify trends which are not the result of screening.

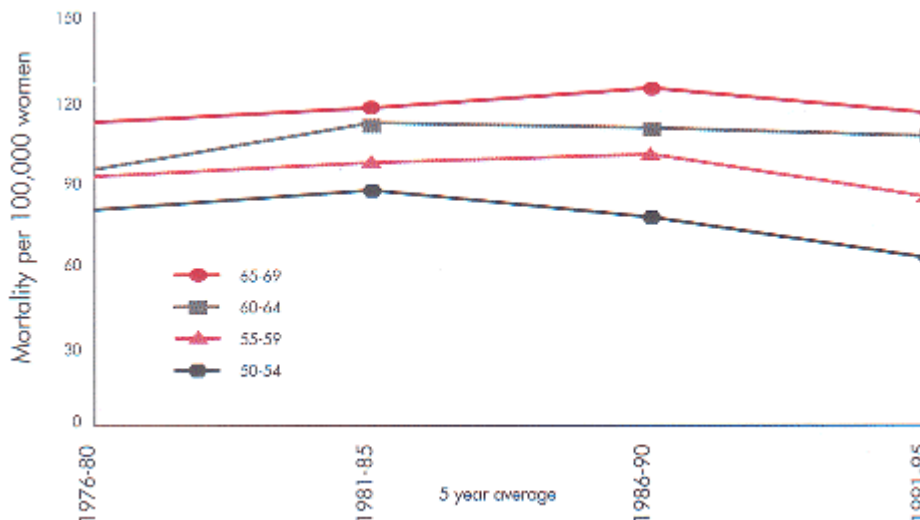
International breast cancer mortality rates have levelled off over the past five years after previous increases<sup>17</sup>. Data for England and Wales show a downturn in mortality at all ages and one which is too early to be due entirely to screening<sup>11</sup>.

**Figure 4: Age specific mortality from breast cancer, Wales 1972-95**



It is more difficult to demonstrate clear trends in age specific mortality data for Wales alone as the numbers of deaths involved are smaller and subject to random fluctuation. (Fig 4)

**Figure 5: Age specific mortality from breast cancer, Wales 1976-95**



Using 5 year averages, decreases in the 55-69 age groups for the five years 1991-95 are evident in Wales, but for the 50-54 and 60-64 age groups these decreases started in the pre-screening period 1986-90. (Fig5)

Decreases affect women across a broad range of age groups and are likely to be due to earlier diagnoses and better treatment rather than the direct result of breast cancer screening.

Further analysis of mortality rates for all ages in Wales is necessary. The impact of screening has to be assessed against the background of falling mortality. The task is to identify the proportion of future mortality reductions due directly and indirectly to screening. The Unit plans to investigate whether there are any demonstrable differences in mortality rates

between the areas in Wales which started screening in 1989 and those which started in 1992.  
The results will be reported in 1998.

# Planning for the Future

## Introduction

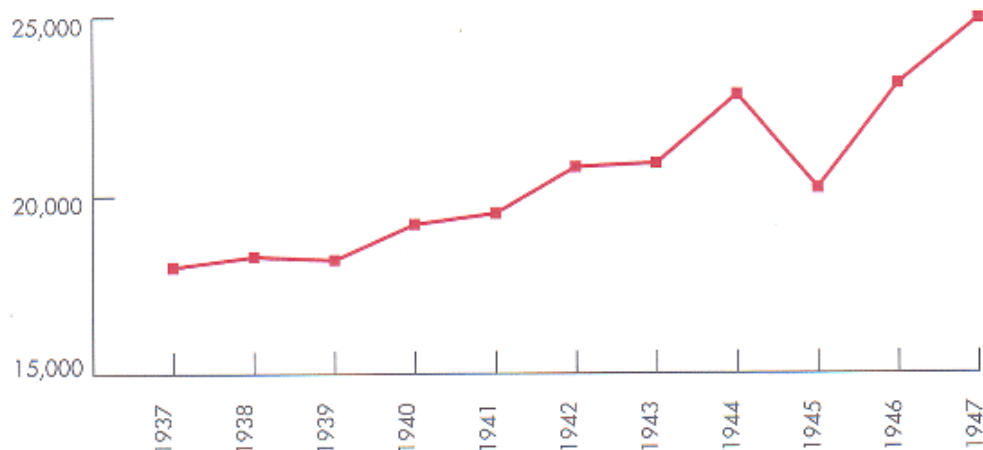
This chapter considers some of the challenges that Breast Test Wales faces in the coming years as a result of changes in the population and possible changes in national screening policy.

## The Impact of the 'Baby Boom'

Breast Test Wales serves an eligible population that is increasing significantly and will continue to increase for a number of years.

In the 1940s the birth rate in Britain increased dramatically following a period during the 1930s in which the birth rate had declined. Figure 6 shows the annual number of female births in Wales from 1937 to 1947.

**Figure 6: Female Births in Wales**



Women born during the 1940s are now in or approaching the 50-64 age range that Breast Test Wales invites for screening. As a result, the number of women in Wales eligible to be invited for breast screening will rise by almost 10% between 1996 and 2000. The number of eligible women will also continue to increase by approximately 1% each year for a number of years beyond 2000.

Breast Test Wales must ensure that it can invite and screen these additional women without jeopardising the quality of screening and without increasing the interval between screens. This is to be achieved through the appointment of additional radiographers and administrative staff and the purchase of additional radiological sessions, beginning in 1997/98. Through improvements in efficiency, it may be possible to fund this expansion from within Breast Test Wales' existing funding levels.

## **Possible Changes in Screening Policy**

Breast test Wales currently invites women aged 50-64 for screening every three years, in line with UK policy. Two view mammography is used the first time a woman is screened, with a single view being used for subsequent screens.

The frequency of screening, target age group and number of mammographic view have been the subject of national multi-centre trials (see also the previous chapter). In addition, pilot projects, designed to assess the feasibility of inviting women aged 65 and over for screening, have been established elsewhere in the UK. As the results of these trials and projects become available over the next few years, the government will be faced with decisions on future screening policy, based not only on clinical effectiveness, but also on value for money when compared with other health services.

There would be considerable organisational difficulties in introducing any major change in screening policy that increased the screening work load, whilst ensuring that quality standards are met and the screening interval is not increased. However, increasing the number of multi-disciplinary teams would also present further opportunities to align Breast test Wales' screening services with the evolving symptomatic breast services across Wales. Also, any expansion of screening would reduce the number of cases being seen in the symptomatic sector.

### **Inviting Women Aged Over 64**

This change has been demanded by Age Concern and other groups and is currently the subject of Department of Health funded pilot projects. Breast cancer is more common in older women, and there is little evidence that uptake amongst women aged over 64 would be unacceptably low.

The change most commonly discussed is to invite women aged 65-69 in addition to those aged 50-64. However, such a change would lead to some women being invited for two additional screens, whilst others would be offered only one. The alternative is to invite women up to the age of 70, which would result in all women being offered two additional screens. This latter, more equitable, option is used by Breast Test Wales for planning purposes.

Inviting women aged 50-70 would increase Breast Test Wales' workload by approximately 23%, taking into account a slightly lower expected uptake amongst older women and a reduced number of self referrals. This increase would be in addition to the increased work load resulting from the baby boom. The combined effect would increase work load by 35% over 1996 levels by 2000.

Breast Test Wales would require a further three multi-disciplinary assessment teams and would need to appoint approximately five whole time equivalent (WTE) radiographers, together with additional radiography helpers, breast care nurses, medical secretaries and clerk/receptionists. The additional screening would also necessitate the use of an additional mobile screening unit.

### **Using Two-View Mammography at Second and Subsequent Screens**

Evidence suggests that this would increase the cancer detection rate and, particularly importantly, the small cancer detection rate at second and subsequent screens, leading to a greater reduction in mortality. Such a change is strongly supported by many screening radiologists. These advantages must be set against the disadvantages of increased financial cost and increased exposure to radiation.

It takes a radiographer approximately 30% longer to screen a woman for a second or subsequent time using two-view mammography than it does using a single view. As some are being screened for the first time, this overall change in policy would increase the overall time spent carrying out screening mammography by approximately 24%. When combined with the baby boom the effect would increase radiographic screening work load by approximately 36% over 1996 levels by 2000. There would, however, be a much lower increase in work load for Breast Test Wales' consultant teams and for the administration of the programme.

Breast Test Wales would need to appoint approximately six WTE extra radiographers, together with additional helpers and some administrative support. At least one, and possibly two additional mobile screening units would be required.

**Reducing the Screening Interval from Three to Two Years**

The results of the Frequency Trial, in which Breast Test Wales participated, will be published during 1998. Reducing the interval to two years would increase Breast test Wales' work load by 50%, equivalent to 65% over 1996 levels by 2000 when combined with the effect of the baby boom. This would have a dramatic effect on the staffing, facilities and equipment required to deliver the screening programme in Wales.

# Conclusion

It gives me great pleasure to contribute the closing remarks for this Annual Report. The Report demonstrates that high standards of service continue to be provided and this is entirely due to the commitment shown by every member of staff in Breast Test Wales. The aim of providing high quality screening, whilst minimising the anxiety caused to women, remains foremost in our minds.

Two main factors have made Breast Test Wales one of the most successful breast screening programmes in the United Kingdom. Firstly, quality assurance is an integral part of every aspect of the breast screening programme. Secondly, the delivery of the programme is based on teamwork. These factors have enabled us to maintain our high standards and will enable us to respond positively to the challenges which undoubtedly lie ahead, some of which are outlined in the Report.

Following the transfer of the organisation to Velindre NHS trust, there have been and will be many areas for fruitful collaboration with our colleagues in Velindre Hospital and the Welsh Cancer Intelligence & Surveillance Unit. We are grateful to the Trust Management and Board who have continued to support Breast Test Wales in maintaining its distinct identity, which has played a considerable role in our continuing success.

There will be further opportunities to work in partnership with our colleagues caring for women with symptomatic breast disease, and also with those who provide other screening programmes for the population of Wales.

Breast Test Wales' achievements are a tribute to the vision and hard work of my predecessors, Dr. Elizabeth Roberts and Dame Deidre Hine. Breast Test Wales has also been supported by throughout by many colleagues in the NHS and Welsh Office; we owe a particular debt of gratitude to Dr. John Pritchard, Chief Scientific Adviser, Welsh Office, who provides us with advice on all aspects of quality assurance.

Finally, Breast Test Wales can only succeed while women in Wales have confidence in our service and continue to respond positively to our invitations for screening. Our partnership with the women of Wales is, in the end, the most important contributor to our success.

***Dr Cerilan Rogers***

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