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The Auckland Breast Cancer Register: a special project of the Auckland Breast Cancer Study Group

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Abstract

Aims The Auckland Breast Cancer Register (ABCR) has been established in response to the need for a comprehensive database of breast cancer cases from the Auckland area.

Methods The database records patient demographics, diagnosis, treatment options, prognosis and long-term outcome (annual follow up). Data from 1204 cases, recorded between June 2000 and June 2002 are reported.

Results The major findings are that 34% of women had breast cancer detected by screening only (47% in the group eligible for free screening within the Breast Screen Aotearoa screening programme); 84% of patients had invasive carcinoma; 13% had ductal carcinoma in situ (DCIS); and 3% fine needle aspiration only. Forty nine per cent of invasive tumours were =2cm. Grade 3 tumours were found in 53% of patients under 40 years old compared with 26.8% 40 years or older. Mastectomy was performed in 56% of patients with invasive cancer and 33% of those with DCIS. Axillary surgery was performed in 94% of patients with invasive cancer and 39% had involved nodes. Seventy nine per cent of patients were referred for an opinion from an oncologist. Radiotherapy was given to 77% of these patients, chemotherapy to 33%, and hormone therapy to 57%.

Conclusions The ABCR will provide essential healthcare information that will lead to better understanding of breast cancer in Auckland and more effective delivery of the clinical resources available in the Auckland region.

The Auckland Breast Cancer Study Group (ABCSG), established in 1976, brought together a multidisciplinary group of clinicians with a particular interest in breast cancer management and research. As such, the membership includes representatives from both the public and private sectors in the fields of radiology, surgery, pathology, breast-care nursing, medical and radiation oncology, and biostatistics.

Between 1976 and 1985 the study group established a comprehensive database of 2700 cases of breast cancer in the Auckland region. This computerised database, with continued follow up, has provided important information on the incidence, pattern and management of breast cancer in a mixed ethnicity community and it has provided the resource for some 30 publications. The register was discontinued in 1985 following concerns expressed over privacy issues.

In 1996 the members of ABCSG agreed unanimously that a new breast cancer register should be established throughout the Auckland region. Against a background of important advances in all areas of breast cancer, including genetics, detection,

conservative surgery and chemo/endocrine adjuvant therapy, there was a need for a new, comprehensive database as a resource for ongoing audit and research.

In New Zealand there is clearly a need for data on breast cancer incidence, and analysis of survival by multiple presenting factors including clinical stage of disease. The Auckland region, particularly, presents a unique opportunity to accrue the details of clinical presentation and management in Maori, Pacific Island, and other ethnic groups, which will lead to a better understanding of why outcomes are worse in some groups than others.[1] Information about current practice plays a key role in supporting evidence-based care,[2,3] and allows multidisciplinary teams to provide high-quality care. Each of the specialty groups within the team uses internationally recognised guidelines and protocols to provide high-quality care. The ABCSG is not attempting to establish guidelines or recommended practice documents.

The group has links to the Australia–New Zealand Breast Cancer Trials Group and the Swiss-based International Breast Cancer Study Group. It has worked for almost 20 years with both these organisations in the promotion and data management of a range of ethically approved clinical trials in both early and advanced breast cancers. The Secretariat for ABCSG is situated in the Oncology Department at Auckland Hospital but is independently administered and funded solely by charitable donations.

A subcommittee of the ABCSG met regularly to determine aims and develop a new breast cancer register. In June 2000 the Auckland Breast Cancer Register (ABCR) commenced accrual having received approval from the Auckland Ethics Committee. The Register was also declared a Quality Assurance Activity under Part VI of the Medical Practitioners Act 1995.

The aims of the Register are to collect in a timely, accurate and confidential manner a predetermined set of data. These data will:

1. document the patients being diagnosed and treated;
2. determine risk factors and prognostic variables for disease relapse;
3. update individual patient progress annually to assess recurrence-free and overall survival;
4. allow review of the patterns of care and the multidisciplinary aspects of breast cancer management;
5. allow review of defined patient groups and their outcomes compared with predicted outcomes;
6. allow appropriate comparative analysis with other similar overseas studies;
7. allow comparison of patient outcomes within and outside trials to assess how representative of the overall population outcomes in trials are;
8. direct further research.

Methods

All patients who are New Zealand residents residing in the greater Auckland region and have a diagnosis of breast cancer after 1 June 2000 are eligible to be on the Register. These patients are identified by pathology reports sent from the National Cancer Registry. All clinicians involved with the care of patients with breast cancer were invited to participate. Participating clinicians agreed to approach all their patients presenting with newly diagnosed breast cancer and provide them with a

patient information sheet and consent form. Detailed information on the initial diagnosis and treatment is recorded, then follow-up forms are sent annually to the clinician and information on the diagnosis and treatment of any loco-regional and or metastatic disease is collected. Confidentiality of the information collected for the Register is maintained at all times. A summary of aggregated data is generated annually and the data will be analysed and the results offered for publication in peer-reviewed journals.

Results

Patient accrual Data accrued between June 2000 and June 2002 are summarised in this article. Of 1497 patients identified as eligible, 1204 (including 10 men, 0.83%), have given consent to be registered. Eighteen (1.2%) patients refused consent and 18 patients died before consent could be sought. The remaining 257 (17.2%) patients were not approached by their clinicians.

These figures demonstrate that approximately 80% of all the cases of breast cancer diagnosed in the Auckland region between June 2000 and June 2002 are represented on the ABCR database. All clinicians, public and private, who treat breast cancer cases in the Auckland region have patients registered on the ABCR. However, the main limiting factor for 100% representation is the requirement from the Health Information Privacy Code 1994 to seek individual informed consent. Those patients easily treated 'disappear' from the system very quickly, thus their consent becomes difficult or impossible to obtain.

Identified breast cancer cases were distributed between public (60.6%) and private services (39.4%). These figures are based upon initial diagnosis and surgical treatment because some treatment options, such as radiotherapy, are offered only within the public service and therefore many patients are treated by both public and private sectors.

Age distribution At the time of diagnosis, 71.9% of the patients were aged 50 and over, with 28.1% being over 65 years old (Table 1). It is of interest to note that seven of the ten male patients were over 70.

Table 1. Age distribution of patients accrued on Auckland Breast Cancer Register, June 2000 to June 2002

Age group (years)	Patients	
	n	%
Under 40	86	7.1
40–49	252	20.9
50–64	528	43.9
65–69	94	7.8
70–79	156	13.0
80+	88	7.3
Total	**1204**	**100.0**

Ethnicity Ethnicity was determined from the National Health Index (NHI). The majority of patients identified themselves as European (62.0%), with 5.3% identifying as NZ Maori, 5.4% Pacific Island, and 4.2% Asian. For 23.1% of patients ethnicity was indicated as 'Other' or 'Not stated'.

Family history One hundred and forty eight (12.3%) patients gave a history of a first-degree relative (mother, sister or daughter) who had breast cancer; of these, 13 (8.8%) patients reported a second-degree relative also. Twenty one (1.7%) patients had more than one first-degree relative with breast cancer.

Clinical presentation Data for clinical presentation were available for 1181 (98.1%) cases. Six hundred and ninety four women (58.8%) presented with clinical signs or symptoms, such as a lump, pain, nipple change or skin abnormality, while 487 (41.2%) patients had a screen-detected cancer. However, 83 (17.0%) of these screen-detected patients were also found to have a clinically evident abnormality, and some may have attended screening because of this. It is of interest to note that 289 (24.5%) women had undergone a previous mammogram. However, of the 509 women in the age group eligible for inclusion in the Breast Screen Aotearoa programme, only 169 (33.2%) had undergone a previous mammogram. Detection rate by age group is seen in Table 2.

Table 2. Age groups of patients presenting with clinically evident or screen-detected breast cancer (n = 1181)

Age group (years)	Screen detection alone n (%)	Clinical detection alone n (%)	Screen detection and clinical evidence n (%)
Under 40	5 (0.4)	78 (6.6)	1 (0.1)
40–49	54 (4.6)	177 (16.3)	14 (1.2)
50–64	274 (23.2)	192 (16.2)	52 (4.4)
65+	71 (6.0)	247 (20.9)	16 (1.4)
Total	**404 (34.2)**	**694 (58.8)**	**83 (7.0)**

Radiology Mammographic findings were analysed for a total of 1135 patients, with 1042 (91.8%) having mammographic features of carcinoma. Breast ultrasound was performed for 922 patients, with 821 (89.0%) having ultrasound features of carcinoma.

Of 910 patients on whom both mammography and breast ultrasound were performed, 877 (96.4%) had malignant lesions detected by either mammography, ultrasound or both, with only 33 cases (3.6%) not identified by either of these imaging techniques.

Definitive diagnosis Data for definitive diagnosis were available for 1185 (98.4%) patients. A definitive diagnosis was confirmed by core biopsy alone in 632 (53.3%) patients and fine needle aspiration (FNA) alone in 292 (24.6%). A small number of patients (181, 15.3%) required both FNA and core biopsy for confirmation and a further 80 (6.7%) patients had an excision biopsy for definitive diagnosis. The procedure used for core biopsy was described in 67.3% of cases; of these, 77.9% were ultrasound-guided biopsies.

Type of cancer Invasive carcinoma with or without an in situ component was diagnosed in 1014 (84.2%) of the 1204 cases, ductal carcinoma in situ (DCIS) alone was diagnosed in 154 (12.8%) cases. The other 36 (3.0%) patients had an FNA to determine a malignant breast carcinoma, but did not proceed with further surgical intervention because of comorbidity condition or patient refusal to undergo surgery.

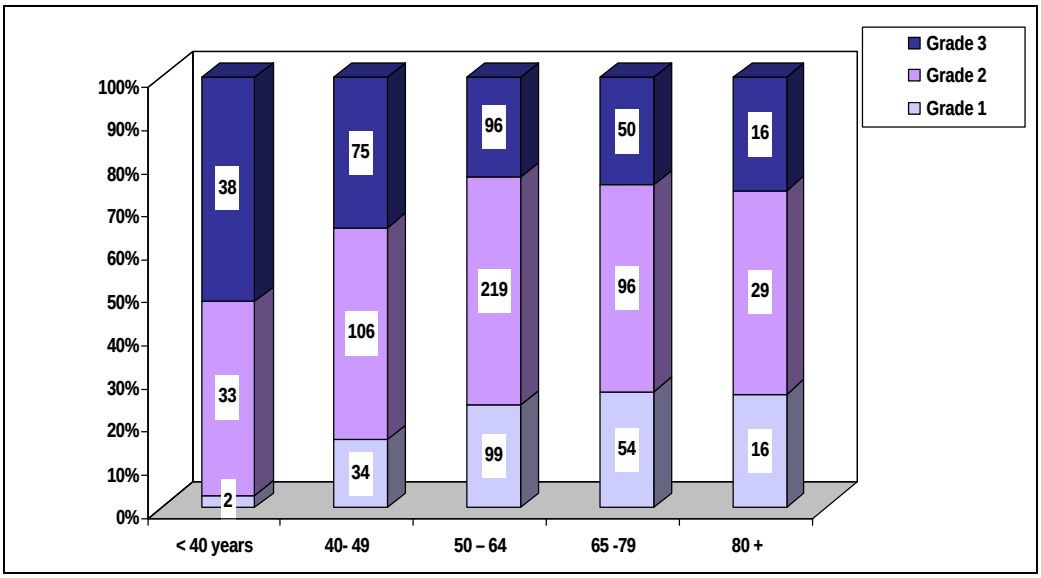
Tumour size (TStage) Tumour size, as reported from the pathology results, is shown in Table 3. In 48.7% of patients with invasive cancer the tumour was ≤2 cm. Patients with TX staging had neo-adjuvant therapy, therefore true tumour size could not be assessed, or declined surgery (Table 3).

Table 3. Tumour size (TStage) in Auckland Breast Cancer Registry patients, June 2000 to June 2003

TStage	Patients	
	n	%
Tis (DCIS)	151	12.5
T1 (≤2.0 cm)	586	48.7
T2 (2.1-5.0 cm)	325	27.0
T3 ≥5.0 cm)	63	5.2
T4	13	1.1
TX	66	5.5
Total	**1204**	**100.0**

Grade of cancer Tumour grade was reported for 967 (97.4%) of 993 surgical patients with invasive tumours. Grade 1 tumour was diagnosed in 205 (21.2%) patients, grade 2 in 483 (49.9%) patients, and grade 3 in 279 (28.9%) patients. However, 53% of patients under 40 presented with grade 3 tumours compared with 26.8% of patients over 40 (Figure 1).

Figure 1. Percentage of patients in each age group with a grade 1, 2 or 3 tumour (data labels = number of patients)



Nottingham Prognostic Index (NPI) The NPI,[4] a model of prognosis developed from tumour size, grade and nodal involvement (tumour size (cm) x 0.2 + grade + nodes (0 = 1, 1–3 = 2, ≥4 = 3)) could be calculated for 905 (89.3%) of 1014 patients

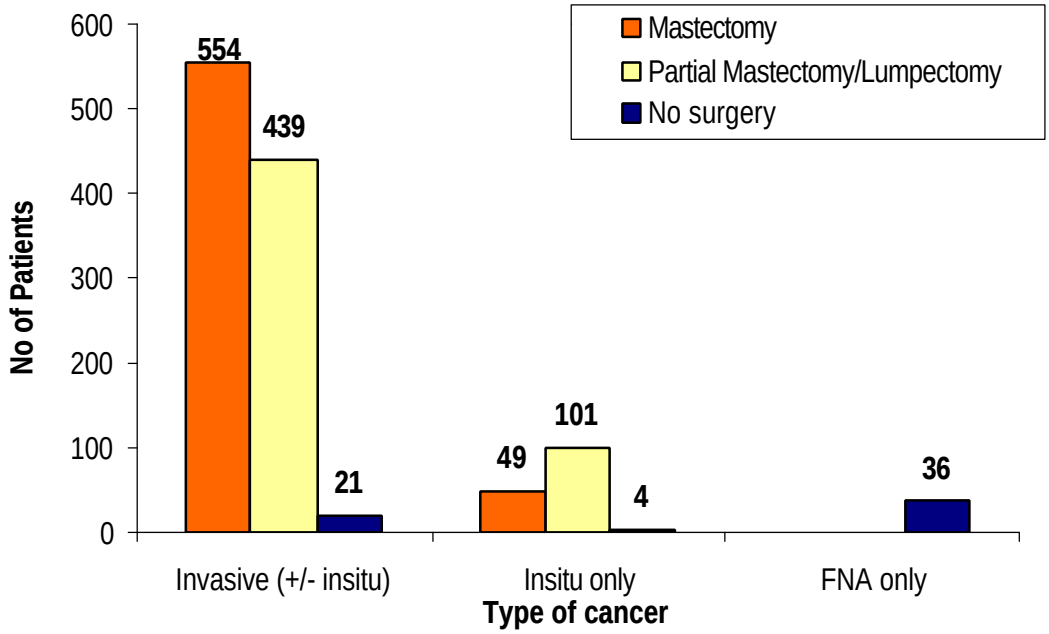
diagnosed with invasive breast cancer. Patients for whom NPI could not be calculated had no surgical intervention, did not have an axillary dissection, or had neo-adjuvant treatment (chemotherapy/hormone therapy and/or radiotherapy prior to surgical intervention) (Table 4).

Table 4. Range of Nottingham Prognostic Index (NPI) scores for patients with invasive breast cancer

NPI range	Patients	
	n	%
Not known	109	10.7
=2.40	124	12.2
2.41–3.40	219	21.6
3.41–4.40	207	20.4
4.41–5.39	200	19.7
=5.40	155	15.3
Total	**1014**	**100.0**

Hormone receptor status The pathologist reported receptor status for 962 (79.9%) patients. Oestrogen-positive tumours were found in 722 (75.1%) patients and progesterone-positive tumours in 640 (66.5%) patients. Both receptors were positive for 606 (63.0%) patients. One hundred and sixty five patients were also tested for Her2 status, and 52 patients were status 2+ or 3+ using immunostaining techniques.

Figure 2. Type of definitive surgery by type of cancer (n = 1204)



Type of definitive surgery by type of cancer Five hundred and fifty four patients (55.8%) with invasive cancer had mastectomy and 439 (44.2%) had a partial

mastectomy. In patients diagnosed with in situ cancer alone, 49 (32.7%) had mastectomy, 101 (67.3%) a partial mastectomy, but 28 (27.7%) of these patients had only a diagnostic lumpectomy and no further surgery. Sixty one patients did not have primary surgery (Figure 2).

Breast reconstruction One hundred and eleven women (18.4%) treated by mastectomy also chose to have breast reconstruction. Sixteen had an implant, 19 latissimus dorsi reconstruction, and 76 underwent a TRAM (transverse rectus abdominus myocutaneous) flap reconstruction. However, these data do not account for the number of women who may be on the waiting list for reconstruction.

Axillary surgery Axillary node dissection was performed for 934 (94.1%) of the 993 patients who underwent surgery for invasive cancer. Axillary nodes were involved in 367 (39.3%) patients and 567 (60.7%) patients had negative nodes. Of the 150 patients with in situ disease only, 28 (18.7%) had axillary surgery and none of these patients had nodal involvement.

Oncology referral Of the 1204 patients registered with the ABCR between June 2000 and June 2002, 949 (78.8%) were referred to a medical and/or radiation oncologist for consideration of local and/or systemic treatment. Of these, 846 (89.1%) patients had adjuvant treatment (Table 5), 36 (3.8%) had neo-adjuvant treatment alone, and 38 (4.0%) had both neo-adjuvant and adjuvant treatments. Adjuvant radiotherapy treatment was given to 81.3% of patients who had a partial mastectomy, and 35.0% who had mastectomy.

Table 5. Adjuvant oncology treatment given to patients referred to medical and/or radiation oncologists (n = 846)

Adjuvant treatment	Patients n (%)
Radiotherapy	650 (76.8)
Mastectomy	211 (35.0)
Partial mastectomy	439 (81.3)
Chemotherapy	282 (33.3)
Hormone therapy	485 (57.3)
Chemotherapy and hormone therapy	148 (17.5)

Recurrence and deaths At this early stage of data collection, 102 (8.5%) patients have been diagnosed with a recurrence: 66 with metastatic disease, 18 with loco-regional recurrence, and 18 with both. Six patients had another primary breast cancer diagnosed in the contralateral breast.

A total of 65 patients have died, 40 from breast cancer and 25 from other causes (Table 6).

Table 6. Patient outcome within a maximum of two years from initial presentation

Outcome	n	Comments
Loco-regional recurrence	18	9 within six months post-diagnosis 9 less than six months post-diagnosis 16 at presentation
Metastatic recurrence	66	13 within six months post-diagnosis 37 less than six months post-diagnosis
Loco-regional and metastatic recurrence	18	7 within six months post-diagnosis 11 less than six months post-diagnosis
Second primary breast cancer	6	
Deceased	65	40 breast cancer 25 other causes

Discussion

Given that the data presented in this paper are from the first two years of data collection, detailed analyses would be premature. Of the 1497 patients identified as eligible for inclusion in the Register, only 18 (1.2%) patients have refused consent (8 of these refusing all treatment). We would hope that with continued development and acceptance of the Register this figure would fall, as would the number of patients who have not been asked to participate by their clinicians. We recognise that the data collection generates extra work, but believe that the need to document current practice justifies this.

Most women present with clinical symptoms, such as a lump. In the 50- to 64-year age group, when women are eligible for free screening through the Breast Screen Aotearoa programme, 62% of tumours were diagnosed at screening; however, 15.9 % of these were also clinically evident. It appears that women and doctors may be using the screening programme for diagnostic mammography of clinical abnormalities. This will distort the screening figures. It is worrying that overall more than 50% of women are still presenting with clinical disease. There is clearly a need to increase recruitment to screening within the target group, particularly Maori and Polynesian women.[1] Of the 509 women who would have been eligible for a breast screen since screening became free in 1999 only 169 (33.2%) had undergone a previous mammogram. However, these figures may be merely reflecting the relative newness of free breast screening. With greater public awareness and acceptance of the breast screen programme, it is hoped and expected that these figures will improve.

Mammography remains the primary screening technique in the diagnosis of breast cancer, with a mammographic detection rate of 92% in this patient group. This is comparable to detection rates reported in the literature.[5,6] However, breast ultrasound, in conjunction with mammography, has become an integral part of the diagnostic work up for patients with clinical symptoms or mammographically detected abnormalities. Ultrasound was also the method of choice in 77.9% of patients who underwent image-guided needle biopsy.

Core biopsy, which allows differentiation between DCIS and invasive cancer, is clearly preferred over FNA for definitive diagnosis, as demonstrated in this patient

group.[7] Pleasingly, only a small number of patients required excision biopsy to confirm the diagnosis.

The pathological characteristics of the tumours at this early stage of the Register are in line with those reported in the literature.[8,9] Morrow et al report that 92% of tumours were infiltrating ductal, or lobular, 50.4% T1, and 75% N0 (T1 and T2 tumours only were included in this study).[9] In the present study, 18.5% of patients who underwent breast-conserving surgery for invasive cancer had nodal involvement, which is consistent with Morrow et al; however, 44.3% of patients requiring mastectomy had nodal involvement, which is high compared with other studies.[8–10] There was also a trend for younger patients to present with more aggressive disease, with 53% of patients under 40 years old having a grade 3 tumour compared with 26.8% over 40 years.

The incidence of a family history of breast cancer was higher than that reported in the literature.[11–13] However, these data are self-reported and may not reflect a true familial rate. It would be interesting to further investigate these reports, but privacy regulations makes this event unlikely in the near future (consent would have to be sought from every relative for their records to be reviewed).

According to the guidelines the rate of breast-conserving surgery (44.8%) might be considered low.[2,14,15] However, these same guidelines would exclude 6.6% of the present population because of T3 and T4 tumours. In addition, some patients with T2 tumours may have been advised to have a mastectomy by their surgeons because the size of the tumour relative to the breast size may not have allowed clear margins to be obtained with an acceptable cosmetic result.[14] Furthermore, the present study includes 11% of New Zealand Maori and Polynesian patients, who as a group seem to present with a more advanced stage of breast cancer than other ethnic groups.[1]

Many women also choose to have a mastectomy even though breast-conserving surgery is feasible. Barriers to adjuvant treatment include transport difficulties, distance from radiotherapy unit, obligations at home, and fear of radiotherapy. Some women are also anxious about the possibility of recurrence even though it is now well accepted that the two forms of local treatment are equivalent for outcome.[9,16] In addition, some women may opt for mastectomy and immediate reconstruction, instead of breast-conserving surgery.

Morrow et al report rates of breast-conserving surgery ranging from 54% in the Northeast and Pacific regions, to 32% in Southern and Midwest regions of the USA, with an overall rate of 42.6% which is lower than the present report.[9] However, cases with T1 and T2 tumours only were included. There is growing evidence to suggest that the rate of mastectomy is dropping, albeit more slowly than guidelines recommend.[9,10] A further decrease might be encouraged by targeting improved participation in screening programmes and improvement in information and education of both patients and physicians.[16,17]

Referral to medical or radiation oncology for additional therapy is common and possibly reflects the widespread involvement of multidisciplinary groups in the identification of patients who may benefit from oncology treatment. Additionally, it may also reflect the high number of clinical research trials coordinated through the Oncology Department. We have not analysed oncology treatment practices or

outcome measures, as numbers for individual therapies remain small and follow up short.

Despite the brevity of the annual follow ups, 102 (8.5%) patients had further disease diagnosed within two years of initial presentation. Sixteen of these patients had metastatic disease diagnosed at presentation and nine patients had a loco-regional recurrence diagnosed within six months of initial diagnosis. The latter may in part represent progression of undiagnosed primary disease rather than recurrence.

The database is providing detailed information on breast cancer in Auckland for the first time since the previous database had to be discontinued in 1985. The rapid acceptance of the Register has already led to an expanding workload. After only two years staffing requirements for documentation have increased from 0.5 FTE to 2.0 FTE and are anticipated to grow further. While this has significant funding implications we remain convinced that the value of the Register will justify the costs. Once established, wider coverage might be considered.

All members of the ABCSG are directly involved in the diagnosis and treatment of breast cancer patients, and the ABCR was established so that the best possible outcomes could be achieved for individual patients. The value of cancer registries and high-quality audit or surveillance in cancer control is well documented.[18] To fully achieve the aims of the ABCR, 100% accrual is necessary, but, as stated earlier, the primary limiting factor is the requirement for individual informed consent. Even though all the participating clinicians have the highest regard for patient privacy and confidentiality, it is recognised that there are situations in which patients can not be approached for their individual informed consent and indeed in many audit tools such consent is not required.

The ABCSG is currently trying to address this issue and has made an application to the Auckland Ethics Committee to review the national and international guidelines for a waiver of individual informed consent for this audit of information already in the medical record. At the time of writing no decision had been reached. However, this issue is one that also needs to be addressed by the New Zealand public; as Jocelyn Chamberlain stated, in a review of breast cancer screening in New Zealand, 'If the popular feeling remains "Privacy at all costs" then it must be recognised that one of those costs is ineffective and inefficient public health systems.'[19]

There is an extensive literature supporting the association between process of care and outcomes in breast cancer. Aspects of detection, diagnostic evaluation and therapy are known to have an important effect on quality of life and mortality. There is a broad consensus on screening, diagnosis and treatment strategies for breast cancer, and many studies on the patterns of care in oncology focus on breast cancer.[3] As such, we would propose that breast cancer is an ideal condition (common, protocol driven, managed by multidisciplinary teams) to act as an audit tool for cancer therapy per se.

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