



**NATIONAL BREAST
CANCER CENTRE**

INCORPORATING THE
OVARIAN CANCER PROGRAM

National Survey of
Coordinated Care in Breast Cancer

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Coordinated Care in Breast Cancer**

March 2004

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EXECUTIVE SUMMARY

Breast cancer is the most common cause of cancer death for women in Australia, with over 11,300 new cases diagnosed and over 2500 women dying each year from the disease.¹ Despite progress in the past decade in early detection, diagnosis and treatment for women with breast cancer in Australia, there is still scope for improvement. Screening, diagnosis, treatment and supportive care are provided by different services, often with little coordination, leading to fragmented care, sub-optimal management,² and high health care costs.^{2,3,4,5} The need to improve the coordination of cancer services has been highlighted in a number of documents outlining priorities in cancer.^{3,4,6,7} A key Australian Government initiative for 2003–2005 is the development and implementation of a series of National Service Improvement Frameworks (NSIF) for cancer and other national health priority chronic conditions with the aim of streamlining the patient journey and pathways of care.⁸ Attention is focused on a set of critical intervention points considered to offer the greatest potential for improving health outcomes and ensuring that all Australians have access to the best evidence-based care.

Identification of service improvements that will best meet patient needs requires an understanding of the journey for patients with or at risk of developing cancer, and an examination of clinical, service and system-level issues. As the NSIFs consider the provision of appropriate cancer care to all Australians, service delivery models need to take account of the location, service type and level of expertise of the treatment centre. The National Breast Cancer Centre designed the *National Survey of Coordinated Care in Breast Cancer* to provide an insight into current approaches to the coordination of care for women with breast cancer by exploring the views of healthcare professionals about the care pathway, from awareness of programs to inform women about early detection programs, to referral pathways, availability of local protocols for implementation of evidence-based guidelines, and availability of audit programs. The survey explored the perceptions of 95 surgeons, medical and radiation oncologists and supportive care professionals from both public and private hospitals in rural and urban locations, and with different breast cancer caseloads. Considerable emphasis was placed on communication between services and shared approaches, while strategies to provide care that meets the needs of women were also explored.

It is important to remember that the results reported are the perceptions of individual healthcare professionals and as such may be subject to bias. Despite the limited sample size, the survey highlights differences between urban and rural centres, between high-caseload centres and those treating few patients with breast cancer. Some differences between the public and private sector are also apparent.

Between one-third and two-thirds of respondents reported awareness of programs to inform women, general practitioners and community health professionals about screening and

symptomatic assessment services, with awareness predominantly higher in urban, high-caseload and public hospitals. Among the professions surveyed, surgeons and supportive care professionals were most aware of these programs.

Sixty one per cent of the 23 surgeons interviewed indicated that they were aware of a breast assessment or diagnostic clinic in their region. Awareness was much higher for surgeons from urban areas (86%) compared with those from rural areas (22%).

More than 70% of respondents considered that it was very unlikely that there would be problems in referral between screening, diagnostic, treatment and supportive care services. There was a slight but not significant tendency for those in low-caseload and private hospitals to indicate that problems may arise. Despite this apparent confidence, 60% of respondents indicated that they had experienced some delays in referral in the past six months and were able to recommend ways in which the process could be improved. These suggested improvements are highlighted in the key issues arising from this report (see page 58).

Awareness of programs to inform women, general practitioners and other health workers about treatment services was slightly lower than for screening and symptomatic assessment, with 46–59% of respondents indicating awareness of such programs. Again those who were aware practiced predominantly in high-caseload, urban and public facilities and awareness was highest among surgeons.

Around half of all respondents indicated that all services for breast cancer in their region communicate and work well together, with surgeons believing this to a greater extent than other professionals (74% compared with 40–53%). This finding is a cause for concern in that at least half of all healthcare professionals surveyed perceived that not all services communicate and work well with each other. Some suggestions for dealing with this were offered by respondents and are incorporated into the key issues arising from the report.

A reassuring finding is that more than 90% of surgeons and oncologists reported high levels of communication between surgery and oncology services in relation to test results, treatment plans and supportive care needs of women, although there was a tendency for this to be lower in rural areas. Most surgeons and oncologists also reported a shared approach to continuing medical education (CME) activities, facilities and protocols (75%) and to quality assurance (69%). Once again this occurred to a greater extent in urban contexts.

Two-thirds of surgeons and supportive care professionals reported high levels of communication and shared approaches to continuing medical education, protocols and quality assurance between surgery and supportive care services, with the highest levels of communication reported in

high-caseload and in public facilities. A high proportion of oncologists and supportive care professionals also reported good communication and shared approaches.

Two-thirds of respondents indicated that regular multidisciplinary meetings for treatment planning are held in their region. The majority of these respondents (81%) were practicing in urban areas compared with 41% in rural areas, and 86% were practicing in high-caseload hospitals compared with 61% in medium-caseload and 17% in low-caseload hospitals. One finding worth follow-up was that 10% of respondents who worked in high-caseload hospitals indicated that multidisciplinary meetings are not held.

Awareness of structural approaches to the support of coordinated care was lower than might be expected, in particular for respondents from rural areas and from medium–low-caseload hospitals. Fifty nine percent of respondents indicated that regular communications skills training had been held in the past 12 months, 47% indicated that quality assurance processes are usual for diagnostic services and 61% indicated that quality assurance processes are usual for treatment services. One-quarter of respondents indicated that consumers are usually involved in planning for diagnostic services and one-third indicated that consumer involvement is usual for treatment services. Only 23% indicated that special information services about diagnosis are usual for women from non-English speaking backgrounds. Thirty four per cent of respondents were indicated that special information services are usual for treatment services but very few of those were from private facilities.

While the results of this survey cannot be assumed to be fully representative of the national picture, they do provide directions for follow-up. Many of the findings confirm what is already known – that there are differences between the urban and rural settings and between hospitals treating high and low numbers of women with breast cancer. The findings are unlikely to be limited to breast cancer and are likely to carry broader application to cancer care in general. The NSIF for cancer marks an important step in ensuring equity of service provision and care for cancer patients in Australia. This survey highlights current gaps in service provision that could help to inform the identification of critical intervention points to improve cancer care in Australia.

INTRODUCTION

Breast cancer is the most common cause of cancer death for women in Australia, with over 11,300 new cases diagnosed and over 2500 women dying each year from the disease.¹ Survival from breast cancer can be improved through high-quality screening, diagnosis and treatment, while the well-being of women with breast cancer can be increased by appropriate supportive care. Over the past decade, much has been achieved in ensuring optimal diagnosis and treatment for women with breast cancer in Australia. A national population-based mammography screening program is in place and considerable progress has been made in establishing an evidence-based approach to the diagnosis, management and supportive care of women with the disease.

Despite this progress, there is still scope for improvement. In Australia, screening, diagnosis, treatment and supportive care are provided by different services, often with little coordination, leading to fragmented care and sub-optimal management.² In addition to the physical and emotional costs for the women and their families, the costs to the health care system are high.^{2,3,4} In 1997 it was estimated that breast cancer costs Australia over \$169.5 million annually to diagnose and treat.⁵

The need to improve the coordination of cancer services has been highlighted in a number of documents outlining priorities in cancer.^{3,4,6} The *Australian Priorities for Action in Cancer Control 2001–2003*⁴ identified 13 priority actions for cancer control, one of which was: *...reorganising breast cancer management to ensure seamless continuity of care from screening, first presentation with symptoms, to diagnosis, treatment and follow-up care. Optimising Cancer Care in Australia*,⁷ a report produced by key cancer control groups in 2003, highlights the need to reform cancer services into a ‘*more patient-centred model*’ (p.11) and calls for strategic reform and reorganisation of service delivery in cancer care. A key initiative for 2003–2005 is the development and implementation of a series of National Service Improvement Frameworks (NSIF) for cancer and other national health priority chronic conditions with the aim of streamlining the patient journey and pathways of care.⁸

National Service Improvement Frameworks: an overview

In October 2002, the Australian Health Ministers’ Advisory Council (AHMAC) agreed to the development of the NSIFs, to provide a framework for driving improvement in health service delivery for the national health priority chronic conditions, including cancer. The development and implementation of the NSIFs is the responsibility of the National Health Priority Action Council (NHPAC), a subcommittee of AHMAC. The aim of the NSIFs is to identify areas of need throughout the continuum of care for patients with a particular disease or condition. Attention is

focused on a set of critical intervention points considered to offer the greatest potential for improving health outcomes and ensuring that all Australians have access to the best evidence-based care.

The NSIF for cancer will act as a prototype for the other national health priority chronic diseases. The draft framework, in preparation by the Institute for Health Research,⁸ outlines what level of care Australians with or at risk of cancer should expect through the Australian health care system, irrespective of where they live (see Figure 1, page 13).

Identification of service improvements that will best meet patient needs requires an understanding of the journey for patients with or at risk of developing cancer, and an examination of clinical, service and system-level issues. A comparison of current practice with the needs of individuals with or at risk of cancer, and evidence for the effectiveness of different services will identify the gaps in current care. As the NSIFs consider the provision of appropriate cancer care to all Australians, the service delivery models developed need to take account of the location, service type and level of expertise of the treatment centre.

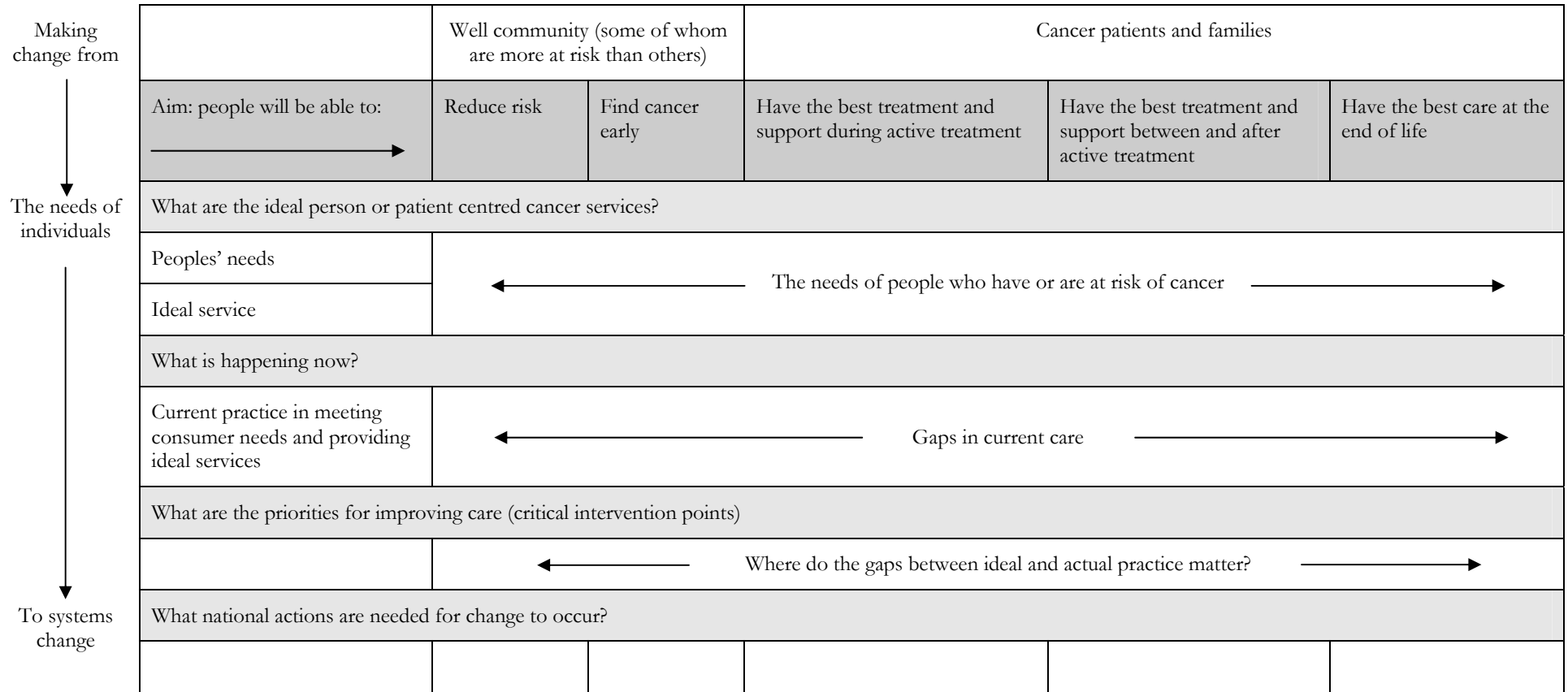
Informing the cancer NSIF: the *National Survey of Coordinated Care in Breast Cancer*

The development of appropriate models of care for individuals with or at risk of developing cancer is hampered by a lack of information about current approaches to coordination of care in Australia. The National Breast Cancer Centre designed the *National Survey of Coordinated Care in Breast Cancer* to provide an insight into current approaches by exploring the views of healthcare professionals about referral pathways, coordination of care and communication between services in their regions. To reflect the diversity of health service delivery settings and models of care in Australia, surgeons, medical and radiation oncologists and supportive care professionals from both public and private hospitals in rural and urban locations, and with different breast cancer caseloads were included in the survey.

The survey explored the perceptions of healthcare professionals about the care pathway, from awareness of programs to inform women about early detection programs, to referral pathways, availability of local protocols for implementation of evidence-based guidelines, and availability of audit programs. Considerable emphasis was placed on communication between services and shared approaches, while strategies to provide care that meets the needs of women were also explored.

The survey outcomes are described in the context of the draft organisational framework developed for the NSIF for cancer (Figure 1). As the survey examined the pathway of care from diagnosis onwards, the area of risk reduction is not covered by this report. Care at the end of life is only briefly covered. The survey responses provide an insight into current care pathways for patients with breast cancer in Australia and will inform national improvements in service delivery.

Figure 1 Draft Organising Framework for the National Service Improvement Framework for Cancer⁸



METHODS

Study overview

A telephone survey was undertaken with healthcare professionals providing care for women with breast cancer across Australia in June–November 2003. Healthcare professionals were from private and public hospitals in urban and rural locations in Australia with a large (100 or more cases per year), medium (30–99 cases per year) or low caseload (1–29 cases per year) of breast cancer.

Surgeons, medical oncologists, radiation oncologists and supportive care professionals (defined as the individual responsible for providing psychosocial support to women with breast cancer within the hospital) providing care for women with breast cancer at each hospital or in the region serviced by that hospital were surveyed.

Recruitment

Chief Executive Officers (CEOs) from hospitals involved in a previous National Breast Cancer Centre project (*National Profile Study of Multidisciplinary Care*), who at that time had agreed for the hospital to take part in a second survey, were invited by letter to participate in the survey. The 60 hospitals included:

- 38 urban and 22 rural hospitals
- 41 public and 19 private hospitals
- 22 high-caseload, 19 medium-caseload and 19 low-caseload hospitals.

The CEO of each participating hospital was asked to complete a consent form and to nominate a local coordinator within the hospital. The local coordinator was subsequently contacted with an explanation of the survey and asked to identify a surgeon, radiation oncologist, medical oncologist and supportive care professional within the hospital or within the region serviced by the hospital who is frequently involved in the management of breast cancer at their hospital. Within low-caseload hospitals, the individuals most commonly involved in the management of breast cancer were identified.

With the assistance of the local coordinator, each of the nominated healthcare professionals was sent a letter seeking their agreement to participate in a telephone interview, together with

information about the survey and a consent form (Appendix I). The healthcare professionals were asked to return a signed consent form to the National Breast Cancer Centre who forwarded the names and contact details to an independent consultancy contracted to conduct the telephone survey. Considerable effort was put into this phase to maximise recruitment.

Data collection

Survey instrument

The survey instrument (see Appendix II) was developed by the National Breast Cancer Centre with input from the project team. The survey instrument was pilot tested with a small number of healthcare professionals, including representatives from each of the relevant disciplines outlined above, and final amendments made before the start of the main survey. Interview questions were programmed into a computer-aided telephone interviewing (CATI) system, which allowed data to be entered directly into a computer database. An informal pilot of the survey was conducted with National Breast Cancer Centre staff after programming to improve the wording and flow of the questions.

The survey instrument included closed and open questions to allow collection of qualitative and quantitative data.

Interviews

The healthcare professionals who returned a consent form were contacted by an interviewer from the independent interview company to make an appointment for the interview. Attempts to contact each participant were generally made between the hours of 9 am to 9 pm EST. Up to six attempts were made to establish initial contact with each participant, and if the participant was unable to attend the scheduled appointment, up to a further five attempts were made to conduct the interview. In two cases, healthcare professionals who had originally consented were unable to participate in the survey due to time constraints.

Privacy

Interviews were confidential and responses were de-identified prior to data analysis. Although the National Breast Cancer Centre had access to the names of the health professionals interviewed, it did not have access to any information enabling linkage of participants with survey responses. Consent forms were stored in a locked filing cabinet.

Survey data were password secured and lists of participating health professionals were held at the interview company in a password secured database. Access to data and participant lists was limited to three personnel at the independent interview company: the interviewer, the project coordinator and the CATI programmer.

The participating hospitals and the health professionals who were interviewed will not be identified in any subsequent documents, presentations or publications arising from this survey either by name or by institution.

Data analysis

Quantitative data were analysed descriptively using SPSS®. In most cases simple cross-tabulations were performed to compare the pattern of responses of urban and rural hospitals, public and private hospitals, high-, medium- and low-caseload hospitals and responses from different disciplines, and a Chi-Square statistic was calculated. The categories 'Don't know' and 'Not Applicable' were included in these analyses.

For questions involving a scale, or a calculated mean or score, a non-parametric test (Kruskal-Wallis) was also used. As this test assumes only an ordered (ordinal) scale, answers of 'Don't know' or 'Not Applicable' are not part of a scale and must be considered as missing data. Differences between various demographic groups in the proportion of 'Don't know' and 'Not applicable' responses can be observed in the cross-tabulations and were examined in separate Kruskal-Wallis tests with a simple binary scale. (1=Don't know, 0 = any other answer).

Many questions involved a simple three-part scale where 1=Rarely/Never; 2=Sometimes; 3=Usually. To determine whether a particular question was answered differently to another, paired sample T-tests were performed. In this case, the scale was considered to be reasonably close to an interval scale (ie the difference between 'rarely/never' and 'sometimes' is about the same as that between 'sometimes' and 'usually'). 'Don't know and 'Not applicable' answers were considered as missing values.

Common themes were developed to group qualitative responses to allow some quantitative thematic analysis of these responses.

The sample was assumed to be a reasonable reflection of the actual population being studied. Hence it was unlikely that each subgroup would be an equivalent size. None of the statistical tests performed assumes equal size groups.

RESULTS

Response rate

Figure 2 (page 27) provides a summary of the responses received. A total of 31 hospitals agreed to participate in the survey. At least one respondent was recruited from each consenting hospital, with a total of 95 interviews completed. It was not possible to recruit a representative from each of the four professions (surgery, medical oncology, radiation oncology, supportive care) from every hospital. The breakdown of respondents by hospital is as follows:

- 18 hospitals provided the full complement of 4 professions
- 4 hospitals provided 3 professions
- 7 hospitals provided 2 professions
- 2 hospitals provided 1 profession.

Figure 2 shows the breakdown of these respondents by location, service type, caseload, profession and State/Territory. Table 1 shows further detail about the State/Territory breakdown of the respondents.

Survey responses

Find cancer before signs if possible

The survey explored awareness of programs to inform women and healthcare professionals about mammographic screening services in the region (Table 2).

Awareness of programs to inform women about mammographic screening services

Overall 64% (n=61) of respondents were aware of programs that had been run in the previous 12 months to inform women how to access mammographic screening services. Awareness was highest among respondents from urban areas, public hospitals and those with a high caseload, and among surgeons and supportive care professionals. There was a significant difference in the pattern of responses by service type ($p=0.009$) (respondents aware: public 72%; private 35%).

Awareness of programs to inform GPs about mammographic screening services

Overall, 35% (n=33) of respondents were aware of programs that had been run in the previous 12 months to inform GPs about mammographic screening services. Awareness was highest among respondents from urban areas, public hospitals and those with high caseloads, and among surgeons. Only 7% of respondents from low-caseload hospitals were aware of such programs. There were no statistical differences in the pattern of responses given by any of the groups.

Awareness of programs to inform community health workers about mammographic screening services

Overall, 35% (n=33) of respondents were aware of programs that had been run in the previous 12 months to inform community health workers about mammographic screening services. There were no significant differences in the pattern of responses given when split by location, service type or caseload. However, there was a significant difference in the pattern of responses when split by profession ($p=0.001$) (surgeons and supportive care workers more aware than other professions).

Find early signs of cancer if possible

The survey explored awareness of programs to inform women and healthcare professionals about symptomatic assessment services in the region (Table 3) and the availability of breast assessment/diagnostic clinics (Table 4).

Awareness of programs to inform women about symptomatic assessment services

Overall, 46% (n=44) of respondents were aware of programs that had been run in the past 12 months to inform women how to access symptomatic assessment services. Awareness was highest among respondents from urban areas, public hospitals, those with high caseloads, and among surgeons and supportive care professionals. There was a significant difference in the pattern of responses by service type ($p=0.004$) (respondents aware: public 52%; private 25%). A trend to significance was also seen in the pattern of responses from high-, medium- and low-caseload hospitals ($p=0.051$) (respondents aware: high 56%; medium 45%; low 14%).

Awareness of programs to inform GPs about symptomatic assessment services

Overall, 39% (n=37) of respondents were aware of programs that had been run in the past 12 months to inform GPs about symptomatic assessment services. Awareness was highest among respondents from urban areas, public hospitals, those with high caseloads, and among surgeons.

There was a significant difference in the pattern of responses by location ($p=0.024$) (respondents aware: urban 48%; rural: 19%).

Awareness of programs to inform community health workers about symptomatic assessment services

Overall, 35% ($n=33$) of respondents were aware of programs that had been run in the past 12 months to inform other healthcare workers about symptomatic assessment services. No significant differences in the pattern of responses were seen by location, service type or caseload. However, there was a significant difference in the pattern of responses by profession ($p<0.001$) (surgeons and supportive care professionals more aware than other professions).

Availability of breast assessment/diagnostic clinics

Overall, 61% ($n=14$) of the 23 surgeons interviewed indicated that they were aware of a breast assessment or diagnostic clinic in their region (the question was not asked of other healthcare professionals). There was a significant difference in the pattern of responses by location ($p=0.004$) (respondents aware: urban 86%; rural 22%). There was also a trend towards a significant difference by caseload ($p=0.055$) (respondents from high-caseload hospitals more likely to indicate awareness of a clinic).

Of the 14 surgeons who indicated there was a clinic in their region:

- 79% indicated that most women would easily find out about the clinic
- all, regardless of location, service type or caseload, indicated that women would find out about the clinic via their GP
- 43% indicated that women would find out about the clinic via local advertisements.

Have the right diagnosis and referral

The survey explored healthcare professionals' overall perceptions of the efficiency of referral between the different services (Table 5). Communication between services was explored in more detail in separate questions and the responses are described in the next section.

Referral between services

Overall, 77% ($n=73$) of respondents indicated that it was very unlikely that there would be problems in referral between screening and treatment, or between diagnostic and treatment services, and 71% ($n=67$) indicated that it was very unlikely that there would be problems between treatment and supportive care services. There were no significant differences in the pattern of

responses between the different groups, although respondents from private hospitals, those with low caseloads and supportive care workers were more likely to indicate that problems may arise.

Despite this apparent confidence in the efficiency of referrals, 60% (n=57) of all respondents indicated that, in the past six months, women with breast cancer had not always been referred to them without undue delay. Suggestions for improving the referral process provide an insight into the perceived reasons for these delays (Table 6). Common themes in responses are given below (as responses were open ended, respondents often gave examples representing more than one theme):

- improving clinician communication (eg through multidisciplinary meetings, and inclusion of GPs in the treatment team) (n=13)
- establishing referral protocols (n=12)
- referring patients earlier in the patient's journey (n=12)
- educating GPs (n=8)
- educating clinicians/other members of the treatment team (n=8)
- increasing resources (n=6)
- educating women (n=5).

Delays in diagnosis

Of the 23 surgeons interviewed, 39% (n=9) reported that at least one of the last 20 patients they had seen had experienced undue delays in diagnosis. Perceived causes of these delays included (more than one reason could be given by each respondent):

- patients delaying presentation following discovery of symptoms (n=9)
- incorrect or incomplete initial patient assessment (n=6)
- GPs delay obtaining biopsy or referring patients to specialists (n=4).

Examples of some of the reasons for these delays are listed in Table 7.

Have the best treatment and support

A large proportion of the questions in the survey focused on treatment and supportive care. Questions explored awareness of programs to inform women and healthcare professionals about

treatment services (Table 8) and then went on to explore the relationship between different services and the level of interaction between these groups (Tables 9–15).

Awareness of programs to inform women about treatment services

Overall, 59% of respondents were aware of programs that had been run in the past 12 months to inform women about how to access treatment services. Awareness was highest among respondents from urban areas, public hospitals and those with high-caseloads, and among surgeons and supportive care professionals. A significant difference was seen when comparing the pattern of responses by service type ($p=0.031$) (respondents aware: public 63%; private 45%).

Awareness of programs to inform GPs about treatment services

Overall, 47% of respondents were aware of programs that had been run in the past 12 months to inform GPs about treatment services. Awareness was highest among respondents from urban areas, public hospitals and those with high caseloads, and among surgeons. A significant difference was seen when comparing the pattern of responses by location ($p=0.002$) (respondents aware: urban 59%; rural 23%) and by caseload ($p=0.03$) (respondents aware: high 64%; medium 36%; low 14%).

Awareness of programs to inform community health workers about treatment services

Overall, 46% of respondents were aware of programs that had been run in the past 12 months to inform community health workers about treatment services. Surgeons and supportive care professionals appeared to be more aware of such programs than other healthcare professionals. However, no significant differences were seen in the pattern of responses when split by location, service type, caseload or profession.

Communication and relationship between all services

Overall, 51% of respondents indicated that all services for breast cancer in their region communicate and work together, while 45% indicated that some services communicate and work together (Table 9). There was no difference in the pattern of responses when assessed by location or service type. However, more respondents from low-caseload hospitals indicated that few services work well together (low: 14%; high 2%; medium 0%) while surgeons were more likely to indicate that all services work together compared with the other professions (74% vs 40–53% for other professions).

Responses to open-ended questions provided examples of ways in which services work well together or reasons for services working well together. These included:

- good communication between services and individual healthcare professionals (87%, n=83)
- including communication strategies such as regular multidisciplinary care meetings (53%, n=50)
- referral systems are direct and/or easy (26%, n=25)
- location of services (16%, n=15) all at one site or very close to other services
- psychosocial support is provided (17%, n=16) from very early on and/or in an ongoing way
- service provision is prompt (18%, n=17).

Quotations demonstrating some of these viewpoints are given in Table 10.

Communication between individual services was then explored in more detail.

Communication and shared approaches between treatment services

Responses to a number of questions indicate differences in the perceived level of communication between the different treatment specialties (surgery, medical oncology, radiation oncology) (Table 11).

Over 90% of surgeons and oncologists indicated that surgeons and oncologists communicate with each other about individual women's results and about their treatment plans, while 78% indicated that communication usually occurs about women's supportive care needs. There was a significant difference in the pattern of responses when split by location for:

- communication of results ($p=0.003$) (communication usual: urban 100%; rural 76%)
- communication of treatment plans ($p=0.009$) (communication usual: urban: 100%; rural 81%)
- communication of supportive care needs ($p=0.017$) (communication usual: urban: 85%; rural 62%).

Questions also explored the perceived level to which shared approaches are in place between treatment services (Table 11).

Over 75% of surgeons and oncologists indicated that they usually take part in CME activities together, have agreed common protocols, and share facilities where appropriate, while 69% indicated that these services have shared approaches to quality assurance. Some significant differences were seen in the pattern of responses:

- joint CME activities usually occur: by profession ($p=0.004$) (surgeons and medical oncologists more likely to indicate that joint CME activities occur compared with radiation oncologists)
- agreed common protocols usually in place: by location ($p=0.039$) (urban 85%; rural 57%)
- approaches to quality assurance usually shared: by location ($p=0.02$) (urban 76%; rural 52%)
- facilities usually shared where appropriate: by location ($p=0.015$) (urban 87%; rural 52%); by profession ($p=0.045$) (surgeons 83%; medical oncologists 83%; radiation oncologists 62%).

Communication and shared approaches between surgery and supportive care

In general, the majority of surgeons and supportive care professionals surveyed indicated a high level of communication between the two services. Over 65% of these professions indicated that the two services usually communicate about women's results, treatment plans and supportive care needs. A similar proportion indicated that shared approaches are taken to CME activities, quality assurance and use of facilities, and that agreed common protocols are usually in place. However, some significant differences in the pattern of responses to a number of questions indicate differences in the level of communication between surgery and supportive care services when split by service type and by caseload (Table 12):

- communication about individual women's results: by caseload ($p=0.011$) (communication usual: high 84%; medium 56%; low 50%)
- communication about individual women's treatment plans: by service type ($p=0.016$) (communication usual: public 72%; private 45%); by caseload ($p=0.007$) (communication usual: high 88%; medium 50%; low 37%)
- communication about women's supportive care needs: by service type ($p=0.039$) (communication usual: public 75%; private 45%); by caseload ($p=0.003$) (communication usual: high 92%; medium 50%; low 37%)
- joint CME activities usually occur: by service type ($p<0.001$) (public 80%; private 18%); by caseload ($p=0.004$) (high 88%; medium 56%; low 25%)
- agreed common protocols usually in place: by caseload ($p=0.004$) (high 92%; medium 44%; low 25%)

- approaches to quality assurance usually shared: by service type ($p=0.043$) (public 75%; private 36%); by caseload ($p=0.006$) (high 88%; medium 50%; low 38%).

Communication and shared approaches between oncology and supportive care

In general, the majority of oncologists and supportive care professionals indicated a high level of communication regarding individual women's needs, with over 90% indicating that the two services usually communicate about women's results and around 80% indicating that communication about women's treatment plans and supportive care needs usually occurs. Joint CME activities, common protocols, shared approaches to quality assurance and shared facilities were reported as usual occurrences by 64–79% of the respondents. There were no significant differences in the pattern of responses when split by location, caseload or profession. However, significant differences in responses to two questions indicate differences in the perceptions of the level of communication between oncology and supportive care services by different service types (Table 13):

- joint CME activities usual ($p=0.005$) (public 75%; private 33%)
- shared facilities usual ($p=0.03$) (public 84%; private 60%).

Provision of multidisciplinary care

Overall, 68% of respondents indicated that regular multidisciplinary meetings are held for treatment planning in their region (Table 14). There was a significant difference in the pattern of responses when split by location ($p<0.001$) (regular multidisciplinary meetings held: urban 81%; rural 41%); by caseload ($p<0.001$) (regular multidisciplinary meetings held: high 86%; medium 61%; low 17%); and by profession ($p=0.046$) (regular multidisciplinary meetings held: surgery 77%; medical oncology 77%; radiation oncology 52%; supportive care 67%). Interestingly, 10% of high-caseload hospitals indicated that multidisciplinary care meetings are not held.

Structural/organisational elements of coordinated care

Several questions investigated structural and organisational elements of coordinated care that are central to the NSIF model. These included questions relating to communication skills training, quality assurance and service planning (Table 15) and questions relating to other service issues such as involvement of consumers in planning and advisory structures, and availability of programs for women from non-english speaking backgrounds (Table 16).

Education and training

Overall, 59% of respondents indicated that there had been communication skills training for clinicians in the past 12 months. There was a significant difference in the pattern of responses when split by location ($p=0.001$) (communications skills training held: urban 72%; rural 32%); and by caseload ($p=0.039$) (communications skills training held: high 72%; medium 52%; low 29%).

Quality assurance/audits

Overall, 47% of respondents indicated that quality assurance programs are usually established for diagnostic services while 61% of respondents indicated that quality assurance programs are usually established for treatment services. A significant difference was seen in the pattern of responses when split by profession ($p=0.049$), with more surgeons indicating awareness of quality assurance programs for diagnostic services than the other professions. While the result regarding diagnostic services is not necessarily surprising, it is noteworthy that 12% of respondents were unaware of whether quality assurance programs were available for treatment services. The number of 'don't know' responses was highest for those from rural hospitals (16%), medium-caseload hospitals (16%) and low-caseload hospitals (21.5%).

In total, 40% of respondents indicated that audits of practice are usually established for diagnostic services, while 54% indicated that audits of practice are usually established for treatment services. In both cases, there was a significant difference in the pattern of responses when split by profession ($p=0.023$ and $p<0.001$ for diagnostic and treatment audits, respectively), with surgeons more aware of such audits than other professions. Again, 12% of respondents indicated that they were unaware of whether audits of practice were established for treatment services, with numbers particularly high for those from rural hospitals (39%) and low-caseload hospitals (21%).

Other service planning

Overall, 24% of respondents indicated that consumers are usually involved in planning and advisory structures for diagnostic services, and 31% indicated consumer involvement in planning and advisory structures for treatment services. No significant differences were seen between the groups.

Only 23% of respondents indicated that special information or programs are usually available for women from non-english speaking and indigenous backgrounds for diagnostic services. There was a significant difference in responses when split by profession ($p=0.041$) with radiation oncologists less aware of these programs than other professions (5% v 17–36%).

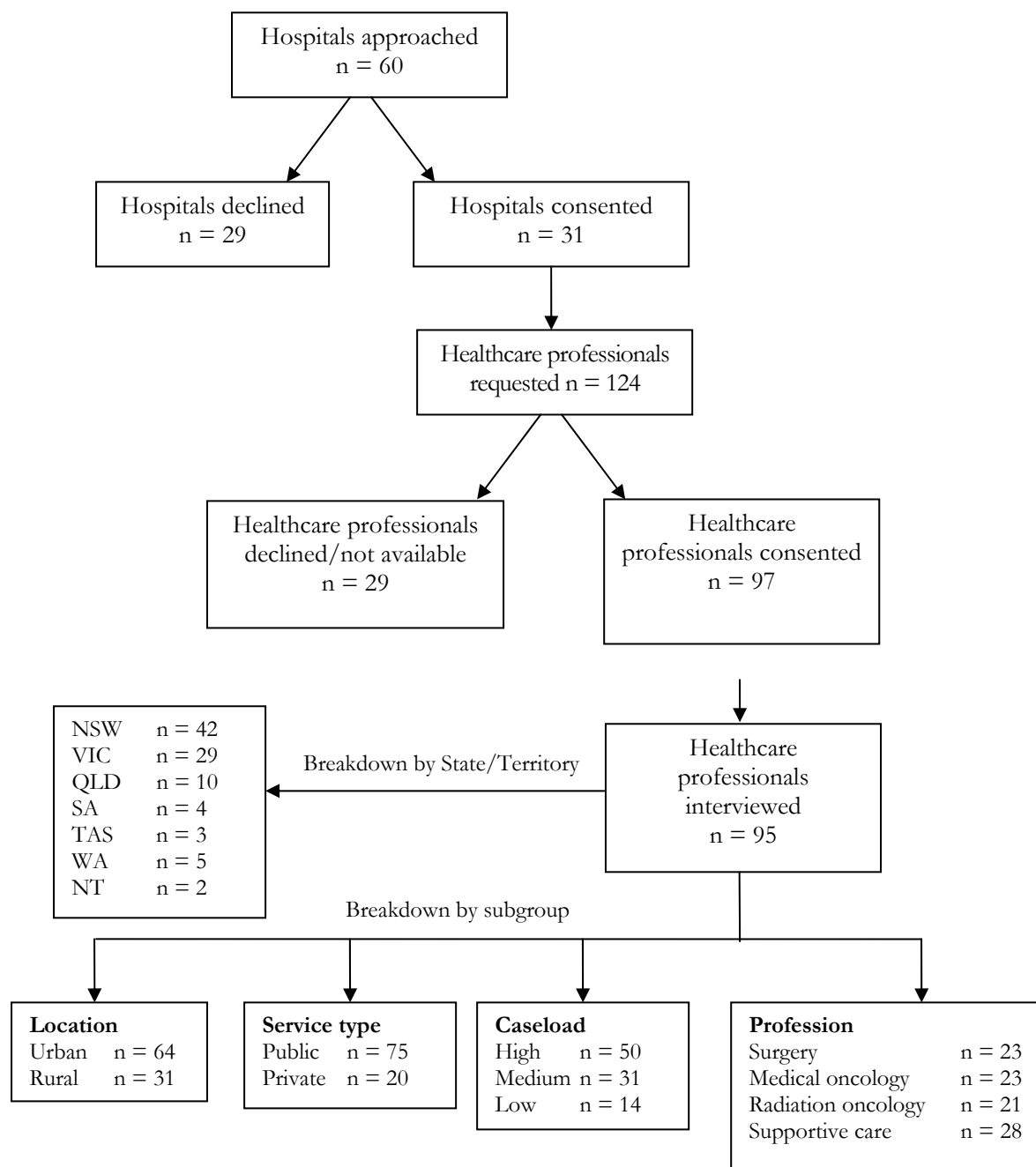
Similarly, only 34% of respondents indicated that special information or programs are usually available for women from non-english speaking and indigenous backgrounds for treatment services.

There was a significant difference when split by service type ($p=0.014$), with respondents from public hospitals more likely to indicate that programs were in place compared with those from private hospitals (41% v 5%). Overall, 27% of respondents indicated that programs were rarely or never in place, and 14% did not know whether programs were in place.

Have the right care at the end of life

No specific questions were asked regarding care at the end of life. However, responses to questions regarding services that work well together indicate mixed perceptions of the ease of referral to palliative (see Table 17).

Figure 2 Survey sample



For a breakdown of each subgroup, by State/Territory, see Table 1

Table I Breakdown of respondents by State/Territory

Subgroup		State/Territory														Total (%)	
		NSW		VIC		QLD		SA		TAS		WA		NT		n	%
		n	%	n	%	n	%	n	%	n	%	n	%	n	%		
Location	Urban	26	62	23	79	8	80	2	50	0	0	5	100	0	0	64	67
	Rural	16	38	6	21	2	20	2	50	3	100	0	0	2	100	31	33
Service type	Public	32	76	25	86	10	100	0	0	3	100	5	100	0	0	75	79
	Private	10	24	4	14	0	0	4	100	0	0	0	0	2	100	20	21
Caseload	High	19	45	15	51.5	10	100	2	50	0	0	4	80	0	0	50	53.5
	Medium	17	41	10	35	0	0	0	0	3	100	1	20	0	0	31	32.5
	Low	6	14	4	13.5	0	0	2	50	0	0	0	0	2	100	14	15
Profession	Surgery	11	26	7	24	2	20	1	25	1	33.3	1	20	0	0	23	24
	Medical	7	17	9	31	3	30	0	0	1	33.3	2	40	1	50	23	24
	Radiation	12	28.5	6	21	1	10	1	25	0	0	1	20	0	0	21	22
	Supportive	12	28.5	7	24	4	40	2	50	1	33.3	1	20	1	50	28	30
Total		42	100	29	100	10	100	4	100	3	100	5	100	2	100	95	100

Table 2 Awareness of programs to inform women and healthcare professionals about screening services

Programs:	Aware?	Location		Service type		Caseload			Profession				Total (%) n = 95
		Urban (%) n = 64	Rural (%) n = 31	Public (%) n = 75	Private (%) n = 20	High (%) n = 50	Medium (%) n = 31	Low (%) n = 14	Surg (%) n = 23	MO (%) n = 23	RO (%) n = 21	SC (%) n = 28	
To inform women how to access screening services	Yes	69	55	72	35	74	58	43	78	52	48	75	64
	No	6	13	7	15	6	10	14	4	4	14	11	8
	Don't know	25	32	21	50	20	32	43	18	44	38	14	28
To inform GPs about screening services	Yes	41	23	37	25	44	32	7	52	26	29	32	35
	No	12	13	13	10	12	16	7	9	13	19	11	13
	Don't know	47	64	50	65	44	52	86	39	61	52	57	52
To inform community health workers about screening services	Yes	34	36	35	35	36	42	14	61	17	10	46	35
	No	11	6	9	10	12	3	14	13	9	19	0	14
	Don't know	55	58	56	55	52	55	72	26	74	71	54	51

Bold areas indicate a statistically significant difference in the pattern of responses (p<0.05)

Shaded areas indicate a highly statistically significant difference in the pattern of responses (p<0.01)

Table 3 Awareness of programs to inform women and healthcare professionals about assessment services

Programs:	Aware?	Location		Service type		Caseload			Profession				Total (%) n = 95
		Urban (%) n = 64	Rural (%) n = 31	Public (%) n = 75	Private (%) n = 20	High (%) n = 50	Medium (%) n = 31	Low (%) n = 14	Surg (%) n = 23	MO (%) n = 23	RO (%) n = 21	SC (%) n = 28	
To inform women how to access assessment services	Yes	50	39	52	25	56	45	14	52	39	28	61	46
	No	19	22	23	10	20	19	22	22	13	24	21	20
	Don't know	31	39	25	65	24	36	64	26	48	48	18	34
To inform GPs about assessment services	Yes	48	19	43	25	52	29	14	65	35	24	32	39
	No	11	19	14	10	10	19	14	4	13	24	14	14
	Don't know	41	61	43	65	38	52	72	30	52	52	54	47
To inform community health workers about assessment services	Yes	31	42	36	30	32	45	22	57	22	0	53	35
	No	16	10	13	15	16	10	14	17	9	29	4	14
	Don't know	53	48	51	55	52	45	64	26	69	71	43	52

Bold areas indicate a statistically significant difference in the pattern of responses (p<0.05)

Shaded areas indicate a highly statistically significant difference in the pattern of responses (p<0.01)

Table 4 Availability of breast assessment/diagnostic clinics in region

	Aware?	Location		Service type		Caseload			Total (%)
		Urban (%)	Rural (%)	Public (%)	Private (%)	High (%)	Medium (%)	Low (%)	
Availability of breast assessment/ diagnostic clinic (n=23 – surgeons only)	Yes	86	22	61	60	83	29	50	61
	No	14	78	39	40	17	71	50	39

If answer 'yes' to above question (n=14):

	Answer:	Location		Service type		Caseload			Total (%)
		Urban (%)	Rural (%)	Public (%)	Private (%)	High (%)	Medium (%)	Low (%)	
How many women with a breast symptom would easily find out about the clinic?	Few	8	0	9	0	0	50	0	7
	Some	17	0	18	0	20	0	0	14
	Most	75	100	73	100	80	50	100	79
Would woman find out about the clinic via GP?	Yes	100	100	100	100	100	100	100	100
	No	0	0	0	0	0	0	0	0
Would woman find out about the clinic via local advertisement?	Yes	42	50	46	33	30	100	50	43
	No	58	50	54	67	70	0	50	57

Bold areas indicate a statistically significant difference in the pattern of responses (p<0.05)

Shaded areas indicate a highly statistically significant difference in the pattern of responses (p<0.01)

Table 5 Perceptions of referrals between different services

Services:	How likely are problems in referral?	Location		Service type		Caseload			Profession				Total (%) n = 95
		Urban (%) n = 64	Rural (%) n = 31	Public (%) n = 75	Private (%) n = 20	High (%) n = 50	Medium (%) n = 31	Low (%) n = 14	Surg (%) n = 23	MO (%) n = 23	RO (%) n = 21	SC (%) n = 28	
Screening and treatment	Very likely	2	3	3	0	0	3	7	0	0	0	7	2
	Quite likely	3	0	1	5	4	0	0	4	0	0	4	2
	Quite unlikely	12	23	13	25	10	20	29	4	13	19	25	16
	Very unlikely	80	71	78	70	82	74	64	92	74	81	64	77
	Don't know	3	3	4	0	4	3	0	0	13	0	0	3
Diagnosis and treatment	Very likely	2	3	3	0	2	0	7	0	0	5	4	2
	Quite likely	3	0	1	5	2	3	0	0	0	5	4	2
	Quite unlikely	19	23	15	30	18	13	29	13	4	14	35	18
	Very unlikely	76	71	80	65	78	81	64	87	92	76	57	77
	Don't know	0	3	1	0	0	3	0	0	4	0	0	1
Treatment and supportive care	Very likely	0	6.5	3	0	0	3	7	0	0	0	7	2
	Quite likely	11	6.5	8	15	8	13	7	9	4	9	14	9
	Quite unlikely	20	13	16	25	18	16	22	17	18	29	11	18
	Very unlikely	69	74	73	60	74	68	64	74	78	62	68	71

Bold areas indicate a statistically significant difference in the pattern of responses (p<0.05)

Shaded areas indicate a highly statistically significant difference in the pattern of responses (p<0.01)

Table 6 Suggestions of ways to improve the efficiency of referrals

Topic	Quote	Profession: hospital
Improving clinician communication	<i>“it could be improved by a joint clinic of surgeons, radiation oncologists and medical oncologists – we now have individual clinics and patients get referred from one specialist to the next”</i>	RO: public, urban, high-caseload
	<i>“multidisciplinary meetings would help the process of referral”</i>	MO: public, urban, medium-caseload
	<i>“we will also be inviting GPs who refer to the local hospitals to come to the multidisciplinary meetings”</i>	SC: public, rural, medium-caseload
	<i>“improve direct communication between GPs and myself – this is difficult because of time constraints and availability of personnel”</i>	SU: private, urban, high-caseload
Establishing referral protocols	<i>“having a recognised, single point of contact for referral would be good”</i>	SC: public, urban, high-caseload
	<i>“a system of referral to the local breast care nurse would be a great help – it would allow us to follow-up those women promptly”</i>	SC: public, rural, medium-caseload
	<i>“the process could be improved if there was a blanket recommendation to come to the oncologist first rather than to the radiotherapist”</i>	MO: public, rural, low-caseload
	<i>“we have an area-wide electronic booking appointment system for social work and clinic time – sometimes I will phone the patient directly as it saves the patient from being ‘lost’ in the system”</i>	SC: public, urban, medium-caseload
Referring patients earlier in the patient’s journey	<i>“it’s important for it (the referral) to be at the time of diagnosis, to make it more efficient”</i>	SC: public, urban, high-caseload
	<i>“by being involved at an earlier stage”</i>	MO: public, urban, high-caseload
	<i>“earlier referrals – we need to get them quite early rather than after surgery”</i>	SC: private, rural, low-caseload
	<i>“get the surgeons to refer the patients as soon as possible, and not wait for the post-operative meeting”</i>	MO: public, urban, high-caseload
	<i>“it could improve with the opportunity to consult with the patient prior to surgery, not just after”</i>	RO: public, rural, medium-caseload

Table 6 Suggestions of ways to improve the efficiency of referrals (cont'd)

Topic	Quote	Profession: hospital
Educating GPs	<i>“better education of GPs – to obtain knowledge about which cases are urgent and which are not”</i>	SU: public, rural, medium-caseload
	<i>“by better educating GPs about how to distinguish between possibly suspicious lesions and benign lesions, and also in diagnostic procedures – knowing which are the most appropriate investigations to ask for”</i>	SC: public, urban, high-caseload
	<i>“provide useful information to GPs regarding access pathways”</i>	SU: public, urban, high-caseload
Education	<i>“educate staff – when problems have occurred it has always been when new staff or agency staff have been involved”</i>	SC: private, urban high-caseload
	<i>“improve education to make sure that people referring are familiar with all the available services”</i>	SU: public, urban, high-caseload
	<i>“a better knowledge generally amongst referring practitioners about the role of social work and how it can help patients”</i>	SC: private, rural, low-caseload
Increasing resources	<i>“because of staff shortages, women are not able to be seen quickly”</i>	RO: public, urban, high-caseload
	<i>“increase the amount of clinic time we have to see the ladies so they are not waiting too long”</i>	RO: public, urban, high-caseload
	<i>“it could be improved if there were more medical oncologists available”</i>	MO: public, rural, medium-caseload
Educating women	<i>“I think we’ve got to improve our advertising in the community – from time to time you need to remind women”</i>	SU: public, urban, high-caseload
	<i>“education for women so they don’t deny symptoms”</i>	SU: public, urban, high-caseload

SU, surgeon; MO, medical oncologist; RO, radiation oncologist; SC, supportive care professional

Table 7 Perceptions of surgeons in reasons for delays in patient diagnosis

Topic	Quote	Hospital
Patients delaying presentation	<i>“caused by patients’ reluctance to follow through and because other events in their lives cause delay”</i>	Private, urban, high-caseload
	<i>“women sometimes choose to ignore their symptoms for various reasons including fear or (other) psychological reasons”</i>	Public, rural, high-caseload
Incorrect or incomplete patient assessment	<i>“it was an incomplete initial assessment and that’s why it (the cancer) was missed”</i>	Public, urban, medium-caseload
	<i>“in one instance a woman was misdiagnosed and did not get to the screening program until one year later”</i>	Public, urban, high-caseload
	<i>“mainly because of inadequate assessments due to breast implants”</i>	Private, rural, low-caseload
Delays in GP referrals to specialists	<i>“delays caused by GPs not sending patients when they should”</i>	Public, urban, high-caseload
	<i>“GPs interpret test results wrongly, then there is a time delay in getting second opinions”</i>	Public, urban, high-caseload
	<i>“a reluctance by GPs to have a diagnostic biopsy done prior to referring to a specialist – a GP will get a mammogram that is suspicious but won’t do a biopsy”</i>	Public, rural, medium-caseload

Table 8 Awareness of programs to inform women and healthcare professionals about treatment services

Programs:	Aware?	Location		Service type		Caseload			Profession				Total (%) n = 95
		Urban (%) n = 64	Rural (%) n = 31	Public (%) n = 75	Private (%) n = 20	High (%) n = 50	Medium (%) n = 31	Low (%) n = 14	Surg (%) n = 23	MO (%) n = 23	RO (%) n = 21	SC (%) n = 28	
To inform women how to access treatment services	Yes	64	48	63	45	66	58	36	65	48	48	71.5	59
	No	12	16	16	5	16	10	14	13	13	24	7	14
	Don't know	23	36	21	50	18	32	50	22	39	28	21.5	27
To inform GPs about treatment services	Yes	59	22.5	50	35	64	35	14	74	48	33	36	47
	No	8	22.5	15	5	6	23	14	4	9	24	14	13
	Don't know	33	55	35	60	30	42	72	22	43	43	50	40
To inform other healthcare professionals about treatment services	Yes	45	46	44	55	44	48	50	61	35	33	54	46
	No	16	17	19	10	16	16	21	17	9	29	14	17
	Don't know	39	37	37	35	40	36	29	22	57	38	32	37

Bold areas indicate a statistically significant difference in the pattern of responses (p<0.05)

Shaded areas indicate a highly statistically significant difference in the pattern of responses (p<0.01)

Table 9 Perceptions of communication between different services

	To what extent does this happen?	Location		Service type		Caseload			Profession				Total (%) n = 95
		Urban (%) n = 64	Rural (%) n = 31	Public (%) n = 75	Private (%) n = 20	High (%) n = 50	Medium (%) n = 31	Low (%) n = 14	Surg (%) n = 23	MO (%) n = 23	RO (%) n = 21	SC (%) n = 28	
Communication between breast cancer services	All services	50	52	50	55	50	58	36	74	39	52	39	51
	Some services	47	42	48	35	48	39	50	26	57	48	50	45
	Few services	1.5	6	1	10	2	0	14	0	0	0	11	3
	Don't know	1.5	0	1	0	0	3	0	0	4	0	0	1

Bold areas indicate a statistically significant difference in the pattern of responses ($p < 0.05$)

Shaded areas indicate a highly statistically significant difference in the pattern of responses ($p < 0.01$)

Table 10 Perceptions of respondents about ways in which services work well together

Topic	Quote	Profession: hospital
Good communication	<i>“we work together closely, and communicate personally”</i>	MO: public, urban, high-caseload
	<i>“there is a constant flow of information between our two services with regular mail, email, telephone calls; we also have cross invitations to any forums or programs that are running”</i>	SC: private, rural, low-caseload
	<i>“referrals are very prompt; communication is excellent”</i>	SC: public, rural, high-caseload
	<i>“our hospital is small enough to have personal relationships”</i>	SU: private, rural, low-caseload
	<i>“we are at an advantage because we are a smaller service: we all know each other well, maintaining a close relationship, and because of it we are well coordinated”</i>	SC: public, rural, high-caseload
Multidisciplinary care	<i>“there is good communication via telephone, email, mail; we also have weekly multidisciplinary meetings to discuss the critical patients”</i>	RO: public, urban, high-caseload
	<i>“there is never a problem with communication as we have multidisciplinary meetings with all the relevant medical services”</i>	SU: public, urban, medium-caseload
	<i>“we have regular meetings where all new patients with breast cancer are discussed and the meetings are attended by all the disciplines involved”</i>	SU: public, urban, medium-caseload
	<i>“with the multidisciplinary assessment clinics, patients can see everyone on the same day”</i>	RO: public, urban, high-caseload
	<i>“our communication at the multidisciplinary meetings makes it possible for the patient to be seen almost immediately”</i>	RO: private, urban, medium-caseload
Referral systems	<i>“once a patient is booked in for surgery she is immediately referred to a breast cancer nurse and her name is added to the list of patients to be discussed at the multidisciplinary meetings”</i>	SC: public, rural, medium-caseload
	<i>“new referrals from the discharge planner to the breast care nurse always happen”</i>	SC: public, rural, medium-caseload

Table 10 Perceptions of respondents about ways in which services work well together (cont'd)

Topic	Quote	Profession: hospital
Location of services	<i>“our clinics overlap in many ways: we are right next door to each other and we can interrelate and cross referrals, which makes communication and appointments very timely and efficient”</i>	RO: public, rural, medium-caseload
	<i>“we share the same building”</i>	SC: public, urban, high-caseload
	<i>“as a freestanding cancer centre, all the services are provided onsite and the links between the different disciplines are very strong”</i>	SU: public, urban, high-caseload
Psychosocial support	<i>“the breast care nurse gets to see the patient soon after diagnosis”</i>	RO: public, rural, medium-caseload
	<i>“patients get referred and managed promptly by all the available services”</i>	SU: private, urban, high-caseload
	<i>“normally the counsellor is present at the time of diagnosis and through that the counsellor is one of the means of communicating to the other specialists involved”</i>	SC: public, urban, high-caseload
Prompt service provision	<i>“the connection between the radiologist and the oncologist mean prompt investigations and results are achieved”</i>	RO: public, rural, low-caseload
	<i>“if BreastScreen have diagnosed a breast cancer, I get a call to make an appointment urgently”</i>	SC: public, urban, high-caseload
	<i>“it’s a very prompt service: we communicate directly so patients are seen quickly”</i>	MO: public, urban, medium-caseload
	<i>“it is a very responsive service, probably because of direct communication: if any changes in treatment plans are required they are instituted very smoothly without any problem to the patient”</i>	MO: public, urban, medium-caseload

Table 11 Perceptions of communication and shared approaches between treatment services

Topic:	Level of communication	Location		Service type		Caseload			Profession			Total (%) n = 67
		Urban (%) n = 46	Rural (%) n = 21	Public (%) n = 53	Private (%) n = 14	High (%) n = 37	Medium (%) n = 20	Low (%) n = 10	Surg (%) n = 23	MO (%) n = 23	RO (%) n = 21	
Individual women's treatment results	Sometimes	0	14	6	0	0	10	10	0	4	9.5	4.5
	Usually	100	76	92	93	97	90	80	91	96	90.5	92.5
	Not applicable	0	10	2	7	3	0	10	9	0	0	3
Individual women's treatment plans	Sometimes	0	9.5	4	0	0	10	0	0	4	5	3
	Usually	100	81	94	93	97	90	90	91	96	95	94
	Not applicable	0	9.5	2	7	3	0	10	9	0	0	3
Individual women's supportive care needs	Sometimes	15	24	17	21.5	16	10	40	17	17	19	18
	Usually	85	62	79	71.5	81	85	50	74	83	76	78
	Not applicable	0	14	4	7	3	5	10	9	0	5	4
Continuing medical education	Rarely or never	2	9.5	4	7	3	5	10	4	9	0	4.5
	Sometimes	13	14	11	21.5	8	15	30	4	0	38	13
	Usually	85	62	81	64.5	86	80	40	83	87	62	78
	Not applicable	0	9.5	2	7	3	0	10	9	0	0	3
	Don't know	0	5	2	0	0	0	10	0	4	0	1.5

Bold areas indicate a statistically significant difference in the pattern of responses (p<0.05)

Shaded areas indicate a highly statistically significant difference in the pattern of responses (p<0.01)

Table 11 Perceptions of communication and shared approaches between treatment services (cont'd)

Topic:	Level of shared approach	Location		Service type		Caseload			Profession			Total (%) n = 67
		Urban (%) n = 46	Rural (%) n = 21	Public (%) n = 53	Private (%) n = 14	High (%) n = 37	Medium (%) n = 20	Low (%) n = 10	Surg (%) n = 23	MO (%) n = 23	RO (%) n = 21	
Common protocols	Rarely or never	2	9.5	6	0	2.5	5	10	9	4	0	4.5
	Sometimes	13	19	13	21.5	11	15	30	4	17.5	24	15
	Usually	85	57	77	71.5	84	75	50	78	78.5	71	76
	Not applicable	0	9.5	2	7	2.5	0	10	9	0	0	3
	Don't know	0	5	2	0	0	5	0	0	0	5	1.5
Quality assurance	Rarely or never	4.25	14	6	14.5	2.7	10	20	4.3	9	9.5	7.3
	Sometimes	15	5	11	14.5	16	10	0	4.3	17.5	14.25	12
	Usually	76.25	52.5	72	57	76	65	50	78	65	62	69
	Not applicable	2.25	9.5	4	7	2.7	5	10	9	4.25	0	4.3
	Don't know	2.25	19	7	7	2.7	10	20	4.3	4.25	14.25	7.3
Shared facilities	Rarely or never	6.5	9.5	6	14.5	2.75	15	10	9	9	5	8
	Sometimes	4.5	24	11	7	2.75	15	30	0	4	28	10
	Usually	87	52	77	71.5	89	65	50	82	82.5	62	76
	Not applicable	0	9.5	2	7	2.75	0	10	9	0	0	3
	Don't know	2	5	4	0	2.75	5	0	0	4	5	3

Bold areas indicate a statistically significant difference in the pattern of responses ($p < 0.05$); Shaded areas indicate a highly statistically significant difference in the pattern of responses ($p < 0.01$)

Table 12 Perceptions of communication and shared approaches between surgery and supportive care services

Topic:	Level of communication	Location		Service type		Caseload			Profession		Total (%) n = 51
		Urban (%) n = 32	Rural (%) n = 19	Public (%) n = 40	Private (%) n = 11	High (%) n = 25	Medium (%) n = 18	Low (%) n = 8	Surg (%) n = 23	SC (%) n = 28	
Individual women's treatment results	Rarely or never	12	21	10	36	4	16.5	50	13	18	15.5
	Sometimes	16	16	16.5	9	12	28	0	9	21	15.5
	Usually	72	63	72.5	55	84	55.5	50	78	61	69
Individual women's treatment plans	Rarely or never	9	16	5	36	4	11	37.5	9	14	12
	Sometimes	16	31.5	22.5	18	8	39	25	13	29	21.5
	Usually	75	52.5	72.5	46	88	50	37.5	78	57	66.5
Individual women's supportive care needs	Rarely or never	9.5	32	15	27	0	28	50	13	21	17.5
	Sometimes	9.5	21	10	27	8	22	12.5	9	18	14
	Usually	81	47	75	46	92	50	37.5	78	61	68.5
Continuing medical education	Rarely or never	13	31.5	10	55	4	22	62.5	18	21	19.5
	Sometimes	9	16	10	18	4	22	12.5	4	18	12
	Usually	75	52.5	80	18	88	56	25	78	57	66.5
	Don't know	3	0	0	9	4	0	0	0	4	2

Bold areas indicate a statistically significant difference in the pattern of responses (p<0.05)

Shaded areas indicate a highly statistically significant difference in the pattern of responses (p<0.01)

Table 12 Perceptions of communication and shared approaches between surgery and supportive care services (cont'd)

Topic:	Level of shared approach	Location		Service type		Caseload			Profession		Total (%) n = 51
		Urban (%) n = 32	Rural (%) n = 19	Public (%) n = 40	Private (%) n = 11	High (%) n = 25	Medium (%) n = 18	Low (%) n = 8	Surg (%) n = 23	SC (%) n = 28	
Common protocols	Rarely or never	6	11	5	18	0	11	25	13	4	8
	Sometimes	13	21	10	36.5	4	22.25	37.5	8.5	21	15.5
	Usually	75	47	72.5	36.5	92	44.5	25	70	61	64.5
	Don't know	6	21	12.5	9	4	22.25	12.5	8.5	14	12
Quality assurance	Rarely or never	6.3	26	12.5	18	0	22	37.5	22	7	13.5
	Sometimes	6.3	11	2.5	27.5	0	11	25	4	11	8
	Usually	72	58	75	36.5	88	50	37.5	65	68	66.5
	Not applicable	6.3	0	2.5	9	8	0	0	9	0	4
	Don't know	9	5	7.5	9	4	17	0	0	14	8
Share facilities	Rarely or never	3	10.5	5	9	0	5.5	25	13	0	6
	Sometimes	6.5	10.5	5	18	4	5.5	25	0	14	8
	Usually	84.5	74	85	64	92	78	50	83	79	80
	Not applicable	3	0	0	9	0	5.5	0	0	3.5	2
	Don't know	3	5	5	0	4	5.5	0	4	3.5	4

Bold areas indicate a statistically significant difference in the pattern of responses (p<0.05)

Shaded areas indicate a highly statistically significant difference in the pattern of responses (p<0.01)

Table 13 Perceptions of communication and shared approaches between oncology and supportive care services

Topic:	Level of communication	Location		Service type		Caseload			Profession			Total (%) n = 72
		Urban (%) n = 50	Rural (%) n = 22	Public (%) n = 57	Private (%) n = 15	High (%) n = 38	Medium (%) n = 24	Low (%) n = 10	MO (%) n = 23	RO (%) n = 21	SC (%) n = 28	
Individual women's treatment results	Rarely or never	0	9	3.5	0	0	4	10	4.5	0	4	3
	Sometimes	14	14	10.5	27	13	12.5	20	4.5	14	21	14
	Usually	86	77	86	73	87	83.5	70	91	86	75	83
Individual women's treatment plans	Rarely or never	4	9	3.5	13	3	12	0	0	5	11	6
	Sometimes	12	14	10.5	20	10	17	10	17	5	14	12
	Usually	82	77	84	67	84	71	90	83	90	71	81
	Not applicable	2	0	2	0	3	0	0	0	0	4	1
Individual women's supportive care needs	Rarely or never	2	9	3.5	6.7	0	8	10	0	0	11	4
	Sometimes	18	14	14	26.7	18	17	10	13	19	18	17
	Usually	80	77	82.5	66.7	82	75	80	87	81	71	79
Continuing medical education	Rarely or never	10	18	11	20	8	21	10	13	9.5	14.5	12
	Sometimes	12	23	12	27	8	25	20	9	14	21.5	15
	Usually	72	54.5	75	33	76	50	70	78	67	57	67
	Don't know	6	4.5	2	20	8	4	0	0	9.5	7	6

Bold areas indicate a statistically significant difference in the pattern of responses (p<0.05)

Shaded areas indicate a highly statistically significant difference in the pattern of responses (p<0.01)

Table 13 Perceptions of communication and shared approaches between oncology and supportive care services (cont'd)

Topic:	Level of shared approach	Location		Service type		Caseload			Profession			Total (%) n = 72
		Urban (%) n = 50	Rural (%) n = 22	Public (%) n = 57	Private (%) n = 15	High (%) n = 38	Medium (%) n = 24	Low (%) n = 10	MO (%) n = 23	RO (%) n = 21	SC (%) n = 28	
Common protocols	Rarely or never	8	14	9	13	5	17	10	13	9	7	10
	Sometimes	8	4	5	13	8	8	0	13	5	4	7
	Usually	76	64	74	67	79	58	80	65	67	82	72
	Not applicable	2	4	3	0	3	4	0	4.5	5	0	3
	Don't know	6	14	9	7	5	13	10	4.5	14	7	8
Quality assurance	Rarely or never	8	18	11	13	5	17	20	17	9	7	11
	Sometimes	10	18	11	20	8	17	20	17	5	14	13
	Usually	70	50	68	47	79	42	60	57	67	68	64
	Not applicable	2	9	5	0	0	12	0	9	5	0	4
	Don't know	10	5	5	20	8	12	0	0	14	11	8
Share facilities	Rarely or never	8	4	5	13	5.3	12.5	0	4	4.8	10.5	7
	Sometimes	6	14	9	7	5.3	12.5	10	9	4.8	10.5	8
	Usually	78	82	84	60	84	67	90	83	81	75	79
	Not applicable	4	0	0	13	0	8	0	0	4.8	4	3
	Don't know	4	0	2	7	5.3	0	0	4	4.8	0	3

Bold areas indicate a statistically significant difference in the pattern of responses ($p < 0.05$); Shaded areas indicate a highly statistically significant difference in the pattern of responses ($p < 0.01$)

Table 14 Provision of multidisciplinary care

	Regularity	Location		Service type		Caseload			Profession				Total (%) n = 95
		Urban (%) n = 64	Rural (%) n = 31	Public (%) n = 75	Private (%) n = 20	High (%) n = 50	Medium (%) n = 31	Low (%) n = 14	Surg (%) n = 23	MO (%) n = 23	RO (%) n = 21	SC (%) n = 28	
Multidisciplinary meetings for treatment planning	Regular	81	41	72.5	53	86	61	17	77	77	52	67	68
	Occasional	5	28	9.5	21	4	10	50	0	0	24	22	12
	Not held	14	31	18	26	10	29	33	23	23	24	11	20

Bold areas indicate a statistically significant difference in the pattern of responses ($p < 0.05$)

Shaded areas indicate a highly statistically significant difference in the pattern of responses ($p < 0.01$)

Table 15 Structural/organisational components of care: education, quality assurance and audits

	Regularity	Location		Service type		Caseload			Profession				Total (%) n = 95
		Urban (%) n = 64	Rural (%) n = 31	Public (%) n = 75	Private (%) n = 20	High (%) n = 50	Medium (%) n = 31	Low (%) n = 14	Surg (%) n = 23	MO (%) n = 23	RO (%) n = 21	SC (%) n = 28	
Communication skills training held in the last 12 months	Regular	72	32	56	70	72	51	29	61	61	52	61	59
	Occasional	20	52	33	20	20	39	50	35	35	38	18	30.5
	Not held	8	16	11	10	8	10	21	4	4	10	21	10.5
Quality assurance programs for diagnostic services	Rarely or never	3	3	4	0	0	10	0	0	0	5	7	3
	Sometimes	9	9.5	10.5	5	10	6	14	22	0	0	14	10
	Usually	52	39	46.5	50	50	45	43	65	39	48	39	47
	Not applicable	14	9.5	12	15	14	10	14	4	22	14	11	13
	Don't know	22	39	27	20	26	29	29	9	39	33	29	27
Quality assurance programs for treatment services	Rarely or never	5	10	8	0	6	7	7	0	9	10	7	6
	Sometimes	17	19	17	20	16	19	21.5	13	22	33	7	18
	Usually	64	55	59	70	68	55	50	74	56	38	71	61
	Not applicable	5	0	3	5	4	3	0	0	4	5	4	3
	Don't know	9	16	13	5	6	16	21.5	13	9	14	11	12
Audit programs for diagnostic services	Rarely or never	3	10	7	0	2	9.5	7	0	4	0	14	5
	Sometimes	8	6	9	0	6	9.5	7	17.5	0	10	4	7
	Usually	42	35	39	45	44	36	36	65	30	33	32	40
	Not applicable	17	10	14.5	15	16	13	14	4.5	22	19	14	15
	Don't know	30	39	30.5	40	32	32	36	13	44	38	36	33

Table 15 Structural/organisational components of care: education, quality assurance and audits (cont'd)

	Regularity	Location		Service type		Caseload			Profession				Total (%) n = 95
		Urban (%) n = 64	Rural (%) n = 31	Public (%) n = 75	Private (%) n = 20	High (%) n = 50	Medium (%) n = 31	Low (%) n = 14	Surg (%) n = 23	MO (%) n = 23	RO (%) n = 21	SC (%) n = 28	
Audit programs for treatment services	Rarely or never	8	10	12	5	8	13	14	0	9	14	18	10
	Sometimes	17	6	20	20	18	19	29	9	39	33.5	3.5	20
	Usually	61	35	55	50	60	55	29	87	39	33.5	53.5	54
	Not applicable	5	10	2.5	10	4	3	7	0	4	5	7	4
	Don't know	9	39	10.5	15	10	10	21	4	9	14	18	12

Bold areas indicate a statistically significant difference in the pattern of responses (p<0.05)

Shaded areas indicate a highly statistically significant difference in the pattern of responses (p<0.01)

Table 16 Structural/organisational components of care: other services

	Regularity	Location		Service type		Caseload			Profession				Total (%) n = 95
		Urban (%) n = 64	Rural (%) n = 31	Public (%) n = 75	Private (%) n = 20	High (%) n = 50	Medium (%) n = 31	Low (%) n = 14	Surg (%) n = 23	MO (%) n = 23	RO (%) n = 21	SC (%) n = 28	
Involvement of consumers in planning/advisory structures for diagnostic services	Rarely or never	12.5	26	16	20	12	22.5	21.5	26	9	10	21	17
	Sometimes	17	10	13.5	20	18	13	7	26	13	14	7	15
	Usually	30	13	25.5	20	30	22.5	7	26	9	24	36	24
	Not applicable	12.5	6	12	5	12	10	7	4.5	17	14	7	10
	Don't know	28	45	33	35	28	32	57.5	17.5	52	38	29	34
Involvement of consumers in planning/advisory structures for treatment services	Rarely or never	16	39	20	35	22	16	43	35	22	14	21.5	23
	Sometimes	25	19	24	20	22	32.5	7	13	22	38	21.5	23
	Usually	34	23	33.5	20	34	32.5	14	35	26	14	43	31
	Not applicable	3	0	1	5	2	2	0	0	4	5	0	2
	Don't know	22	19	21.5	20	20	16	36	17	26	29	14	21
Special information programs re: diagnosis for women from NESB and indigenous backgrounds	Rarely or never	20	23	20	25	22	29	0	13	13	24	32	21
	Sometimes	17	9.5	13	20	10	26	7	30.5	9	19	3.5	15
	Usually	25	19	28	5	30	13	21.5	30.5	17	5	35.5	23
	Not applicable	13	9.5	12	10	12	9.5	14.5	4	17	14	11	12
	Don't know	25	39	27	40	26	22.5	57	22	44	38	18	29

Table 16 Structural/organisational components of care: other services (cont'd)

	Regularity	Location		Service type		Caseload			Profession				Total (%) n = 95
		Urban (%) n = 64	Rural (%) n = 31	Public (%) n = 75	Private (%) n = 20	High (%) n = 50	Medium (%) n = 31	Low (%) n = 14	Surg (%) n = 23	MO (%) n = 23	RO (%) n = 21	SC (%) n = 28	
Special information programs re: treatment for women from NESB and indigenous backgrounds	Rarely or never	27	29	27	30	26	36	14	17.5	30.5	29	32	27
	Sometimes	23	19	16	45	22	19	29	30.5	13	33	14	22
	Usually	36	29	41	5	38	32	21	26	39	24	43	34
	Not applicable	5	0	3	5	4	3	0	0	4.5	5	4	3
	Don't know	9	23	13	15	10	10	36	26	13	9	7	14

Table 17 Perceptions of respondents about ways in which other services work with palliative care

Services	Quote	Profession: hospital
SC and palliative care	<i>I refer clients to palliative care and we liaise during that period with each other</i>	SC: private, rural, low caseload
Oncology and palliative care	<i>While in hospital these work together well but once the patient is discharged into the community it is often not as well supported</i>	RO: private, urban, high
	<i>The palliative care clinician often sits in my clinic and we see the patient together and she is able to come to the video conference every two weeks</i>	MO: private, rural low
	<i>Palliative care could be improved: patients are not always sick enough to require admission. It is sometimes difficult to place them in a place for the management of symptoms</i>	RO: private, urban, high
	<i>More stress and strain could be alleviated if these services were able to work more closely together. There are patients that will suffer more stress and strain as a result especially women without a partner or children to care for her.</i>	RO: public, rural, low
	<i>It's hard to get patients seen quickly by palliative care. Urgent referrals are getting harder to organise.</i>	RO: public, rural, medium
	<i>We need more palliative care specialists. The service is a bit thin on the ground at the moment.</i>	RO: public, rural, medium
Surgery and palliative care	<i>A pain management specialist who is very good for palliative care in the area is very readily approachable. Everything works well together in the region.</i>	SU: private, rural, low
	<i>Correspondence between all the specialist services and myself is very good and further down the track we have an extremely supportive and communicative palliative care service</i>	

DISCUSSION

The NSIF for cancer aims to identify opportunities for improving cancer control in Australia by comparing optimal services with current service provision. The outcomes from this survey provide an insight into the coordination of care for women with breast cancer in different regions of Australia whose treatment is managed within different service delivery models. It is important to remember that the results reported are the perceptions of individual healthcare professionals and as such may be subject to bias.

An attempt was made to recruit healthcare professionals from urban and rural locations, from both the public and private sector and from hospitals with high, medium and low caseloads of breast cancer. Not every hospital approached provided the full complement of professions whose input was required (surgery, medical oncology, radiation oncology, supportive care). This was particularly the case for low-caseload hospitals, where women are often referred to other centres within the state for treatment. In these situations, healthcare professionals from other centres or regions with links to the hospital were approached. However, in some situations, no appropriate link was identified or the individual had already been surveyed in association with another hospital.

Despite the limited sample size, a number of differences are apparent in the pattern of responses given by healthcare professionals from different regions, service types, caseloads and professions; some of these differences reached statistical significance. A large number of tests were performed, and it is important to recognise that one in every 20 tests could return a significant result at the 0.05 level purely by chance. There were, however, more significant results than could have occurred by chance alone. Due to the sample size, it was not possible to analyse the results from each subgroup on a State/Territory basis. In many cases, the results confirm what is already known – that there are significant differences in the coordination of care for women with breast cancer between urban and rural settings and between institutions treating different breast cancer caseloads.

Find cancer early

Screening

Early detection is the best method for reducing mortality from breast cancer. There is evidence and widespread agreement that implementation of population screening with mammography can substantially reduce deaths from breast cancer.^{9,10} The NSIF for cancer states that all people in

Australia should have enough information to decide whether to participate in population screening programs. This survey indicates awareness among around 70% of healthcare professionals from urban areas, public hospitals and those with high breast cancer caseloads of programs to inform women in the region about mammographic screening services. Awareness was lower for those from rural, private and medium–low-caseload hospitals. The BreastScreen Australia program is a fully implemented national screening program that aims to ensure equity of access for all women in Australia. It is therefore unlikely that BreastScreen Australia does not service the regions covered by the institutions surveyed. However, availability does not necessarily equate with awareness or uptake and it is important that processes are in place to inform women of the existence and benefits of screening programs. One of the factors with the greatest impact on women’s attendance for mammographic screening is encouragement by a healthcare professional. The fact that healthcare professionals from rural areas, private hospitals and hospitals treating low numbers of women with breast cancer were unaware of programs to promote awareness highlights a possible need for more active campaigns targeting these groups. These results should be considered together with results from a recently completed National Breast Cancer Survey of perceptions of women in Australia about breast health, including awareness of screening programs. A report from this Breast Health Survey is in development.

Awareness of programs to inform GPs and community health workers about screening services was around 35%, with almost half of all respondents unaware of whether such programs were in place. This is not necessarily surprising given it is likely to be the GPs and community health workers to whom these programs are targeted who would be most aware of their existence. However, the need for GP education and improved communication between general practice and specialist breast cancer services was highlighted as an issue that needs to be addressed by several healthcare professionals surveyed. In developing such educational strategies, consideration should be given to raising awareness of screening services.

Diagnosis

The NSIF for cancer highlights the importance of high-quality diagnostic services and appropriate referral. Specialist diagnostic breast cancer clinics provide a venue for assessment and diagnosis of women with breast cancer. Responses from the 23 surgeons surveyed confirm that urban areas and centres with high caseloads are more likely to have a diagnostic or assessment clinic than rural and medium–low-caseload centres. This is to be expected, with clinics being a cost-effective option in areas where high numbers of women with breast cancer are seen and a wide range of services and facilities are available. While a dedicated diagnostic breast clinic may not be a feasible option in

areas where only a small number of women are diagnosed with breast cancer and resources are limited, it is important that the diagnosis and referral systems in these areas are of an equivalent standard, through links to larger specialist centres.

As over half of the women with breast cancer in Australia are diagnosed outside the screening setting, it is important that information about symptomatic assessment services is widely available. Overall awareness of programs to inform women about symptomatic assessment services was lower than for screening services (46%). Again, healthcare professionals from urban areas, public hospitals and those with high caseloads were most aware of these programs. Awareness of programs to inform GPs and community health workers about symptomatic assessment services was similar to that for screening services (39% and 35%, respectively).

Referral

The NSIF for cancer states that referral pathways for diagnosis and treatment should be clearly defined. A large majority of the healthcare professionals surveyed indicated that it was very unlikely that problems in referral would occur between screening, diagnosis, treatment and supportive care. Despite this, over 60% indicated that they had experienced some delay in referral in the past six months. Improved communication and use of referral protocols, as well as programs to educate GPs, other healthcare professionals and women, were some of the suggestions made to improve the referral process. The need for adequate communication and defined referral pathways is a strong theme that emerges throughout the results of this survey.

Treatment and supportive care

The NSIF for cancer emphasises the importance of a seamless and continuous journey through the care continuum for cancer patients. An integral part of ensuring such continuity of care is appropriate liaison between and integration of screening, diagnostic and treatment services. Half of the healthcare professionals surveyed indicated that all services within their region work well together, with communication, multidisciplinary meetings and direct referral systems viewed as important components of this process. Strategies to improve this process in areas where communication is weak and referral systems are absent need to be considered so that a collaborative approach is the norm, regardless of location or caseload.

Communication between services about women's results, treatment plans and supportive care needs is essential in ensuring continuity of care. The healthcare professionals surveyed indicated a

generally high level of communication about results and treatment plans between treatment services and supportive care. However significant differences based on caseload, location and in some cases, service type were apparent. In particular, issues in communication between surgery and oncology services tended to be dependent on location, while issues between surgery and supportive care tended to be dependent on caseload. These results are not necessarily surprising given the fact that rural locations are less likely to have all key professions at one location, while involvement of a specialist breast nurse in the breast care team is more likely in high caseload hospitals. These findings emphasise further the need for established protocols, referral pathways and methods of communication to be encouraged and adequately resourced in rural and low-caseload centres and in the private sector.

Multidisciplinary care

The importance of access by cancer patients to all relevant expertise and facilities, together with the knowledge that care providers are working as part of a team is highlighted in the NSIF for cancer. A number of other national policy documents, including *Priorities for Action in Cancer Control*⁵ and *Optimising Cancer Care in Australia*,⁶ emphasise the need for a multidisciplinary approach to cancer care. There are different degrees of multidisciplinary care. One approach involves case conference meetings for the purposes of treatment planning. The benefits of multidisciplinary care meetings in ensuring communication and appropriate referral for patients are illustrated by some of the open-ended responses given by the healthcare professionals surveyed. Around half of the healthcare professionals surveyed cited strategies such as multidisciplinary meetings as the reason for good communication and smooth referral processes within a hospital or region.

This survey has highlighted significant differences in the degree to which multidisciplinary meetings are held, with respondents from rural hospitals and those with low caseloads far less likely to hold or participate in multidisciplinary meetings. A survey of the same 60 hospitals approached to take part in the current survey in 2000 indicated that the proportion of hospitals holding regular multidisciplinary care meetings in which some or all new cases of breast cancer were considered was 75% for high-caseload hospitals, 55% for medium-caseload hospitals and 5% for low-caseload hospitals.¹¹ As only 31 hospitals are represented in the current survey, results cannot be compared directly and it is therefore not possible to tell whether the higher results (high 86%; medium 61%; low 17%) reflect an actual increase since 2000 or are the result of a sample bias.

The National Breast Cancer Centre has recently completed a three-year national demonstration project examining the outcomes, barriers, enablers and costs of implementing strategies to improve multidisciplinary care for breast cancer in Australia. The report on this project *Multidisciplinary Care*

*in Australia: a National Demonstration Project in Breast Cancer*¹² highlights the need for adequate resourcing of multidisciplinary care meetings across a range of cancers and chronic diseases to support the implementation of multidisciplinary care strategies. Results from the current survey indicate that priority should be given to fostering links to larger specialist groups by rural and low-caseload centres.

It is interesting that radiation oncologists were less likely to report the occurrence of multidisciplinary care meetings compared with the other professions surveyed. This suggests that the meetings described by other healthcare professionals may not involve all key professions involved in the care of women with breast cancer. The National Breast Cancer Centre has previously highlighted the fact that current funding models do not encourage participation by healthcare professionals in multidisciplinary care meetings and has recommended a modification of hospital funding models and specialist and general practitioner payment schedules to support attendance by all key team members at multidisciplinary meetings.¹²

Communication with women

Inherent to a patient-centred model of care is the need for every woman to understand who is managing her care and what will happen to her during her cancer journey. This relies on the ability of the healthcare professionals who manage her care to be able to provide information and feedback in an appropriate manner. Communication skills training programs are available for healthcare professionals from a number of providers, including the National Breast Cancer Centre. However, results from this survey indicate that awareness of these programs is currently limited to urban areas and centres with high breast cancer caseloads. Results from this survey indicate that a more widespread approach needs to be taken to communication skills training, in particular for those healthcare professionals practicing in low-caseload or rural areas. Targeting cancer issues in general rather than breast cancer alone, could improve affordability and uptake of such training.

Structural and organisational issues

The NSIF for cancer states that patients should be confident that they are being treated according to the best available evidence. The availability of ongoing educational activities for healthcare professionals, together with established quality assurance and audit processes, is important in assuring awareness of and compliance with clinical practice guidelines and other evidence-based recommendations.

This survey indicates that some quality assurance programs and audits of practice are in place. Understandably, given the sample, awareness was higher for programs and audits relating to treatment services than for diagnostic services, and surgeons were generally more aware of these than the other professions surveyed. However, over 25% of respondents were unaware of whether quality assurance or audit programs were in place for diagnostic services and 12% were unaware of whether quality assurance or audit programs were in place for treatment services. While this is less surprising for diagnostic services, given the sample, the lack of awareness of programs for treatment services highlights opportunities for encouraging greater uptake of quality improvement processes, including participation in clinical audits.

The NSIF for cancer states that information about diagnosis and treatment should be appropriate for patients' educational status and cultural background. However, fewer than 35% of healthcare professionals surveyed indicated awareness of special information or programs about treatment and diagnostic services for women from non-english speaking and indigenous backgrounds. Further research is needed to examine the availability of information and programs in regions populated with a high proportion of women from non-english speaking and indigenous backgrounds. At minimum, access to interpreter services for major ethnic populations should be available. The marked difference in responses between the public and private sectors could be a result of differences in the demographics of patients treated within the two sectors. Regardless, awareness of how to access such programs should be common to all health care services.

Care at the end of life

While no specific questions were asked about end of life care, comments made by healthcare professionals during the survey indicate mixed perceptions of the relationship between treatment services and palliative care. Issues apparent from the quotes support the need for better communication and referral pathways, together with improved resourcing within the palliative care arena. The relationship between treatment services and palliative care is an area that should be examined further in future studies.

Conclusions

The results of the *National Survey of Coordinated Care for Women with Breast Cancer* provide a snapshot of the perceptions of a cross section of healthcare professionals involved in the management of women with breast cancer in Australia about factors influencing the care pathway for these women.

Despite limited numbers, differences have been demonstrated in perspectives of healthcare professionals from a range of locations, service types, caseloads and professions.

The need to provide appropriate cancer care to all Australians regardless of location, service type and access to a centre of expertise has been acknowledged in the NSIF for cancer. The results of this survey highlight current differences between urban and rural centres and between high-caseload centres and those treating few patients with breast cancer. Some differences between the public and private sector are also apparent. These differences are unlikely to be limited to breast cancer and are likely to carry broader application to cancer care in general.

The issues identified here provide further support for the need to improve communication and referral pathways between diagnostic, treatment and supportive care services within rural areas and regions outside the catchment area serviced by the larger breast clinics. The National Breast Cancer Centre has previously made recommendations regarding resourcing to support the widespread implementation of multidisciplinary care strategies for cancer care.¹¹ In addition, the need for strategies to involve healthcare professionals in encouraging awareness of screening, symptomatic assessment and treatment services in rural areas is apparent, as is the importance of ensuring that healthcare professionals are aware of how to access services for women from non-english speaking and indigenous backgrounds.

The NSIF for cancer marks an important step in ensuring equity of service provision and care for cancer patients in Australia. This survey highlights current gaps in service provision that could help to inform the identification of critical intervention points to improve cancer care in Australia.

Key issues

Issues highlighted by this survey that warrant further attention include the need for:

1. better methods for promoting awareness of screening, symptomatic assessment and treatment services in rural areas, in the private sector and in hospitals that treat low numbers of women with breast cancer
2. development and implementation of protocols, referral pathways and communication strategies to facilitate appropriate and timely referral of women with breast cancer, particularly in rural areas, the private sector and in locations where the number of women diagnosed with breast cancer is low
3. provision of infrastructure and administrative assistance to establish links to specialist centres from rural centres and low-caseload facilities

4. strategies to encourage national uptake of communication skills training, in particular in rural areas or locations where the number of women diagnosed with breast cancer is low; a focus on 'cancer issues' rather than breast cancer alone will improve the cost-effectiveness of training
5. quality improvement strategies, with broad application to cancer care in general, to support health service providers in reviewing and undertaking quality assurance and audit programs for all services
6. better methods for promoting awareness of services for women from indigenous and non-English speaking backgrounds, such as the availability of interpreter services.

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APPENDICES

APPENDIX I: INFORMATION FOR HEALTHCARE PROFESSIONALS

National Survey of Coordinated Care in Breast Cancer

Health professional information form

The <<name of hospital>> wishes to invite you to participate in the *National survey of coordinated care in breast cancer* that is being conducted by the National Breast Cancer Centre. This survey will investigate how breast cancer care is integrated within specific localities of Australia and identify opportunities for improving care. You have been selected to participate in this survey because you are involved in managing women with breast cancer treated at this hospital.

Background

There are over 10,000 new cases of breast cancer each year in Australia. Survival from breast cancer can be improved through high quality screening, diagnosis and treatment and the well being of women increased by appropriate supportive care. Over the past decade, much has been achieved in ensuring that women receive best care in the diagnosis and treatment of breast cancer. There is a national mammographic screening program in place and considerable progress has been made in establishing an evidence based approach to the diagnosis, management and supportive care of women with breast cancer.

However, relatively little is known about service delivery across Australia in relation to continuity of care and integration between different service components. For instance to what extent is/are there:

- Organised pathways to link screening, diagnosis, treatment and support in providing integrated care that meets the needs of individual women
- Communication between groups and services
- Provision of care in accordance with the following principles: seamless transition between services; evidence based care including local protocols; audit, review and

quality improvement; multidisciplinary care; appropriate and acceptable to women, equitable and efficient

- Public accountability
- Quality improvement
- Monitoring of process and outcome
- Promotion of the Breast Cancer Service to ensure women and health care providers know of the service and how to gain access to it

The *National Survey of Coordinated Care in Breast Cancer* is designed to provide information about the extent to which breast cancer services are perceived as being coordinated currently; it will also identify opportunities and potential strategies for improving coordinated care.

The survey

The aim of the survey is to

1. Explore the views of key informants about the organisation of breast cancer services in their region by identifying:
 - Perceived strengths of the current organisation of services
 - Perceived opportunities for improvement of current organisation of services
 - Case studies of care pathways which could be improved
2. Explore the views of key informants about:
 - The extent to which there are defined referral pathways and flows of information
 - The extent to which there is interaction within and between components of care/different services for a) multidisciplinary treatment decisions, b) continuing medical education, c) agreement about protocols
 - Whether there are local protocols or strategies to implement evidence based guidelines
 - Whether there are audit programs in place
 - Whether relevant information for consumers is routinely offered

- The extent to which consumers are involved in the advisory and planning structures
- The extent to which strategies are in place to provide care that meets the needs of women from non-English speaking and indigenous backgrounds or living in rural and remote areas
- Whether publicly available reports about breast cancer services are readily to hand and used

Your involvement

- You have been selected as a survey participant because you are involved in managing women with breast cancer treated at this hospital.
- Your involvement entails participation in a telephone survey conducted by an external interview company experienced in conducting telephone surveys.
- Interviews will entail about 20–30 minutes of your time.

Procedure

- If you agree to participate in this survey, we ask that you sign the attached consent form and return it the liaison person (see attached) at the hospital.
- The names of consenting participants (and signed consent forms) will be forwarded to the National Breast Cancer Centre. The National Breast Cancer Centre will then forward names of participants to the interview company.
- The interview company will contact you directly to arrange a suitable time for an interview.
- The interviews will be conducted at the arranged time with responses being entered directly into the database of the interview company.
- The interview company will return to the National Breast Cancer Centre only de-identified databases and frequency distributions.
- A report will be submitted to the Department of Health and Ageing.

Security and privacy

The conduct of the *National Survey of Coordinated Care in Breast Cancer* has ethics approval from the NSW Cancer Council and conforms to the Council's privacy and confidentiality guidelines. In brief, the following steps will be taken to ensure protection of the individuals and the data arising from the survey:

- Interviews will be confidential and the names of the health professionals will not be linked to survey responses entered into the database of the interview company. All databases and responses will be de-identified.
- The National Breast Cancer Centre will know the names of consenting participants but will not have access to information that will enable linkage of survey participants with survey responses.
- The health professionals will not be identified in documents, presentations or publications arising from the survey either by name or by institution.

Interview participant consent form (B.1)

I hereby agree to participate in the ‘*National Survey of Coordinated Care in Breast Cancer*’ as an interview participant

I understand that:

- Interviews will be organised and conducted by an independent interviewer.
- Interviews will be confidential and my name will not be linked to survey responses entered into the database of the interview company. All databases and responses will be de-identified.
- The National Breast Cancer Centre will know that I have consented to be interviewed but will not have access to information that will enable linkage of my responses with my name.
- I will not be identified in documents, presentations or publications arising from the survey either by name or institution.

Signed _____ Date _____

Contact details

Title _____

Name _____

Department _____

Telephone () _____

Facsimile () _____

Mailing address _____

Email _____

Please return signed consent form to:

APPENDIX II: SURVEY INSTRUMENT

Good morning/afternoon/evening. I'm calling for the **National Survey of Coordinated Care in Breast Cancer**. Could I speak to.....

WHEN RESPONDENT IS ON PHONE:

Good morning/afternoon/evening. I'm calling for the National Survey of Coordinated Care in Breast Cancer to conduct your interview. The interview should take about 15 to 20 minutes. Is now a good time to speak?

We're interested in finding how breast cancer services operate in YOUR REGION

by REGION we mean the catchment of "hospital"

and particularly the ways in which they work together. We hope to use this information to improve care and referral pathways. By referral pathways we mean the ways in which women move from one component of care to the next, e.g. the ways in which women diagnosed with breast cancer in the mammographic screening program are referred to treatment services.

In answering these questions, we would like you to think about all breast cancer services in YOUR REGION, including: community information, screening, diagnosis, treatment (incl. surgery, radiotherapy, systemic adjuvant therapy), supportive care, community services and palliative care. We would like you to include private and public sector services, whether they are provided locally or require travel.

Questions 1 and 2 are to be **asked of all respondents**

PART I REFERRAL PATHWAYS

Thinking back over the past twelve months, in YOUR REGION have there been any of the following programs:

[1. YES 2. NO 8. DON'T KNOW]

Q1a. Programs to inform general practitioners about breast cancer in terms of:

- Screening
- Assessment of breast symptoms
- Treatment

Q1b. Programs to inform other community health workers (eg indigenous health workers, community nurses) about breast cancer in terms of:

- Screening
- Assessment of breast symptoms
- Treatment

Q1c. Programs to inform women about how to access services in relation to breast cancer: {the following services?}

- Screening
- Assessment of breast symptoms
- Treatment

Q2. Thinking back over the past twelve months, in YOUR REGION has there been any communication skills training for clinicians?

[1. YES 2. NO 8. DON'T KNOW]

(The following questions are to be asked of **surgeons only**) {which/how many?}

Q3. Is there a breast assessment or diagnostic clinic in YOUR REGION for women with symptoms?

[1. YES 2. NO 8. DON'T KNOW]

(Questions 2{3}a, 3b, 3c, are to be asked only if the answer to Question 3 is 'Yes')

Q3a. How would a woman with a breast symptom find out about the breast assessment clinic? [ENTER 1 IN ALL THAT APPLY]

- GP
- Advertised locally
- [TYPE IN OTHER - 88. DON'T KNOW]

Q3b. How many women who find a breast symptom, do you think would easily find out about the clinic? [READ SCALE AS PRESENTED]

- Most
- Some
- Few
- None
- 8. DON'T KNOW [DO NOT READ]

Q3c. Of all women with symptoms, what proportion would be assessed at the clinic? [READ SCALE AS PRESENTED]

- less than 20%
- 20–40%
- 40–60%
- 60–80%
- 80–100%
- 8. DON'T KNOW [DO NOT READ]

(The following question is to be **asked of surgeons only**)

Q4. Thinking back over the last 20 women you have seen with breast cancer, how many of them had unnecessary delays in diagnosis?

- Women with unnecessary delays range 1–20
- None
- Don't know/don't remember

Q4y. What has caused these delays?

How might delays have been avoided?

Thinking back over the past six months:

Q6b. Were women with breast cancer referred to you at "hospital" referred as quickly as possible? [READ SCALE AS PRESENTED]

- Always
- Most of the time
- Some of the time
- Rarely {or never?}
- Don't know [DO NOT READ]

Q6a. Thinking back over the LAST 6 MONTHS, were there any women for whom the process of referral to you had NOT been straightforward?

[READ SCALE AS PRESENTED]

- Most (more than 60%)
- Many (40%-60%)
- Some (10%-30%)
- A few (less than 10%)
- None
- DON'T KNOW [DO NOT READ]

Q6cb. How could the process of referrals be improved?

[TYPE IN RESPONSE - 88. DON'T KNOW]

(The following question is to be asked of **All respondents**)

Q7. For women treated at "hospital", how likely is it that problems will occur in referral between ...

Screening and treatment

Would you say that problems are ... [READ SCALE AS PRESENTED]

- Very unlikely
- Quite unlikely
- Quite likely
- Very likely
- DON'T KNOW [DO NOT READ]

Diagnosis and treatment

Would you say that problems are ... [READ SCALE IF NECESSARY]

Treatment and supportive care

Would you say that problems are ... [READ SCALE IF NECESSARY]

- Q8a. How could these problems with referral between SCREENING AND TREATMENT best be addressed?**
- Q8b. How could these problems with referral between DIAGNOSIS AND TREATMENT best be addressed?**
- Q8c. How could these problems with referral between TREATMENT AND SUPPORTIVE CARE best be addressed?**

PART 2: COMMUNICATION AND LINKAGES BETWEEN COMPONENTS

Now we would like to ask you some questions about the ways in which different services for women with breast cancer communicate and work together. By 'services' we mean: diagnostic, screening, treatment and supportive care services. Again, we'd like you to think about all the breast cancer services for women in YOUR REGION, in the public and private sectors, whether they are provided locally or require travel.

Would you like me to repeat the introductory remarks I read before?

- Q9. To what extent would you say that services for breast cancer in your region communicate and work together?**

[READ SCALE AS PRESENTED]

- All services communicate and work closely together
- Some services communicate and work closely together
- Few services communicate or work closely together
- No services communicate or work closely
- DON'T KNOW [DO NOT READ]

- 10. Which of the breast cancer services work closely together?**

Q10y. Can you provide examples of ways in which THESE services work together particularly well in your region?

[INTERVIEWER TO EXPLORE WHAT HAPPENS AND HOW IT IS ACHIEVED]

11. Which breast cancer services should work more closely together?

Q11y. Can you give provide any examples of the problems that arise from THESE services not working together?

Q12. In YOUR REGION to what extent do you feel that DIAGNOSTIC AND SCREENING SERVICES currently:

- Usually
 - Sometimes
 - Rarely or never
- A Communicate about individual women's results
- B Communicate about individual women's treatment plans
- C Communicate about individual women's supportive care needs
- D Take part in continuing medical education together
- E Have agreed common protocols
- F Have shared approaches to quality assurance
- G Share facilities when appropriate

Q13. To what extent do you feel that SCREENING AND SURGERY SERVICES at "hospital" currently:

- A Communicate about individual women's results
- B Communicate about individual women's treatment plans
- C Communicate about individual women's supportive care needs
- D Take part in continuing medical education together

- E Have agreed common protocols
- F Have shared approaches to quality assurance
- G Share facilities when appropriate

Q14. To what extent do you feel that DIAGNOSTIC AND SURGERY SERVICES at "hospital" currently:

- A Communicate about individual women's results
- B Communicate about individual women's treatment plans
- C Communicate about individual women's supportive care needs
- D Take part in continuing medical education together
- E Have agreed common protocols
- F Have shared approaches to quality assurance
- G Share facilities when appropriate

Q15. To what extent do you feel that the different COMPONENTS OF TREATMENT, that is, surgery, medical oncology and radiation oncology at "hospital":

- A Communicate about individual women's results
- B Communicate about individual women's treatment plans
- C Communicate about individual women's supportive care needs
- D Take part in continuing medical education together
- E Have agreed common protocols
- F Have shared approaches to quality assurance
- G Share facilities when appropriate

Q16. To what extent do you feel that SURGERY AND SUPPORTIVE CARE SERVICES at "hospital":

- A Communicate about individual women's results
- B Communicate about individual women's treatment plans

- C Communicate about individual women's supportive care needs
- D Take part in continuing medical education together
- E Have agreed common protocols
- F Have shared approaches to quality assurance
- G Share facilities when appropriate

Q17. To what extent do you feel that ONCOLOGY AND SUPPORTIVE CARE SERVICES at "hospital": ... [READ ITEM THEN SCALE]

- A Communicate about individual women's results
- B Communicate about individual women's treatment plans
- C Communicate about individual women's supportive care needs
- D Take part in continuing medical education together
- E Have agreed common protocols
- F Have shared approaches to quality assurance
- G Share facilities when appropriate

Q18. Which statement best describes the approach used at "hospital" for communication between clinicians to develop a treatment plan?

- 1 Regular multidisciplinary meetings are held for treatment planning
- 2 Occasional/irregular multidisciplinary meetings are held depending on caseload or need
- 3 There are no multidisciplinary meetings for the purpose of treatment planning; clinicians communicate on an individual basis as required
- 4 There are no multidisciplinary meetings for the purpose of treatment planning and there is little or no discussion between clinicians

(All of the questions in Part 3 are to be asked of **all respondents**)

PART 3: CARE WITHIN SERVICES

In this last part of the interview, we would like to ask you about the way some separate components of care are organised.

Q19. Thinking about all of the DIAGNOSTIC SERVICES in your region, have the following been established:

- Rarely or never
 - Sometimes
 - Usually
 - NOT APPLICABLE
 - DON'T KNOW [DO NOT READ]
- A Quality assurance program
- B Involvement of consumers in planning and advisory structures
- C Audit of practice
- D Special information or programs to care for women from non-English speaking and indigenous backgrounds

Q20. Thinking about all of the TREATMENT SERVICES in your region, have the following been established:

[READ SCALE AFTER FIRST ITEM]

- Rarely or never
 - Sometimes
 - Usually
 - NOT APPLICABLE
 - DON'T KNOW [DO NOT READ]
- A Quality assurance program

- B Involvement of consumers in planning and advisory structures
- C Audit of practice
- D Special information or programs to care for women from non-English speaking and indigenous backgrounds