

## MODELS OF CANCER CARE AND SUPPORT IN NSW

### GUEST EDITORIAL

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There is growing evidence that those affected by cancer carry a psychosocial as well as a physical burden. This issue of the *NSW Public Health Bulletin* highlights the importance of the different models of supportive care offered to people affected by cancer.

Cancer care in NSW is provided through a model of delivery described in the report *Optimising Cancer Management—A Cancer Care Model for NSW*. This model was developed by the Cancer Care Model Working Party, which consisted of representatives from clinical specialty groups, consumers, The Cancer Council NSW, rural area health services, and the NSW Department of Health. The model is an organisational framework to meet the common needs of all patients with cancer and their families—carers across NSW. It supports the application of best practice from a clinical management perspective as well as providing supportive care services for patients throughout the continuum of their experience of cancer. The model represents a reorientation of the existing organisational arrangements for cancer, and it is anticipated that this reorientation will facilitate the development of strategies for the implementation of the model at the area health service level.

However, it remains a challenge to identify ways in which individual area health services can effectively implement the recommendations of the model. Tynan et al. briefly describe two initiatives underway in the South Western Sydney Area Health Service.

The importance of an evidence base to support the recommendations of the model cannot be overemphasised. This includes evidence of:

- a substantial burden of illness of cancer;
- efficient strategies for identifying those who are most in need of assistance from the health care system;
- the implementation of effective interventions.

The article by Girgis et al. describes how an initiative of The Cancer Council NSW allows for the routine assessment of the levels of psychosocial and physical effects of cancer experienced by individual patients, and provides efficient feedback of this information to their treatment team. This facilitates assistance in

*continued on page 266*

## CONTENTS

- 265 **Guest editorial: Models of cancer care and support in NSW**
- 266 **Area Cancer Control Network: From cottage industry to strategic care**
- 269 **Cancer patients' supportive care needs: Strategies for assessment and intervention**
- 272 **The importance of communication skills to effective cancer care and support**
- 274 **Psychosocial guidelines in cancer care and support**
- 277 **Multidisciplinary care for women with breast cancer: A national demonstration program**
- 280 **A successful volunteer program showcased during the International Year of Volunteering: The Cancer Council NSW's Breast Cancer Support Service**
- 
- 282 **EpiReview: Legionnaires' disease, NSW, 1991–2000**
- 
- 285 **Communicable Diseases: October 2001**
-

response to areas of identified need. Importantly, proposed interventions are tailored to the capacities of the individual treatment centres. This increases the likelihood of the adoption of the overall strategy for care without requiring substantial additional resources.

The articles by Butow and Turner describe the evidence base for interventions to improve the psychosocial outcomes for patients, including an emphasis on the importance of effective communication and on the provision of support as outlined in the National Health and Medical Research Council's recently released *Psychosocial Clinical Practice Guidelines*.

Finally, two specific models of cancer care are described in the articles by Luxford et al. and Burton et al. The first is a demonstration project of the effect, cost, and acceptability of multidisciplinary cancer care in Australia. In this, the Year of the Volunteer, the following paper by Burton et al. emphasises the

important and growing role of volunteers in providing a support service for women with breast cancer in NSW, as part of The Cancer Council NSW's Breast Cancer Support Service.

While there is now a growing acceptance that supportive care is as important as clinical treatment in the overall management of cancer, the challenge will be to ensure that the provision of evidence based supportive care remains on the agenda of both health professionals and decision makers. ■■

A copy of *Optimising Cancer Management—A Cancer Care Model for NSW*, and other reports in this cancer care series, can be downloaded from the NSW Department of Health's Web site at [www.health.nsw.gov.au](http://www.health.nsw.gov.au).

## AREA CANCER CONTROL NETWORK: FROM COTTAGE INDUSTRY TO STRATEGIC CARE

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The South Western Sydney Area Health Service (SWSAHS) serves a population of three quarters of a million people. This population experiences comparatively high levels of social disadvantage, is drawn from a diverse multicultural background, and is geographically dispersed through urban, semi-rural, and rural localities. The SWSAHS is committed to cancer prevention and to improving treatment outcomes and service satisfaction for patients with cancer. This article describes two of the many initiatives underway for the local implementation of the Area Cancer Control Network, an approach to cancer services based on the recommendations from the *Optimising Cancer Management Initiative—Final Report to the Expert Advisory Group*.<sup>1</sup>

### OVERVIEW

There is a considered view, and some evidence, that improving the delivery of cancer services will subsequently improve both the clinical outcomes for patients and organisational efficiency.<sup>2,3,4</sup> The perception that health services are complex systems arises in part from the difficulty in obtaining a basic prerequisite for good management: namely, good information. Nowhere is this more obvious than in the current

management of cancer services. The challenge to implementing *Optimising Cancer Management—A Cancer Care Model for NSW*,<sup>5</sup> or the Area Cancer Control Network as it is locally known, is the paucity of robust organisational and clinical information to support planning and management within the SWSAHS, or to enable outcomes and efficiencies between area health services to be compared.<sup>6,7</sup>

The priority of the Area Cancer Control Network strategy has been to develop two implementation frameworks. The first is for an Area Clinical Cancer Information System (ACCIS) to capture both clinical and organisational data (Figure 1). The second is a comprehensive planning framework to guide the required structural and management changes. Cancer services will be organised around the nine common cancer tumour sites—such as breast, colo-rectal, and lung—using the planning framework.

### INFORMATION SYSTEM FRAMEWORK

The first step in developing the ACCIS is to establish an area clinical cancer registry. Cancer services are poorly informed of outcomes linked to particular types of treatment, such as treatment-specific survival rates and the long-term effect of treatments that for many survivors of cancer may include serious physical and psychosocial morbidity.<sup>8,9</sup> The benefits of area-based clinical cancer registries are evident in the work of the Ontario and British

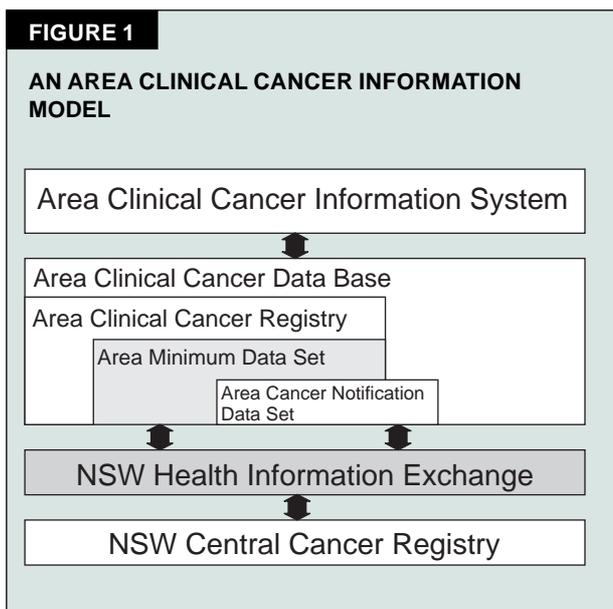
Columbian Registries where it has been possible to demonstrate the organisational effects of cancer service delivery on patient outcomes.<sup>10</sup>

In NSW, the central registry system does not collect clinically relevant staging information, descriptions of local treatment regimens, or outcome data. The lack of this information is a significant impediment to improving the safety and quality of cancer services. Implementing an area-based clinical cancer registry was identified as integral to the success of Area Cancer Control Networks.<sup>11,12,13</sup> The particular advantage of area-based clinical cancer registries will be the capture of clinical data describing radiotherapy and chemotherapy treatments, which are most often delivered on an outpatient basis and, unlike surgery, are only reported in aggregate form.

To support area-based clinical cancer registries a minimum data set, data dictionary, and business case have been developed by the NSW Department of Health as part of the recommendations in the *Optimising Cancer Management* report.<sup>5</sup> This initiative will still require funding for it to be implemented in the major teaching hospitals, and to enable the exchange of data between the area health services.<sup>1</sup>

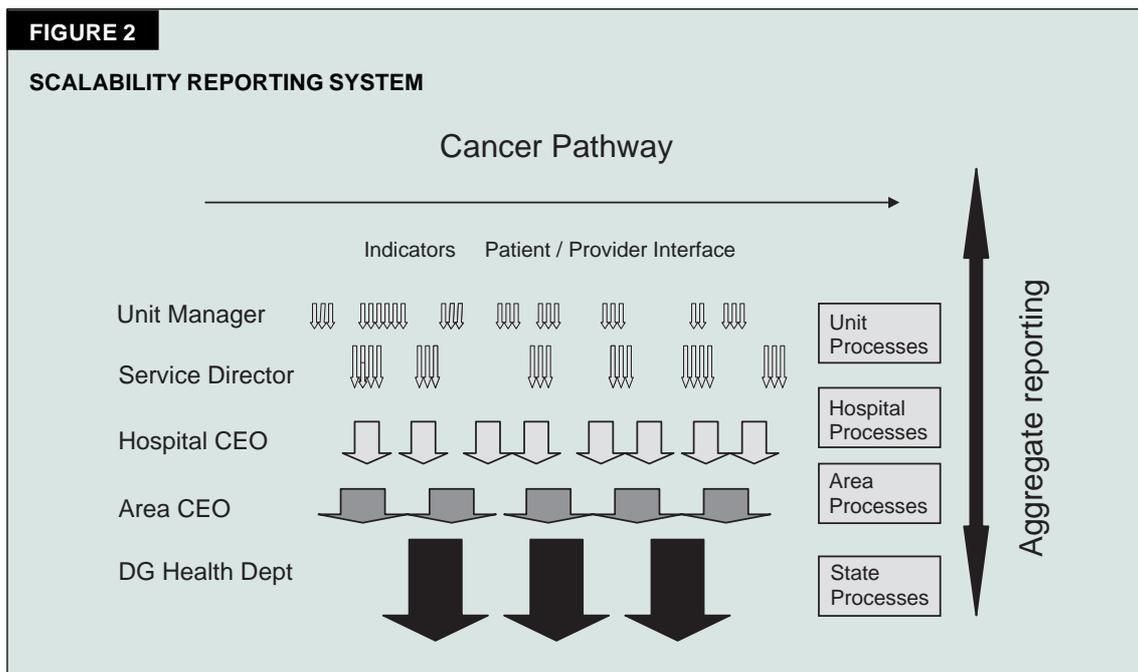
In SWSAHS, a locally-funded plan has been developed to implement the area-based clinical cancer registry. This required teasing out the relationship between at least 14 other information technology initiatives arising from local, state and national health portfolios. Some of these are the:

- Radiation and Medical Oncology Information Management and Technology Plan;
- Patient Administration Systems Project;



- Clinical Information Systems (Point of Care) Project;
- Community Based Health Information Development Project;
- Cancer Clinical Data Model;
- Health Information Exchange;
- NSW Central Cancer Registry Information Management and Technology Strategy.

The proposed Radiation Information Management System is the logical backbone for an area-based clinical cancer registry.<sup>12,13</sup> However, until it is implemented, the Surgical Audit Database—developed by the Division of Surgery at the Liverpool Health Service—is a suitable alternative and an invaluable precedent for solutions to both technical



and local governance issues. The area-based clinical cancer registry must also be able to collect data from private pathology laboratories, hospitals, and service providers. For both patients and service providers, a satisfactory resolution needs to be found to the significant and topical issue of consent, privacy, and confidentiality.<sup>14</sup> It is uncertain whether the transfer of patient identified information from private service providers to an area-based clinical cancer registry will be obligatory, discretionary, or even legal.

A three-staged plan has been developed to guide the complex task of implementation across multiple sectors and service providers both public and private. The area-based clinical cancer registry must be embedded into the information and technology plan of the area health service, to ensure that it is integrated with other information and technology initiatives of the area, and not be left as a stand-alone initiative. The three stages are to:

- pilot the collection of the minimum data set at Liverpool Health Service and develop the business case for the optimal system architecture and governance structure;
- establish a fully working registry at one pilot site;
- sequentially deploy the system throughout the public and private services in the area.

Ideally, to avoid duplication and incompatibility of data definitions and storage, it is critical to develop a system that is uniform across NSW. In the absence of a strategic central approach we advocate forming data alliances between the area health services.

### **KEY PERFORMANCE INDICATORS AND TUMOUR SITE GROUPS**

For quality improvement in clinical practice the area-based clinical cancer registry must develop and incorporate key performance indicators, as well as a scalable reporting system for these indicators. A scalable reporting system is one with the ability to interrogate and aggregate key performance indicators generated at multiple levels of organisational and clinical activity: state, area, hospital and clinic. Without the capacity of an information system to condense data while maintaining the integrity of the original source, the volume and complexity of information generated from multiple sites and service providers becomes overwhelming and the benefits cannot be fully realised (Figure 2).

Management of the Area Cancer Control Network has been organised along cancer tumour sites for the nine common cancers. This structure acknowledges the different needs, volumes of patients, and service plans required for each group of cancers. Acute care clinicians with a specific professional interest have been appointed as tumour site leaders to implement evidence based clinical protocols, provide policy advice to the area, and develop key performance indicators to monitor quality, measure

activity, describe treatment outcomes, and establish benchmarking. It is expected that standing reports of the key performance indicators developed for the service will be generated from the Area Clinical Cancer Registry for action by these groups.

It is proposed that each tumour site leader will build upon existing professional interest groups and extend them to include multi-disciplinary representation. It is envisaged that each group will develop service plans within the planning framework encompassing the full range of cancer services from health promotion, screening, diagnosis, treatment, palliation and support services. There is no expectation of additional resources to support cancer services, therefore existing resources must be identified for reallocation. Finding sufficient management and clerical resources to support these groups is also problematic.

### **CONCLUSION**

The area-based cancer control network can only be validated by the collection of data, and this establishes accurate information as the cornerstone of cancer services. By implementing an area-based clinical information system it will be possible to assess clinical and organisational outcomes and use the information for all aspects of quality improvement. The benefits of information can only be realised if action is possible. The tumour site leaders and multi-disciplinary groups will monitor their own key performance indicators and are responsible for responding to ensure the best value and outcomes for their service. Regardless of structural and management differences the common element for all area health services is the need to develop good clinical and organisational information systems.

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## CANCER PATIENTS' SUPPORTIVE CARE NEEDS: STRATEGIES FOR ASSESSMENT AND INTERVENTION

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This article describes some of the work undertaken over the last decade by The Cancer Council NSW—through the Cancer Education Research Program (CERP) and the Cancer Services Unit—to measure the supportive care needs of cancer patients, and identify effective strategies for attending to these needs as part of routine clinical practice.

Cancer is a major cause of morbidity and mortality throughout the world, with nine million people newly diagnosed each year and five million people dying from the disease.<sup>1</sup> In Australia, cancer is the second most common cause of death, accounting for approximately one quarter of all deaths.<sup>2</sup> Approximately 55,000 cases of cancer are diagnosed each year, the most common being cancers of the breast, prostate, colon–rectum, lung, and melanoma. Due in part to the focus on early detection and improved clinical management of cancer, five-year survival rates indicate that more people are now living with cancer, and for longer periods of time.<sup>1,3</sup>

Most cancer patients now undergo a combination of effective—but nonetheless traumatic—treatments such as the surgical removal of the cancer, radiotherapy, chemotherapy, and hormone therapies. Although these treatments have the potential to cure some cancers, and to prolong the lives of patients with other cancers, they are associated with a wide range of physical and psychosocial problems. The psychosocial morbidity experienced by cancer patients has been estimated using a number of different strategies including the assessment of quality of life; satisfaction with care; and, more recently, needs assessment. Quality of life research has indicated that the diagnosis and subsequent treatment of cancer impairs cancer patients' work and social activities, management of the home, family and other relationships, sleep patterns, and sexual activity.<sup>4–7</sup> In addition, studies exploring the

psychological sequelae of cancer have suggested that cancer patients experience clinically significant levels of anxiety and depression.<sup>5,7–13</sup>

Although both cancer specialists and patients may accept physical and psychosocial problems as an inevitable part of the disease and its treatment,<sup>14,15</sup> these problems can have a substantial affect on cancer patients' compliance with their treatment and with outcomes. For example, it has been estimated that up to one-third of patients will abandon chemotherapy prematurely as a result of the physical and psychosocial symptoms, despite the potentially life-threatening consequences of such action.<sup>16</sup> Therefore, it is important for cancer specialists to be aware of the prevalence of such problems among their cancer patients and to do their best to prevent them where possible or to address them when they occur.

The routine assessment of cancer patients' unmet needs in the clinical setting has the potential to quickly identify issues of concern for the patient, which can then be brought to the attention of the treatment team for appropriate intervention. In contrast to assessments of satisfaction and quality of life, needs assessments directly assess and identify specific issues for patients, as well as the perceived magnitude of those needs. In this context, 'needs' can be defined as the requirement of some action or resource that is necessary, desirable or useful to attain optimal well-being.<sup>17</sup> Needs assessment enables individuals—and sub-groups of patients with higher levels of needs—to be identified and targeted with appropriate early interventions; and allows those aspects of health services that require improving to be identified and prioritised.<sup>18</sup>

Research on the needs of patients with cancer has identified high levels of unmet need and a difference in the types of unmet needs depending on the cancer population studied. For example, high levels of unmet need in the provision of information have been reported in studies with different types of cancer

TABLE 1

**THE 10 AREAS OF NEED, EXPERIENCED IN THE PREVIOUS MONTH, RANKED HIGHEST BY PATIENTS COMPLETING THE SUPPORTIVE CARE NEEDS SURVEY ACROSS ALL TREATMENT GROUPS AND CENTRES OF CARE**

Item	% of sample reporting a moderate–high need	Domain
Fears about the cancer spreading	40	Psychological
Fears about the cancer returning	39	Psychological
Concerns about the worries of those close to you	38	Psychological
To be informed about the things you can do to help yourself to get well	36	Health system–information
Lack of energy and tiredness	33	Physical–daily living
Not being able to do the things you used to do	33	Physical–daily living
Uncertainty about the future	32	Psychological
To be informed about the cancer which is under control or diminishing (that is, remission)	32	Health system–information
To be informed about your test results as soon as feasible	31	Health system–information
Concerns about the ability of those close to you to cope with caring for you	30	Psychological

patients,<sup>19,20</sup> with breast cancer patients<sup>21,22</sup> and with melanoma patients.<sup>23</sup> Other studies of patients undergoing treatment for cancer have reported high levels of physical–daily living needs.<sup>24–28</sup> Most recently, the largest published study describing the prevalence and predictors of unmet needs among cancer patients ( $n=888$ ) across NSW, using the Supportive Care Needs Survey,<sup>29</sup> revealed that cancer patients continue to experience high levels of unmet needs across a range of domains, including: psychological support, health system and information, physical and daily living, patient care and support, and sexuality. In the survey, 59 items were presented with a stem question of ‘In the last month, what was your level of need for help with’, with response options: ‘No need, not applicable’, ‘No need, satisfied’, ‘Low need’, ‘Moderate need’ and ‘High need’. As indicated in Table 1, the highest levels of need were found to be in the psychological domain, which accounted for half of the top 10 unmet needs identified in this study, with a further three items from the health system and information needs domain and two relating to their physical and daily living. The results of this state-wide survey also showed that subgroups of patients experienced different types of needs, with the predictors of reporting some unmet need for help varying according to the domain examined.<sup>30</sup>

The main purpose of assessing the physical symptoms and unmet needs of people diagnosed with cancer is the improvement of their care. However, such assessments can only result in improvement of care if: a) the team providing treatment is aware of the physical and psychosocial problems of individual patients; and b) strategies are available to address the issues raised by individual patients.

In an effort to improve the coordinated care of people with cancer, The Cancer Council NSW is planning a multi-faceted collaborative initiative with cancer treatment centres and health services across the state. The aim of the

proposed Cancer Services Quality Improvement program is to implement and evaluate a program to facilitate better psychosocial management of cancer patients by health services. It will consist of the following components:

- **needs assessment:** Based on methodology developed and trialed by CERP, all cancer patients attending the participating centres will complete a touchscreen computer survey in the waiting room, prior to their appointment with their oncologist, to assess their unmet needs, anxiety and depression and physical symptoms;
- **clinician feedback:** Research undertaken by CERP indicates that the awareness of oncologists of their individual patient’s physical and psychosocial outcomes is less than optimal, thus limiting the opportunity for them to intervene to address their patient’s needs.<sup>31</sup> Hence, each individual patient’s results will be printed immediately following their completion of the survey and provided to the clinician in a summary form. Those issues identified by their patient involving routine clinical management can be reviewed. Results of a pilot study of this feedback strategy indicates promising outcomes for patients;<sup>32</sup>
- **multidisciplinary workshops:** Treatment centres will clearly have different levels of access to services and personnel who are able to address individual patients’ needs. It is therefore imperative that a tailored approach be taken to the provision of interventions. To identify appropriate clinical pathways and referral systems for patients with different psychological, social and living needs, a structured workshop will be conducted with the multidisciplinary team of each participating cancer treatment centre or health service. The workshop would ensure that there are effective management and referral processes in operation across the centre (to social workers, psychologists, cancer support groups, volunteers, etc). The *Psychosocial*

*Clinical Practice Guidelines: Information, support and counselling for women with breast cancer*, endorsed by the National Health and Medical Research Council, will inform the provision of effective interventions to improve patients' psychosocial care;<sup>33</sup>

- **patient financial assistance scheme:** The Cancer Council NSW may implement a financial assistance scheme to provide both no interest loans and (immediate, smaller) welfare grants to patients experiencing financial difficulties. This financial assistance scheme would be a referral point for cancer treatment centres;
- **professional education:** Further professional education and resources on survival rates and support topics will be provided, as requested by participating centres;
- **benchmarking:** CERP will analyse individual treatment centre data and provide summary reports for every 100 patients. Furthermore, comparative data for all centres combined will be provided to allow comparison of individual centre outcomes to outcomes for the whole group.

The coordinated process described above is currently being piloted and is one approach to ensure that cancer patients receive optimal psychosocial assessment and care during the management of their cancer.

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## THE IMPORTANCE OF COMMUNICATION SKILLS TO EFFECTIVE CANCER CARE AND SUPPORT

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In the last decade there has been an increasing emphasis on the teaching of communication skills. Why is this now considered so important, and does communication really influence patient outcomes in cancer care? The rationale for communication skills training in cancer care comes from a number of related points:

- good communication is a basic component of good clinical care, without which even the technical aspects of medicine cannot be effectively delivered;
- cancer carries with it a high psychological burden, thus the costs of poor communication are particularly salient in this patient population;
- the literature suggests there are currently substantial problems in doctor–patient communication;
- there is clear evidence that effective communication can make a difference to patient outcomes such as understanding and psychological adjustment;
- cancer patients place good communication high on their priorities for care;
- doctors regard their current training as inadequate, and cite communication difficulties as a major contributor to stress and burn-out;
- research has proven that communication skills can be taught and maintained.

This article presents the rationale for training in communication skills to be a priority for teams caring for cancer patients.

Kurtz, Silverman and Draper, in their text on teaching communication skills in medicine, state strongly that ‘communication skills are not an optional extra in medical training; without appropriate communication skills, all our other clinical efforts can easily be wasted’.<sup>1</sup> It has been estimated that doctors engage in 200,000 consultations in a professional lifetime, during which diagnoses are made, treatments are discussed, health care is delivered and patients’ needs are assessed and met. Furthermore, numerous other interactions between

members of the health team and patients involve communication at their core. The communication tasks in such interactions typically involve the gathering and delivery of information, and the provision of emotional support. Arguably, cancer patients have a particularly strong need for good communication in these domains.

Surveys of cancer patients show an increasing desire over time, especially among younger patients, to know everything about their cancer, and to be involved in making treatment decisions.<sup>2–5</sup> For example, over 90 per cent of patients in Lobb et al.’s study of patients with early stage breast cancer wanted to know their chance of being cured and the staging details of their cancer.<sup>2</sup> In another Australian study,<sup>6</sup> over 60 per cent of cancer patients seeing an oncologist for the first time indicated a preference for making a treatment decision either in collaboration with their doctor or on their own. Medical ethics has shifted from a paternalistic stance to one emphasising patient autonomy, with informed consent seen as the gold standard for achieving this end. However, informed consent requires much from both parties. Doctors are required to impart complex and potentially threatening information in a manner tailored to patient needs, provide a clear recommendation, and encourage a collaborative framework of decision-making. Such skills are not easily developed.

While a high standard of communication is often evidenced in cancer care, the literature suggests gaps and areas of particular difficulty. For example, while patients often report high satisfaction with overall care, Wiggers et al. reported much lower satisfaction (20–30 per cent) on items dealing with specific content areas and patient control.<sup>7</sup> Patients were very dissatisfied with information about treatment benefits, side effects and symptom control, and about achieving a sense of control over their life. Complaints about the amount of information provided, the manner in which it is given, and its comprehensibility, were also commonly reported in a recent audit of hospital services in England.<sup>8</sup> Indeed, the majority of malpractice allegations arise from a communication breakdown.<sup>9</sup>

Cancer patients also have high emotional needs. Prevalence rates for depression are reported as between

47 per cent and 58 per cent,<sup>10,11</sup> in comparison to a 5.8 per cent prevalence rate of depression in the general population, estimated in the general United States population.<sup>12</sup> Despite being common, psychological problems such as depression are still under-detected and under-treated in oncology practice.<sup>13</sup> Early studies found that only 15 per cent of patients who merited psychiatric intervention were referred as part of usual care, and that even after a psychiatric liaison service was established, around 50 per cent of patients with major affective disorder were not referred by clinical oncology staff.<sup>14</sup>

Many studies have reported the difficulties medical practitioners face in detecting psychological concerns and addressing emotional issues with patients. For example, an Australian study used a standardised questionnaire to measure patients' levels of anxiety and depression before a consultation, and compared these with oncologists' perceptions. Most oncologists were unable to predict their patients' psychological status to a degree that was better than chance.<sup>15</sup> In another study,<sup>16</sup> 298 patients with heterogeneous cancers had their initial consultation with one of nine oncologists audio-taped. Transcripts of the audio-taped consultations were analysed and cue frequency, cue type (informational or emotional), and doctor responses (responded to or not responded to) were recorded. Patients gave a median of two cues per consultation, of which about 30 per cent were for emotional support. Oncologists responded appropriately to only about 28 per cent of these cues, with some oncologists systematically responding to more cues than others. Interestingly, the consultations of those oncologists who responded to most information cues were significantly shorter than those of oncologists who responded to fewer cues.

There is now a large literature showing that patients who are satisfied with doctor–patient communication:

- understand more about their illness and complex combinations of treatments and drugs that are used;
- are more compliant—that is, are more likely to follow instructions and follow treatment plans;
- demonstrate better psychological adjustment—that is, are less anxious and depressed;
- are generally more satisfied with their care and with the physician.<sup>17–20</sup>

For example, an English study found a significant positive impact on patient well-being—even a year after diagnosis—of seeing a doctor who encouraged patient participation in decision-making.<sup>19</sup>

Doctors, too, appear to benefit from communicating well. There is evidence that doctors who are anxious and lack confidence in responding to patients' emotional needs are those who are at most risk of 'burnout'.<sup>21</sup>

The variability of practitioners' current practices, the potential of the consultation process to adversely affect both providers of care and patients, and the strong evidence

for better outcomes with better communication, suggests that communication skills training should be a priority for cancer teams. This has been recognised, not only by patient advocate groups who have called for further training for doctors in management of psychosocial aspects of cancer care,<sup>22</sup> but also by the clinicians themselves who have indicated interest in participating if appropriate programs were available.<sup>23</sup>

An evidence-base for effective communication practices within the treatment team is now available, at least in some areas. Randomised controlled trials and meta-analyses have been conducted showing the effectiveness of these interventions for improving well-being, reducing psychological distress, and effectively managing major effective disorders among cancer patients.<sup>24,25</sup> The recently released National Health and Medical Research Council psychosocial clinical practice guidelines have been developed to assist members of the treatment team to provide evidence-based supportive care to meet the various psychosocial needs expressed by their patients.<sup>26</sup> The majority of the recommendations reflect changes in the clinician–patient interaction, but advice is also given about appropriate circumstances for referral for group support, counselling, psychiatric and/or other interventions.

While the literature in this area is comparatively small, there is evidence that training programs in communication skills can make a difference both to doctor behaviour and patient outcomes. Such programs have been reported to lead to doctors using more of the targeted consultation skills in assessments with simulated patients, to increase clinicians' confidence in communicating effectively with patients and to enhance clinicians' positive attitudes towards patients' psychosocial needs.<sup>27,28</sup> The effect on patient outcomes has not been studied extensively, because of the complexities and size of the studies required. However, one small study from the United States found that 18 patients of specialist oncologists who had been randomised to a communication skills workshop, reported feeling less depressed and more in control than the 18 patients of doctors in the control group.<sup>29</sup>

In conclusion, there is a strong theoretical rationale and considerable data supporting the importance of effective communication in cancer care. Training programs in key areas identified as problematical by clinicians and patients (such as breaking bad news, discussing prognosis, presenting treatment options, and obtaining consent to clinical trials) are currently available through a number of sources.

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## PSYCHOSOCIAL GUIDELINES IN CANCER CARE AND SUPPORT

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The increasing demands of consumers for attention to the psychosocial aspects of care has been acknowledged with the release of clinical practice guidelines for the psychosocial care of women with breast cancer. This article describes the development of the *Psychosocial Clinical Practice Guidelines: information, support and counselling for women with breast cancer* by the National Breast Cancer Centre, which have been endorsed by the National Health and Medical Research Council.<sup>1</sup> These Guidelines provide a valuable model for the promotion of psychosocial care for all patients with cancer.

### BACKGROUND TO THE DEVELOPMENT OF THE GUIDELINES

Approximately 10,000 Australian women are diagnosed with breast cancer every year. In addition to the demands of their physical treatment, these women must contend with complex practical, emotional, and psychological demands. Between 20–30 per cent of women with breast cancer experience a reduction in their quality of life due to emotional distress and a disruption of their roles;<sup>2</sup> however, emotional support and access to appropriate information remain major unmet needs of Australian cancer patients.<sup>3</sup> The depth of community feeling about the emotional effects of breast cancer entered the public

domain with the 1995 publication *Report on the management and treatment of breast cancer*,<sup>4</sup> which was based on an inquiry conducted by the House of Representatives Standing Committee on Community Affairs. The Report concluded:

‘Despite the proven high incidence of serious psychosocial morbidity in breast cancer patients, in Australia at least very little has been done to either investigate the extent and severity of that morbidity or to provide a suitable means of addressing it either as a preventive measure or as a therapeutic measure.’<sup>4</sup>

### **NATIONAL BREAST CANCER CENTRE INITIATIVES**

In response to these community concerns about the human costs of breast cancer, the Commonwealth Government opened the National Health and Medical Research Council National Breast Cancer Centre in 1995. A key goal of the Centre was to ensure that all women with breast cancer receive adequate psychosocial, physical and practical support. The Psychosocial Working Group (now Psychosocial Expert Advisory Group) was convened to assist in achieving this goal. This multi-disciplinary group undertook to identify the extent of the emotional effect of breast cancer and the ways in which this burden could be reduced. Given the perception of many that psychosocial interventions lack scientific credibility, it was considered crucial that any report be based on the best available evidence. Thus, the Group commissioned seven comprehensive and systematic reviews of the breast cancer literature. Although in many cases there is evidence specifically related to breast cancer, in some cases the evidence was generic to all cancers—for example, being given the diagnosis of cancer. All reviews examined in detail the design and quality of studies, and rated the level of evidence according to the standards advocated by the NHMRC.<sup>5</sup> The Group also engaged in extensive consultation with consumers, and health professionals involved in all aspects of cancer care, to ensure that any recommendations made had clinical relevance and utility. A draft document detailing recommendations about the psychosocial care of women with breast cancer was distributed for public consultation, and the feedback from this was incorporated into the guidelines along with comments from relevant experts, representatives of the professional colleges, and consumer representatives.

### **FROM EVIDENCE AND CONSULTATION TO GUIDELINES**

Clinical practice guidelines were developed on the basis of the best available evidence and extensive consultation. The Guidelines were piloted in 1998 as part of a multi-centred trial of a specialist breast nurse ‘model of care’ at treatment centres in Melbourne, Perth, Adelaide, and Dubbo. Aspects of the Guidelines were also incorporated into communication skills training programs for senior oncologists delivered during 1998 and 1999. In 1997,

the opinion of the National Breast Cancer Centre Consumer Advisory Group was obtained to supplement feedback from the pilot testing. A final draft of these guidelines *Psychosocial Clinical Practice Guidelines: Providing information, support and counselling for women with breast cancer* was endorsed by the NHMRC in December 1999, and were officially launched in February 2000.

### **CONTENT AND STYLE OF THE GUIDELINES**

The Guidelines promote integration of psychosocial care into all aspects of the care of women with breast cancer, and as such are designed for use by all members of the treatment team. Endorsement by the NHMRC confirms that psychosocial care is no longer an ‘optional extra’.

In addition to background information about emotional morbidity, there are specific recommendations about the provision of information, including breaking the news of the diagnosis of breast cancer, recurrent or metastatic disease. Many of the recommendations are based on Level I evidence (that is, evidence obtained from a systematic review of all relevant randomised control trials) and Level II evidence (that is, evidence obtained from at least one properly designed randomised control trial). For example, providing appropriate detailed information promotes understanding and increases the psychological wellbeing of women.<sup>6</sup> Similarly, providing women with information about a procedure they are about to undergo reduces emotional distress and improves psychological and physical recovery.<sup>7</sup> Detailed evidence is also presented about the emotional impact of practical needs and financial issues. Evidence is cited for the role of specialist breast nurses in the provision of information, emotional support, and maintaining continuity of care.<sup>8</sup>

The Guidelines highlight the benefit of discussing feelings with a member of the treatment team or counsellor,<sup>5</sup> and the efficacy of interventions to treat psychological distress.<sup>9,10</sup> One of the strengths of the Guidelines is the clear approach to the identification of emotional distress. Health professionals whose training in this area is limited may feel concerned about compounding the distress of patients by broaching psychosocial issues. However, the Guidelines offer practical examples of the ways in which emotional concerns can be explored. In addition, the Guidelines challenge the notion that being depressed or anxious in response to a devastating diagnosis is always a ‘normal’ reaction, detailing approaches to the diagnosis and treatment of anxiety and depression. Identification of those at increased risk of psychological distress may allow for early detection and treatment, or even the prevention of disorder.<sup>1</sup>

### **DISSEMINATION AND IMPLEMENTATION**

Translating evidence-based clinical practice guidelines into routine clinical care is not simple. Evidence suggests that factors that promote increased uptake include

endorsement by professional organisations,<sup>11</sup> and the valuable role of clinical opinion leaders.<sup>12</sup> With this in mind, copies of the Guidelines have been disseminated to the key professional colleges seeking their endorsement, and copies sent to breast surgeons, medical and radiation oncologists, and consultation-liaison psychiatrists have been accompanied by a 'champion letter' written by a prominent member of the respective professional group. Copies have also been distributed to cancer treatment centres, palliative care units, and divisions of general practice.

Many of the recommendations of the Guidelines do not require new infrastructure, but they do require enhanced communication skills and awareness of psychosocial issues. The National Breast Cancer Centre has taken a leadership role in the promotion of communication skills training throughout Australia, and key sections of the Guidelines have been incorporated into communication skills training for oncologists and surgeons. This 'hands on' delivery of information with active involvement, and discussion with colleagues is felt by doctors to be most likely to have an effect.<sup>13</sup>

Clinical practice guidelines have their detractors. Barriers to uptake include the perception that guidelines reduce clinical autonomy, and advocate 'cookbook' medicine.<sup>14</sup> Resource issues and time constraints have also been cited,<sup>15</sup> and an Australian survey of surgeons revealed concerns about medico-legal implications of clinical practice guidelines,<sup>16</sup> although it appears unlikely that clinical practice guidelines will promote litigation.<sup>17</sup>

## CONCLUSION

Health professionals who work with patients with cancer have long felt concerned about the best ways to assist their patients to cope with the disease. Although the implementation of these evidence-based guidelines poses challenges, there is the very real potential to improve health care outcomes, including a reduction in psychological morbidity, improved wellbeing and patient satisfaction with care.

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# MULTIDISCIPLINARY CARE FOR WOMEN WITH BREAST CANCER: A NATIONAL DEMONSTRATION PROGRAM

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This article describes the benefits of a multidisciplinary approach to the care of women with breast cancer and describes a demonstration project to investigate the effect, cost, and acceptability of implementing multidisciplinary care in Australia.

## WHY BREAST CANCER?

Breast cancer is the most common cause of cancer deaths among Australian women.<sup>1</sup> In NSW in 1999, 3,463 women were newly diagnosed with breast cancer.<sup>2</sup> The average lifetime risk of breast cancer is about one in 11 women. Each year, over 2,600 women in Australia die from the disease.<sup>1</sup> It is estimated that it costs Australia \$169.5 million to diagnose and treat the disease and there are considerable physical and emotional costs for the 10,000 women diagnosed each year and their families.<sup>3</sup>

Today, effective diagnosis and treatment of this complex disease with many different possible clinical pathways relies on the skills of many clinical specialties and is best achieved when these specialists work together in multidisciplinary teams. Recommendations about the management of breast cancer—a national health priority—are available in a number of practice guidelines for Australian clinicians including the treatment and support of women with early and advanced breast cancer.<sup>4,5,6</sup>

## THE BENEFITS OF MULTIDISCIPLINARY CARE

Multidisciplinary care is a team approach to the provision of cancer care by multiple medical and allied health disciplines. Multidisciplinary care includes the liaison and cooperation of all members of the team together and with the patient to diagnose, treat and manage to the highest standard of care all aspects of breast cancer from diagnosis through to follow-up.<sup>7</sup>

Available evidence indicates that multidisciplinary care has the potential to reduce mortality from breast cancer, improve the quality of life of women with the disease, and reduce health care costs.<sup>8,9,10</sup>

Care involving a range of clinicians ‘...ensures that all relevant treatment methods that have a place in modern management are properly considered’.<sup>10</sup> Research indicates that currently some women may not be provided with the full range of management options. In one American study, the initial treatment recommendations received by women during a single or sequential consultation were compared with a second opinion provided by a multidisciplinary panel.<sup>11</sup> For 43 per cent of the women, the multidisciplinary

panel would have recommended a different treatment in accord with guideline recommendations, most frequently being breast conserving treatment instead of mastectomy.<sup>11</sup>

There are a number of models of multidisciplinary care. In the United Kingdom, an advisory board model is used, as outlined in the Calman-Hine report,<sup>12</sup> which focuses on functional aspects of multidisciplinary care. This approach has been found to be effective in the UK setting.

## THE AUSTRALIAN CONTEXT

Based on the available evidence, the *NHMRC Clinical Practice Guidelines for the Management of Early Breast Cancer* recommend treatment of women with breast cancer in a multidisciplinary setting.<sup>4</sup> However, a survey of Australian surgeons about their opinions of the early breast cancer guidelines found that even though most clinicians supported the recommendation, 34 per cent of rural surgeons (11 per cent urban) indicated that they would find it difficult to implement the recommendations about multidisciplinary care in their practice.<sup>13</sup>

There is no comprehensive information describing how, or to what extent, institutions managing women with breast cancer in Australia have adopted a multidisciplinary approach. As a result, there is very little information about the potential role of multidisciplinary care in Australia or the policy or funding implications of such an approach. However, some small Australian studies have indicated that high quality care is not limited to large, urban areas but rather is achievable in regional areas, if access to the full range of clinical specialties is established.<sup>14,15</sup> The establishment of ‘virtual’ cancer centres in the future may also facilitate a greater integration of care.

The National Breast Cancer Centre is conducting a study to profile the provision of multidisciplinary care in a representative sample of hospitals from all states and territories in Australia. With assistance from relevant health departments from each state and territory, including the NSW Department of Health, a total of 60 lead clinicians from hospitals involved in the treatment of women with breast cancer, stratified by caseload, have participated in the study. A questionnaire has been completed by the clinicians via a structured telephone interview. Data collection for the study was completed in late April 2001 and the results will soon be reported. The results will provide an insight into the multidisciplinary care services available to women with breast cancer in Australia.

## A NATIONAL DEMONSTRATION PROJECT

The National Breast Cancer Centre is coordinating a National Multidisciplinary Care Demonstration Project that is investigating the cost, acceptability, and impact

**TABLE 1****PRINCIPLES OF MULTIDISCIPLINARY CARE**

(NATIONAL MULTIDISCIPLINARY CARE DEMONSTRATION PROJECT)

<b>Principle of care</b>	<b>Outcome</b>
<p><b>Team</b></p> <ul style="list-style-type: none"> <li>The disciplines represented by the 'core' team should minimally include surgery, oncology (radiation and medical oncology), pathology, radiology and supportive care. The individual woman's general practitioner will be part of her team.</li> <li>In order to ensure that the woman has access to the full range of therapeutic options, the 'core team' may be expanded or contracted to include services (may be off site), such as genetics, psychiatry, physiotherapy and nuclear medicine.</li> </ul> <p><b>Communication</b></p> <ul style="list-style-type: none"> <li>A communications framework should be established which supports and ensures interactive participation from all relevant team members at regular and dedicated case conference meetings.</li> <li>Multidisciplinary input should be considered for all women with breast cancer, however, not all cases may ultimately necessitate team discussion.</li> </ul> <p><b>Full therapeutic range</b></p> <ul style="list-style-type: none"> <li>Geographical remoteness and/or small size of the institution delivering care should not be impediments to the delivery of multidisciplinary care for women with breast cancer.</li> <li>The members of the team should support the multidisciplinary approach to care by establishing collaborative working links.</li> </ul> <p><b>Standards of care</b></p> <ul style="list-style-type: none"> <li>All clinicians involved in the management of women with breast cancer should practice in accord with guideline recommendations.</li> <li>The treatment plan for a woman should consider individual patient circumstances and wishes.</li> <li>Discussion and decisions about treatment options should only be considered when all relevant patient results and information are available.</li> <li>In areas where the number of new cancers is small, formal collaborative links with larger units/centres should give support and foster expertise in the smaller unit.</li> <li>Maintenance of standards of best practice is supported by a number of activities which promote professional development.</li> </ul> <p><b>Involvement of the woman</b></p> <ul style="list-style-type: none"> <li>Women with breast cancer should be encouraged to participate as a member of the multidisciplinary team in treatment planning.</li> <li>The woman diagnosed with breast cancer should be fully informed of her treatment options as well as the benefits, risks and possible complications of treatments offered. Appropriate literature should be offered to assist her in decision making. This information should be made available to the woman in a form that is appropriate to her educational level, language and culture.</li> <li>Supportive care is an integral part of multidisciplinary care. Clinicians who treat women with breast cancer should inform them of how to access appropriate support services.</li> <li>The woman with breast cancer should be aware of the ongoing collaboration and communication between members of the multidisciplinary team about her treatment.</li> </ul>	<p>The 'breast cancer care team' is established and known.</p> <p>Referral networks established for non-core team specialist services.</p> <p>Communication mechanisms are established to facilitate case discussion by all team members.</p> <p>A local protocol is established for deciding which cases may not require team discussion.</p> <p>Systems are established for ensuring that all women have access to all relevant services.</p> <p>Systems are established to support collaborative working links between team members.</p> <p>Local clinician data is consistent with national benchmarks.</p> <p>The final treatment plan should be acceptable to the woman, where possible.</p> <p>Final reports are available to all core team members before treatment planning.</p> <p>Systems are established for the exchange of knowledge and expertise between larger and smaller caseload centres.</p> <p>Systems are established for the support of professional education activities.</p> <p>Women are supported to have as much input into their treatment plan as they wish.</p> <p>All women should be fully informed about all aspects of their treatment choices.</p> <p>All clinicians involved in the management of women with breast cancer should ensure that women have information about and access to support services.</p> <p>Women with breast cancer feel that their care is coordinated and not fragmented.</p>

on patterns of the approach in four demonstration sites. The findings of the project will be used to make recommendations about the implementation of multidisciplinary care and are anticipated to help improve the coordination of treatment received by women with breast cancer, irrespective of location.

The National Multidisciplinary Care Demonstration Project commenced in February 2000, with primary funding provided by the Commonwealth Department of Health and Aged Care. The project is overseen by a Steering Committee, chaired by Professor Christine Ewan, and participating sites were selected by a subgroup chaired by Emeritus Professor Tom Reeve.

The participating demonstration sites are multifacility collaborations located in North Queensland, Western Victoria, Central Victoria and north-eastern New South Wales. Each collaboration contains at least one rural facility—for example, the NSW collaboration includes Prince of Wales Hospital, Tamworth, and Grafton Base Hospitals.

Acknowledging that overseas models of multidisciplinary care may not apply to the Australian health care system, a set of principles of multidisciplinary care were developed to guide the project. The principles were developed by a subgroup of the project Steering Committee, which included Mr Bruce Barraclough, and was led by Dr Helen Zorbas (Centre Clinical Director). The principles relate to the team, communication, the therapeutic range, standards of care, and involvement of the woman (Table 1). The principles recommend the establishment of a multidisciplinary team with representation from a range of disciplines, including surgery, oncology (radiation and medical oncology), pathology, radiology, supportive care, and general practices.

The way in which multidisciplinary care is best implemented will vary between sites; each collaboration has nominated strategies that they will implement to improve care in accord with the principles of multidisciplinary care. For example, the challenge of geographical remoteness has led a number of collaborations to use telemedicine for multidisciplinary case conferencing. Other strategies include the appointment of a Breast Care Nurse as a focal point for patients being treated by several facilities within a collaboration.

The evaluation of the three-year demonstration project includes a survey of women treated within the collaborations before and after the commencement of nominated multidisciplinary strategies, a clinical audit, a cost analysis, surveys of clinicians, and the logging of multidisciplinary activities. The Demonstration Project will be completed in December 2002, with recommendations being made to the Commonwealth.

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# A SUCCESSFUL VOLUNTEER PROGRAM SHOWCASED DURING THE INTERNATIONAL YEAR OF VOLUNTEERING: THE CANCER COUNCIL NSW'S BREAST CANCER SUPPORT SERVICE

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How often do we read in or hear through the media the story of survivors, often referred to as heroes of events or incidents? These survivors portray courage, inner strength, resilience, and many other admirable qualities. Consider the influence of these portrayals on our own lives. We can apply a similar context to cancer survivors.

The Cancer Council NSW has long recognised the value of survivors who, in the role of trained volunteers, can show the importance of 'having been there'. Today, due to the advances in cancer treatments, more cancer patients will survive their experience of cancer. In Australia, the five-year relative survival ratio for all cancers is now 57 per cent in females and 46 per cent in males.<sup>1</sup> If cancer survivors are well recruited, trained, and supported, they can act as mentors for newly-diagnosed cancer patients and their carers. This article describes an evaluation of the volunteer program of The Cancer Council NSW's Breast Cancer Support Service (BCSS).

## BACKGROUND

The BCSS harnesses the positive experiences and recovery of volunteers to assist people newly diagnosed with breast cancer. The BCSS has been operating for over 25 years with great success. For many years the BCSS was entirely a volunteer run program; however, since the 1980s The Cancer Council NSW has provided funding for the infrastructure.

The BCSS is a major cancer support volunteer program, with more than 400 volunteers in NSW. The volunteers include women and men located throughout rural and urban areas. The service aims to ensure that volunteers are matched to new referrals as closely as possible by age, treatment type, social setting, and culture where applicable. The Cancer Council NSW strongly supports the view that the role of the volunteer cannot be replaced by a health professional. Unlike volunteers, health professionals have not experienced a diagnosis of cancer, its treatment, or its survival.

The BCSS relies on trained volunteers who have had a diagnosis of breast cancer. Survivors must be two years post-diagnosis and considered suitable by their treating specialist to apply. The selection process involves a formal panel interview, followed by an intensive training

program over two days. At the end of training, it is decided whether applicants are suitable to become volunteers. The first few visits for a volunteer are closely supported by a coordinator, who also debriefs the volunteer. New volunteers also have a follow-up meeting with other volunteers six weeks into their role.

## STATEWIDE EVALUATION

During 1998–2000, the Cancer Education Research Program of The Cancer Council NSW conducted a statewide evaluation of the service.<sup>2-5</sup> The evaluation included surveys of volunteers, service coordinators, consumers, breast surgeons, and other health professionals from NSW public and private hospitals. Here, we focus exclusively on the volunteer and coordinator components.

The aims of the volunteer and coordinator components were to examine the levels of satisfaction among these groups, particularly in relation to their roles and responsibilities, and to ascertain their opinions of how the service might be improved and further promoted. Telephone interviews were conducted with 287 volunteers and 21 coordinators (85 per cent and 88 per cent of all eligible to participate, respectively). Most volunteers had visited at least 10 women in the 12 months preceding the interview (68 per cent) and reported that the majority of visits took place in hospitals (64 per cent) after women had had surgery (83 per cent).

### Volunteer responses

Almost all volunteers agreed that most visits they made were positive and rewarding (98 per cent), and that they were able to help women by sharing experiences (96 per cent). Qualitative data collected in the interviews indicated that many volunteers gained particular satisfaction in being able to 'give something back' after their own experience of breast cancer and felt it was rewarding to let other women know they were not alone. Some volunteers commented about the need for further training, as many women asked for information about a broad range of issues. These diverse issues included breast reconstruction, spiritual issues, relaxation techniques, accessing prostheses and special clothing, and dealing with husbands and partners. Volunteers also commented about the need to promote the service ('We need to encourage early referral and promote it to all members of the medical community'); and about how to improve the service ('The service needs more volunteers, especially from different backgrounds').

### Coordinator responses

Coordinators expressed high levels of satisfaction in dealing with volunteers and felt supported in their role by The Cancer Council NSW. Coordinators reported that

it was easy to match new referrals and volunteers by characteristics such as age (79 per cent). However, it was sometimes difficult to match by characteristics such as personal circumstances such as having young children and by similar treatment types (39 per cent and 42 per cent, respectively). This was especially the case for coordinators in rural areas, where the number of volunteers on whom they could call was limited. With regards to improving the service, several coordinators commented about how they had designed better systems to ensure women were told about the BCSS: 'I'm going to develop a protocol with the local nursing unit manager, so there's a clear procedure for ringing the service whenever a new patient is diagnosed'. Qualitative data also revealed the specific issues that coordinators faced in promoting the service, particularly to women from rural areas: 'Many women are electing to have a mastectomy because they can't afford to be away from home for six weeks and have the radiotherapy during that time. But women aren't getting referred back to services in their own home towns. No one is there for them'.

### **Implementation of recommendations**

Currently strategies are being developed to implement the recommendations made as a result of the evaluation. Recently, The Cancer Council NSW has been able to expand the service across NSW, through partnerships at the area health service level. This partnership has enabled the program to expand its capacity across all rural areas, helping to ensure access and equity for all consumers. The Cancer Council NSW is indebted to this continued collaboration with those area health services that have agreed that the BCSS program should be part of the role of senior health professionals in their areas.

The Cancer Council NSW has had the commitment of area health services in the following regions: the North West, Central West, Mid West, North Coast, Mid North Coast, Central Coast, Illawarra, South Coast, Southern and Great Murray. The commitment to providing the coordination in each area is a vital component to the program's success. The backgrounds of the 18 coordination staff include women's health coordinators, palliative care coordinators, Breastscreen nurse counsellors, stomal therapists, oncology nurse consultants, and cancer care coordinators.

### **New challenges**

With the changing environment of breast cancer care, the BCSS faces numerous challenges. First, many women are now being discharged from hospital less than 48 hours after surgery.<sup>6</sup> Consequently, it is often difficult to match a referral in a timely fashion that allows a woman to sufficiently recover from her surgery and be psychologically ready to meet a volunteer. In past years, many volunteers were not participating in the workforce and were more readily available to make visits. However, the evaluation reported that more than 50 per cent of volunteers were engaged in full-time or

part-time employment. As a result, more careful planning is required in the referral process.

A second challenge for the service is the availability and role of the breast care nurse. Many major cancer care centres across NSW are now employing either specialist breast nurses or part-time breast nurses. The Cancer Council NSW views this as an opportunity to enhance the services offered to those people diagnosed with breast cancer. Recently, the Cancer Council NSW conducted some interviews with breast care nurses operating in the Sydney metropolitan area. This identified many opportunities to work together, in areas such as the training of new BCSS volunteers and in updating programs. This will allow a greater understanding of both the roles of the service and the breast care nurse and may open opportunities for further collaboration. For the person diagnosed with breast cancer, the future appears much brighter with the expansion of support in this area.

The Cancer Council NSW will continue to encourage the role of volunteers in its support programs. The model used by the BCSS has been translated into programs for people diagnosed with prostate and colorectal cancer. A pilot colorectal program is in operation at Nepean Hospital, which was initiated at the request of a patient in consultation with her surgeon. This program is currently being evaluated. The Cancer Council NSW is keen to explore further how the volunteer model can be successfully implemented in the case of other cancers and will continue to seek support for volunteer programs by developing and fostering partnerships within the current health system.

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## LEGIONNAIRES' DISEASE, NSW, 1991–2000

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Reports of Legionnaires' disease can create alarm in the community because of the fear of outbreaks of illness, yet the vast majority of cases occur sporadically. Legionnaires' disease is characterised by general malaise, a lack of appetite, muscle aches and headache, followed by high fever, chills, a dry cough and pneumonia. Abdominal pain and diarrhoea may occur. Up to 39 per cent of hospitalised patients may die, and the death rate is higher among people who have other underlying diseases. Risk factors for the disease include male gender, older age, smoking, diabetes, chronic lung disease, renal disease, cancer, and immune suppression.<sup>1</sup>

At least 35 species of *Legionella* have been identified.<sup>1</sup> Most reported cases of Legionnaires' disease in NSW are caused by *L. pneumophila*, and less commonly *L. longbeachae* infections. *L. pneumophila* outbreaks have been associated with inhalation of water that has become aerosolised from contaminated cooling towers or occasionally from domestic water supplies.<sup>2,3</sup> The mechanism of infection with *L. longbeachae* is unclear, but it is likely to involve the inhalation of organisms with dust during the handling of potting mix, soil, or other contaminated materials.<sup>4,5</sup>

Cases of Legionnaires' disease are notifiable throughout Australia. In NSW, cases are routinely investigated by public health units (PHUs). PHU officers interview each notified case of Legionnaires' disease to identify possible exposures, should other patients emerge who report similar exposures. Where the interviews indicate that patients have had common exposures, PHU officers initiate epidemiological and environmental studies that include physical and microbiological assessment of the possible exposures. This article reviews the characteristics of people notified with Legionnaires' disease in NSW for the years 1991–2000.

### METHODS

Under the NSW Public Health Act 1991, all laboratories and hospitals must notify suspected cases of Legionnaires' diseases to the local PHU. The case definition for Legionnaires' disease is a person with the signs and symptoms of pneumonia in whom *Legionella* has been isolated; or who has a positive *Legionella* antigen in their urine or respiratory secretions; or who has a four-fold or greater rise in antibody titre between acute and convalescent sera. PHU staff record case details on a confidential statewide database. We analysed the characteristics of cases of Legionnaires' disease and

**FIGURE 1**

**REPORTS OF LEGIONNAIRES' DISEASE, NSW, 1991 TO 2000, BY MONTH OF ONSET.**

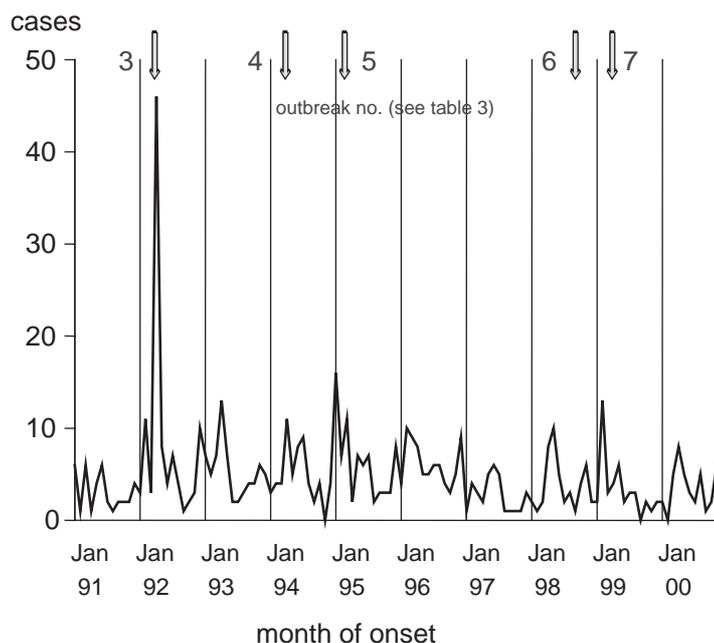


TABLE 1

**PATIENTS NOTIFIED HAVING, AND DEATHS RESULTING FROM, LEGIONNAIRES' DISEASE, PRESENTED BY YEAR OF ONSET, SEX, AND AGE GROUP, NSW, 1991–2000**

Characteristic	Total		<i>L. pneumophila</i>		<i>L. longbeachae</i>		Other–Unknown	
	Cases <i>n</i>	Deaths <i>n</i> (%)	Cases <i>n</i>	Deaths <i>n</i> (%)	Cases <i>n</i>	Deaths <i>n</i> (%)	Cases <i>n</i>	Deaths <i>n</i> (%)
<b>Total</b>	577	56 (10)	317	31 (10)	133	10 (8)	127	15 (12)
<b>Year of onset</b>								
1991	37	4 (11)	16	1 (6)	0	0 (0)	21	3 (14)
1992	104	8 (8)	80	7 (9)	14	0 (0)	10	1 (10)
1993	66	8 (12)	34	6 (18)	13	2 (15)	19	0 (0)
1994	60	8 (13)	30	3 (10)	8	0 (0)	22	5 (23)
1995	75	6 (8)	35	4 (11)	16	0 (0)	24	2 (8)
1996	74	9 (12)	34	5 (15)	30	2 (7)	10	2 (20)
1997	33	3 (9)	18	3 (17)	9	0 (0)	6	0 (0)
1998	46	5 (11)	22	0 (0)	19	4 (21)	5	1 (20)
1999	41	2 (5)	22	1 (5)	12	1 (8)	7	0 (0)
2000	41	3 (7)	26	1 (4)	12	1 (8)	3	1 (33)
<b>Sex</b>								
Male	402	40 (10)	236	23 (10)	81	7 (9)	85	10 (12)
Female	172	16 (9)	79	8 (10)	52	3 (6)	41	5 (12)
Unknown	3	0 (0)	2	0 (0)	0	0 (0)	1	0 (0)
<b>Age group (years)</b>								
<5	4	0 (0)	1	0 (0)	0	0 (0)	3	0 (0)
5–24	12	0 (0)	6	0 (0)	0	0 (0)	6	0 (0)
25–44	102	3 (3)	62	2 (3)	17	0 (0)	23	1 (4)
45–64	230	22 (10)	137	11 (8)	48	3 (6)	45	8 (18)
65–84	216	27 (13)	102	16 (16)	64	5 (8)	50	6 (12)
85+	13	4 (31)	9	2 (22)	4	2 (50)	0	0 (0)

TABLE 2

**CHARACTERISTICS OF PATIENTS NOTIFIED HAVING LEGIONNAIRES' DISEASE—INCLUDING RATE PER 100,000 POPULATION—PRESENTED BY RESIDENCE, SEX, AGE GROUP, AND DIAGNOSTIC TESTS, NSW, 1991–2000**

Characteristic	Total		<i>L. pneumophila</i>		<i>L. longbeachae</i>		Other–unknown	
	Cases	Rate	Cases	Rate	Cases	Rate	Cases	Rate
<b>Total</b>	577	9.3	317	5.1	133	2.2	127	2.1
<b>Residence</b>								
Sydney area	390	10.7	242	6.7	133	3.7	58	1.6
Other NSW	177	7.0	71	2.8	90	3.5	63	2.5
Unknown	10	–	4	–	0	–	6	–
<b>Sex</b>								
Male	402	13.1	236	7.7	81	2.6	85	2.8
Female	172	5.5	79	2.5	52	1.7	41	1.3
Unknown	3	–	2	–	0	–	1	–
<b>Age group (Years)</b>								
<5	4	0.9	1	0.2	0	0	3	0.7
5–24	12	0.7	6	0.3	0	0	6	0.3
25–44	102	5.4	62	3.3	17	0.9	23	1.2
45–64	230	17.6	137	10.5	48	3.7	45	3.4
65–84	216	30.8	102	14.6	64	9.1	50	7.1
85+	13	18.4	9	12.8	4	5.7	0	0
<b>Laboratory confirmed</b>	516	8.4	303	4.9	127	2.1	86	1.4
Serology	258	4.2	140	2.3	81	1.3	37	0.6
Antigen	32	0.5	22	0.4	6	0.1	4	0.1
Culture	115	1.9	89	1.4	13	0.2	13	0.2

TABLE 3

## NOTABLE OUTBREAKS OF LEGIONNAIRES' DISEASE, NSW, 1987–2000

No.	Date	Place	Reported cases	Deaths	Likely source
1	April 1987 <sup>6</sup>	Wollongong	44 <sup>a</sup>	9	Shopping mall cooling tower
2	April 1989 <sup>7</sup>	Western Sydney	12 <sup>b</sup>	Not stated	Bowling club, source unclear
3	April 1992 <sup>7</sup>	South Western Sydney	26	6	Fairfield business district, source unclear
4	April 1994 <sup>8</sup>	Western Sydney	4 <sup>c</sup>	Not stated	Hotel cooling tower
5	Jan 1995 <sup>9,10</sup>	Western Sydney	11	3	Shopping mall cooling tower
6	Nov 1998 <sup>11</sup>	Western Sydney	3	0	Work place cooling tower(s)
7	Feb 1999 <sup>12</sup>	Wentworth and Western Sydney	7	0	Source unclear

(a) 45 others symptomatic

(b) organism species not available

(c) 28 symptomatic persons identified in an epidemiological study

associated deaths notified to PHUs between 1991 and 2000. Incidence rates were calculated using average Australian Bureau of Statistics estimated mid-year populations for each year. From reports provided by PHUs, we identified outbreaks between 1987 and 2000.

## RESULTS

### Case notifications (1991–2000)

For the 10-year period 1991 to 2000, 577 cases of Legionnaires' disease were reported in NSW (Table 1). Of these cases, 516 (89 per cent) were confirmed by laboratory tests. Of all cases, 317 (55 per cent) were identified as caused by *L. pneumophila*, 133 (23 per cent) by *L. longbeachae* and six (one per cent) by other species (including five *L. micdadei* and one *L. bozemanni*) or unspecified species (121 [21 per cent]). Cases were more often males (70 per cent of all cases, with a rate more than twice that of females), and older (with the rate generally increasing with age for all *Legionella* species) (Table 2). The rate of disease due to *L. pneumophila* among Sydneysiders was more than twice that for other residents of NSW. Differences in rates by area of residence were not as distinct for other species of *Legionella*.

Of all cases, 56 people (10 per cent) were reported to have died. This case-fatality rate was similar for both the species of *Legionella* and sex of the person, but increased with the age of the person (P for trend test < 0.001).

### Outbreak investigations (1987–2000)

Seven outbreaks of Legionnaires' disease,<sup>6–12</sup> all due to a common source, were investigated in NSW. In the 14-year period all were likely to be due to *L. pneumophila* serogroup 1 (Table 3, Figure 1). These outbreaks included at least 107 cases and 18 deaths. (At least 51 of these outbreak-associated cases and three of the deaths were reported during the 10 years 1991–2000, representing less than 10 per cent of all cases during that period.) All seven outbreaks occurred in the warmer months between November and April; four

occurred in April. Six outbreaks occurred in the western part of Sydney, and one in Wollongong (south of Sydney). While contaminated cooling towers were suspected to be the source for all these outbreaks, links to a specific source were made in only four.

## DISCUSSION

These data indicate that Legionnaires' disease is relatively uncommonly reported in NSW, and that most cases (>90 per cent) are sporadic (that is, unrelated to recognised outbreaks). The death rate for notified cases is just under 10 per cent. Available demographic data indicate that the risk increases with age, and is higher in males than females. Cases due to the more common agent, *L. pneumophila*, occur at a higher rate in urban areas (perhaps related to the higher density of cooling towers in the city), and for unclear reasons, more often in western Sydney than in other parts of Sydney.

These data have several limitations. First, many people infected with *Legionella* bacteria do not present to medical practitioners—or, if they do, may not have diagnostic tests done—consequently many infections are likely to go undiagnosed and unreported.<sup>8</sup> Second, most case notifications are based on people with a serological diagnosis, and as this can be an unreliable means of diagnosis in the absence of paired acute and convalescent clinical specimens, some cases included here may not be true cases. Third, in over one fifth of cases the causal organism was not specified, although many of these were reported as laboratory-confirmed. This may represent deficiencies in completeness of laboratory reporting or data coding errors, indicating a need for improved data recording and checking.

Because of its seriousness, the prevention of Legionnaires' disease remains a high priority. Building managers must follow existing standards to minimise cooling tower contamination with *L. pneumophila*.<sup>13,14</sup> Prevention of infection with other species including *L. longbeachae* is

more difficult, because the mode of transmission is uncertain. Strategies include reducing exposures to potting mix and other soil dusts by moistening dusty materials, wearing masks, and thoroughly washing hands after gardening.

As for many infectious diseases, the identification of the exact source of a sporadic case of Legionnaires' disease is almost always impossible, because the causal organisms are common in the environment, and people are exposed to a wide range of potential sources every day (for example, aerosolised water from domestic or commercial water supplies, air conditioning systems, and dust). Nonetheless, early notification of cases allows PHU staff to investigate exposures that may be shared with other cases, suggesting a possible controllable source. While cases in the seven outbreaks reported here represent only a small proportion of all cases, it is very likely that prompt identification and control of the sources—as well as the more general alerts to building managers to ensure that cooling towers are checked and cleaned in the absence of an identified point source—help prevent further infections.

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## COMMUNICABLE DISEASES REPORT, OCTOBER 2001

### TRENDS

Spring is the season when the number of **pertussis** infections tends to increase. Earlier hopes that the large pertussis epidemic was decreasing has not been fulfilled (Figure 1). Notifications of this disease have increased once more, and high numbers have been reported from many areas, notably Northern Sydney, Greater Murray, Northern Rivers and Macquarie health areas (Table 1). All age groups appear to be affected. We estimate that the epidemic will continue into the spring in very high numbers. Clinicians are urged to consider the diagnosis in patients with chronic coughing illnesses, especially if accompanied by inspiratory whooping, paroxysms, and post-tussive vomiting. The administration of erythromycin to cases and their immediate contacts can control further spread of the disease. Public health units can advise on the timing of this treatment. In addition, it is important to

remind both new parents and their visitors that people with coughing illnesses should avoid contact with young infants.

Cases of **meningococcal disease** were reported in line with seasonal expectations during winter. To the end of August, 177 cases of this disease were reported, including five people who have died. Intravenous penicillin can be life saving in suspected cases, and clinicians should notify suspected cases to their local public health unit in order to facilitate contact tracing and the instigation of preventive measures.

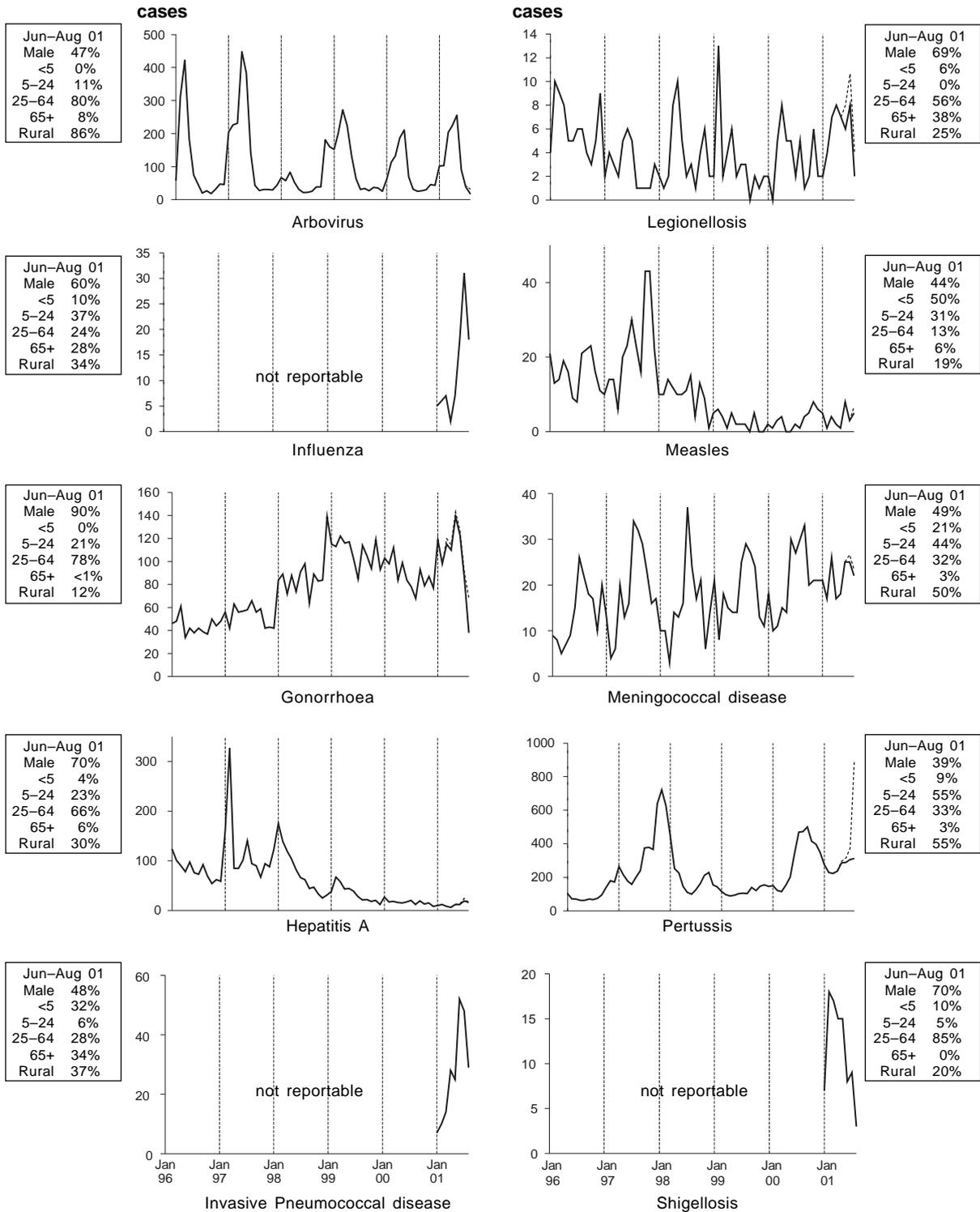
Reports of **influenza** appear to have peaked in August. Most cases were due to influenza A virus, and a minority were due to influenza B. The information that is available suggests that the 2001 influenza vaccine formulation protected against these strains. ☐

**FIGURE 1**

**REPORTS OF SELECTED COMMUNICABLE DISEASES, NSW, JANUARY 1996 TO AUGUST 2001, BY MONTH OF ONSET**

These are preliminary data: case counts for recent months may increase because of reporting delays. Laboratory-confirmed cases, except for measles, meningococcal disease and pertussis — actual . . . . . predicted after adjusting for likely reporting delays.

NSW population	
Male	50%
<5	7%
5-24	28%
25-64	52%
65+	13%



\* For definition, see NSW Public Health Bulletin, April 2000

**TABLE 1 REPORTS OF NOTIFIABLE CONDITIONS RECEIVED IN AUGUST 2001 BY AREA HEALTH SERVICES**

Condition	Area Health Service (2001)													Total for Aug†	Total To date†					
	CSA	NSA	WSA	WEN	SWS	CCA	HUN	ILL	SES	NRA	MNC	NEA	MAC			MWA	FWA	GMA	SA	CHS
<b>Blood-borne and sexually transmitted</b>																				
AIDS	-	-	1	-	-	-	-	-	1	-	-	-	-	-	-	-	-	-	3	66
Chancroid*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Chlamydia (genital)*	43	35	29	10	-	10	-	17	77	18	11	28	6	4	-	17	-	5	312	2,912
Gonorrhoea*	6	3	4	-	-	3	-	-	46	-	1	6	-	-	-	-	-	-	70	881
Hepatitis B — acute viral*	-	-	-	-	1	-	-	-	1	1	-	-	-	-	-	-	-	-	3	52
Hepatitis B — other*	81	36	23	-	-	9	-	8	55	2	2	6	2	-	3	-	-	230	2,830	
Hepatitis C — acute viral*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	94
Hepatitis C — other*	75	24	103	4	-	39	-	27	92	33	45	22	6	7	1	8	-	18	504	5,708
Hepatitis D — unspecified*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	11
HIV infection*	2	-	2	-	1	-	5	-	-	-	-	1	-	-	-	1	-	-	13	222
Syphilis	16	-	7	-	-	1	-	-	16	5	1	3	-	1	-	-	-	-	50	495
<b>Vector-borne</b>																				
Arboviral infection (BFV)*	-	-	-	-	-	-	-	-	-	5	8	-	-	-	-	-	-	-	13	335
Arboviral infection (Other)*	1	-	1	-	-	-	-	-	1	-	-	-	-	1	-	1	-	-	5	46
Arboviral infection (RRV)*	-	-	-	-	-	-	-	-	-	3	5	-	1	-	-	-	-	-	9	717
Malaria*	-	3	2	-	-	2	-	1	1	-	-	-	-	-	-	3	-	-	12	100
<b>Zoonoses</b>																				
Anthrax	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Brucellosis*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Leptospirosis*	-	-	-	-	-	-	-	-	-	1	1	-	-	-	1	-	-	-	3	46
Lysavirus	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Psittacosis	-	-	-	-	1	-	-	-	1	1	1	-	-	-	-	-	-	-	3	20
Q fever*	-	-	-	-	-	-	-	-	-	3	1	1	1	1	-	-	-	-	6	96
<b>Respiratory and other</b>																				
Blood lead level*	-	3	-	-	-	3	-	2	-	-	-	-	1	1	-	4	-	-	14	297
Influenza	4	2	6	-	1	-	-	2	4	4	3	3	-	-	-	-	-	-	29	92
Invasive pneumococcal infection	-	5	6	-	-	3	-	4	9	-	-	1	-	1	-	-	-	-	29	209
Legionnaires' longbeachae*	-	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	21
Legionnaires' pneumophila*	-	3	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	4	25
Legionnaires' (Other)*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1
Leprosy	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1
Meningococcal infection (invasive)	1	2	-	1	5	3	-	2	3	2	1	-	3	2	1	-	-	-	26	177
Tuberculosis	6	5	2	-	-	-	-	2	6	-	-	-	-	-	1	-	-	-	22	241
<b>Vaccine-preventable</b>																				
Adverse event after immunisation	-	1	-	-	-	-	-	-	-	-	-	-	-	-	-	1	-	-	2	54
H.influenzae b infection (invasive)*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	8
Measles	-	3	-	-	-	-	-	1	-	-	-	1	-	-	-	-	-	-	5	30
Mumps*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	18
Pertussis	9	114	38	-	36	7	-	24	16	44	20	21	35	14	-	62	-	440	2,413	
Rubella*	-	-	-	-	-	-	-	-	1	-	-	1	-	-	-	-	-	-	2	41
Tetanus	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
<b>Faecal-oral</b>																				
Botulism	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Cholera*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1
Cryptosporidiosis*	-	1	2	-	-	-	-	-	-	-	1	-	-	-	-	-	-	-	4	110
Food borne illness (not otherwise specified)	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	16
Gastroenteritis (in an institution)	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	258
Giardiasis*	-	9	8	-	-	1	-	-	8	6	4	1	1	-	5	-	-	43	665	
Haemolytic uraemic syndrome	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	5
Hepatitis A*	1	2	2	-	4	1	-	-	3	-	1	1	-	-	-	-	-	15	103	
Hepatitis E*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	9
Listeriosis*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	11
Salmonellosis (not otherwise specified)*	6	11	6	1	1	2	-	2	18	3	3	5	-	2	1	5	-	66	1,155	
Shigellosis	-	3	1	-	-	-	-	1	4	-	1	-	-	-	-	-	-	10	93	
Typhoid and paratyphoid*	-	1	-	-	2	-	-	-	1	-	-	-	-	-	-	-	-	4	27	
Verotoxin producing E. coli*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

\* lab-confirmed cases only † includes cases with unknown postcode

CSA = Central Sydney Area	WEN = Wentworth Area	NRA = Northern Rivers Area	MAC = Macquarie Area	GMA = Greater Murray Area
NSA = Northern Sydney Area	SWS = South Western Sydney Area	MNC = North Coast Area	MWA = Mid Western Area	SA = Southern Area
WSA = Western Sydney Area	CCA = Central Coast Area	NEA = New England Area	FWA = Far West Area	CHS = Corrections Health Service

## NSW PUBLIC HEALTH BULLETIN

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Dr Michael Giffin is managing editor.

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### Submission of articles

Articles, news and comments should be 1000–1500 words or less in length and include a summary of the key points to be made in the first paragraph. References should be set out in the Vancouver style, described in the *New England Journal of Medicine*, 1997; 336: 309–315. Send submitted articles on paper and in electronic form, either on disc (Word for Windows is preferred), or by email. The article must be accompanied by a letter signed by all authors. Full instructions for authors are available on request from the managing editor.

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