

National Health and Hospitals Reform Commission
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Please find attached National Breast and Ovarian Cancer Centre's submission on the National Health and Hospitals Reform Commission's draft Principles to shape Australia's health system.

We welcome the opportunity to review the draft Principles and support this important initiative to guide the future design and governance of health care in Australia.

Please contact A/Prof Christine Giles on 02 9357 9404 or via email on christine.giles@nbocc.org.au should you require any further information about our response.

Yours sincerely



Dr Helen Zorbas
Director

National Breast and Ovarian Cancer Centre (NBOCC)* is Australia's independent national authority and information source on breast and ovarian cancer. Funded by the Australian Government, NBOCC works in partnership with health professionals, cancer organisations, researchers, governments and those diagnosed to improve outcomes in breast and ovarian cancer.

NBOCC supports the establishment of a National Health and Hospitals Reform Commission (NHHRC) to shape the future of Australia's health care system. We welcome the opportunity to comment on the proposed Principles to guide this process of reform and the future design and governance of health care in Australia. This response will comment on the draft Principles and suggest proposals for consideration relevant to the values, approach and experience of NBOCC.

SUMMARY OF NBOCC KEY MESSAGES

- NBOCC has pioneered a collaborative approach to improving outcomes in breast and ovarian cancer where the consumer voice is involved at all levels. NBOCC supports the design of a health care system that is both responsive to and shaped around the needs of patients and their families.
- NBOCC supports the provision of evidence-based treatment and care delivered by appropriately trained staff.
- NBOCC has taken a leading role in promoting the uptake of multidisciplinary cancer care in Australia to link rural and regional clinicians with the knowledge and experience of colleagues in metropolitan centres, thus improving equity of access to health care services and minimising the need for patient travel. This model of care has applicability beyond cancer in the management of other chronic diseases.
- NBOCC supports the principle that all Australians have equity of access to health care services regardless of their geographic location, socio-economic status, language, culture or indigenous status. NBOCC also encourages innovative initiatives to 'close the gap' between Indigenous health status and that of other Australians.
- NBOCC supports initiatives to redress the balance in the health system to include a greater focus on prevention and recognises that healthy lifestyle strategies are needed to prevent and reduce the impact of chronic disease. NBOCC also acknowledges that a component of preventative health is the prevention of disease recurrence. General practitioners play a pivotal role in preventative health, early detection of disease and appropriate intervention. Additionally, public awareness campaigns and population screening programs are vital in encouraging the early detection of disease. NBOCC supports initiatives to increase cancer screening participation rates, overall and specifically in the Indigenous population.
- A comprehensive health care system includes the provision of follow-up care, support and information for people beyond their initial diagnosis and treatment built on a strong foundation of primary care.
- NBOCC supports a holistic approach to care that recognises not only a person's physical needs but their emotional, psychological, practical, cultural, spiritual and social needs.
- NBOCC supports strategic, evidence-based, long term planning for the Australian health care system beyond the three-year election cycle.
- The collection of nationally consistent data and ensuring this data is accessible in a timely manner is essential to health system transparency and accountability. High-quality and comprehensive data is essential for future health planning, financing and service decisions.
- The current management model of health service delivery can lead to a lack of autonomy at the hospital and area level, and therefore little flexibility in responding to the health needs of the local community. NBOCC supports the uptake of innovative models of care such as multidisciplinary care, which promotes evidence-based practice, continuity of care and collaboration between clinicians, reducing the hospital silo effect.
- NBOCC strongly supports a health system culture of reflective improvement and innovation built on a solid evidence base.

*In February 2008, National Breast Cancer Centre (NBCC) changed its name to National Breast and Ovarian Cancer Centre (NBOCC).

SUMMARY OF NBOCC PROPOSALS

Principle: People and family centred

- That evidence-based information be available for patients and families in a timely and accessible manner throughout their journey through the health care system.
- That technology to support multidisciplinary care case conferencing be made more widely available to support uptake of this model of care.
- That evidence of multidisciplinary care is provided against NBOCC's multidisciplinary care indicators.

Principle: Equity

- That Australian Health Care Agreement funding levels are set to provide adequate levels of health care services across metropolitan, regional and rural areas so all Australians have equity of access regardless of geography or socioeconomic status.
- That the multidisciplinary model of cancer care be supported for the management of other chronic diseases.
- That local and international success stories in Indigenous health are studied for application beyond their current use.
- That a more structured system of Indigenous health worker training, registration and support is established.
- That health professionals are supported to undertake Indigenous cultural competency training.

Principle: Shared responsibility

- That public health initiatives focus on health in the context of 'wellness' rather than 'sickness'.
- That communication skills be recognised as a compulsory professional competence for all health professionals and as part of continuing professional development.
- That fee for service arrangements should be evidence-based and have built in performance indicators and benchmarks.
- That smart technology solutions are supported to improve the management of people with complex health conditions.

Principle: Strengthening prevention and wellness

- That a cross sector approach is taken to preventative health with shared models and learning for benefits across a range of diseases.
- That the role of primary health practitioners in early detection strategies be supported through educational and funding initiatives.

Principle: Comprehensive

- That general practitioners are supported in their pivotal role of providing continuity of care throughout a person's journey through the health care system.
- That the primary care role is enhanced through education and funding to explore new paradigms/models of holistic health care.
- That initiatives are supported to boost access to multidisciplinary services in rural and regional Australia.

Principle: Taking the long term view

- That emerging technologies and therapies are monitored with a view to developing a long term, evidence-based approach to their potential provision in an equitable and sustainable way.

Principle: Transparency and accountability

- That a nationally coordinated, comprehensive, accessible and de-identified cancer database is established within two years to support cancer control including service delivery and for research applications.
- That the collection of nationally consistent cancer data by all States and Territories be included as a performance indicator under Australian Health Care Agreements for both cancer registry data and clinical registration.
- That the linking of data is supported, including Medicare data, as a cost-effective means of developing a national cancer database that complies with privacy standards.
- That the implementation of common data standards is supported to facilitate the combined use of data.
- That research and development in data collection methodologies is supported to optimise data availability and quality.

Principle: A respectful and ethical system

- That patients are provided with psychosocial support along their journey through the health care system and are encouraged to expect this support.
- That services implement psychosocial care as a standard part of care and provide evidence of this against NBOCC's indicators of psychosocial care.

Principle: Responsible spending on health

- That there be continued support for population health planning at the local/regional level.
- That services provide evidence of multidisciplinary care and data which supports key health outcomes as a requirement of funding agreements.
- That the provision of information and communication technologies is supported to promote the uptake of multidisciplinary care.

Principle: A culture of reflective improvement and innovation

- That there be greater integration of research and clinical expertise.
- That the NBOCC model of translational research be more broadly applied beyond cancer to improve the quality of services, care and health system performance across a range of chronic diseases.

Proposed design principles

PRINCIPLE: PEOPLE AND FAMILY CENTRED

Since its inception, NBOCC* has pioneered a collaborative approach where its program of work is both informed by and responsive to the needs of patients and their families. This collaboration extends across all aspects of the patient journey and pathway of care from pre-diagnosis through to treatment, follow-up care and issues regarding recurrence and survivorship.

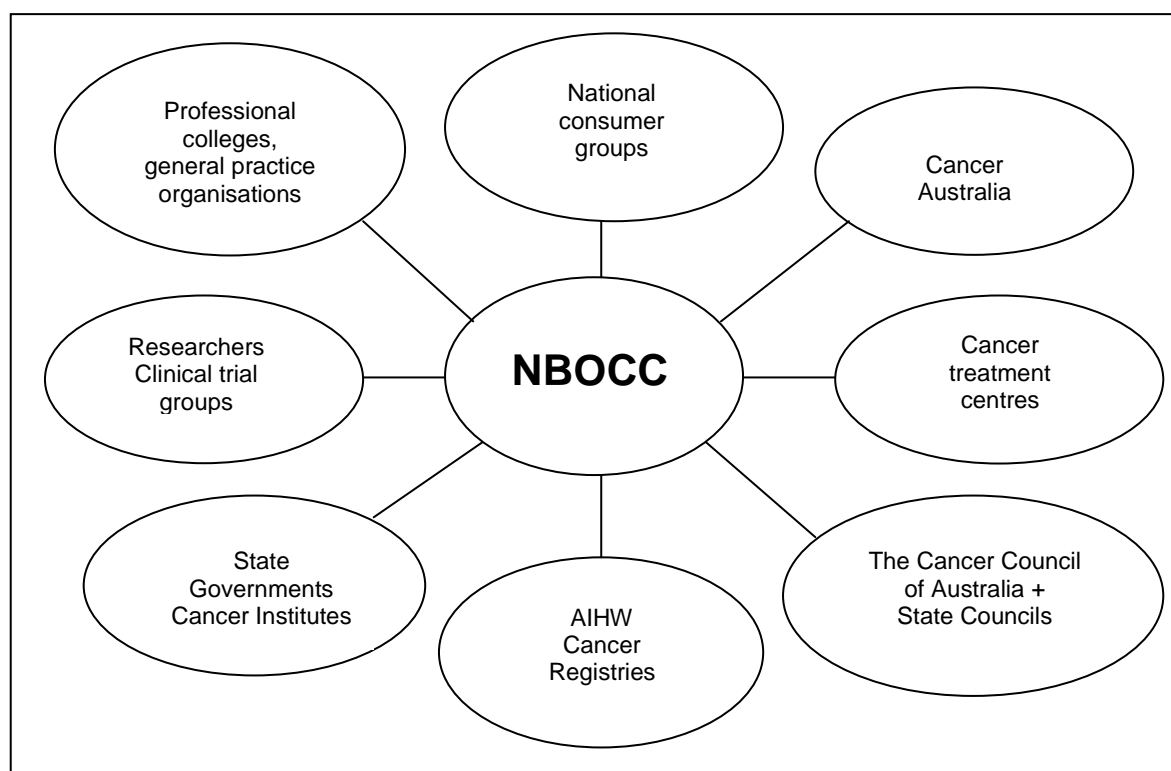


Figure 1: NBOCC network of national collaboration

Recognising the importance of the consumer voice

NBOCC held the first national conference of breast cancer patients (consumers) in 1998, which resulted in the establishment of the national consumer organisation Breast Cancer Network Australia. Today, the consumer voice is involved at all levels of NBOCC – from representation on all working groups guiding individual projects to membership on the Board of Directors. This collaborative and patient-centred approach is core to NBOCC's successful model and we would strongly support the design of a health care system that is both responsive to and shaped around the needs of patients and their families. Another example of the success of consumer involvement is Breast Cancer Network Australia's 'Seat at the Table Program' for breast cancer consumers, which has been lauded nationally and internationally.

A patient-centred approach is one that understands the person as a whole, not just a disease, and determines the design of a system which has relevance to the individual.

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Assistance to navigate pathways of care

NBOCC considers the provision of reliable and evidence-based information to be an integral component of a patient-centred health care system. The health care system is complex to navigate, particularly when a person is faced with the additional stress of a diagnosis such as cancer. Supporting information needs at all stages of the cancer journey is a major platform of NBOCC's work. This includes the provision of evidence-based information for those diagnosed (guiding them through all aspects of their diagnosis, treatment and care), and information to support the partners and families of those diagnosed – recognising that they have different information needs yet can actually experience higher levels of stress than the person diagnosed (NBCC & National Cancer Control Initiative, 2003). *See sections relating to the 'Comprehensive' and 'A respectful and ethical system' Principles for further details regarding the importance of care coordination, primary care and psychosocial care.*

NBOCC supports the provision of evidence-based information for both the person diagnosed and their family. However, this information needs to be supported by appropriate distribution strategies to ensure it reaches those who need it most at the appropriate time in their journey through the health care system. NBOCC experience shows there is a need for information in both hard copy format and online in a number of languages. There is an opportunity to provide evidence-based patient information in the form of a 'living document', so it can be reviewed and updated as new evidence emerges. New and emerging technologies including web 2.0, which embrace collaboration, interaction and information sharing, should be supported as information distribution channels.

Summary

- NBOCC has pioneered a collaborative approach to improving outcomes in breast and ovarian cancer.
- NBOCC supports the design of a health care system that is both responsive to and shaped around the needs of patients and their families.

Proposal

- That evidence-based information be available for patients and families in a timely and accessible manner throughout their journey through the health care system.

Providing the best possible care for patients

NBOCC strongly supports the provision of evidence-based treatment and care delivered by appropriately trained staff. This form of care is optimal and represents best practice. While it is desirable if this care can be delivered close to a patient's home, NBOCC recognises that there are times when specialised services are required and people may need to travel to receive the best possible care. However, where patients have to travel, ongoing support is required through nationally consistent and appropriately funded Government travel schemes.

NBOCC has taken a leading role in investigating and promoting multidisciplinary care in Australia, where clinicians in rural and regional areas can link in with a team of colleagues in metropolitan centres to discuss a patient's care, thus minimising the need for patient travel. NBOCC's *Principles of Multidisciplinary Care* (Zorbas et al. 2003) emphasise the need for:

- a team approach, involving core disciplines integral to the provision of good care, including general practice, with input from other specialties as required,
- communication among team members regarding treatment planning,

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- access to the full therapeutic range for all patients, regardless of geographical remoteness or size of institution,
- provision of care in accordance with nationally agreed standards, and
- involvement of patients in decisions about their care.

This model of care has applicability beyond cancer in the management of other chronic diseases. The wider availability of technologies to support case conferencing, such as videoconference facilities, will support the uptake of multidisciplinary care across Australia, which has been shown to improve the provision of best practice care and the quality of life for patients (Chang et al. 2001).

Summary

- NBOCC supports the provision of evidence-based treatment and care.
- NBOCC has taken a leading role in promoting the uptake of multidisciplinary cancer care in Australia.

Proposal

- That technology to support multidisciplinary care case conferencing be made more widely available to support uptake of this model of care.
- That evidence of multidisciplinary care is provided against NBOCC's multidisciplinary care indicators.

PRINCIPLE: EQUITY

NBOCC supports the principle that all Australians have equity of access to health care services regardless of their geographic location, socio-economic status, language, culture or indigenous status and recognises the importance of a universal health care system in providing this access.

Improving equity of access

Over the last decade there has been a shift of hospital services from public to private. Today, more than half of breast cancer surgery is done in the private sector (Giles C et al. 2008). At the same time, the capacity of the public system to reasonably meet people's medical needs has been constrained (Commonwealth Grants Commission, 2008). These combined factors have reduced access to a range of critical services for cancer patients including care coordination and follow-up care, and women with breast cancer in rural and remote areas are either required to travel in difficult circumstances to receive quality health care or go without. NBOCC proposes that Australian Health Care Agreement funding levels are set to provide adequate levels of health care services across metropolitan, regional and rural areas so all Australians have equity of access regardless of geography or socioeconomic status.

NBOCC's *Directory of hospital based breast cancer services* (www.nbocc.org.au/hsd) and *Directory of gynaecological oncology services* (www.ovariancancerprogram.org.au/dir) aim to improve equity of access by providing patients and referring doctors in rural and regional Australia with detailed information about the range of services available both in their local area and through established referral links to specialist services in other regions. This information helps doctors to make appropriate referrals for their patients and helps patients to make decisions about their treatment choices, irrespective of where they live.

NBOCC is also driving the uptake of multidisciplinary cancer care in Australia to improve patient care in small facilities and geographically isolated areas by linking rural and regional health care professionals with the knowledge and experience of cancer teams in larger centres. This model of care has application beyond cancer for management of other chronic diseases and provides an opportunity to engage both primary care and community based care providers.

Summary

- NBOCC supports the principle that all Australians have equity of access to health care services regardless of their geographic location, socio-economic status, language, culture or Indigenous status.
- In recent years there has been a reduction in access to health care services.

Proposal

- That Australian Health Care Agreement funding levels are set to provide adequate levels of health care services across metropolitan, regional and rural areas so all Australians have equity of access regardless of geography or socioeconomic status.
- That the multidisciplinary model of cancer care be supported for the management of other chronic diseases.

‘Closing the gap’

NBOCC supports initiatives to ‘close the gap’ between Indigenous health status and that of other Australians. We support innovative approaches and believe there is an opportunity for a more flexible approach to funding streams reaching across diseases through cross sector and community partnerships. It is also important to study the success stories in the area of Indigenous health and investigate their application beyond current use.

Through its work in Indigenous health worker education, NBOCC recognises the important role these health professionals have to play in closing the gap and supports initiatives to increase and support this workforce through more formal training pathways, mentoring and opportunities for career development. A more structured system of Indigenous health worker registration would provide better communication channels and support. NBOCC recognises that cultural competency of health professionals in cancer service delivery could improve practice and outcomes for Indigenous patients by addressing patients’ needs in the ‘foreign’ environment of the hospital system. NBOCC is working to identify areas for research into Indigenous cultural competency training, areas where awareness levels could be raised and areas for resource development. There is an opportunity to work closely with the Indigenous community in the re-design of the health care system to improve outcomes and begin to ‘close the gap’.

Summary

- NBOCC encourages innovative initiatives to ‘close the gap’ between Indigenous health status and that of other Australians.

Proposal

- That local and international success stories in Indigenous health are studied for application beyond their current use.
- That a more structured system of Indigenous health worker training, registration and support is established.
- That health professionals are supported to undertake Indigenous cultural competency training.

PRINCIPLE: SHARED RESPONSIBILITY

NBOCC agrees that responsibility for health and wellbeing and the success of the health care system involves shared responsibility between individuals, the community and health professionals.

Supporting people to make healthy choices

Individuals have a responsibility regarding the choices they make in relation to their lifestyle and personal risk behaviours. However, to make healthy choices, people require access to information and tools to support their decision-making. NBOCC's online calculator *Your risk and breast cancer* (www.nbocc.org.au/risk) translates the evidence about risk factors for breast cancer into a meaningful tool for individuals and puts the evidence into play for each woman who uses it. Through a series of questions, the tool calculates each woman's personal level of breast cancer risk compared to another woman of her age and provides useful information about lifestyle changes she may wish to make to reduce her risk of the disease. This method of information provision empowers people by putting health choices in a positive context of risk reduction.

Summary

- To make healthy choices, people require access to information and tools to support their decision-making.

Proposal

- That public health initiatives focus on health in the context of 'wellness' rather than 'sickness'.

Communicating rights and responsibilities

Patient charters of rights are useful documents in setting out what patients are entitled to expect from the health care system and the responsibilities of both the patient and health care providers. NBOCC supports the establishment of the Australian Commission on Safety and Quality in Health Care's National Patient Charter of Rights as an effective way of promoting the partnership between the patient and their treatment team.

Summary

- NBOCC supports the establishment of a National Patient Charter of Rights to promote the partnership between the patient and treatment team.

Improving the communication of health professionals

Health professionals have a responsibility to communicate clearly with their patients. Evidence shows the way a clinician and the treatment team relates to, and communicates with a patient can significantly benefit the patient and their family, including improvements in psychosocial adjustment, decision-making, treatment compliance and satisfaction with care (NBCC & NCCI, 2003). Through its international model of best practice, NBOCC supports health professionals by conducting evidence-based communication skills training at the local level and advocates for communication skills to be a compulsory professional competence for all health professionals.

Proposal

- That communication skills be recognised as a compulsory professional competence for all health professionals and as part of continuing professional development.

Assistance with the management of complex health conditions

While there is individual responsibility involved in maintaining health and wellbeing, it must be acknowledged that there is a limit to which illness can be prevented. When a person is diagnosed with a complex health condition, it is the responsibility of the health care system to provide assistance for them to manage this illness, particularly chronic conditions such as many cancers. As indicated above, a major component of this involves ensuring people have access to a full range of speciality services, either locally at health service hubs or via established referral pathways and travel support. As noted above, there is an opportunity to engage both primary care and community based care providers and to put in place incentives to reward this engagement.

In addition, there is an opportunity for the application of smart technology solutions to improve links between treatment teams and patients in rural and regional areas. Technology, such as video conferencing and hand-held patient information devices to monitor patients and communicate test results, has the potential to reduce the number of face-to-face follow-up visits required and therefore reduce patient travel while still providing ongoing support and assistance in patient management of their condition.

Proposal

- That fee for service arrangements should be evidence-based and have built in performance indicators and benchmarks.
- That smart technology solutions are supported to improve the management of people with complex health conditions.

PRINCIPLE: STRENGTHENING PREVENTION AND WELLNESS

NBOCC supports initiatives to redress the balance in the health system to include a greater focus on preventative health.

Reducing burden of disease through preventative health measures

In 2000-2001 breast cancer had a lifetime treatment cost of \$11,897 (NBCC & Australian Institute of Health and Welfare, 2006). It is estimated that ten per cent of breast cancers worldwide can be attributed to physical inactivity (Mezzetti et al. 1998) and about five per cent of breast cancers in Australia are attributable to alcohol consumption (NBOCC 2008) – both modifiable factors. Cancer Research UK (2007) has estimated that if women began to make healthy changes to their lifestyles now, that by 2024 one in ten cases of breast cancer could be prevented. This highlights the potential to decrease the burden of disease on the system by reducing the number of women diagnosed with breast cancer.

Obesity, smoking, physical inactivity and alcohol consumption are well established risk factors for a number of chronic diseases, including several types of cancer. A 2008 report from the Australian Institute of Health and Welfare has highlighted that 40 per cent of Australian women are overweight or obese and this level is on the rise. The same report indicated that two-thirds of Australians are not exercising enough to benefit their health. All of these findings indicate the need for healthy lifestyle strategies to prevent and reduce the impact of chronic disease. NBOCC supports a cross sector approach to preventative health with shared models and learning for benefits across a range of diseases. It may also be useful to engage with agencies such as the Oxford Health Alliance to share experiences at an international level.

NBOCC also acknowledges that a component of preventative health is the prevention of disease recurrence. This will have most application in the follow-up stage of a patient's care. It is vital that patients are provided with adequate support, education and follow-up to manage their condition, prevent recurrence if possible, or if recurrence does occur, to ensure it is detected early. NBOCC is working to improve breast and ovarian cancer follow-up care through the updating of clinical practice recommendations in this area.

Summary

- NBOCC supports initiatives to redress the balance in the health system to include a greater focus on prevention.
- Healthy lifestyle strategies are needed to prevent and reduce the impact of chronic disease.
- NBOCC acknowledges that a component of preventative health is the prevention of disease recurrence.

Proposal

- That a cross sector approach is taken to preventative health with shared models and learning for benefits across a range of diseases.

Early detection and appropriate intervention

Early detection of disease and appropriate intervention can lead to decreased morbidity and mortality as well as cost savings for the health system. NBOCC has a track record of promoting early detection and awareness to find disease early. Studies have indicated that women who participate in preventative health examinations with general practitioners are significantly more likely to undergo breast cancer mammography screening, thereby increasing their chances of early detection of the disease (Fenton et al. 2007). NBOCC recognises the important role of primary care in preventative health, early detection of disease and appropriate intervention. NBOCC supports general practitioners in this role through the development of educational resources and training workshops to ensure the appropriate investigation and referral of people who present with breast or ovarian cancer symptoms.

Ensuring people with symptoms of disease consult their general practitioner is a crucial step towards early detection. A survey of 3000 Australian women conducted by NBCC (2005) found 37 per cent of women who experienced a change in the look or feel of their breast waited more than one month to see their general practitioner and 23 per cent of women did not see a doctor at all. Public information campaigns encompassing mass media and online elements, such as NBOCC's breast and ovarian cancer awareness campaigns, have been shown to be effective in educating the community about disease symptoms and the importance of early detection.

Cancer screening programs also play a vital role in the early detection of disease. Research shows breast cancer screening reduces deaths from breast cancer by approximately 35 per cent in women aged 50-69 years (World Health Organisation International Agency for Research on Cancer, 2002). Mammographic screening can detect cancers in their earliest stages, when they are small and can be treated most successfully. A NBCC/Australian Institute of Health and Welfare Report (2007) shows that the five-year survival rate for women whose breast cancers are 10mm or less in diameter is almost as high as for women

without breast cancer (98 per cent relative survival rate). This survival rate declined to 73 per cent for women with larger cancers of 30 mm or more in diameter. Overall, 87 per cent of women diagnosed with breast cancer today can expect to be alive five years after their diagnosis. This represents a significant improvement on the five-year survival rate of 71 per cent for women diagnosed in 1982-1986 (NBCC & AIHW 2006).

NBOCC supports initiatives to increase screening participation rates in the target age group from the current rate of approximately 56 per cent to achieve the benchmark rate of 70 per cent identified by the National Health and Hospitals Reform Commission (2008) for the next Australian Health Care Agreements. NBOCC also supports initiatives to increase screening rates amongst Indigenous women. Indigenous women experience higher rates of breast cancer mortality than the non-Indigenous population and have lower levels of participation (35 per cent) in mammography screening (AIHW 2007). NBOCC also supports the implementation of new technologies, such as digital mammography.

Summary

- General practitioners play a vital role in preventative health, early detection of disease and appropriate intervention.
- Public awareness campaigns are vital in encouraging the early detection of disease.
- NBOCC supports the continuation of population health screening programs and initiatives to increase cancer screening participation rates, overall and specifically in the Indigenous population.

Proposal

- That the role of primary health practitioners in early detection strategies be supported through educational and funding initiatives.

PRINCIPLE: COMPREHENSIVE

People have a multiplicity of different health needs throughout their lifetime as well as throughout the management of a chronic condition or illness.

Comprehensive continuity of care

Using breast cancer as an example, with more women surviving breast cancer than ever before, the next challenge for the health care system is to ensure we expand the focus to include life beyond breast cancer or 'survivorship' and deal with issues related to the long term impact of diagnosis and treatment on physical and emotional health. Many breast cancer survivors experience high levels of stress and anxiety associated with the fear that cancer may return. Survivors can also experience a range of problems about body image after surgery, loss of fertility for younger women, fatigue, financial, work and relationship issues (NBCC & NCCI, 2003). These issues traditionally coincide with a time when there is reduced contact with the acute health care team. A comprehensive health system includes the provision of appropriate follow-up care, support and information for people beyond their initial diagnosis and treatment.

Additionally, follow-up care needs to be more comprehensive than just the detection of recurrence. There is need for comprehensive follow-up of a person's overall health and wellbeing, including their psychosocial wellbeing. For example, along with cancer recurrence, osteoporosis, cardiovascular insufficiency and lymphoedema are all comorbidities experienced by women who have been treated for breast cancer. Therefore, a holistic

approach to follow-up care is required to detect and manage the onset of such conditions. NBOCC is investigating new models of follow-up care for women with breast cancer, such as shared care, that integrates oncology with primary care follow-up. The aim of this model is to provide a community based, holistic approach to follow-up care, ensuring equity of access and quality of outcomes for women with breast cancer.

The pivotal role of primary care

Coordinating the transition between different stages of care along the patient journey is another challenge the health system faces. General practitioners are ideally placed to provide continuity of care throughout a person's journey through the health care system. General practitioners are also best placed to provide health and wellbeing advice to reduce risk of disease or disease recurrence. It is noted that the pivotal role of the general practitioner underpins 13 of the 19 intervention points in the National Service Improvement Framework for Cancer (National Health Priority Action Council, 2005), where the Government might most usefully invest to reduce death and distress from cancer – from risk reduction through to palliation. This reflects the importance of having a strong foundation of primary care as an integral component of the Australian health care system.

Summary

- A comprehensive health care system includes the provision of follow-up care, support and information for people beyond their initial diagnosis and treatment.
- A strong foundation of primary care is an integral component of the Australian health care system.

Proposal

- That general practitioners are supported in their pivotal role of providing continuity of care throughout a person's journey through the health care system.
- That the primary care role is enhanced through education and funding to explore new paradigms/models of holistic health care.
- That initiatives are supported to boost access to multidisciplinary services in rural and regional Australia.

Proposed governance principles

PRINCIPLE: TAKING THE LONG TERM VIEW

NBOCC supports strategic, long term planning for the Australian health care system beyond the three-year election cycle.

A strategic, evidence-based approach

Where possible, long term planning should be informed by research evidence, expert opinion and consensus canvassing a range of stakeholder voices. NBOCC has developed an innovative approach to the translation of evidence into practice through extensive collaboration with stakeholders, including health care providers, consumers, Government and researchers. The NBOCC approach ensures evidence-based information is available in a timely manner and appropriate format for all health professionals and women diagnosed with breast or ovarian cancer.

Monitoring emerging technologies and research requires a long term view to its potential benefits and impact on the health care system. One emerging area, for example, is the trend towards targeted cancer therapies. As knowledge increases about the features of different tumour types, new treatments can be developed to better target individual cancers. While this provides better outcomes for patients, it also results in more costly therapies because the initial development costs are shared among fewer users. The provision of multiple specialised treatments may also have implications for health service delivery. Trends such as this need to be monitored with a view to developing a long term, evidence-based approach to the potential provision of such treatments in an equitable and sustainable way.

Summary

- NBOCC supports strategic, evidence-based, long term planning for the Australian health care system beyond the three-year election cycle.

Proposal

- That emerging technologies and therapies are monitored with a view to developing a long term, evidence-based approach to their potential provision in an equitable and sustainable way.

PRINCIPLE: TRANSPARENCY AND ACCOUNTABILITY

NBOCC considers the collection of nationally consistent, timely and accessible data essential to health system transparency and accountability. NBOCC has written to the Minister for Health and Ageing to request that consideration be given to the issue of nationally consistent cancer data collection and that it be accessible under the new Australian Health Care Agreements.

Improving data collection and accessibility

High-quality and comprehensive data is essential for future health planning, financing and service decisions. Yet the collection of nationally consistent data and access to this data is currently constrained by differences in practices of population-based cancer registries, clinical registries, impediments to data linkage and significant data gaps across the public and private sectors. These and other constraints place serious limits on the current system's capacity to monitor cancer control, identify emerging issues and plan cancer services.

Nationally consistent, accessible and linked data collections across the public and private sectors and all States and Territories would inform population health research, health surveillance and monitoring, and the evaluation and improvement of health service delivery. Moreover, it would result in improved ability to better assess the impact of policy changes and system response to policy settings and the opportunity to examine and propose alternate, cost-effective service pathways.

NBOCC has engaged with cancer registries nationally and with clinical groups to promote consistency in cancer data collection and reporting including the development of minimum data sets for breast and gynaecological cancer. NBOCC will be conducting further work in this area as part of its upcoming business plan to refine and implement the minimum data sets and to report on data trends in breast and ovarian cancer. NBOCC's policy paper on the topic of nationally consistent data collection, which includes a proposed model for data linkage, is attached with this submission.

Summary

- The collection of nationally consistent data and ensuring this data is accessible in a timely manner is essential to health system transparency and accountability.
- High-quality and comprehensive data is essential for future health planning, financing and service decisions.

Proposal

- That a nationally coordinated, comprehensive, accessible and de-identified cancer database is established within two years to support cancer control including service delivery and for research applications.
- That the collection of nationally consistent cancer data by all States and Territories be included as a performance indicator under Australian Health Care Agreements for both cancer registry data and clinical registration.
- That the linking of data is supported, including Medicare data, as a cost-effective means of developing a national cancer database that complies with privacy standards.
- That the implementation of common data standards is supported to facilitate the combined use of data.
- That research and development in data collection methodologies is supported to optimise data availability and quality.

PRINCIPLE: A RESPECTFUL AND ETHICAL SYSTEM

A respectful and ethical system involves a holistic approach to care that recognises not only a person's physical needs but their emotional, psychological, practical and social needs. For example, a diagnosis of cancer marks the beginning of a journey full of emotional, psychological, physical and practical challenges. These challenges can relate to the shock of a cancer diagnosis and fears about the future, or perhaps due to the physical side-effects of treatment such as nausea and fatigue. There are also the practical costs of treatment for consideration and the financial implications of taking time off work. More specific emotional problems can range from concerns about body image after treatment to periods of anxiety or depression. Research shows approximately 20-35 per cent of cancer patients experience depression. This can have a major impact on a person's capacity to cope with their diagnosis and may reduce patient adherence to recommended treatments (NBCC & NCCI, 2003).

The importance of psychosocial care

Patients should be provided with psychosocial support along their journey through the health care system and should be encouraged to expect this support to assist with any emotional, physical or practical challenges they are facing. Additionally, Australia has one of the most multicultural populations in the world and it is essential that the Australian health care system recognises that people have different cultural and spiritual sensitivities and that treatment and support services have the capacity to cater to these needs.

NBOCC has conducted significant work in the area of psychosocial care and produced the world-first *Clinical practice guidelines for the psychosocial care of adults with cancer* in collaboration with the National Cancer Control Initiative. The guidelines cover all stages of care from diagnosis through to treatment and palliation and have been designed for use by all members of the treatment team. Implementation of the guidelines has the potential to improve health outcomes for patients with cancer, including a reduction in psychological morbidity and emotional distress of cancer patients and their families, improved wellbeing and increased satisfaction with care (NBCC & NCCI, 2003). A suite of resources has been developed to supplement the guidelines including a psychosocial care referral checklist and a consumer resource to promote the uptake of NBOCC recommendations into routine clinical practice.

Summary

- NBOCC supports a holistic approach to care that recognises not only a person's physical needs but their emotional, psychological, practical and social needs.
- NBOCC developed the world-first *Clinical practice guidelines for the psychosocial care of adults with cancer*.

Proposal

- That patients are provided with psychosocial support along their journey through the health care system and are encouraged to expect this support.
- That services implement psychosocial care as a standard part of care and provide evidence of this against NBOCC's indicators of psychosocial care.

PRINCIPLE: RESPONSIBLE SPENDING ON HEALTH

Management and funding of health care services

The current management model of health service delivery consisting of at least three levels of management – central, area and hospital – can lead to a lack of autonomy at the hospital and area level, and therefore little flexibility in responding to the health needs of the local community. A population health approach at the local/regional level underpins appropriate public health outcomes and should inform service configuration. NBOCC is supportive of funding mechanisms to reward best practice, evidence-based care. Conversely, care should not be delivered where there is evidence of its harm.

Supporting the uptake of innovative models of care

NBOCC has taken a leading role in promoting the uptake of a multidisciplinary model of cancer care. However, Australia presents a challenge for the implementation of multidisciplinary care, given its geography and significant regional differences in population, resource availability and access.

There is evidence that decisions made by a multidisciplinary team are more likely to be in accord with evidence-based guidelines than those made by individual clinicians (Chang et al. 2001). Furthermore, multidisciplinary care promotes continuity of care and collaboration between clinicians, reducing the hospital silo effect.

NBOCC has developed recommendations for multidisciplinary cancer care in Australia and a range of resources to promote uptake of this model of care. However, an NBOCC forum series (2006) highlighted a lack of adequate facilities, such as digital imaging, pathology viewers, video/teleconference facilities and other telemedicine initiatives, as barriers to the implementation of multidisciplinary care. These information and communication technologies are particularly important in linking rural and regional health professionals with a wider multidisciplinary team to provide high quality care. There is an opportunity to invest in information and communication technologies to link larger centres, where specialist services are based, with smaller regional sites and community based services.

Summary

- The current management model of health service delivery can lead to a lack of autonomy at the hospital and area level, and therefore little flexibility in responding to the health needs of the local community.
- Multidisciplinary care promotes evidence-based practice, continuity of care and collaboration between clinicians, reducing the hospital silo effect.

Proposal

- That there be continued support for population health planning at the local/regional level.
- That services provide evidence of multidisciplinary care and data which supports key health outcomes as a requirement of funding agreements.
- That the provision of information and communication technologies is supported to promote the uptake of multidisciplinary care.

PRINCIPLE: A CULTURE OF REFLECTIVE IMPROVEMENT AND INNOVATION

NBOCC strongly supports a health system culture of reflective improvement and innovation built on a solid evidence base. As a founding member of the Health Services Research Association of Australia and New Zealand, NBOCC supports continued investment in health service research to develop this evidence base and drive improved health service delivery and health outcomes.

NBOCC supports priority being given to research to improve clinical care. This means research priorities are informed by the needs of clinicians and conversely, that the application of research into clinical care can be facilitated through this active integration of clinical and research expertise.

NBOCC's successful model of translational research

Reflective improvement and innovation is central to NBOCC's work model. Since its inception in 1995, NBOCC has pioneered an innovative approach to the translation of evidence into practice, centred on a systematic evidence-based approach, a strong consumer focus and collaboration with stakeholders. Through this approach, NBOCC contributes to national cancer control through behavioural, social, organisational, systems and population-level initiatives.

The NBOCC model, or 'evidence loop', is based on the Deming Cycle of 'plan, do, study, act' to promote continuous quality improvement. In recognition of the successes achieved in breast cancer, the Australian Government extended NBOCC's mandate in 2001 to coordinate the first National Ovarian Cancer Program. Innovation is essential to NBOCC's approach, with projects consistently studying, developing and promoting new models of care to improve service delivery including multidisciplinary care, the specialist breast nurse model and new models of follow-up cancer care.



Figure 2. The NBOCC 'evidence loop'

NBOCC also supports the sharing of practices. NBOCC's successful model of translational research has broader applicability beyond cancer. This model has the potential to play a key role in improving the quality of services, care and health system performance across a range of chronic diseases for the health of all Australians.

Summary

- NBOCC strongly supports a health system culture of reflective improvement and innovation built on a solid evidence base.
- NBOCC supports greater integration of research and clinical expertise.

Proposal

- That there be greater integration of research and clinical expertise.
- That the NBOCC model of translational research be more broadly applied beyond cancer to improve the quality of services, care and health system performance across a range of chronic diseases.

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