



WITNESS STATEMENT OF ROBERT JOHN SHEDDEN THOMAS

I, Professor Robert John Shedden Thomas OAM, Deputy Chairperson of the Victorian Comprehensive Cancer Centre, of Level 10, 305 Grattan Street, Melbourne, Victoria 3000, say as follows:

Background

- 1 I am a Special Advisor on Health to the Victorian Government and University of Melbourne, and Chair of the Advisory Board of Cancer Australia. I am co-chair of the National Cancer Expert Reference Group (**NCERG**), an Australian Government committee. I am also Deputy Chair of the Victorian Comprehensive Cancer Centre (**VCCC**) and one of two independent members of the VCCC Board.

Attached to this statement and marked 'RT-1 is a copy of my current curriculum vitae.

- 2 I have practised as a surgeon most recently as Director of Surgical Oncology at Peter MacCallum Cancer Centre. My experience made me passionate about cancer system reform, and as Chief Cancer Advisor to Government over the past 10 years I have worked to provide all Victorians with the benefits of multidisciplinary care, appropriate psychosocial support for cancer consumers and carers, and access to the best translational research.
- 3 I am giving evidence to the Royal Commission into Victoria's Mental Health System in my personal capacity.

The Victorian cancer system

- 4 The Victorian Health system consists of multiple institutions governed by local Boards. In general there is no system approach to the delivery of care. The Victorian cancer system is ill defined but grew out of the recognition that no one institution could provide for all the needs of the cancer patient. The cancer system aims to provide optimal care for all Victorians. Within this conceptual system, there are a number of programs and initiatives that have been developed. Among these are creation of the integrated cancer services and the concept of metropolitan and regional cancer centres. While there is no formal linkage between these entities, there are semi-formal linkages between the various entities across Victoria, which are the basis of the 'system'
- 5 Some years ago, the Victorian Government adopted a number of principles to help manage the expected increase in the number of cancer patients as a result of the ageing population. A new Ministerial Advisory Committee had oversight of a cancer reform

agenda based on a commissioned plan 'A cancer services framework for Victoria (2003)'. The integrated cancer services arose from this plan and there was agreement that the Peter MacCallum Cancer Centre should move to Parkville from East Melbourne. This paved the way for the development of the concept of the VCCC. The VCCC was developed originally to link the Parkville institutions but its first Board took the decision to include a total of 10 leading medical research, academic and clinical institutions with the shared goal of improving outcomes for Victorian cancer patients. The functions and objectives of the VCCC include improving the clinical care of all Victorians, improving research into cancer and providing educational opportunities for people interested in cancer care.

Introduction to the VCCC

- 6 The VCCC is Australia's first comprehensive cancer centre as broadly defined by the National Cancer Institute, Bethesda, Maryland USA. A comprehensive cancer centre, as created in the VCCC, provides the framework to encourage an integrated and multidisciplinary approach to research, education and clinical care for cancer consumers. The VCCC was established in recognition of the fact that collaboration between institutions or partners facilitates cancer research and clinical care, providing significant benefits to researchers and cancer consumers.
- 7 The VCCC is both government and partner funded. It also has access to philanthropy and conventional funding bodies. It has a general brief to improve cancer care for all Victorians. Its role is to provide both leadership for cancer-related programs and funding support for clinical research, clinical trials and education programs. In principle, the VCCC does not undertake research, clinical trials or clinical care itself. These are conducted by the VCCC's partners, and where appropriate by other institutions in Victoria. The VCCC partners are both public hospitals and research institutes, broadly geographically located. However the VCCC does have a responsible leadership role in a new research Centre for Cancer Immunotherapy based on Level 11 of the VCCC building where it is partnered by the Peter MacCallum Cancer Centre and the University of Melbourne. This provides a strong core of productive research directly associated with the VCCC
- 8 The VCCC by its structure has direct linkages with its partners, and also has indirect and subtle connections to health services across Victoria allowing them to be aligned with the VCCC's strategy. Its role is complex, being an influential and inspirational resource-supported platform for encouraging collaboration and integration, rather than a structured system or service provider.

Research and collaboration

VCCC's strategies to inspire and foster research and collaboration

- 9 The VCCC funds and promotes a multifaceted, collaborative program of research, clinical trials and education initiatives. It can encourage sharing of effective clinical practices and influence the activities of its partner organisations. The VCCC employs around 45 people whose role is to facilitate the complex research-based government-approved program. Within its complex research objectives, there are elements related to laboratory research, traditional medicine, genomics, nursing and psycho-oncology amongst others. Enhancement of clinical trials recruitment has been a key instruction from government. A prominent partner of the VCCC is the University of Melbourne, particularly demonstrated in the advancement of health services research with data collection and analysis.
- 10 One strategy deployed by the VCCC to inspire collaborative action is the embracing of research and clinical champions. These appointed leaders are individuals employed by and drawn from the partners. They are paid by funds from the VCCC for this work and they are responsible for collaborative research in their area of interest across the partners. For example the breast cancer lead, a prominent clinician and researcher, is tasked to enhance research and clinical care in the breast cancer domain across all the VCCC partners.
- 11 In the context of cancer treatment, the VCCC has support from the Department of Health and Human Services in accessing strong data collection processes across its alliance. This is, in part, due to the influence of the research and clinical champions operating amongst its partner health services. These datasets are available to interested groups to enable research including laboratory, clinical and health services research. Cancer therapeutic programs are based on data evaluation and monitoring of the effectiveness of that program. This is because practitioners must have an in time understanding of the efficacy of current treatment models so that any non-effective elements can be redirected. In the mental health space, the lack of this type of collaborative data collection appears to be a block to developing more effective models of care.
- 12 The impact the VCCC has can also be attributed in part to the development of a culture where linkages and networking are part of its main function. This means that the VCCC is designed to add value to the partners' activities by collaborative work. Leadership and appropriate resource delivery (including funding) within clinical streams is key to the success of such a venture. Another part of the VCCC's success is that it has provided a focus of attention for both government as well as protagonists in the health field. This is because it has the capacity to support consumer involvement and the multi-disciplinary professionals in the promotion of clinical research and clinical trials. It has provided a real sense of focus for cancer matters within the Victorian health system.
- 13 For any strategy to be effective, it is necessary that adequate funding and resources are provided. These are critical to promote collaboration between partners to advance research. For organisations that cannot do clinical research on their own, the provision of

supporting resources makes a huge difference, when properly targeted, to allow for the carrying out of this work. Often an organisation or group of organisations can only deliver on research and collaborative projects when provided with a person or persons to provide the project management, data collection, communication or administrative support required to just make it happen.

International models and learnings for a mental health collaborative centre

- 14 There are many collaborative cancer centres operating internationally and they have a wide variety of governance arrangements and models that vary depending on local in -place services and how each centre can best align with those services. It is thus difficult to determine general learnings from the operation of these alliances. However the concepts previously outlined are common to all successful centres overseas. Encouragement of collaboration across different institutions both to maximise research output and enhance clinical care are uniform features of comprehensive cancer centres across the world. I have no information about mental health centres which may exist.
- 15 At its simplest, the most effective model to influence activity is to provide seed funding and required support through project officers for collaborative research, program development and knowledge sharing between otherwise different institutions within the particular collaborative cancer centre. Most international collaborative centres have a 'light touch' administrative hand over a system for allocation of support of research projects between different institutions within the alliance. In essence the collaborative centre should not compete with its partner organisations
- 16 The establishment of a Victorian Collaborative Centre for Mental Health and Wellbeing could play a key role in several areas. It would be an internationally recognised Centre of Excellence, with a particular reputation and skill usually in one or a small number of particular areas of Mental Health. It would facilitate the development of multidisciplinary teams both intrinsic and also networked across other organisations. It could provide clinical care to a special area of clinical activity and aim for world leading research in this area of interest. The Centre cannot do everything, though. It could impact on the rest of the mental health system by facilitating data collection and analysis across Victoria and by metropolitan and regional networking thus providing support across the whole spectrum of Victorian mental health organisations. It could first provide a facility for the development of standardised or optimal pathways for care in mental health across the whole sector. This would bring together many different groups and disciplines in mental health to facilitate interaction and collaboration and create an acceptance of a practical way ahead for each of the varied elements of clinical need. It could then evaluate the outcomes of such treatment pathways to support clinical research with clinical trials of different therapies. It would also have a powerful role in developing the next generation of academic research driven psychiatrists.

- 17 It is a complex but productive task to either empower a collaborative centre to impact on Victorian-wide mental health management and, where appropriate, to lead by example and encourage allegiance to an agreed system of care. Integrated and collaborative clinical research in the mental health sector would be a key driver of improved care across Victoria and the different clinical streams.
- 18 Collaborative organisations such as the VCCC need to be well-resourced, with definite objectives, and must be staffed by professionals who are inspirational leaders in the relevant field. The health system is sometimes described as a complex adaptive system. It is multifaceted, has variable funding, and different professions all of which can be resistant to change. The only way a comprehensive collaborative centre can have impact is by persuasion, evidence and inspirational leadership. This of course has to be backed with human resources to support the practical implementation of improvement programs.

Multidisciplinary care: research benefits for mental health

- 19 Some of the most significant successes in an appropriate and effective multidisciplinary collaborative interaction between professional groups, researchers and consumers is the advancement of innovative new research projects, and the sharing of knowledge around clinical care. One approach to facilitate this collaboration, very successful in the cancer field, was the creation of the cancer care pathways by such an interaction between professional groups.
- 20 The optimal care pathways (**OCP**) program provided a vehicle for change in the cancer space. The OCPs were developed in recognition of the fact that the diagnosis and treatment of cancer is a complex path for consumers to navigate. The OCPs help by mapping the care journey for different types of tumours based on current best practice. The program is an example of where multidisciplinary care was introduced even in areas where it was regarded as impossible, such as regional, rural or remote communities or in private practices. I would expect that a similar program would be applicable to mental health.
- 21 I discuss OCPs in more detail under the heading 'Optimal Care Pathways' in paragraphs 44 to 67 below.
- 22 A vibrant research enterprise should permeate all the activities of collaborative centres and clinical care programs across Victoria. This is important, as everything we do in medicine must have an evidence base. It is generally accepted that research-led clinical care is the best type of clinical care. The reason for this relates to the inspiration and involvement of those undertaking clinical work. Clinicians in these settings have a deeper sense of what is going on clinically, are genuinely interested in the outcomes and are actively thinking about the link between their clinical work and their research work.

Further, where clinical research is being done, the outcomes for consumers are always better. This is why the VCCC is primarily designed to encourage research to get better outcomes for consumers of cancer treatment.

- 23 With this in mind, research activities in the mental health sector could be reorganised and revitalised to ensure they are fit for purpose through research and clinical leadership from a collaborative centre for mental health. The collaborative centre provides a vehicle for this to occur. The centre must define the areas where collaboration will add value to work which may be currently proceeding often in specialised units.
- 24 It is critical to have health services research undertaken 'on the ground' to evaluate changes in the way care delivery is completed. In other words, community clinical research and clinical trials are essential across the whole spectrum, including in the mental health sector. Clinical research is key to a vibrant and effective health program.
- 25 This can only be done with inspiration centrally and an effective networking system across both metropolitan and regional areas. This is a complex task, but an exercise critical to the success of the aims of any collaborative centre.

Translational research and integrated service delivery

- 26 Translational research implies taking research findings and using them for clinical care, usually via a clinical trial. It is a key part of clinical research and a key part of the functioning of a collaborative centre.
- 27 Many studies have shown that consumers have best outcomes in a research-led clinical environment. For example, consumers in clinical trials can have better outcomes irrespective of whether they are recipients of active or placebo treatments. Ideally, every consumer should be part of some type of clinical trial or clinical evaluation.
- 28 Further, following pathways of care and clinical practice guidelines have been demonstrated to improve clinical outcomes for cancer consumers. Such pathways and guidelines are developed and improved upon through translational research.
- 29 The most important conditions necessary to enable translational research are the commitment of resources and personnel support for the implementation and delivery of the research, and a culture of research activity amongst all health professionals working in this area. Expecting clinicians and those with other roles to manage research projects without project or program support significantly limits the prospects of successful implementation of translational research.

Integrated service delivery: learnings from cancer care

- 30 Integrated service delivery implies a program of service delivery agreed by all practitioners which is multidisciplinary in nature. Such a program is supported, enhanced and evaluated by clinical research methodology.
- 31 The pairing of integrated service delivery and research environments is best supported by the commitment of resources, in particular people who can complete project-support work as well as financial support. Practitioners who are already busy delivering services require support to enable integrated service delivery and research.
- 32 The Integrated Cancer Services (**ICS**) had five aims when they were originally established to improve integration of patient care and help the introduction of supportive cancer care both outside and inside the hospital setting. Those five key metrics are: (i) multi-disciplinary care, (ii) psycho-social support, (iii) care coordination, (iv) reduction in variation of outcomes and (v) effective referral practices.
- 33 ICS's are outside the health services' and research institutions' own operations and were designed to ensure consumers received better integrated care. They are structured with a director and manager with oversight and responsibility from a health service which received funding from government and are responsible for the use of those funds. There are nine ICS in Victoria – three metropolitan ICS, five regional ICS and one paediatric ICS.

Challenges in integrated service delivery

- 34 One of the key challenges in implementing the ICS model was acceptance by the clinical community of an entity outside their control. Originally, the ICS's were established in a barren landscape where the issues they were interested in were not part of general clinical practice. The great effect of the ICS's has been to gradually demand that a program of more holistic care is offered to all, that hospitals look outside their own walls to ensure consumer care extends across a region and into communities rather than just the care received onsite in a particular hospital.
- 35 In the context of cancer care, one of the key difficulties in integrating a diverse range of services has been creating a link between general practitioners and hospitals. More recently, the Primary Health Networks have worked with the ICS to implement pathways of care for cancer consumers. Integration across the spectrum of providers of care has been and still is extraordinarily difficult, primarily related to structural and administrative differences between the various providers.
- 36 ICS have a set of government-funded objectives. They are linked to a health service with a clinical director and a program manager and were the first services to start evaluating local data about clinical outcomes. ICS are directed to get close to consumers and

understand local environments. In this way, they are a key element in any networking of clinical services across a community.

- 37 These services sit outside the traditional medical program, but allow for consumers to be supported and managed in a system with greater effect and continuity of care.

ICS model and regionalisation

- 38 The ICS have been extremely valuable in the regions. They were able to bring far flung health services into a system which offered patients the chance of a coordinated approach. Important aspects for regional service planning across ICS include strong clinical leadership, a sympathetic CEO of the relevant regional hospital involved with ICS, and an understanding of the needs of the particular local community served by the ICS.
- 39 ICS have been given linked data of the cancer activity in the relevant local area which has been invaluable in engaging local hospitals and practitioners in understanding the problems, including outcomes in their locality.
- 40 The strengths of this approach relate to funding opportunities for personnel to support projects and be active in the regions. The weaknesses relate to issues of real responsibility and capacity to be effective in a mixed health system with different funding streams. The lessons from the cancer integrated services could be well incorporated into a mental health variant. I suggest a patient registration function be incorporated into any integrated mental health service.
- 41 The Victorian health system is complex, with variable funding elements across various disciplines. Trying to get a group of people who provide clinical care together to provide integrated care is not straightforward. ICS is one model to enable this to happen and those services are critical for delivery of on the ground care across disciplines and different care providers along pathways of care reaching from hospitals and GPs into community care.
- 42 The effectiveness of this process can be reviewed by way of simple audits. For example, ensuring that the result of a review meeting is inputted into the relevant hospital's reporting mechanism is a positive step to measure the efficacy of care provided through ICS's. In the context of regional care, it is important for regional health services to ensure consumers in the surrounding areas are linked into multi-disciplinary team meetings and that in-home care is available where necessary. The ICS model establishes mechanisms to have all of these services working together.
- 43 In the mental health sector, the care pathway presently depends on the individual practitioner. There is not a system of care approach as there is for cancer consumers. Cancer consumers are on a set of tram tracks (with options for consumer determination

along the journey) for the provision of optimal care for the duration of their interaction with health services and support services. It is not possible to dictate this concept to clinical practitioners. The levers for control are not easily available. It is a matter of research, evidence, communication, inspiration and logic to ensure clinical practitioners are aligned with and committed to a particular program or pathway of care. This can be sourced from a collaborative centre.

Optimal Care Pathways

Introduction to OCPs

44 An Optimal Care Pathway is a descriptive standard of care for a person with a particular type of cancer. Broadly, OCPs are effective in helping to clarify how a consumer's care can be managed in an organised way. The seven steps in all OCPs are:

- (a) prevention and early detection;
- (b) presentation, initial investigations and referral;
- (c) diagnosis, staging and treatment planning;
- (d) treatment;
- (e) care after initial treatment and recovery;
- (f) managing recurrent, residual, or metastatic disease; and
- (g) end-of-life care.

Attached to this statement and marked 'RT-2' is a copy of the document titled "Optimal care pathway for women with breast cancer".

45 The OCPs are a service delivery document which states that there is no resiling from the concept of excellence of care. This is a standard of care that a consumer can expect if they are diagnosed with cancer. Historically, there was no consistent pattern for managing cancer care. In addressing this gap, an iterative process was followed with sessions attended by a few hundred practitioners with a view to articulating an evidence-based process for best-care for cancer consumers. This is not to be confused with clinical practice guidelines. Instead, it articulated how a consumer with a particular type of cancer required treatment from practitioners with specific expertise and would be treated in a particular way, with a multi-disciplinary approach and with specific supports and community care.

46 The OCPs contain a lot of common material suitable and needed for all cancer consumers. They can be used by consumers to be informed about their care but are mostly used by organisations who use it as a guide for treating particular cancers.

However, each OCP has elements tailored for the particular needs of individual cancer consumers.

- 47 The design of these pathways began within the common cancers and are also tumour specific. These had a specific diagnosis and referral starting point.
- 48 It also required creation of specific OCPs that were not tumour specific, but applied to different groups of consumers. For example the OCP for Aboriginal and Torres Strait Islander Australians or the paediatric OCP. These are potentially important areas in the mental health space.
- 49 The pathways capture the proposition that the consumer, the carer team and family support all need to be part of a group that have to be interacted with and engaged with in making decisions to get the consumer through a complex treatment process. There is no resiling from that concept.

Implementing OCPs

- 50 The OCPs are the most impactful activity for getting alignment of clinical practice across all sectors. Key lessons are professional engagement, data collection about outcomes and activity, and evidence-based demonstration of effectiveness and the provision of a standard of care that is both easily understood but with some 'teeth'. One form of 'teeth' would be funding related to output and performance. However this is a constant difficulty in the reform of health service delivery. This means that funding is not given as a fee-for-service but instead is given for a particular type of care that could be measured against the type of care described in the OCPs.
- 51 Another type of 'teeth' is the use of an audit to check performance. In the refresh of the OCPs, there is a type of checklist designed for consumers, and perhaps health services, to use to audit their own processes and make sure they know how to provide care for a consumer on a certain care pathway. This checklist allows for an audit after the fact to structure feedback that has some impact on the situation. This is a simple but effective method of encouraging engagement of consumers and practitioners.

OCPs and mental health care

- 52 In the context of mental health, the difficulty in making a diagnosis and then making a referral of the consumer to a specific service is currently different to the experience of cancer consumers. I believe the principles which lie behind the provision of coordinated cancer care can be modified and applied for the benefit of the mental health patient. There are four principles which I believe should guide mental health care. These are:

- a. *first*, any person requiring mental health care will be engaged and approached on a multi-disciplinary pathway of care;
- b. *secondly*, the pathway of care will be appropriate to the needs of that person;
- c. *thirdly*, the person will be the centre of the system; and
- d. *fourthly*, empathy and kindness will be an universal commitment from all healthcare providers.

53 I would expect OCPs for mental health to be designed by professionals working on the ground together with consumers with lived experience of mental health diagnoses. This is because those health professionals, including research clinicians, and consumers are best-placed to identify how mental health issues for specific groups can be managed. It is then possible to create streams to address the lifecycle of care for a particular consumer. The question is not whether that particular class of consumer would be forced into this stream.

54 As an example, a starter for a pathway might be identifying how to refer a person who is concerned about their mental health but does not know where to go after presenting to their general practitioner, or elsewhere. This person should never be 'let go' but should be monitored and managed throughout their care pathway so that there is continuity of care. The technical side of care is often the easy aspect. The consumer support, continuity of care and quality of impactful care is harder and the most important. It is most important because there is a human being behind each particular disease and the aim is for them to be happy and comfortable throughout the care pathway. Leaving aside the technical care, which it goes without saying must be acceptable and high quality, the issue is to ensure that the consumer does not go away dissatisfied despite receiving adequate care.

OCPs and multidisciplinary cancer care

55 A structure is in place to deliver multidisciplinary care for cancer consumers in Victoria. It has been controversial but is now pretty well accepted. This is not unique to Victoria but is a process which has developed across the world. The structure of multidisciplinary care has two elements in the context of cancer care: multidisciplinary team planning and multidisciplinary care delivery. Multidisciplinary team planning refers to a meeting at the diagnosis, staging and treatment planning step of the care pathway where the multidisciplinary team agree on a recommended treatment plan having regard to the consumer's clinical and psychosocial factors. Multidisciplinary care delivery is an integrated team approach to treatment in which medical and allied health professionals consider relevant treatment options and collaboratively develop a treatment and care plan for each consumer.

- 56 We have a national group, the National Cancer Expert Reference Group, which is a committee of the Council of Australian Governments (**COAG**). These pathways are all endorsed by COAG and so have a high-level status. These are agreed across all jurisdictions in Australia. This high level endorsement is of extreme importance to the acceptance of the OCPs amongst practitioners.
- 57 Clinicians are also enthusiastic about participating in developing or refreshing the care pathways. This is a part of the engagement exercise to ensure clinicians are inspired to participate in the drafting and updating of the OCPs. Funding is critical for the success of this model.
- 58 The pathways are currently being refreshed. The OCPs are broad enough that specific research advances do not mean that they require constant updating. Instead, the NCERG are responsible for making a decision regarding adapting or updating the pathways having regard to any changes in clinical practice, including research. The NCERG has considered a five-year review cycle sufficient.

Specialist services: paediatric and youth services

- 59 One of the first concerns informing the design of the paediatric ICS was that all children should have expert care if they developed cancer. So the creation of a services framework indicating the referral processes for children with cancer was a huge driver for the ICS. The need for modern elements of supportive care for children was also recognised.
- 60 There was also a need to manage the expectations of two large providers of cancer services to children after the Monash Children's Hospital commenced operations. The focus was to provide a system of care and referral for low volume but high impact childhood cancer sufferers. This also involved managing the needs of regional, rural and remote children cancer consumers and the formalisation of supportive care processes in an environment with multiple interested parties, including the consumer's family.
- 61 Volume and service specialisation heavily reflected the decision to go to the concept of a state-wide service rather than regionalisation. However, outreach services enabled integrated care locally in association with those central organisations.
- 62 The Adolescents and Young Adults (**AYA**) program was developed over the last 10-15 years. Until the development of that program, there was little recognition of the particular needs of the AYA group. Young people have particular needs which were not previously recognised or met, which are distinct from both needs of adult consumers as well as infant or child consumers. These include unique needs related to education, sexual development and the way in which young consumers interact with the health system. The AYA program is a key part of any pathway of care. This is relevant to mental health care because there are a huge number of AYA mental health consumers. The transfer of

responsibility and funding to the AYA consumers provided the impetus for a huge leap in enthusiastic involvement by young people. This is potentially a powerful example for young people with mental health issues.

- 63 A key part of a collaborative centre will be to have linkages with all other providers of care, including for AYA consumers.
- 64 The collaborative centre could have a role for a few years setting up the ground rules for pathways of care. There is time to be invested in getting the broad pathways and inspiration right first. The control of referrals for example needs time to be developed and implemented and the collaborative centre should prioritise this at the outset.
- 65 Any care pathway program should have a powerful statement of intent from government confirming that they will have a role in managing and supporting to facilitate care in all these areas of Victoria. One of the biggest difficulties facing any collaborative centre is out in the community where there are a number of different service providers operating. Careful thought is needed as to the best way to structure the clinical care pathways for consumers of mental health services out in the community.

Family and carer engagement

- 66 It is critically important that there is intelligent and informed support from families and carers in any cancer situation. In the context of cancer care, the OCPs mandate this type of interaction. We should say to consumers that we will look after them, involve their family, their carers and treat them in a multi-disciplinary way. There still needs to be continual emphasis on a supportive, informative patient approach within the health system.
- 67 One of the most important ways to better facilitate family-centred practice and the sharing of information with families is through education, communication and centrality of the consumer in the care system. Having an explicable journey of care is key. It is not acceptable to leave a consumer and their family or carers to find their own next port-of-call during their care pathway.

Workforce

- 68 The most powerful condition to enable professionals to continually learn about emergent research and evidence in their field, and to translate these into practice, is an appropriate research-led environment and an atmosphere of integrated care education. The education of a new generation of academic holistic psychiatrists should be a key demand of the collaborative centre.

- 69 Clinical leadership and clinical champions are critical to support workforces in accepting and embracing changes in the way that they work. Understanding the needs, anxieties and problems of the workforce is also important and provision of appropriate support and understanding of their needs is key.
- 70 In the context of cancer care, we ensured that the concepts of integrated care, multidisciplinary care and supportive care were understood by workforces and consumers. It was not a question of converting professionals to that concept. Instead, it was a matter of ensuring consumers and professionals operated within that same evidence based framework.
- 71 Sometimes, although rarely, there is a need to resolve conflicts about what is the best treatment option or next step for a consumer. Ultimately, a consumer must always 'belong' to one practitioner and, at the end of the day, the lead clinician is responsible for making the final recommendation about a consumer's care. That can create complexities in a multidisciplinary approach and must be considered.

Innovation

- 72 One of the most effective governance structures to ensure active engagement in the design and delivery of services is a system which rewards clearly articulated outcomes assessed against reported data.
- 73 There is a real benefit for a 3 to 5 year collaborative consumer-focussed program to be developed for a new state-wide system which is well resourced, empathic and with continuity of care. This can only be done by working on the ground and building up. In the context of cancer care, the VCCC convened over 100 meetings amongst practitioners to articulate how such a collaborative system would work. A collaborative system for mental health care would likely require more work given the wide variety of services involved in providing mental health care.
- 74 In the context of how those meetings should be convened, a statement of priorities must be used as a circuit-breaker to develop the systems of care. It is then a matter of the practitioners meeting to articulate a clearly defined objective for any collaborative centre. Just like OCPs, there should be a template of management identifying particular points to be addressed so that coherence from the discussion is achieved.

Digital technologies

- 75 Digital technologies are used in cancer care. There are digital information packages for cancer patients that are available. Additionally, clinical trials and research using telehealth is important to the VCCC. However, at the moment, the VCCC does not have a forward looking programme in relation to digital technologies. Victoria does not have a very good

electronic medical record system and the IT systems of primary care are not linked to the secondary or tertiary care IT systems. Worldwide the introduction of electronic medical records has failed to facilitate connectivity between institutions and their patients, requiring specific pathway digital production and guidance for best effect.

- 76 Paradoxically the COVID-19 crisis has facilitated change and the introduction of new telehealth both for multidisciplinary care and individual initiatives which will have ongoing impact. The COVID-19 impact on the health system is likely to produce change in other elements of health system practices which may be relevant to the concept of the collaborative centre, for example the clustering of health services.

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print name Robert J S Thomas

date 12 May 2020



Royal Commission into
Victoria's Mental Health System

ATTACHMENT RT-1

This is the attachment marked 'RT-1' referred to in the witness statement of Robert Thomas dated 12 May 2020.

CURRICULUM VITAE

ROBERT JOHN SHEDDEN THOMAS, OAM MBBS, FRACS, FRCS, MS (Melb.)

Personal Details

Name: Robert John Shedden THOMAS

Some points of interest from early Thomas Family History in Australia

- c1846-1853 – Paternal great, great grandfather Samuel Howell Thomas was Clerk and Collector (Manager) of the Melbourne Hospital, Victoria
- c1870-1882 - His Son, Ebenezer John Thomas my great grandfather was the first Secretary of the Department of Premier and Cabinet, Government of Victoria.
- c1880-1950 His son, Henry Darby Thomas my grandfather, was trained in Medicine at Guy's hospital London and worked as a GP in Melbourne 1920-50
- c1900-30 Charles Davis – Maternal great grandfather was Director General Public works NSW circa 1900-30, instrumental in building of Sydney Harbour Bridge and Burrinjuck Dam

Biography

Professor Robert JS Thomas, OAM

Professor Thomas is the Special Advisor on Health to the Victorian Government and University of Melbourne, and Chair of the Advisory Board of Cancer Australia. He is co-chair of the National Cancer Expert Reference Group (NCERG) an AHMAC and

Australian Government committee. He is Deputy Chair of the Victorian Comprehensive Cancer Centre. His current mission with NCERG is to achieve implementation of the Optimal Care Cancer pathways, a program of work agreed by all jurisdictions. These pathways, now backed by large linked datasets are set to guide provision of uniform care to all populations and reduce variation in outcomes and costs

As past Chair of the Victorian Cancer Agency and one of the original members of the Agency he worked with Government to provide new recurrent funding for cancer research in Victoria. He was instrumental in developing large scale collaborative cancer research programs across Institutions in Victoria.

Professor Thomas is passionate about cancer system reform, and as Chief Cancer Advisor to Government over the past 10 years has worked to provide all Victorians with the benefits of multidisciplinary care, appropriate psychosocial support for cancer patients and carers, and access to the best translational research. He implemented the innovative Cancer Service Framework for Victoria over this period. He is the previous Director of Surgical Oncology and interim CEO at Peter MacCallum Cancer Centre, in Melbourne, Australia and holds the position of Distinguished Fellow in Surgical Oncology at Peter Mac. With linkages to USA he established, and was the first Chair, of the Surgical Oncology section of the RACS and commenced International Clinical Trials in Surgical Oncology in Melbourne. He established one of the early clinical tissue banks when at the Western Hospital as Foundation Chair and the facility allowed mutational events to be described in resected cancer and included the first report of mutation in the PI3-Kinase gene in Colon cancers. He led this laboratory both at the Western Hospital and at Peter MacCallum Cancer Centre for some 18 years.

He has significant linkages with many international groups including Imperial College Hospital London, The Kings College Hospital, London and the International Prevention Research Institute Lyon France, and been the Australian representative on many internal benchmarking studies into Cancer Outcomes, including the ICBP. He was Chair of the international WISH (World innovation Summit on Health) Forum entitled Delivering Affordable Cancer Care, based in Qatar

Appointments

Current Appointments

2017 - present	Professorial Fellow, University of Melbourne, Advisor on Health
2016 - present	Deputy Chair, Victorian Comprehensive Cancer Centre
2016 - present	Chair, Advisory Board Cancer Australia
2015 - present	Member, Advisory Board of Asquire Ltd (UK)
2014 - present	Chair, WISH Affordable Cancer Care Committee International, Qatar and Imperial College London
2013 - present	Member, Advisory Board Ecancer medicine, European Institute of Oncology, Milan, Italy
2010 - present	Distinguished Fellow, Surgical Oncology Peter MacCallum Cancer Centre, Melbourne, Victoria
2010 - present	Senior Research Fellow, International Prevention Research Institute, Lyon, France
2009 - present	Chair, National Cancer Expert Reference Group
2009 - present	Honorary Professorial Fellow, Department of Medicine, University of Melbourne
2006 - present	Honorary Senior Research Associate, The Cancer Council, Victoria

Previous Appointments

2007 to 2016	Member, Steering Committee, Victorian Comprehensive Cancer Centre Development
2006 to 2016	Member, Eminent Advisory Group, ANZ Journal of Surgery
2004 to 2016	Member, Surgical Oncology Committee, Royal Australasian College of Surgeons
2009 - 2016	Chair, Ministerial Consultative Committee, Victorian Cancer Agency

2007 to 2015	Member/Chair, Clinical Services Working Party, Victorian Comprehensive Cancer Centre Development
2012 - 2013	Interim Chief Executive Officer - Peter MacCallum Cancer Centre
2007 - 2013	Member, Cabrini Institute Council, Cabrini Health, Victoria
2007 - 2010	Board Member, Royal Women's Hospital, Melbourne, Victoria
1999 - 2009	Professor and Director of Division of Surgical Oncology, Peter MacCallum Cancer Centre, and University of Melbourne, Victoria, Australia
2005 - 2008	Director, Western & Central Melbourne Integrated Cancer Services
2003 - 2007	Member, Ministerial Taskforce for Cancer, Department of Human Services, Victorian Government
2003 - 2007	Chair, Clinical Services Working Party of Ministerial Taskforce for Cancer, Victorian Government
2003 - 2006	Chair, NHMRC Grant Review Panel 6c
2000 - 2006	Editor-In-Chief, Australian & New Zealand Journal of Surgery
2001 - 2004	Member of Awards Assembly, General Motors Cancer Research Foundation, New York, New York, USA
2001 - 2003	Foundation Chairman, Surgical Oncology Group, Royal Australasian College of Surgeons
1995 - 1997	President, Clinical Oncological Society of Australia
1992 - 1999	Professor of Surgery, Department of Surgery (Royal Melbourne and Western Hospitals), Melbourne
1993 - 1995	President-Elect, Clinical Oncological Society of Australia
1985 - 1995	Member, Court of Examiners, Royal Australasian College of Surgeons

Other Appointments

2007 to 2008	Member, National Quality and Professional Development National Advisory Group
2006 to 2007	Member, Interim Committee of Victorian Cancer Agency
2001 to 2007	Member, Faculty (Board) of Medicine, Dentistry and Health Sciences, University of Melbourne
2002 to 2006	Chair, CAN/TCCA Committee for the Revision of the Colorectal Cancer Guidelines
2000 to 2004	Member, Federal Government Department of Health National Bowel Screening Pilot Implementation Committee
1998 to 2004	Member, Australian Cancer Society Oncology Education Committee
1999 to 2002	Representative, College of Surgeons and College of Physicians, Federal Government Department of Health Quality of Use Pathology Committee
1999 to 2002	Member, National Cancer Control Initiative Colorectal Cancer Screening Project Advisory Committee
1992 to 2002	Member, Anti Cancer Council of Victoria Co-operative Oncology Group
2000 to 2001	Visiting Professor in the Department of Surgery, The University of Hong Kong
1999 to 2000	National Surgical Oncology Representative, Medical and Scientific Committee, The Cancer Council of Australia
1999 to 2001	Member, National Cancer Control Initiative National Colorectal Care Survey
1999 to 2000	Member, Medicare Services Advisory Committee (MSAC)
1999 to 2000	Member (representing RACS), PET Review, MSAC Supporting Committee
1998 to 2000	Member, National Cancer Control Initiative Guidelines Implementation Working Party
1998 to 2000	Member, National Cancer Control Initiative Consumer Guidelines Sub Committee

1998 to 2000	Representative, Combined Australasian Colleges of Surgeons and Physicians Cancer Strategies Group, Federal Government Department of Health
1992 to 2000	Member, Anti Cancer Council of Victoria Genetics Advisory Committee
1998 to 1999	Clinical Director, SMACC Western Hospital. (SMACC - General Surgery, Oncology, Gastroenterology, Neurology, Neurosciences, Intensive Care Unit and Emergency Department)
1998 to 1999	Clinical Chairman, North Western Health (encompassing General Surgery, Gastroenterology, Oncology at the Royal Melbourne, Western, Williamstown Hospital and Northern Hospitals)
1996 to 1999	Chairperson and Co-Convenor, Principal Committee for the Development of Evidence Based Guidelines for the Management of Colorectal Cancer
1998 to 1999	Chairperson, Board of Examiners in Final Year Surgery, The University of Melbourne
1992 to 1999	Honorary Surgeon, Royal Melbourne Hospital
1992 to 1999	Chairperson, Anti Cancer Council of Victoria Gastrointestinal Study Committee of the Centre for Clinical Research in Cancer
1998 to 1999	Member, New Curriculum Committee, The University of Melbourne
1997 to 1998	Member, NCCI Management Committee
1994 to 1998	Chairperson, 4th Year Board of Examiners, Faculty of Medicine, Dentistry & Health Sciences, The University of Melbourne
1983 to 1998	Member, Editorial Board, Australian and New Zealand Journal of Surgery
1992 to 1998	Chairman, Division of Surgery Western Hospital
1996 to 1998	Clinical Director, Network Services, Royal Melbourne Hospital/Western Hospital/Williamstown Hospital Surgery, Oncology & Gastroenterology
1996 to 1997	External Examiner, University of Malaysia Medical School, Kuala Lumpur
1996 to 1997	Acting Head, Department of Surgery, The University of Melbourne - Royal Melbourne Hospital/Western Hospital

1994 to 1997	Final Fellowship Examiner, Royal College of Surgeons, Edinburgh
1990 to 1995	Member, Committee of Australian Gastrointestinal Tumour Group
1990 to 1991	Chairman, Organising Committee of ASM, Clinical Oncological Society of Australia
1990 to 1992	Chairman, Department of General Surgery, Royal Melbourne Hospital
1989 to 1992	Deputy Chairman, Senior Medical Staff, Royal Melbourne Hospital
1982 to 1987	Honorary Secretary, Senior Medical Staff, Royal Melbourne Hospital
1980 to 1992	Appointed to Staff Royal Melbourne Hospital, Melbourne as Surgeon
1975 to 1979	Senior Lecturer, University Department of Surgery, Royal Melbourne Hospital
1974 to 1992	Consultant General Surgeon, Surgeon to Lymphoma Clinic, Peter MacCallum Hospital, Melbourne

Academic - Training and Qualifications

1960 to 1965	Undergraduate Education, Faculty of Medicine, University of Melbourne
1965	Graduated MBBS, University of Melbourne
1992	Awarded MS by Thesis, "Photodynamic Therapy for Oesophageal Cancer", University of Melbourne
1966 to 1970	Resident Medical Officer/Surgical Registrar, Royal Melbourne Hospital, Melbourne
1971	Surgical Registrar, Birmingham Accident Hospital, Birmingham, UK
1972 - 1973	Surgical Registrar, Charing Cross Hospital, London,
1973 - 1974	Clinical and Research Fellow in Surgery, Massachusetts General Hospital, Harvard Medical School, Shriners Burns Institute, Boston, USA
	Assistant to Surgical Associate Group, Massachusetts General Hospital, USA
	Instructor in Surgery, Harvard Medical School, Boston, USA
1975 – 1992	Senior Lecturer, Department of Surgery, University of Melbourne and Surgeon, Royal Melbourne Hospital
1975 - 1992	Surgeon, Peter MacCallum Cancer Hospital, Melbourne
1992 - 1999	Professor of Surgery, Department of Surgery, Western Hospital, Melbourne
2000 - 2010	Professor of Surgery, Department of Surgical Oncology, Peter MacCallum Cancer Centre, East Melbourne

Honours and Awards

2009	Nomination for Australian of the Year - 2010
2009	Peter MacCallum Cancer Centre Distinguished Fellow Award for "Outstanding contributions to improving cancer care locally, nationally and internationally"
2008	Order of Australia Medal for "Outstanding contributions to the development of Surgical Oncology and Editorship and reform of the ANZ Journal of Surgery"
2007	Excellence in Surgery, Royal Australasian College of Surgeons for "Distinguished service in the field of Surgical Oncology and editorial services to the ANZ Journal of Surgery"
2006	Cancer Council of Victoria Service Award
2000	Australian Cancer Society Service Award

Invitation to Lecture (incomplete listing)

2017 Invited lecture on cancer reform and Pathway development in Australia, ANZGOG conference Melbourne

Many invited lectures across Australia and overseas regarding development and implementation of cancer reforms and optimal care pathways

2016 Cancer pathway development Hume cancer centre opening

2106 World Cancer Forum UICC meeting, Interaction of Government and policy development to achieve cancer reform

7th WA State Cancer Conference, Perth, March 2011

- *Individualised cancer treatment – how do we make it work in our health system?*

Clinical Oncology Society of Australia (COSA) Cancer Conference, Melbourne, November 2011

- *Surgical Safety: A state-wide view*

Union for International Cancer Control (UICC) World Cancer Congress, Shenzhen, China, August 2010

- *High performing cancer systems: aligning regional/state/national performance improvement strategies in cancer – state level alignment in Victoria*

International Prevention Research Institute (iPRI) Conference, Lyon, June 2010

- *Victorian Cancer Mutation Project*
- *Victoria's Cancer System*

Grand Rounds Presentation, Peter MacCallum Cancer Centre, Melbourne, 1 February 2010

- *Cancer Care for the 21C – reflections and plans*

Victorian Cooperative Oncology Group (VCOG), Melbourne, 2 December 2009

- *Regional linkages in Victoria*

Gippsland Regional Integrated Cancer Service (GRICS) Annual Forum, La Trobe Regional Hospital, Traralgon, 23 November 2009

- *Welcoming address and keynote presentation*

Clinical Oncology Society of Australia (COSA) Cancer Conference, Queensland, 17 November 2009

- *Regional linkages to comprehensive cancer centres*

Ludwig Institute for Cancer Research Translational Oncology Conference, The Grand Hyatt Hotel, Melbourne, 6 November 2009

- *Welcome address*

Asian National Cancer Centre Alliance (ANCCA) Meeting, China, 23-29th October 2009

- *Cancer Developments in Australia*

Premier's VCE Awards, Melbourne Convention Centre, Melbourne, 21 July 2009

- *Invited Presenter*

Grand Rounds Presentation, Peter MacCallum Cancer Centre, Melbourne, 22 June 2009

- *Victoria's Cancer Action Plan*

1st Annual Sir Peter MacCallum Free Public Lecture, Swanston Hall, Melbourne Town Hall, 26 May 2009

- *Opening Address*

National Cervical Cancer Prevention Conference, Sofitel Hotel, Melbourne, 19 February 2009

- *Opening address on behalf of the Hon. Daniel Andrews, MP, Minister for Health*

Cancer Services & Education Consultation Workshop: Cancer Institute NSW, 22 August 2006

- *Keynote Speaker: Improving Cancer Services*

International Society of Surgical Medicine, Durban, South Africa

Surgical Grand Round Meeting, Austin Hospital, Melbourne, July 2004

- *Carcinoma of the Oesophagus*

Media Launch, The Cancer Council of Victoria, 10 December 2003

- *Cancer Survival in Victoria*

Cancer Services Framework and Ministerial Taskforce for Cancer, Sunday 16 November 2003

- *Invited Speaker*

The University of Melbourne: School of Medicine, Melbourne, 2001

- *Defence Mechanisms and Their Failure*

Public Lecture, Melbourne, 2000

- *Cancer Awareness Week*

26th Annual Scientific Meeting, Australasian Society for Parenteral and Enteral Nutrition, Lorne 2000

- *Post-operative Feeding from a Surgical Perspective*
- *Nutritional Support in Cancer Surgery*

Surgical Oncology in the Future, Melbourne 1999

Best Practice Guidelines for Colorectal Cancer, Melbourne 1998

Developing Guidelines for Colorectal Cancer, COSA, Sydney 1998

World Organisation for Specialized Studies on Diseases of the Esophagus (OESO) Conference, Paris, 1996

- *Is there a common cell of origin for cardio-oesophageal cancers?*

University of Malaysia, Kuala Lumpur 1996

- *The Treatment of Cardio-oesophageal Cancer*

36th AGM Queensland Cancer Fund, 1997

- *Clinicians and Cancer Societies*

To many invited lectures to document in this paper over past 20 years

Published Articles

- Chynoweth, J., McCambridge, M. M., Zorbas, H. M., Elston, J. K., Thomas, R. J. S., Glasson, W. J. H., . . . Whitfield, K. M. (2020). Optimal Cancer Care for Aboriginal and Torres Strait Islander People: A Shared Approach to System Level Change.. *JCO Glob Oncol*, 6, 108-114. doi:[10.1200/JGO.19.00076](https://doi.org/10.1200/JGO.19.00076)
- te Marvelde, L., McNair, P., Whitfield, K., Autier, P., Boyle, P., Sullivan, R., & Thomas, R. J. S. (2019). Alignment with indices of a care pathway is associated with improved survival: An observational population-based study in colon cancer patients. In *ASIA-PACIFIC JOURNAL OF CLINICAL ONCOLOGY* Vol. 15 (pp. 64). WILEY. Retrieved from http://gateway.webofknowledge.com/gateway/Gateway.cgi?GWVersion=2&SrcApp=PARTNER_APP&SrcAuth=LinksAMR&KeyUT=WOS:000493438400027&DestLinkType=FullRecord&DestApp=ALL_WOS&UsrCustomerID=d4d813f4571fa7d6246bdc0dfeca3a1c
- White, V., Bergin, R. J., Thomas, R. J., Whitfield, K., & Weller, D. (2019). The pathway to diagnosis and treatment for surgically managed lung cancer patients.. *Fam Pract*. doi:[10.1093/fampra/cmz064](https://doi.org/10.1093/fampra/cmz064)
- Vicendese, D., Marvelde, L. T., McNair, P. D., Whitfield, K., English, D. R., Taieb, S. B., . . . Thomas, R. (2020). Hospital characteristics, rather than surgical volume, predict length of stay following colorectal cancer surgery. *AUSTRALIAN AND NEW ZEALAND JOURNAL OF PUBLIC HEALTH*, 44(1), 73-82. doi:[10.1111/1753-6405.12932](https://doi.org/10.1111/1753-6405.12932)
- Bergin, R. J., Thomas, R. J. S., Whitfield, K., & White, V. (2019). Concordance between Optimal Care Pathways and colorectal cancer care: Identifying opportunities to improve quality and reduce disparities. *JOURNAL OF EVALUATION IN CLINICAL PRACTICE*, 9 pages. doi:[10.1111/jep.13231](https://doi.org/10.1111/jep.13231)
- Vicendese, D., Te Marvelde, L., McNair, P. D., Whitfield, K., English, D. R., Ben Taieb, S., . . . Thomas, R. (2019). Predicting the Whole Distribution with Methods for Depth Data Analysis Demonstrated on a Colorectal Cancer Treatment Study. In *Communications in Computer and Information Science* Vol. 1150 CCIS (pp. 162-182). doi:[10.1007/978-981-15-1960-4_12](https://doi.org/10.1007/978-981-15-1960-4_12)
- Te Marvelde, L., McNair, P., Whitfield, K., Autier, P., Boyle, P., Sullivan, R., & Thomas, R. J. S. (2019). Alignment with Indices of A Care Pathway Is Associated with Improved Survival: An Observational Population-based Study in Colon Cancer Patients.. *EClinicalMedicine*, 15, 42-50. doi:[10.1016/j.eclinm.2019.08.009](https://doi.org/10.1016/j.eclinm.2019.08.009)
- Mileshkin, L., Holliday, L., Aurangabadkar, A., Ball, D., Bowtell, D., Bryant, C., . . . Currow, D. (2018). Development of the optimal care pathway for cancer of unknown primary. In *ASIA-PACIFIC JOURNAL OF CLINICAL ONCOLOGY* Vol. 14 (pp. 88-89). WILEY. Retrieved from http://gateway.webofknowledge.com/gateway/Gateway.cgi?GWVersion=2&SrcApp=PARTNER_APP&SrcAuth=LinksAMR&KeyUT=WOS:000449544200108&DestLinkType=FullRecord&DestApp=ALL_WOS&UsrCustomerID=d4d813f4571fa7d6246bdc0dfeca3a1c

- Bergin, R. J., Emery, J., Bollard, R. C., Falborg, A. Z., Jensen, H., Weller, D., . . . White, V. (2018). Rural-Urban Disparities in Time to Diagnosis and Treatment for Colorectal and Breast Cancer. *CANCER EPIDEMIOLOGY BIOMARKERS & PREVENTION*, 27(9), 1036-1046. doi:[10.1158/1055-9965.EPI-18-0210](https://doi.org/10.1158/1055-9965.EPI-18-0210)
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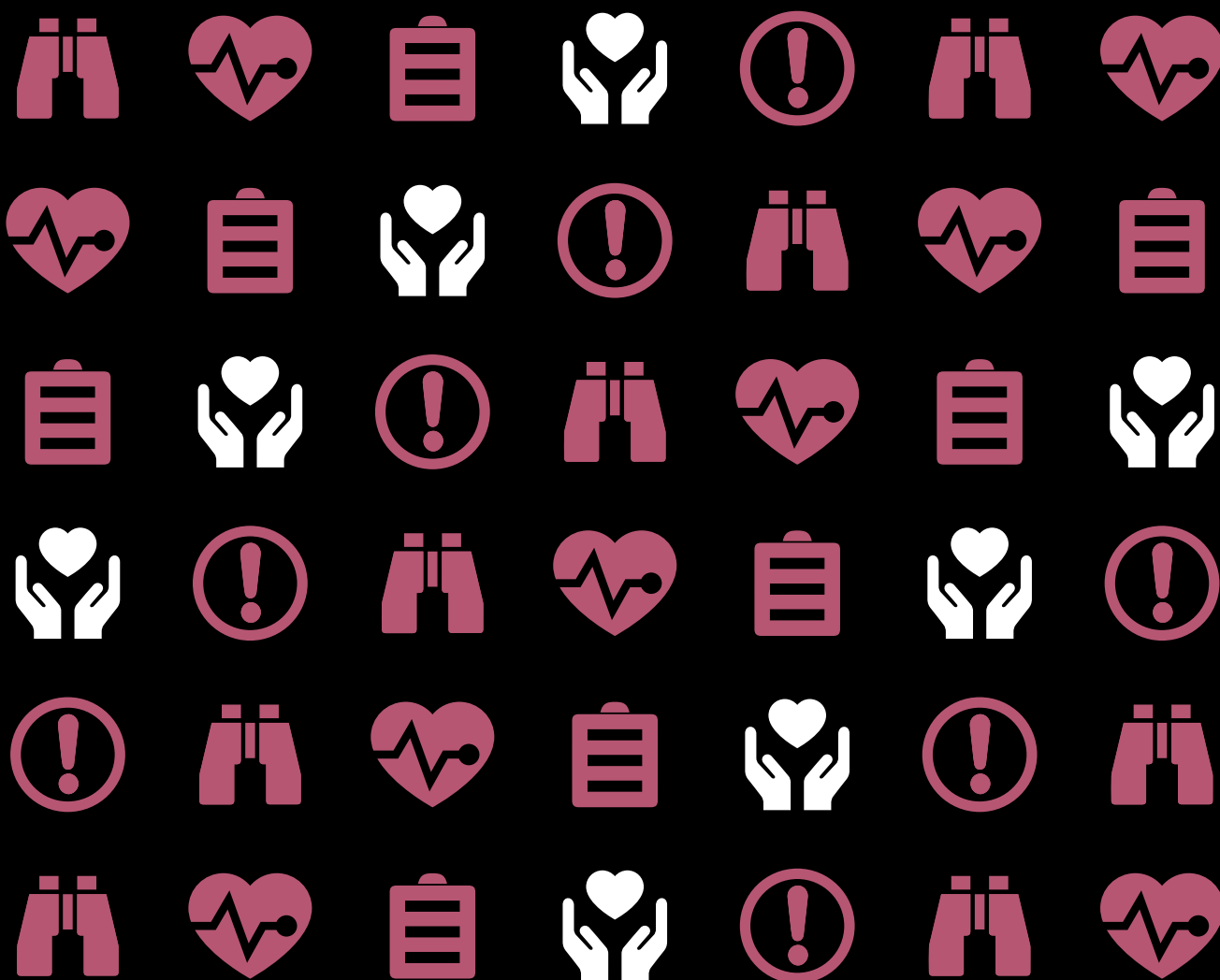
Royal Commission into
Victoria's Mental Health System



ATTACHMENT RT-2

This is the attachment marked 'RT-2' referred to in the witness statement of Robert Thomas dated 12 May 2020.

Optimal care pathway for women with breast cancer



Optimal care pathway for women with breast cancer

Endorsed by



Australian Government
Cancer Australia



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Foreword

The pathway for cancer patients undergoing diagnosis and treatment for cancer is complex and poorly comprehended by those involved. It usually involves multiple healthcare providers and covers a range of institutions, both public and private. The optimal cancer care pathways map this journey for specific tumour types, aiming to foster an understanding of the whole pathway and its distinct components to promote quality cancer care and patient experiences. These pathways act as a reminder that the patient is the constant in this journey and that the health system has a responsibility to deliver the care experience in an appropriate and coordinated manner.

The optimal care pathways are based on a revision of the original patient management frameworks (Department of Health 2007a) which had, for the first time, attempted to map the cancer pathway in an easily understandable form.

The purpose of this work is to improve patient outcomes by facilitating consistent cancer care based on a standardised pathway of care. The pathways are applicable to care whether it is provided in a public or private service. The principles and the expected standards of good cancer care are not expected to differ, even though treatment regimens may vary from patient to patient for a whole variety of reasons.

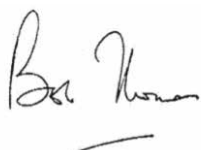
Victoria has undertaken this program of work as part of a national work plan aimed at improving cancer care. This national work plan was developed by the National Cancer Expert Reference Group (NCERG). The NCERG is a panel of experts and jurisdictional and consumer representatives that was established by the Council of Australian Governments (COAG) in 2010. In developing a national work plan for improving cancer care in Australia, the NCERG identified the value of a national approach to delivering consistent and optimal cancer care.

The NCERG has subsequently endorsed these new optimal cancer care pathways, which they agree are relevant across all jurisdictions. Each jurisdiction has been invited to adopt and co-badge these for local use.

A wide range of clinicians, peak health organisations, consumers and carers were consulted and/or participated in their development and I want to thank all concerned for their generous contributions.

I am sure that those providing cancer care will find the specific pathways useful in deciding how best to organise service delivery to achieve the best outcomes for those we care for.

Importantly, readers should note that these care pathways are not detailed clinical practice guidelines. They are not intended to constitute medical advice or replace clinical judgement.



Professor Robert Thomas OAM
Chief Advisor Cancer, Department of Health and Human Services – Victoria

Summary

Please note that not all women will follow every step of this pathway:

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

Step 1

Prevention and early detection

Risk factors: Age, sex, family history, obesity and moderate/heavy alcohol intake are important risk factors. All women should have their individual breast cancer risk assessed.

Women at moderate or high risk should be referred to a family cancer clinic to have their risk further clarified and for possible genetic testing.

Risk reduction: For women at moderate or high risk of breast cancer, anti-hormonal risk-reducing

medication should be considered. Women at very high risk should consider risk-reducing surgery. The surgeon should provide clear information about the objective of the procedure.

Screening: Federally funded mammographic screening is available to asymptomatic women from the age of 40

through the BreastScreen Australia Program. Women aged 50-74 years should consider undergoing a two - yearly screening mammogram. Over-diagnosis needs to be considered, and women invited to screening must be informed of the potential disadvantages as well as the benefits of mammographic screening.

Increased or high risk - refer to the breast optimal care pathway for screening recommendations.

Step 2

Presentation, initial investigations and referral

Signs and symptoms:

The following should be investigated:

- a new lump or lumpiness
- a change in the size or shape of a breast
- a change to a nipple
- nipple discharge that occurs without squeezing
- a change in the skin of a breast
- axillary masses
- an unusual breast pain that does not go away.

Assessments by a general practitioner (GP)

GP should refer all women with a suspicious lesion to a breast assessment clinic.

Examinations/investigations should include a triple test of three diagnostic components:

- medical history and clinical breast examination

- imaging – mammography and/or ultrasound
- non-excision biopsy – fine needle aspiration (FNA) cytology and/or a core biopsy.

These tests should be done within two weeks.

Referral: A positive result on any component of the triple test warrants referral for specialist surgical assessment and/or further investigation. Optimally, the specialist appointment should be within two weeks of a suspected diagnosis.

Communication – lead clinician to:

- provide the woman with information that clearly describes who they are being referred to, the reason for referral and the expected timeframe for an appointment
- support the woman while waiting for the specialist appointment.

Step 3

Diagnosis, staging and treatment planning

Diagnostic work-up for women with breast cancer:

Family history and a medical examination, then consider following sequence of investigations:

- breast imaging tests
- ultrasound of the axilla +/- FNA nodes
- breast core biopsy if not already undertaken
- establishment of breast cancer receptor profile
- assessment for a breast cancer predisposition gene and considered for genetic counselling.

Staging: Appropriate for locally advanced or confirmed nodal disease and for any women with clinical symptoms or clinical suspicion of metastatic disease.

Treatment planning: All newly diagnosed women should be discussed by a multidisciplinary team so

that a treatment plan can be recommended.

Special considerations that need to be addressed at this stage include pregnancy, fertility and prevention of chemotherapy-induced menopause.

Research and clinical trials: Consider enrolment where available and appropriate.

Communication – lead clinician to:

- discuss a timeframe for diagnosis and treatment with the woman/carer
- explain the role of the multidisciplinary team in treatment planning and ongoing care
- provide appropriate information or refer to support services as required.

¹ Lead clinician – the clinician who is responsible for managing patient care.

The lead clinician may change over time depending on the stage of the care pathway and where care is being provided.

Step 4

Treatment:

Establish intent of treatment:

- curative
- anti-cancer therapy to improve quality of life and/or longevity without expectation of cure
- symptom palliation.

Treatment options:

Surgery: Surgery for early breast cancer involves either breast-conserving surgery or mastectomy performed with or without immediate breast reconstruction surgery. Women should be fully informed of their options and offered the option of immediate or delayed reconstructive surgery if appropriate.

Chemotherapy and other systemic therapy:

Chemotherapy or drug therapy may be appropriate as neoadjuvant or adjuvant treatment.

Radiation therapy: In most cases, radiation therapy is recommended for women with early breast cancer after breast-conserving surgery and in selected women after mastectomy.

For detailed information see <<http://canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/clinical-practice-guidelines-management-early-breast-cancer-2nd-ed>>.

Communication – lead clinician to:

- discuss treatment options with the woman/carer including the intent of treatment and expected outcomes
- discuss the treatment plan with the woman's GP.

Step 5

Care after initial treatment and recovery

Cancer survivors should be provided with the following to guide care after initial treatment.

Treatment summary (provide a copy to the woman/carer and her GP) outlining:

- diagnostic tests performed and results
- tumour characteristics
- type and date of treatment(s)
- interventions and treatment plans from other health professionals
- supportive care services provided
- contact information for key care providers.

Follow-up care plan (provide a copy to the woman/carer and her GP) outlining:

- medical follow-up required (tests, ongoing surveillance)
- care plans for managing the late effects of treatment
- a process for rapid re-entry to medical services for suspected recurrence.

Communication – lead clinician to:

- explain the treatment summary and follow-up care plan to the woman/carer
- inform the woman/carer about secondary prevention and healthy living
- discuss the follow-up care plan with the woman's GP.

Step 6

Managing recurrent, residual and metastatic disease

Detection: Some cases of recurrent disease will be detected by routine follow-up in a woman who is asymptomatic. Some cases of metastatic disease will be detected at the same time as presentation with the initial primary breast cancer ('de novo metastatic disease').

Treatment: Where possible, refer the woman to the original multidisciplinary team. Treatment will depend on the location, the extent of recurrence, previous management and the woman's preferences.

Palliative care: Early referral can improve quality

of life and in some cases survival. Referral should be based on need, not prognosis.

For detailed information see <<http://annonc.oxfordjournals.org/content/early/2014/09/17/annonc.mdu385.full.pdf+html>>.

Communication – lead clinician to:

- explain the treatment intent, likely outcomes and side effects to the woman/carer
- initiate a discussion regarding advance care planning if appropriate.

Step 7

End-of-life care

Palliative care: Consider referral to palliative care if not already involved. Ensure that an advance care plan is in place.

Communication – lead clinician to:

- be open about the prognosis and discuss palliative care options with the woman/carer
- establish transition plans to ensure the woman's needs and goals are addressed in the appropriate environment.

Summary – optimal timeframes

Timeframes to treatment: Timeframes should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce women's distress. The following recommended timeframes are based on expert advice from the Breast Cancer Working Group.

Step in pathway	Care point	Timeframe
Presentation, initial investigations and referral	2.1 Signs and symptoms	A patient with signs and symptoms that may be concerning for breast cancer should be seen by their GP within two weeks. Appropriate triaging will identify patients who need to be seen earlier.
	2.2 Assessments by a GP	Tests should optimally be done within two weeks.
	2.3 Initial referral	Ideally the surgeon should see the patient with proven cancer or suspicious features within two weeks. If necessary, prior discussion should facilitate referral.
Diagnosis, staging and treatment planning	3.3 Multidisciplinary team meeting	Results of all relevant tests and imaging should be available for the multidisciplinary team discussion.
Treatment	4.2.1 Surgery	Breast surgery should occur within one month of a decision to treat with surgery (for invasive breast cancer).
	4.2.2 Chemotherapy and systemic therapy	Chemotherapy should be started ideally within four weeks of surgery. Neoadjuvant therapy should be started as soon as practicable. Endocrine therapy should start as soon as appropriate, after completion of chemotherapy and/or radiation therapy.
	4.3 Radiation therapy	For patients who don't have chemotherapy, radiation therapy should commence within eight weeks of surgery. For patients who have chemotherapy, radiation therapy should commence three to four weeks after chemotherapy.

Intent of the optimal cancer care pathway

The optimal cancer care pathway is intended to guide the delivery of consistent, safe, high-quality and evidencebased care for people with breast cancer.

The pathway aligns with key service improvement priorities including providing access to coordinated multidisciplinary care and supportive care and reducing unwanted variation in practice.

The optimal cancer care pathway can be used by health services and professionals as a tool to identify gaps in current cancer services and inform quality-improvement initiatives across all aspects of the care pathway. The pathway can also be used by clinicians as an information resource and tool to promote discussion and collaboration between health professionals and people affected by cancer.

The following key principles of care underpin the optimal cancer care pathway.

Patient-centred care

Patient- or consumer-centred care is healthcare that is respectful of, and responsive to, the preferences, needs and values of patients and consumers. Patient or consumer-centred care is increasingly being recognised as a dimension of high-quality healthcare in its own right, and there is strong evidence that a patient-centred focus can lead to improvements in healthcare quality and outcomes by increasing safety and cost-effectiveness as well as patient, family and staff satisfaction (ACSQHC 2013).

Safe and quality care

This is provided by appropriately trained and credentialled clinicians, hospitals and clinics that have the equipment and staffing capacity to support safe and high-quality care. It incorporates collecting and evaluating treatment and outcome data to improve a woman's experience of care as well as mechanisms for ongoing service evaluation and development to ensure practice remains current and informed by evidence. Services should routinely be collecting relevant minimum datasets to support benchmarking, quality care and service improvement.

Multidisciplinary care

This is an integrated team approach to healthcare in which medical and allied health professionals consider all relevant treatment options and collaboratively develop an individual treatment and care plan for each woman. There is increasing evidence that multidisciplinary care improves patient outcomes.

The benefits of adopting a multidisciplinary approach include:

- improving patient care through developing an agreed treatment plan
- providing best practice through adopting evidence-based guidelines
- improving patient satisfaction with treatment
- improving the mental wellbeing of patients
- improving access to possible clinical trials of new therapies
- increasing the timeliness of appropriate consultations and surgery and a shorter timeframe from diagnosis to treatment
- increasing the access to timely supportive and palliative care
- streamlining pathways
- reducing duplication of services (Department of Health 2007b).

Supportive care

Supportive care is an umbrella term used to refer to services, both generalist and specialist, that may be required by those affected by cancer. Supportive care addresses a wide range of needs across the continuum of care and is increasingly seen as a core component of evidence-based clinical care. Palliative care can be part of supportive care processes. Supportive care in cancer refers to the following five domains:

- physical needs
- psychological needs
- social needs
- information needs
- spiritual needs.

All members of the multidisciplinary team have a role in providing supportive care. In addition, support from family, friends, support groups, volunteers and other community-based organisations make an important contribution to supportive care.

An important step in providing supportive care is to identify, by routine and systematic screening (using a validated screening tool) of the woman and family, views on issues they require help with for optimal health and quality-of-life outcomes. This should occur at key points along the care pathway, particularly at times of increased vulnerability including:

- initial presentation or diagnosis (first three months)
- the beginning of treatment or a new phase of treatment
- change in treatment
- change in prognosis
- end of treatment
- survivorship
- recurrence
- change in or development of new symptoms
- palliative care
- end-of-life care.

Following each assessment, potential interventions need to be discussed with the woman and carer and a mutually agreed approach to multidisciplinary care and supportive care formulated (NICE 2004).

Common indicators in women with breast cancer that may require referral for support include:

- pain or joint pain
- difficulty managing fatigue
- difficulty sleeping
- distress, depression, anxiety or fear
- menopausal symptoms
- living alone or being socially isolated
- having caring responsibilities for others
- cumulative stressful life events
- existing mental health issues
- Aboriginal or Torres Strait Islander status
- poor performance status
- being from a culturally or linguistically diverse background.

Depending on the needs of the woman, referral to an appropriate health professional(s) and/or organisation(s) should be considered including:

- community-based support services (such as Cancer Council Victoria)
- peer support groups (contact the Cancer Council on 13 11 20 or Breast Cancer Network Australia on 1800 500 258 for more information)
- a nurse practitioner and/or specialist nurse
- a psychologist or psychiatrist
- a social worker
- a dietitian
- an exercise physiologist
- a genetic counsellor
- an occupational therapist
- a physiotherapist
- specialist palliative care.

See the **appendix** for more information on supportive care and the specific needs of women with breast cancer.

Care coordination

Care coordination is a comprehensive approach to achieving continuity of care for patients. This approach seeks to ensure that care is delivered in a logical, connected and timely manner so the medical and personal needs of the woman are met.

In the context of cancer, care coordination encompasses multiple aspects of care delivery including multidisciplinary team meetings, supportive care screening/assessment, referral practices, data collection, development of common protocols, information provision and individual clinical treatment.

Improving care coordination is the responsibility of all health professionals involved in the care of patients and should therefore be considered in their practice. Enhancing continuity of care across the health sector requires a whole-of-system response; that is, initiatives to address continuity of care occur at the health system, service, team and individual levels (Department of Health 2007c).

Communication

It is the responsibility of the healthcare system and all people within its employ to ensure the communication needs of patients, their families and carers are met. Every person with cancer will have different communication needs, including cultural and language differences. Communication with patients should be:

- individualised
- truthful and transparent
- consistent
- in plain language (avoiding complex medical terms and jargon)
- culturally sensitive
- active, interactive and proactive
- ongoing
- delivered in an appropriate setting and context
- inclusive of patients and their families.

In communicating with patients, healthcare providers should:

- listen to patients and act on the information provided by them
- encourage expression of individual concerns, needs and emotional states
- tailor information to meet the needs of the woman, her carer and family
- use professionally trained interpreters when communicating with patients from culturally and linguistically diverse backgrounds
- ensure the woman and/or her carer and family have the opportunity to ask questions
- ensure the woman is not the conduit of information between areas of care (it is the providers' and healthcare system's responsibility to transfer information between areas of care)
- take responsibility for communication with the woman
- respond to questions in a way the woman understands
- enable all communication to be two-way.

Healthcare providers should also consider offering the woman a Question Prompt List (QPL) in advance of their consultation and recordings or written summaries of their consultations. QPL interventions are effective in improving communication, psychological and cognitive outcomes of cancer patients (Brandes et al. 2014). Providing recordings or summaries of key consultations may improve the patient's recall of information and patient satisfaction (Pitkethly et al. 2008).

Research and clinical trials

Where practical, patients should be offered the opportunity to participate in research and/or clinical trials at any stage of the care pathway. Research and clinical trials play an important role in establishing efficacy and safety for a range of treatment interventions, as well as establishing the role of psychological, supportive care and palliative care interventions (Sjoquist & Zalcberg 2013).

While individual patients may or may not receive a personal benefit from the intervention, there is evidence that outcomes for participants in research and clinical trials are generally improved, perhaps due to the rigour of the process required by the trial. Leading cancer agencies often recommend participation in research and clinical trials as an important part of patient care. Even in the absence of measurable benefit to patients, participation in research and clinical trials will contribute to the care of cancer patients in the future (Peppercorn et al. 2004).

Optimal cancer care pathway

The optimal cancer care pathway outlines seven critical steps in the patient journey. While the seven steps appear in a linear model, in practice, patient care does not always occur in this way but depends on the particular situation (such as the type of cancer, when and how the cancer is diagnosed, prognosis, management, the women's decisions and her physiological response to treatment).

Breast cancer is the most common cancer in Australian women, accounting for more than 27 per cent of newly diagnosed cancers, and the second most common cause of death from cancer. Breast cancer is uncommon in males, with less than one in 100 cases of breast cancer occurring in men (AIHW 2014). **Please note this document refers to women throughout. This is for practical reasons. The recommendations are intended to apply to all patients.**

Early breast cancer is breast cancer that is contained in the breast and may or may not have spread to lymph nodes in the armpit. Advanced breast cancer usually refers to metastatic breast cancer that has spread to other parts of the body. Locally advanced breast cancer is breast cancer with extensive axillary nodal involvement and that may have spread to areas near the breast, such as the chest wall.

Step 1: Prevention and early detection

This step outlines recommendations for the prevention and early detection of breast cancer.

1.1 Risk factors

Age and sex are important risk factors for developing breast cancer; 70 per cent of cases occur in women over 50 years of age (NBOCC 2009).

Other risk factors include:

- family history of breast cancer and/or other cancers such as ovarian cancer
- not engaging in adequate physical activity (two or more hours of brisk walking or equivalent per week) (NBOCC 2009)
- obesity and weight gain in adulthood
- post-menopausal obesity
- moderate to heavy alcohol intake (more than two standard drinks per day)
- a previous diagnosis of breast cancer
- women diagnosed with DCIS (ductal carcinoma in situ)
- women diagnosed with LCIS (lobular carcinoma in situ)
- never having breastfed
- nulliparity
- past history of specific types of benign breast disease, atypical ductal hyperplasia (ADH) and atypical lobular hyperplasia (ALH) (Hartmann et al. 2014)
- higher mammographic breast density corrected for age and body mass index (BMI) (AIHW 2012)
- older age at menopause or younger age at menarche
- exposure to diethylstilboestrol (DES) in utero (NBOCC 2009)
- late age at first birth
- use of combined hormone replacement therapy and use of the oral contraceptive pill within the last 10 years
- chest radiation therapy before age 40.

By understanding a woman's personal breast cancer risk level, health professionals are able to offer the most appropriate evidence-based prevention and early detection strategies. Thus all women should have their individual breast cancer risk assessed. This will usually initially occur in primary care. Cancer risk assessment should be repeated when major risk factors change (for example, new family cancer history, breast biopsy showing atypical hyperplasia or LCIS).

There are a number of validated computerised breast cancer risk assessment tools that estimate an individual woman's breast cancer risk based on her personal risk factors:

- the IBIS tool available at <www.ems-trials.org/riskevaluator/>
- the Cancer Australia tool available at <<http://canceraustralia.gov.au/affected-cancer/cancer-types/breast-cancer/your-risk/calculate>>
- the Cancer Australia Familial Risk Assessment tool available at <<http://canceraustralia.gov.au/affected-cancer/cancer-types/breast-cancer/your-risk/calculate>>.

In Australia, lifetime population risk of breast cancer is 12 per cent. Cancer Australia defines levels of breast cancer risk as follows:

- average risk: $< 1.5 \times$ population risk
- moderate risk: $1.5\text{--}3 \times$ population risk
- high risk: $> 3 \times$ population risk (NBOCC 2009).

Women at moderate or high risk due to their family cancer history should be referred to a family cancer clinic to have their risk further clarified and for possible genetic testing. Practitioners should refer to the published *eviQ Cancer genetics – breast and ovarian cancer referral guidelines* (eviQ 2015).

Women found to be at high lifetime risk of breast cancer ($> 3 \times$ average) should be advised to consider regular clinical examination, annual mammogram from about five years before their youngest relative developed breast cancer and annual MRI from this age until 50, preferably as part of an organised surveillance and risk-reducing program.

1.2 Risk reduction

All women should be encouraged to optimise their modifiable breast cancer risk factors. Adopting this range of healthy lifestyle choices improves general health, including the risks of several cancers.

Evidence is accumulating that physical exercise reduces breast cancer risk. Even approximately 1.5 hours of exercise per week is associated with a 20 per cent risk reduction (Bernstein et al. 2005). The protective effect of exercise is independent of other factors, such as weight.

Maintaining a healthy body weight, particularly after menopause, is important in reducing the risk of breast cancer. Excess fat in postmenopausal women can result in increased oestrogen levels that increase the risk for breast cancer. Eating a healthy diet, particularly avoiding a high-calorie diet, may be protective against breast cancer.

The use of alcohol is clearly linked with a heightened risk of breast cancer. Avoiding or limiting alcohol intake should be encouraged. Daily consumption of one alcoholic drink is associated with a small increase in risk. Women who drink two to five alcoholic drinks daily have a 1.5 times increased risk compared with non-drinkers.

For women at moderate or high risk of breast cancer, risk-reducing medication should be considered. In addition, women at high risk should consider risk-reducing surgery.

1.2.1 Risk-reducing medication for women at moderate or high risk

For women assessed as having an increased risk of breast cancer, anti-hormonal risk-reducing medication such as tamoxifen or an aromatase inhibitor is an option to lower the risk of developing breast cancer. Decisions about whether to use risk-reducing medication should be based on a clear understanding of the absolute benefits and risks for each individual woman.

1.2.2 Risk-reducing surgery for women at high risk

Risk-reducing surgery may be considered by women at high risk of developing breast cancer (NCI 2015), including those with a mutation in a major breast cancer predisposition gene, such as BRCA1 or BRCA2 (Cancer Council Australia 2015).

Bilateral risk-reducing mastectomy reduces the relative risk of breast cancer by at least 95 per cent (NCI 2015). Even with total mastectomy, not all breast tissue can be removed. The remaining breast tissue may be at risk of becoming cancerous in the future.

Bilateral risk-reducing salpingo-oophorectomy in premenopausal women under the age of 40 reduces the risk of breast cancer by approximately 50 per cent (NCI 2015). Women with a mutation in BRCA1 or BRCA2 are also at substantially increased risk of ovarian and fallopian tube cancers. Bilateral risk-reducing salpingo-oophorectomy reduces the risk of these cancers by 90 per cent.

For women who are considering risk-reducing surgery, the surgeon should provide:

- a clear description of the risk-reducing surgery technique, including options for reconstructive surgery, and clear information about the objective of the procedure
- information about managing menopausal symptoms and other long-term side effects including use of hormone replacement therapy (HRT)
- a discussion about the factors influencing psychosocial wellbeing post risk-reducing surgery.

1.3 Screening

Early detection through screening mammography has several benefits including improved mortality rates, increased treatment options and improved quality of life (Cancer Australia 2009). For women with small tumours at diagnosis (< 10 mm), there is a more than 95 per cent relative five-year survival rate (Cancer Australia 2012).

Federally funded mammographic screening is available to asymptomatic women from the age of 40 through the BreastScreen Australia program. It is recommended that women aged 50–74 consider undergoing a two-yearly screening mammogram. Annual screening may be offered to women at increased risk. For selected women at very high risk, breast MRI screening may be appropriate in addition to mammography. A doctor's referral is not required for screening through BreastScreen Australia but GPs' encouragement is a key factor in women's participation in screening.

Women who have symptoms or signs of breast cancer require prompt investigation of their symptoms, including diagnostic imaging. Screening mammography is not advised for these women as it may lead to false reassurance and delayed diagnosis.

Not all breast cancers are detectable on screening mammograms, and new cancers may arise in the interval between mammograms. Women should be aware of the look and feel of their breasts and report concerns to their GP.

Screening permits early cancer detection of breast cancer, which improves mortality rates. But screening can also lead to anxiety and additional investigations for non-malignant processes. At present it is impossible to predict which cancers detected by screening may progress during a woman's life. For this reason, over-diagnosis needs to be considered, and women invited to screening must be informed of the potential disadvantages as well as the benefits of mammographic screening (Lee & Peters 2013).

Further information

See Cancer Australia's position statement on over-diagnosis at <<http://canceraustralia.gov.au/publications-and-resources/position-statements/overdiagnosis-mammographic-screening>>.

Step 2: Presentation, initial investigations and referral

This step outlines the process for establishing a diagnosis and appropriate referral. The types of investigation undertaken by the general or primary practitioner depend on many factors, including access to diagnostic tests, medical specialists and women's preferences.

A significant proportion of breast cancers are found in apparently asymptomatic women through routine breast screening.

2.1 Signs and symptoms

The following signs and symptoms found by the woman herself or her GP should be investigated:

- a new lump or lumpiness, especially involving only one breast
- a change in the size or shape of a breast
- a change to a nipple, such as crusting, ulceration, redness or inversion
- nipple discharge that occurs without squeezing
- a change in the skin of a breast such as redness or dimpling
- axillary masses
- an unusual breast pain that does not go away (Cancer Australia 2015).

Timeframe for general practitioner consultation

Timeframes for completing investigations should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce women's distress.

The following recommended timeframes are based on expert advice from the Breast Cancer Working Group:¹

A patient with signs that may be concerning for breast cancer should be seen by their GP within two weeks. Appropriate triaging will identify women who need to be seen earlier.

¹ The multidisciplinary experts group that participated in a clinical workshop to develop content for the breast cancer optimal care pathway are listed in the acknowledgements list.

2.2 Assessments by a general practitioner in symptomatic women and mammographic screening in asymptomatic women

2.2.1 Assessments by a general practitioner

The types of investigation undertaken by a general or primary practitioner depend on many factors including access to diagnostic tests and medical specialists and the woman's preferences. GPs should refer all women with a suspicious lesion to a breast assessment clinic (with noted exceptions, where appropriate).

Examinations/investigations should include a triple test of three diagnostic components:

- medical history and clinical breast examination
- imaging – mammography and/or ultrasound
- non-excision biopsy – FNA cytology and/or a core biopsy.

Based on the best available evidence, the triple test provides the most effective means of diagnosing breast cancer in women with breast symptoms.

A positive result on any component of the triple test warrants referral for specialist surgical assessment and/or further investigation irrespective of any other normal test results. This implies that not all three components of the triple test need to be performed to reach the conclusion that appropriate referral is needed. The triple test is positive if any component is indeterminate, suspicious or malignant (NBCC 2006; Zorbas et al. 2006).

2.2.2 Mammographic screening in asymptomatic women

A significant proportion of breast cancers are diagnosed through mammographic screening in women who are asymptomatic.

BreastScreen Australia services operate within the framework of a comprehensive set of national accreditation standards that specify requirements for the safety/quality of diagnostic tests, timeliness of services and multidisciplinary care.

BreastScreen Australia services take responsibility for screening and investigation of screen-detected lesions, including needle biopsies. After multidisciplinary assessment and review of results, recommendations are made for the next steps in management. The woman and her GP are advised of these recommendations in writing. Surgery and ongoing care is typically not part of the BreastScreen program and has to be coordinated by the GP through appropriate surgical referral.

Timeframe for completing investigations

Timeframes for completing investigations should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce women's distress.

The following recommended timeframes are based on expert advice from the Breast Cancer Working Group: Optimally these tests should be done within two weeks.

2.3 Initial referral

If the diagnosis of breast malignancy is confirmed or the results are inconsistent or indeterminate, referral to a breast surgeon is warranted. Referral should include all clinical information, medical and psychosocial background and all images and diagnostic reports (old and new)

Timeframe for referral to a specialist

Timeframes for referral should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce women's distress.

The following recommended timeframes are based on expert advice from the Breast Cancer Working Group:

Ideally the surgeon should see the patient with proven cancer or suspicious features within two weeks. If necessary, prior discussion should facilitate referral.

The supportive and liaison role of the woman's GP and practice team in this process is critical.

2.4 Support and communication

2.4.1 Supportive care

An individualised clinical assessment is required to meet the identified needs of a woman, her carer and family; referral should be as required.

In addition to common issues identified in the **appendix**, specific needs that may arise at this time include:

- appropriate information about the likely tests and processes
- appropriate information for people from culturally and linguistically diverse backgrounds.

2.4.2 Communication with the patient, carer and family

Effective communication is essential at every step of the care pathway. Effective communication with the woman and carers is particularly important given the prevalence of low health literacy in Australia (estimated at 60 per cent of Australian adults) (ACSQHC 2013).

The general or primary practitioner should:

- provide the woman with information that clearly describes who they are being referred to, the reason for referral and the expected timeframe for an appointment
- support the woman while waiting for the specialist appointment including for the emotional distress of dealing with a potential cancer diagnosis.

Step 3: Diagnosis, staging and treatment planning

Step 3 outlines the process for confirming the diagnosis and stage of cancer, as well as planning subsequent treatment. The guiding principle is that interaction between appropriate multidisciplinary team members should determine the treatment plan.

3.1 Staging investigations (diagnostic work-up for women with breast cancer)

The diagnostic work-up for women with breast cancer consists of a thorough history including family history, and a medical examination, after which the following sequence of investigations may be considered:

- appropriate breast imaging tests including bilateral mammography and ultrasound
- ultrasound of the axilla (including FNA of nodes if the axillary ultrasound is abnormal)
- breast core biopsy if not already undertaken (a tissue diagnosis is essential prior to multidisciplinary discussion)
- establishment of breast cancer receptor profile (ER, PR, HER2).

Patients should be assessed for the possibility of a breast cancer predisposition gene and considered for genetic counselling if appropriate.

3.2 Staging investigations for distant disease

Staging is appropriate in women with confirmed nodal disease and for any women with clinical symptoms or clinical suspicion of metastatic disease. Routine computed tomography (CT) and bone scan are not recommended for most women with early breast cancer.

For a woman presenting with de novo metastatic disease, see step 6.

3.3 Treatment planning

3.3.1 The optimal timing for multidisciplinary team planning

Prior to commencing treatment all women with newly diagnosed breast cancer should be discussed in a multidisciplinary team meeting so that a treatment plan can be recommended, including consideration for neoadjuvant therapy. The level of discussion may vary depending on both the clinical and psychosocial factors.

Results of all relevant tests, including all imaging investigations and pathology results, should be available for the multidisciplinary team discussion. Information about the woman's concerns, preferences and social circumstances should also be available. If a woman chooses to have a second opinion, this should be facilitated.

There may also need to be a review of existing treatment plans for women who have been discussed previously.

3.3.2 Responsibilities of the multidisciplinary team

These are to:

- nominate a team member to be the lead clinician (the lead clinician may change over time depending on the stage of the care pathway and where care is being provided)
- nominate a team member to coordinate patient care
- develop and document an agreed treatment plan at the multidisciplinary team meeting
- circulate the agreed treatment plan to relevant team members, including the woman's GP.

3.3.3 Responsibilities of individual team members

The medical practitioner who made the referral is responsible for the woman until care is passed to another practitioner.

The general or primary medical practitioner may play a number of roles in all stages of the cancer pathway including diagnosis, referral, treatment, coordination and continuity of care, as well as providing information and support to the woman and her family.

The care coordinator (usually a breast care nurse) is responsible for ensuring there is continuity throughout the care process and coordination of all necessary care for a particular phase. The person taking this responsibility may change over the course of the pathway.

The lead clinician is a clinician responsible for overseeing the activity of the team and for implementing treatment within the multidisciplinary setting.

3.3.4 Members of the multidisciplinary team for breast cancer

The multidisciplinary team should comprise the core disciplines integral to providing good care. Team membership will vary according to cancer type but should reflect both clinical and psychosocial aspects of care. Additional expertise or specialist services may be required for some women (Department of Health 2007b).

Team members may include a:

- breast surgeon*
- care coordinator (usually a breast care nurse)*
- medical oncologist*
- nurse(s) (with appropriate expertise such as a breast care nurse)*
- pathologist*
- radiation oncologist*
- radiologist*
- clinical trials coordinator
- dietitian
- exercise physiologist
- fertility specialist
- GP
- geneticist and/or genetic counsellor
- occupational therapist
- palliative care specialist
- pharmacist
- physiotherapist
- plastic surgeon
- psychologist
- psychiatrist
- social worker.

* Core members of the multidisciplinary team are expected to attend most multidisciplinary team meetings either in person or remotely.

3.4 Research and clinical trials

Participation in research and/or clinical trials should be encouraged where available and appropriate.

- The Australia and New Zealand Breast Cancer Trials Group (ANZBCTG) coordinates multicentre national and international clinical trials. For more information visit <<https://www.anzbctg.org/content/6/about-australia-new-zealand-breast-cancer-trial-group>>.
- Australian Cancer Trials is a national clinical trials database. It provides information on the latest clinical trials in cancer care, including trials that are recruiting new participants. For more information visit <www.australiancancertrials.gov.au>.

3.5 Special considerations

Special considerations that need to be addressed at this stage include issues around pregnancy, fertility and prevention of chemotherapy-induced menopause.

3.6 Prehabilitation, support and communication

3.6.1 Prehabilitation

Cancer prehabilitation uses a multidisciplinary approach combining exercise, nutrition and psychological strategies to prepare patients for the challenges of cancer treatment such as surgery, chemotherapy and radiation therapy.

Evidence indicates that prehabilitating newly diagnosed patients with cancer prior to starting treatment can be beneficial. This may include conducting a physical and psychological assessment to establish a baseline function level, identifying impairments and providing targeted interventions to improve the patient's health, thereby reducing the incidence and severity of current and future impairments related to cancer and its treatment (Silver & Baima 2013). The supportive and liaison role of the breast care nurse in this process is critical.

Studies have demonstrated that the breast care nurse role enhances early recognition of unmet needs, reduces psychological distress, improves continuity of care and increases understanding of diagnosis and treatment (NBCC 2001). All women should be assessed by a breast care nurse at the time of diagnosis.

Medications should be reviewed at this point to ensure optimisation and to improve adherence to medicines used for comorbid conditions.

3.6.2 Supportive care

Screening with a validated screening tool (such as the National Comprehensive Cancer Network distress thermometer), assessment and referral to appropriate health professionals or organisations is required to meet the identified needs of an individual, their carer and family.

In addition to the common issues outlined in the **appendix**, specific needs that may arise at this time include the following.

- The option of fertility preservation and preservation of ovarian function needs to be discussed prior to starting treatment. Referral to a fertility service for counselling and evaluation of options may be appropriate. For detailed information on fertility preservation refer to Breast Cancer Network Australia's 'Fertility-related choices' available at <https://www.bcna.org.au/sites/default/files/fertility_decision_aid_20120117.pdf>.
- Upper limb and breast lymphoedema following lymphadenectomy is a potential treatment side effect in women with breast cancers (NBCC & NCCI 2003), which has a significant effect on survivor quality of life. Referral (preferably preoperatively) to a health professional with accredited lymphoedema management qualifications, offering the full scope of complex lymphoedema therapy, may be needed.
- Guidance for financial and employment issues (such as loss of income and having to deal with travel and accommodation requirements for rural patients and caring arrangements for other family members) may be required.
- Weight changes, which can be a significant issue for women, may require referral to a dietitian before, during and after treatment.
- Help with the emotional distress of dealing with a cancer diagnosis is often required.
- Family distress if familial cancer identified is a common issue.
- Appropriate information for people from culturally and linguistically diverse backgrounds should be provided.

3.6.3 Communication with the patient

The lead clinician should:

- offer advice to the women and her carers on the benefits of and how to access support from breast cancer peer support groups, groups for carers and special interest groups
- establish if the woman has a regular or preferred GP
- discuss a timeframe for diagnosis and treatment with the woman and carer
- discuss the benefits of multidisciplinary care and make the woman aware that her health information will be available to the team for the discussion at the multidisciplinary team meeting
- provide referral to a fertility specialist prior to beginning treatment (for women who wish to consider childbearing after treatment)
- offer individualised breast cancer information that meets the needs of the woman and carer (this may involve advice from health professionals as well as written and visual resources)
- offer advice on how to access information and support from websites, community and national cancer services and support groups
- use a professionally trained interpreter to communicate with people from culturally or linguistically diverse backgrounds
- review comorbidities prior to surgery to reduce the likelihood of post-operative complications.

3.6.4 Communication with the general practitioner

The lead clinician should:

- ensure regular and timely (within a week) communication with the woman's GP regarding the treatment plan and recommendations from multidisciplinary team meetings
- notify the GP if the woman does not attend appointments
- gather information from the GP including their perspective on the woman (psychological issues, social issues and comorbidities) and locally available support services
- contribute to the development of a chronic disease and mental healthcare plan as required
- discuss shared care arrangements between the multidisciplinary team and the GP
- invite the GP to participate in multidisciplinary team meetings (consider using video- or teleconferencing).

Step 4: Treatment

Step 4 outlines the treatment options for breast cancer. For detailed information on treatment options refer to Cancer Australia's Clinical practice guidelines for the management of early breast cancer (2nd edn) at <<http://canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/clinical-practice-guidelines-management-early-breast-cancer-2nd-ed>>.

Recommendations for managing early breast cancer in women with an identified BRCA1 or BRCA2 gene mutation or who are at high risk of a gene mutation can be found at <<http://canceraustralia.gov.au/about-us/news/new-clinical-practice-guideline-recommendations-management-early-breast-cancer-women-identified>> and aromatase inhibitors adjuvant endocrine therapy post-menopausal receptor-positive early breast cancer at <<http://canceraustralia.gov.au/publications-resources/cancer-australia-publications/aromatase-inhibitors-adjuvant-endocrine-therapy>>.

4.1 Treatment intent

The intent of treatment can be defined as one of the following:

- curative
- anti-cancer therapy to improve quality of life and/or longevity without expectation of cure
- symptom palliation.

The morbidity and risks of treatment need to be balanced against the potential benefits.

The lead clinician should discuss treatment intent and prognosis (if desired by the woman) with the woman and carer prior to beginning treatment.

If appropriate, advance care planning should be initiated with women at this stage. There can be multiple benefits to this such as ensuring the woman's preferences are known and respected after the loss of decision-making capacity (AHMAC 2011).

4.2 Treatment options

The aim of treatment for breast cancer and the types of treatment recommended depend on the type, stage and location of the cancer and the woman's age, health and preferences (Cancer Australia 2015).

The advantages and disadvantages of each treatment and associated potential side effects should be discussed with the woman.

Treatment for early and locally advanced disease

Early and locally advanced breast cancer is treated with curative intent.

4.2.1 Surgery

Surgery for early breast cancer involves either breast-conserving surgery or mastectomy. Breast-conserving surgery followed by radiation therapy is as effective as mastectomy for most women with early breast cancer (Cancer Australia 2015).

Women with a clinically and radiologically negative axilla should be offered sentinel node biopsy. Axillary treatment with surgery and/or radiation therapy should be considered for women with nodal disease.

Oncoplastic breast surgery should be considered where appropriate.

Breast reconstruction surgery

Mastectomy can be performed with or without immediate breast reconstruction surgery. Women should be fully informed of their options and offered the option of immediate or delayed reconstructive surgery if appropriate.

The training and experience required of the surgeons are as follows:

- breast surgeon (FRACS or equivalent, including membership of BreastSurgANZ) with adequate training and experience in breast cancer surgery and institutional cross-credentialling and agreed scope of practice within this area (ACSQHC 2004)
- plastic surgeon with an interest and expertise in breast reconstructive surgery.

Timeframe for commencing treatment

Timeframes for starting treatment should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce women's distress.

The following recommended timeframes are based on expert advice from the Breast Cancer Working Group:

- Breast surgery should occur ideally within one month of a decision to treat with surgery (for invasive breast cancer).

Hospital or treatment unit characteristics for providing safe and quality care include:

- appropriate nursing and theatre resources to manage complex surgery
- 24-hour medical staff availability
- 24-hour operating room access
- specialist pathology expertise
- in-house access to specialist radiology and nuclear medicine expertise.

4.2.2 Chemotherapy and other systemic therapy

Neoadjuvant therapy, usually chemotherapy, may be appropriate for locally advanced breast cancers as well as some larger operable breast cancers to down-stage tumours, either to make them operable or to allow breast-conserving therapy.

For early breast cancers following surgery, a further discussion at the multidisciplinary team meeting will determine the appropriateness and type of systemic therapy. All women with invasive cancer should be considered for systemic therapy.

Targeted/biological therapies and/or anti-hormonal therapies can reduce the risk of recurrence in women with some subtypes of early breast cancer. Trastuzumab in combination with chemotherapy has been shown to significantly improve survival outcomes for women with early stage HER2-positive breast cancer (Perez et al. 2014). All women with hormone receptor-positive breast cancer should be considered for anti-hormonal therapy. Endocrine therapy should be administered for five years and longer in higher risk cases.

Timeframe for commencing treatment

Timeframes for starting treatment should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce women's distress.

The following recommended timeframes are based on expert advice from the Breast Cancer Working Group:

- Chemotherapy should be started ideally within four weeks of surgery.
- Neoadjuvant chemotherapy should start within four weeks of a decision to treat with neoadjuvant chemotherapy.
- Endocrine therapy should start as soon as appropriate, after completion of chemotherapy and/or radiation therapy (and in some cases will be started prior to chemotherapy).

Training, experience and treatment centre characteristics

The following training and experience is required of the appropriate specialist(s):

- Medical oncologists (RACP or equivalent) must have adequate training and experience with institutional credentialling and agreed scope of practice within this area (ACSQHC 2004).
- Nurses must have adequate training in chemotherapy administration and handling and disposal of cytotoxic waste.
- Chemotherapy should be prepared by a pharmacist with adequate training in chemotherapy medication, including dosing calculations according to protocols, formulations and/or preparation.
- In a setting where no medical oncologist is locally available, some components of less complex therapies may be delivered by a medical practitioner and/or nurse with training and experience with credentialling and agreed scope of practice within this area under the guidance of a medical oncologist. This should be in accordance with a detailed treatment plan or agreed protocol, and with communication as agreed with the medical oncologist or as clinically required.

Hospital or treatment unit characteristics for providing safe and quality care include:

- a clearly defined path to emergency care and advice after hours
- access to basic haematology and biochemistry testing
- cytotoxic drugs prepared in a pharmacy with appropriate facilities
- occupational health and safety guidelines regarding handling of cytotoxic drugs, including safe prescribing, preparation, dispensing, supplying, administering, storing, manufacturing, compounding and monitoring the effects of medicines (ACSQHC 2011)
- guidelines and protocols are available to deliver treatment safely (including dealing with extravasation of drugs).

4.2.3 Radiation therapy

In most cases, radiation therapy is recommended for women with early breast cancer after breast-conserving surgery. Radiation therapy should be considered in selected women after mastectomy. Hypofractionated radiation therapy (a three- to four-week course) should be considered for women where appropriate.

Timeframe for commencing treatment

Timeframes for starting treatment should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce women's distress.

The following recommended timeframes are based on expert advice from the Breast Cancer Working Group:

- For women who do not have adjuvant chemotherapy, radiation therapy should commence within eight weeks of surgery.
- For women who have adjuvant chemotherapy, radiation therapy should commence three to four weeks after chemotherapy.

Training, experience and treatment centre characteristics

Training and experience of the radiation oncologist:

- radiation oncologist (FRANZCR or equivalent) with adequate training and experience that enables institutional credentialling and agreed scope of practice within this area (ACSQHC 2004).

Hospital or treatment unit characteristics for providing safe and quality care include:

- appropriately credentialled radiation therapists and physicists
- radiation therapy nurses
- access to CT/MRI scanning for simulation and planning
- mechanisms for coordinating chemotherapy and radiation therapy, especially where facility is not collocated
- access to allied health services.

4.3 Research and clinical trials

Participation in research and/or clinical trials should be encouraged where available and appropriate.

For more information visit <<https://www.anzbctg.org/content/6/about-australia-new-zealand-breast-cancer-trial-group>> and <www.australiancancertrials.gov.au>.

4.4 Complementary or alternative therapies

The lead clinician should discuss the woman's use (or intended use) of complementary or alternative therapies not prescribed by the multidisciplinary team to discuss safety and efficacy and identify any potential toxicity or drug interactions.

The lead clinician should seek a comprehensive list of all complementary and alternative medicines being taken and explore the woman's reason for using these therapies and the evidence base.

Most alternative therapies and some complementary therapies have not been assessed for efficacy or safety. Some have been studied and found to be harmful or ineffective.

Some complementary therapies may assist in some cases and the treating team should be open to discussing the potential benefits for the individual.

If the woman expresses an interest in using complementary therapies, the lead clinician should consider referring them to health professionals within the multidisciplinary team who have knowledge of complementary and alternative therapies (such as a clinical pharmacist, dietitian or psychologist) to help her reach an informed decision.

The lead clinician should assure women who use complementary or alternative therapies that they can still access multidisciplinary team reviews (NBCC & NCCI 2003) and encourage full disclosure about therapies being used (Cancer Australia 2010).

Further information

- See Cancer Australia's position statement on complementary and alternative therapies at <<http://canceraustralia.gov.au/publications-and-resources/position-statements/complementary-and-alternative-therapies>>.
- See the Clinical Oncology Society of Australia's position statement at <www.cosa.org.au/publications/position-statements.aspx>.

4.5 Support and communication

4.5.1 Supportive care

Screening with a validated screening tool and assessment and referral to appropriate health professionals and/or organisations is required to meet the needs of individual women, their families and carers.

In addition to the common issues outlined in the **appendix**, specific issues that may arise include the following.

Physical needs

- Weight changes can be a significant issue for women and may require referral to a dietitian before, during and after treatment.
- Menopause symptoms may require referral to a menopause clinic.
- General healthcare issues (for example, smoking cessation and sleep disturbance) can be referred to a GP.
- Encouraging exercise can be referred to an accredited exercise practitioner.
- Early management for acute pain postoperatively to avoid chronic pain may be needed.
- Reduced sexual interest and sexual dysfunction may require referral to a clinician skilled in this area.
- Treatment for physical symptoms such as pain, arthralgia and fatigue may be needed.
- Decline in mobility and/or functional status as a result of treatment may necessitate a referral to physiotherapy or occupational therapy.
- Upper limb and breast lymphoedema following lymphadenectomy is a potential treatment side effect in women with breast cancers (NBCC & NCCI 2003) that has a significant effect on survivor quality of life. Referral (preferably preoperatively) to a health professional with accredited lymphoedema management qualifications, offering the full scope of complex lymphoedema therapy, may be needed.
- Bowel dysfunction, gastrointestinal or abdominal symptoms as a result of treatment may require support from a dietitian.
- Although treatments have improved, neuropathy, cardiac dysfunction and nausea and vomiting are still serious side effects of cancer chemotherapy. Managing them is important for improving quality of life.
- Women may need support to cope with hair loss (refer to the Look Good, Feel Better program and/or consider scalp cooling).
- Assistance with managing complex medication regimens, multiple medications, assessment of side effects and assistance with difficulties swallowing medications may require referral to a pharmacist.

Psychological needs

- Anxiety/depression, interpersonal problems, stress and adjustment difficulties may require referral to a counsellor or mental health professional.
- Alteration of cognitive functioning in women treated with chemotherapy and radiation therapy requires strategies such as maintaining written notes or a diary and repetition of information (NBCC & NCCI 2003).

Fertility preservation and preservation of ovarian function

- Loss of fertility, sexual dysfunction or other symptoms associated with treatment or surgically or chemically induced menopause require sensitive discussion and possible referral to a clinician skilled in this area (NBCC & NCCI 2003).

Social/practical needs

- Potential isolation from normal support networks, particularly for rural women who are staying away from home for treatment, may necessitate extra support.
- Financial issues related to loss of income and additional expenses as a result of illness and/or treatment may need attention.
- Legal issues (including accessing superannuation, advance care planning, appointing a power of attorney and completing a will) may require advice from relevant professionals.

Information needs

- Appropriate information for people from culturally and linguistically diverse backgrounds should be provided.

4.5.2 Communication with the woman, carer and family

The lead clinician should:

- offer advice to women and carers on the benefits of and how to access support from breast cancer peer support groups, groups for carers and special interest groups
- discuss the treatment plan with the woman and her carer, including the intent of treatment and expected outcomes (a written plan should be provided)
- provide the woman and carer with information on possible side effects of treatment, self-management strategies and emergency contacts.

4.5.3 Communication with the general practitioner

The lead clinician should:

- discuss with the woman's GP their role in symptom management, psychosocial care and referral to local services
- ensure regular and timely two-way communication regarding
 - the treatment plan, including intent and potential side effects
 - supportive and palliative care requirements
 - the woman's prognosis and their understanding of this
 - enrolment in research and/or clinical trials
 - changes in treatment or medications
 - recommendations from the multidisciplinary team.

Step 5: Care after initial treatment and recovery

The transition from active treatment to post-treatment care is critical to long-term health. After completion of initial treatment, women should be provided with a treatment summary and follow-up care plan including a comprehensive list of issues identified by all members of the multidisciplinary team. Transition from acute to primary or community care will vary depending on the type and stage of cancer and needs to be planned. In some cases, women will require ongoing, hospital-based care.

5.1 Survivorship

In the past two decades, the number of people surviving cancer has increased. International research shows there is an important need to focus on helping cancer survivors cope with life beyond their acute treatment. Cancer survivors experience particular issues, often different from women having active treatment for cancer.

Many cancer survivors experience persisting side effects at the end of treatment. Emotional and psychological issues include distress, anxiety, depression, cognitive changes and fear of cancer recurrence. Late effects may occur months or years later and are dependent on the type of cancer treatment. Survivors may experience altered relationships and may encounter practical issues, including difficulties with return to work or study, and financial hardship.

Survivors generally need to see a doctor for regular followup, often for five or more years after cancer treatment finishes. The Institute of Medicine, in its report *From cancer patient to cancer survivor: Lost in transition*, describes four essential components of survivorship care (Hewitt et al. 2006):

- the prevention of recurrent and new cancers, as well as late effects
- surveillance for cancer recurrence or second cancers; and screening and assessment for medical and psychosocial late effects
- interventions to deal with the consequences of cancer and cancer treatments (including management of symptoms, distress and practical issues)
- coordination of care between all providers to ensure the woman's needs are met.

All women should be educated in managing their own health needs (NCSI 2015).

5.2 Post-treatment care planning

5.2.1 Treatment summary

Upon completion of initial treatment, the woman, the woman's carer (as appropriate) and GP should receive a treatment summary outlining:

- the diagnostic tests performed and results
- tumour characteristics
- the type and date of treatment(s)
- interventions and treatment plans from other health professionals
- supportive care services provided
- contact information for key care providers.

5.2.2 Follow-up care

Care in the post-treatment phase is driven by predicted risks (such as the risk of recurrence, developing late effects and psychological issues) as well as individual clinical and supportive care needs. It is important that post-treatment care is evidence-based and consistent with guidelines.

Responsibility for follow-up care should be agreed between the lead clinician, the woman's GP, relevant members of the multidisciplinary team and the woman, with an agreed plan documented that outlines:

- what medical follow-up is required (surveillance for cancer spread, recurrence or secondary cancers, screening and assessment for medical and psychosocial effects)
- care plans from other health professionals to manage the consequences of cancer and treatment
- a process for rapid re-entry to specialist medical services for suspected recurrence.

In particular circumstances, follow-up care can safely and effectively be provided:

- in the primary care setting
- by other suitably trained staff (for example, nurse-led follow-up)
- in a non-face-to-face setting (for example, by telehealth).

The options for follow-up should be discussed at the completion of the primary treatment.

- A woman's follow-up schedule will be planned based on her individual circumstances. Investigations should be determined on a case-by-case basis.
- Most follow-up will involve a history, including updating personal history and enquiry about persistent symptoms that might require investigation to exclude metastatic disease. Family cancer history should be updated.
- If the woman has previously had genetic testing that revealed an unclassified variant in a cancer predisposition gene, the clinician should liaise regularly with the relevant family cancer centre until the variant is classified as benign or pathogenic.
- Physical examination, and particularly breast examination and limb circumference measure, should be conducted. Annual mammography (unless the woman underwent a bilateral mastectomy) should be undertaken. In some cases it may be appropriate to also undertake breast ultrasound or MRI.
- Appropriate follow-up does not involve chest x-rays, bone scans, CT scans, positron emission tomography (PET) scans or blood tests unless the cancer has spread or there are symptoms suggesting metastases.
- Toxicity related to treatment should be monitored and managed, including bone health and cardiovascular health. There is a significant role for physiotherapy in the prevention of osteoporosis.
- Premenopausal women who develop amenorrhoea are at risk of rapid bone loss. There is evidence that oral bisphosphonates are effective in reducing bone loss.
- Continue to prompt general good health.

Adherence to ongoing recommended treatment such as endocrine therapy should be reviewed and side effects managed proactively in order to optimise adherence.

Access to a range of health professions may be required including physiotherapy, occupational therapy, nursing, social work, dietetics, genetic counselling and psychology.

5.3 Research and clinical trials

Participation in research and/or clinical trials should be encouraged where available and appropriate.

For more information visit <<https://www.anzbctg.org/content/6/about-australia-new-zealand-breast-cancer-trial-group>> and <www.australiancancertrials.gov.au>.

5.4 Support and communication

5.4.1 Supportive care

Screening using a validated screening tool and assessment and referral to appropriate health professionals and community-based support services is required to meet the needs of individual women, their families and carers.

In addition to the common issues outlined in the **appendix**, specific issues that may arise include the following.

Physical needs

- Weight changes can be a significant issue for women and may require referral to a dietitian before, during and after treatment.
- Menopause symptoms may require referral to a menopause clinic.
- General healthcare issues (for example, smoking cessation and sleep disturbance) can be referred to a GP.
- Reduced sexual interest and sexual dysfunction may require referral to a clinician skilled in this area.
- Treatment for physical symptoms such as pain, arthralgia and fatigue may be needed.
- Decline in mobility and/or functional status as a result of treatment may necessitate a referral to physiotherapy or occupational therapy.
- Upper limb and breast lymphoedema following lymphadenectomy is a potential treatment side effect in women with breast cancers (NBCC & NCCI 2003) that has a significant effect on survivor quality of life. Referral (preferably preoperatively) to a health professional with accredited lymphoedema management qualifications, offering the full scope of complex lymphoedema therapy, may be needed.
- Bowel dysfunction, gastrointestinal or abdominal symptoms as a result of treatment may require support from a dietitian.
- Although treatments have improved, neuropathy, cardiac dysfunction and nausea and vomiting are still serious side effects of cancer chemotherapy. Managing them is important for improving quality of life.
- Women may need support to cope with hair loss (refer to the Look Good, Feel Better program and/or consider scalp cooling).
- Assistance with managing complex medication regimens, multiple medications, assessment of side effects and assistance with difficulties swallowing medications may require referral to a pharmacist.

Psychological needs

- Family distress, if familial cancer identified, may require support.
- Emotional distress arising from fear of disease recurrence, changes in body image, returning to work, anxiety/depression, interpersonal problems and sexuality concerns may need attention.
- Anxiety/depression, interpersonal problems, stress and adjustment difficulties may require referral to a counsellor or mental health professional.
- Alteration of cognitive functioning in women treated with chemotherapy and radiation therapy requires strategies such as maintaining written notes or a diary and repetition of information (NBCC & NCCI 2003).

Social/practical needs

- Difficulties with return to work or study may require extra support.
- Financial issues related to loss of income and additional expenses as a result of illness and/or treatment may need attention.
- Legal issues (including accessing superannuation, advance care planning, appointing a power of attorney and completing a will) may require advice from relevant professionals.

Information needs

- Appropriate information for people from culturally and linguistically diverse backgrounds should be provided.

5.4.2 Rehabilitation and recovery

Rehabilitation may be required at any point of the care pathway from preparing for treatment through to disease-free survival and palliative care.

Issues that may need to be addressed include managing cancer-related fatigue, cognitive changes, improving physical endurance, achieving independence in daily tasks, returning to work and ongoing adjustment to disease and its sequelae.

5.4.3 Communication with the woman, carer and family

The lead clinician should:

- discuss the management of any of the issues identified in 5.4.1
- offer advice to women and carers on the benefits of and how to access support from breast cancer peer support groups, groups for carers and special interest groups
- explain the treatment summary and follow-up care plan
- provide information about the signs and symptoms of recurrent disease
- provide information about secondary prevention and healthy living.

5.4.4 Communication with the general practitioner

The lead clinician should ensure regular, timely, two-way communication with the woman's GP regarding:

- the follow-up care plan
- potential late effects
- supportive care requirements
- the woman's progress
- recommendations from the multidisciplinary team
- any shared care arrangements
- a process for rapid re-entry to medical services for women with suspected recurrence.

Step 6: Managing locoregional recurrence or metastatic disease

Step 6 is concerned with managing locoregional recurrence and metastatic disease.

Some women will present with symptoms of recurrent disease in the locoregional area or at distant sites, or both. Some cases of recurrent disease will be detected by routine follow-up in a woman who is asymptomatic. All cases should undergo investigation (staging scans) to establish the extent of disease and be rebiopsied if possible; biopsies should have receptor status re-evaluated.

For detailed information on treatment options for advanced breast cancer refer to the ESO-ESMO 2nd international consensus guidelines for advanced breast cancer (ABC2) (Cardoso et al. 2014) at <http://annonc.oxfordjournals.org/content/early/2014/09/17/annonc.mdu385.full.pdf+html>.

6.1 Managing locoregional recurrence

Some women will present with symptoms of recurrent disease in the locoregional area.

6.1.1 Multidisciplinary team

There should be timely referral to the original multidisciplinary team (where possible).

Care coordination is the responsibility of all health professionals involved in the woman's care and should be considered in their practice. This is particularly important for women with metastatic disease or those with multiple comorbidities or supportive care needs.

6.1.2 Treatment

Treatment will depend on the location and extent of the recurrence and on previous management and the woman's preferences. The woman should be reassessed at a multidisciplinary team meeting and treatment may include all modalities of care. All modalities may be considered and the woman should be investigated for distant spread.

In most cases, a combination of anticancer and supportive therapies will provide the most effective overall management of recurrent disease.

Regular assessment of response to therapy should be undertaken and the therapy changed if disease progresses, or as appropriate.

6.1.3 Palliative care

Early referral to palliative care for symptom management can improve the quality of life for women with breast cancer.

6.2 Managing metastatic disease

Some women will present with symptoms of metastatic disease. Some cases of metastatic disease will be detected at the same time as presentation with the initial primary breast cancer ('de novo metastatic disease').

There should be a rebiopsy of accessible sites and re-evaluation of biomarkers.

There should be a complete assessment of the sites of disease including CTs of the abdomen and pelvis and the of the chest, bone scans and blood tumour markers.

6.2.1 Multidisciplinary team

There should be timely referral to the original multidisciplinary team (where possible).

6.2.2 Treatment

Treatment will depend on the location and extent of the cancer and previous treatments, and may include all modalities of therapies including antiresorptive therapy if bone metastases are present.

Regular assessment of the woman's response to therapy should be undertaken and the therapy changed if disease progresses or as appropriate.

In women with hormone receptor-positive breast cancer without rapidly progressing visceral disease, endocrine therapy may be the most appropriate treatment initially with use of chemotherapy when endocrine responsiveness is lost.

Many endocrine therapies are effective in producing antitumour responses in metastatic breast cancer. These can often be used in sequence to gain successive responses to treatment. They include:

- ovarian ablation/suppression in pre-menopausal women
- selective oestrogen receptor modulators such as tamoxifen
- aromatase inhibitors, which block oestrogen production.

6.2.3 Palliative care

Early referral to palliative care can improve the quality of life for people with cancer and in some cases may be associated with survival benefits (Haines 2011; Temel et al. 2010; Zimmermann et al. 2014).

The lead clinician should ensure timely and appropriate referral to palliative care services. Referral to palliative care services should be based on need, not prognosis.

Patients should be encouraged to develop an advance care plan, where appropriate (AHMAC 2011).

Ensure carers and families receive the information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

Further information

Refer women and their carers to Palliative Care Australia via <www.palliativecare.org.au>.

6.3 Research and clinical trials

Participation in research and/or clinical trials should be encouraged where available and appropriate.

For more information visit <<https://www.anzbctg.org/content/6/about-australia-new-zealand-breast-cancer-trial-group>> and <www.australiancancertrials.gov.au>.

6.4 Support and communication

6.4.1 Supportive care

Screening, assessment and referral to appropriate health professionals is required to meet the identified needs of an individual, their carer and family.

In addition to the common issues outlined in the **appendix**, specific issues that may arise include the following.

Physical needs

- Weight changes can be a significant issue for women and may require referral to a dietitian before, during and after treatment.
- General healthcare issues (for example, smoking cessation and sleep disturbance) can be referred to a GP.
- Reduced sexual interest and sexual dysfunction may require referral to a clinician skilled in this area.
- Treatment for physical symptoms such as pain, arthralgia and fatigue may be needed.
- Decline in mobility and/or functional status as a result of treatment may necessitate a referral to physiotherapy or occupational therapy.
- Upper limb and breast lymphoedema following lymphadenectomy is a potential treatment side effect in women with breast cancers (NBCC & NCCI 2003) that has a significant effect on survivor quality of life. Referral (preferably preoperatively) to a health professional with accredited lymphoedema management qualifications, offering the full scope of complex lymphoedema therapy, may be needed.
- Bowel dysfunction, gastrointestinal or abdominal symptoms as a result of treatment may require support from a dietitian.
- Assistance with managing complex medication regimens, multiple medications, assessment of side effects and assistance with difficulties swallowing medications may require referral to a pharmacist.

Psychological needs

- Emotional distress arising from fear of disease recurrence, changes in body image, returning to work, anxiety/depression, interpersonal problems and sexuality concerns may need attention.
- Anxiety/depression, interpersonal problems, stress and adjustment difficulties may require referral to a counsellor or mental health professional.
- Alteration of cognitive functioning in women treated with chemotherapy and radiation therapy requires strategies such as maintaining written notes or a diary and repetition of information (NBCC & NCCI 2003).

Social/practical needs

- Potential isolation from normal support networks, particularly for rural women who are staying away from home for treatment, may need attention.
- Financial issues related to loss of income and additional expenses as a result of illness and/or treatment may need support.
- Legal issues (including accessing superannuation, advance care planning, appointing a power of attorney and completing a will) may require advice from relevant professionals.

Information needs

- Appropriate information for people from culturally and linguistically diverse backgrounds should be provided.

6.4.2 Rehabilitation

Rehabilitation may be required at any point of the care pathway from preparing for treatment through to disease-free survival and palliative care.

Issues that may need to be addressed include managing cancer-related fatigue, cognitive changes, improving physical endurance, achieving independence in daily tasks, returning to work and ongoing adjustment to disease and its sequelae.

6.4.3 Communication with the woman, carer and family

The lead clinician should ensure there is adequate discussion with the woman and her carer about the diagnosis and recommended treatment, including the intent of treatment and possible outcomes, likely adverse effects and supportive care options available.

Initiate a discussion regarding advance care planning with the woman and carer if appropriate.

Step 7: End-of-life care

End-of-life care is appropriate when the woman's symptoms are increasing and functional status is declining. Step 7 is concerned with maintaining the woman's quality of life and addressing her health and supportive care needs as she approaches the end of life, as well as the needs of her family and carer. Consideration of appropriate venues of care is essential. The principles of a palliative approach to care need to be shared by the team when making decisions with the woman and her family.

7.1 Multidisciplinary palliative care

If not already involved, referral to palliative care should be considered at this stage (including nursing, pastoral care, palliative medicine specialist backup, inpatient palliative bed access (as required), social work and bereavement counselling) with GP engagement.

If not already in place, the woman and carer should be encouraged to develop an advance care plan (AHMAC 2011).

The multidisciplinary palliative care team may consider seeking additional expertise from a:

- pain specialist
- pastoral carer or spiritual advisor
- bereavement counsellor
- therapist (for example, music or art).

The team might also recommend accessing:

- home- and community-based care
- specialist community palliative care workers
- community nursing.

Consideration of an appropriate place of care and preferred place of death is essential.

Ensure carers and families receive information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

Further information

Refer the woman and her carer to Palliative Care Australia via <www.palliativecare.org.au>.

7.2 Research and clinical trials

Participation in research and clinical trials should be encouraged where available and appropriate.

For more information visit <<https://www.anzbctg.org/content/6/about-australia-new-zealand-breast-cancer-trial-group>> and <www.australiancancertrials.gov.au>.

7.3 Support and communication

7.3.1 Supportive care

Screening, assessment and referral to appropriate health professionals is required to meet the identified needs of the woman, her carer and family.

In addition to the common issues identified in the **appendix**, specific issues that may arise at this time include:

- emotional and psychological distress from anticipatory grief, existential distress, fear of death/dying, anxiety/depression, interpersonal problems and anticipatory bereavement support for the woman as well as her carer and family
- practical, financial and emotional impacts on carers and family members resulting from the increased care needs of the woman
- legal issues relevant to people with advanced disease such as accessing superannuation early, advance care planning, powers of attorney and completing a will
- information for women and families about arranging a funeral
- specific spiritual needs that may benefit from the involvement of pastoral care
- bereavement support for family and friends
- specific support for families where a parent is dying and will leave behind bereaved children or adolescents, creating special family needs
- physical symptoms including pain and fatigue
- change in physical appearance
- increasing dependence on others
- decline in mobility and/or functional status impacting on her discharge destination.

7.3.2 Communication with the woman, carer and family

The lead clinician should:

- be open to and encourage discussion about the expected disease course, with due consideration to personal and cultural beliefs and expectations
- discuss palliative care options including inpatient and community-based services as well as dying at home and subsequent arrangements
- provide the woman and carer with the contact details of a palliative care service.

7.3.3 Communication with the general practitioner

The lead clinician should discuss end-of-life care planning and transitioning planning to ensure the woman's needs and goals are addressed in the appropriate environment. The woman's GP should be kept fully informed and involved in major developments in the woman's illness trajectory.

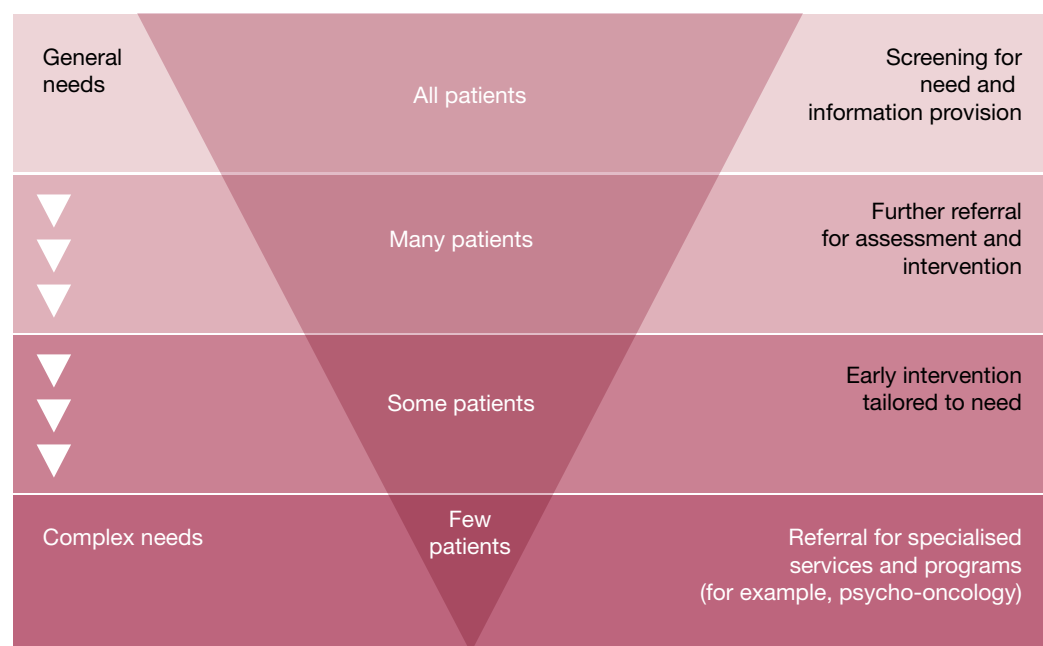
Appendix: Supportive care

Supportive care in cancer refers to the following five domains:

- physical domain, which includes a wide range of physical symptoms that may be acute, relatively short-lived or ongoing, requiring continuing interventions or rehabilitation (NBCC & NCCI 2003)
- psychological domain, which includes a range of issues related to the person's mental health and personal relationships (NBCC & NCCI 2003)
- social domain, which includes a range of social and practical issues that will impact on the individual and their family such as the need for emotional support, maintaining social networks and financial concerns (NICE 2004)
- information domain, which includes access to information about cancer and its treatment, support services and the health system overall (NBCC & NCCI 2003)
- spiritual domain, which focuses on the person's changing sense of self and challenges to their underlying beliefs and existential concerns (NICE 2004).

Fitch's (2000) model of supportive care (Figure 1) recognises the variety and level of intervention required at each critical point as well as the need to be specific to the individual. The model targets the type and level of intervention required to meet women's supportive care needs.

Figure 1: The tiered approach



While all women require general information, only a few will require specialised intervention. Common indicators in women with breast cancer who may require referral to appropriate health professionals and/or organisations include the following:

Physical needs

- Weight changes can be a significant issue for women and may require referral to a dietitian before, during and after treatment.
- Menopause symptoms may require referral to a menopause clinic.
- General healthcare issues (for example, smoking cessation and sleep disturbance) can be referred to a GP.
- Reduced sexual interest and sexual dysfunction may require referral to a clinician skilled in this area.
- Treatment for physical symptoms such as pain, arthralgia and fatigue may be needed.
- Decline in mobility and/or functional status as a result of treatment may necessitate a referral to physiotherapy or occupational therapy.
- Bowel dysfunction, gastrointestinal or abdominal symptoms as a result of treatment may require support from a dietitian.
- Upper limb and breast lymphoedema following lymphadenectomy is a potential treatment side effect in women with breast cancers (NBCC & NCCI 2003) that has a significant effect on survivor quality of life. Referral (preferably preoperatively) to a health professional with accredited lymphoedema management qualifications, offering the full scope of complex lymphoedema therapy, may be needed.
- Although treatments have improved, neuropathy, cardiac dysfunction and nausea and vomiting are still serious side effects of cancer chemotherapy. Managing them is important for improving quality of life.
- Women may need support to cope with hair loss (refer to the Look Good, Feel Better program and/or consider scalp cooling).
- Assistance with managing complex medication regimens, multiple medications, assessment of side effects and assistance with difficulties swallowing medications may require referral to a pharmacist.

Psychological needs

- For some populations (culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islanders, and lesbian, transgender and intersex communities) a breast cancer diagnosis can come with additional psycho-social complexities. Discrimination uncertainty may also make these groups less inclined to seek regular medical and gynaecological care. Access to expert health professionals who possess knowledge specific to the psychosocial needs of these groups may be required.
- Alteration of cognitive functioning in women treated with chemotherapy and radiation therapy requires strategies such as maintaining written notes or a diary and repetition of information (NBCC & NCCI 2003).
- Those with a pre-existing mental health disorder have a higher risk of psychological disturbance.
- Women who have had extensive surgery or who receive a multimodality treatment strategy for breast cancer are at high risk of depression and heightened anxiety. Regular screening for depression and anxiety specifically for these women is required. Strategies such as information provision, relaxation techniques, meditation (Kearney & Richardson 2006) and a referral to a psychologist or psychiatrist as required may be helpful.
- Fear of cancer recurrence is reported to be extremely common in the post-treatment phase. Some women may have disabling symptoms and may benefit from referral to psychology services.
- Distress and depression can be just as common in carers and family members including children.
- Consider a referral to a psychologist, psychiatrist or social worker if the woman is:
 - displaying emotional cues such as tearfulness, distress, avoidance and withdrawal
 - preoccupied with or dwelling on thoughts about cancer and death
 - displaying fears about the treatment process and/or the changed goals of their treatment
 - worried about loss associated with their daily function, dependence on others and loss of dignity
 - becoming isolated from family and friends and withdrawing from company and activities that they previously enjoyed
 - feeling hopeless and helpless about the impact that breast cancer is having on their life and the disruption to their life plans
 - struggling with communicating to family and loved ones about the implications of their cancer diagnosis and treatment
 - experiencing changes in sexual intimacy, libido and function
 - struggling with the diagnosis of metastatic or advanced disease
 - having difficulties with quitting drug and alcohol use
 - having difficulties transitioning to palliative care.

Body image

- Support and counselling from a psychologist, psychiatrist, occupational therapist or social worker may be required.
- Disfigurement and scarring from appearance-altering treatment (and possible need for a prosthetic), which may require referral to a specialist psychologist, psychiatrist or social worker.

Fertility preservation and preservation of ovarian function

- Loss of fertility, sexual dysfunction or other symptoms associated with treatment or surgically or chemically induced menopause require sensitive discussion and possible referral to a clinician skilled in this area (NBCC & NCCI 2003).
- The option of fertility preservation and preservation of ovarian function needs to be discussed prior to treatment starting. Referral to a fertility service for counselling and evaluation of options may be appropriate. For detailed information on fertility preservation refer to Breast Cancer Network Australia's Fertility-related choices available at <https://www.bcna.org.au/sites/default/files/fertility_decision_aid_20120117.pdf>.

Social/practical needs

- Significant restrictions to social activities may require referral to a social worker, occupational therapist, psychologist or psychiatrist.
- Potential isolation from normal support networks, particularly for rural women who are staying away from home for treatment, may be needed.
- Financial issues related to loss of income and additional expenses as a result of illness and/or treatment may require additional support.
- Legal issues (including accessing superannuation, advance care planning, appointing a power of attorney and completing a will) may require referral to relevant professionals.

Spiritual needs

- Women with cancer and their families should have access to spiritual support appropriate to their needs throughout the cancer journey.
- Multidisciplinary teams should have access to suitably qualified, authorised and appointed spiritual caregivers who can act as a resource for women, carers and staff. They should also have up-to-date awareness of local community resources for spiritual care.

Populations with special needs

Elderly women with cancer

Planning and delivering appropriate cancer care for elderly women presents a number of challenges. Improved communication between the fields of oncology and geriatrics is required to facilitate the delivery of best practice care, which takes into account physiological age, complex comorbidities, risk of adverse events and drug interactions, as well as implications of cognitive impairment on suitability of treatment and consent (Steer et al. 2009).

A national interdisciplinary workshop convened by the Clinical Oncology Society of Australia recommended that women over the age of 70 undergo some form of geriatric assessment, in line with international guidelines (COSA 2013). Assessment can be used to determine life expectancy and treatment tolerance as well as identifying conditions that might interfere with treatment including:

- function
- comorbidity
- presence of geriatric syndromes
- nutrition
- polypharmacy
- cognition
- emotional status
- social supports.

Guided intervention using aged care services is appropriate.

Younger women

While there is no accepted definition of 'young' regarding breast cancer, younger women have been defined in previous guidelines as women aged 40 or younger at breast cancer diagnosis (NBCC 2004). Approximately 700 women under the age of 40 are diagnosed with breast cancer in Australia each year (AIHW 2014). Studies suggest that younger women with breast cancer have worse disease-free and overall survival outcomes (NBOCC 2007). Younger women with breast cancer are also likely to face different issues in treatment and follow-up. Concerns may include:

- fertility and pregnancy following treatments
- sexual difficulties at higher rates than older women with breast cancer (NBOCC 2007)
- greater impact on body image (NBOCC 2007)
- needs of dependent children, including child care issues
- increased concerns about the impact of diagnosis and treatment on relationships compared with older women (NBOCC 2007)
- concerns about their employment and financial status
- early menopause.

Pregnancy-associated breast cancer

Pregnancy-associated breast cancer, defined as breast cancer diagnosed during pregnancy or in the year after a pregnancy, accounts for seven per cent of breast cancers in young women (Ives 2009), which is around 100 women annually in Australia. These women typically have higher disease-stage and more aggressive tumour features at diagnosis. However, when matched by age and disease stage with other breast cancer cases, there appears to be no survival difference, except in women diagnosed in the postpartum period, who have higher mortality and increased distant recurrence even after accounting for these factors.

A multidisciplinary team approach is essential in managing this group. Initial investigation of any breast symptom in a pregnant or lactating woman should be the same as any other woman, to avoid diagnostic delays. The treating team should include health professionals involved in the treatment of breast cancer, the care of pregnancy and psychosocial support. The recommended obstetric and cancer management of a woman presenting with gestational breast cancer will be dependent on the fetal gestation and disease status at diagnosis.

Men with breast cancer

Breast cancer in men is uncommon, with about 145 men diagnosed annually in Australia (AIHW 2014). Given the low number of diagnoses and the identification of breast cancer in the general community as a 'female disease', many men who are diagnosed with breast cancer can feel isolated and unsupported. This has the potential to cause significant psychological distress and may lead to anxiety and depression. Those working in the area should be alert to the increased risk for psychological complications, impact on body image and isolation. Peer support may be useful to normalise the feeling and side effects of treatment. All resources should be cognisant of not excluding men as this has the potential to further ostracise an already isolated group.

Aboriginal and Torres Strait Islander communities

The burden of cancer is higher in the Australian Indigenous population (AIHW 2014). Survival also significantly decreases as remoteness increases, unlike the survival rates of non-Indigenous Australians. Aboriginal and Torres Strait Islander people in Australia have high rates of certain lifestyle risk factors including tobacco smoking, higher alcohol consumption, poor diet and low levels of physical activity (Cancer Australia 2013). The high prevalence of these risk factors is believed to be a significant contributing factor to the patterns of cancer incidence and mortality rates in this population group (Robotin et al. 2008).

In caring for Aboriginal and Torres Strait Islander people diagnosed with cancer, the current gap in survivorship is a significant issue. The following approaches are recommended to improve survivorship outcomes (Cancer Australia 2013):

- Raise awareness of risk factors and deliver key cancer messages.
- Develop evidence-based information and resources for community and health professionals.
- Provide training for Aboriginal and Torres Strait Islander health workers and develop training resources.
- Increase understanding of the barriers to care and support.
- Encourage and fund research.
- Improve knowledge within the community to act on cancer risk and symptoms.
- Improve the capacity of Aboriginal and Torres Strait Islander health workers to provide cancer care and support to their communities.
- Improve system responsiveness to cultural needs.
- Improve our understanding of care gaps through data monitoring and targeted priority research.

Culturally and linguistically diverse communities

For women from culturally and linguistically diverse backgrounds in Australia, a cancer diagnosis can come with additional complexities, particularly when English proficiency is poor. In many languages there is not a direct translation of the word 'cancer', which can make communicating vital information difficult. Perceptions of cancer and related issues can differ greatly in those from culturally diverse backgrounds and can impact on the understanding and decision making that follows a cancer diagnosis. In addition to different cultural beliefs, when English language skills are limited there is potential for miscommunication of important information and advice, which can lead to increased stress and anxiety for women. A professionally trained interpreter (not a family member or friend) should be made available when communicating with people with limited English proficiency. Navigation of the Australian healthcare system can pose problems for those born overseas and particular attention should be paid to supporting these women (Department of Health 2009).

Resource list

For patients, families and carers

Australian Cancer Survivorship Centre

Has general and tumour-specific information, primarily focused on the post-treatment survivorship phase

- Telephone: (03) 9656 5207
- <www.petermac.org/cancersurvivorship>

beyondblue

Information on depression, anxiety and related disorders, available treatment and support services

- Telephone: 1300 22 4636
- <www.beyondblue.org.au>

Breast Cancer Network Australia

Specific information on breast cancer

- Telephone: 1800 500 258
- <www.bcna.org.au>

Cancer Australia

Information on cancer prevention, screening, diagnosis, treatment and supportive care for Australians affected by cancer, and their families and carers

- Telephone: 1800 624 973
- <www.canceraustralia.gov.au>

Cancer Council (operated by Cancer Council Victoria)

A confidential telephone support service for people affected by cancer providing information on treatment, cancer support groups and other community resources

- Telephone: 13 11 20 (Monday to Friday, 8.30 am – 5.30 pm)
- <www.cancervic.org.au>

CanTeen

Australian organisation for young people living with cancer that offers support, information and resources

- Telephone: 1800 226 833
- <www.canteen.org.au>

Care Search: Palliative Care Knowledge Network

Information for patients and carers on living with illness and practical advice on how to care and finding services

- Telephone: (08) 7221 8233
- <www.caresearch.com.au>

Look Good, Feel Better

A non-medical, free community service program dedicated to teaching women how to manage the appearance-related side effects caused by cancer treatment

- Telephone: 1800 650 960 (Monday to Thursday 9.00am to 5.00pm)
- <www.lgfb.org.au>

For health professionals

Australian Cancer Trials

Information on the latest clinical trials in cancer care, including trials that are recruiting new participants

- <www.australiancancertrials.gov.au>

Cancer Australia

Information for health professionals including guidelines, cancer guides, reports, fact sheets, DVDs, posters and pamphlets

- <www.canceraustralia.gov.au>

Cancer Council Australia

Information on prevention, research, treatment and support provided by Australia's peak independent cancer authority

- <www.cancer.org.au>

eviQ

Clinical information resource providing health professionals with current evidence-based, peer-maintained, best practice cancer treatment protocols and information relevant to the Australian clinical environment

- <www.eviq.org.au>

National Health and Medical Research Council

Information on clinical practice guidelines, cancer prevention and treatment

- <www.nhmrc.gov.au>

Glossary

Advance care planning – a process of discussing future medical treatment and care based on an individual's preferences, goals, beliefs and values, which can guide future decisions should the person become unable to communicate.

Alternative therapies – treatments that are used in place of conventional medical treatment, often in the hope they will provide a cure.

Care coordinator – the health professional nominated by the multidisciplinary team to coordinate patient care. The care coordinator may change over time depending on the patient's stage in the care pathway and where care is primarily located.

Complementary therapies – supportive treatment used in conjunction with conventional medical treatment. These treatments may improve wellbeing and quality of life and help women deal with the side effects of cancer.

End-of-life care – a distinct phase of palliative care that is appropriate when a woman's symptoms are increasing and functional status is declining despite anti-cancer therapy.

General/primary medical practitioner – the practitioner to whom the woman first presents with symptoms; this may be the general practitioner, an emergency department clinician or a medical professional providing cancer screening services.

Lead clinician – the clinician who is responsible for managing patient care. The lead clinician may change over time depending on the stage of the care pathway and where care is being provided.

Multidisciplinary care – an integrated team approach to healthcare in which medical and allied health professionals consider all relevant treatment options and develop an individual treatment plan collaboratively for each woman (Department of Health 2007b).

Multidisciplinary team – comprises the core disciplines integral to providing good care. The team is flexible in approach, reflects the woman's clinical and psychosocial needs and has processes to facilitate good communication.

Optimal cancer care pathway – the key principles and practices required at each stage of the care pathway to guide the delivery of consistent, safe, high-quality and evidence-based care.

Palliative care – any form of medical care or treatment that concentrates on reducing the severity of disease symptoms.

Patient management frameworks – tumour stream models adopted in Victoria in 2003 to reduce variation in cancer care. The optimal cancer care pathways are updated versions of these models.

Prehabilitation – one or more interventions performed in a newly diagnosed cancer patient that are designed to improve physical and mental health outcomes as the woman undergoes treatment and beyond.

Primary specialist – the person who makes the referral to the multidisciplinary team (such as specialist physician, surgeon, oncologist, palliative care specialist). This person will also make referrals for treatment and will be responsible for overseeing follow-up care.

Rehabilitation – comprises multidisciplinary efforts to allow the woman to achieve optimal physical, social, physiological and vocational functioning within the limits imposed by the disease and its treatment.

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Australian Association of Nuclear

Medicine Specialists

Australian and New Zealand Society of Palliative Care

Australian Chapter of Palliative Medicine,

Royal Australasian College of Physicians

Australian College of Nursing

Australian Institute of Radiography

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