



**INTEGRATIVE  
ONCOLOGY IN  
AUSTRALIA 2016**

**NICM**

The science of integrative medicine



# INTEGRATIVE ONCOLOGY IN AUSTRALIA 2016

Mapping service  
provision and  
exploring unmet needs  
JULY 2017

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## **Collaboration**

Researchers at NICM and the Centre for Health Research, Western Sydney University partnered with South West Sydney Local Health District (SWSLHD) and the registered charity, Oncology Massage Limited (OML).

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# ABSTRACT

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**AIM:** To identify specialised cancer service provision across Australia and providers' and cancer survivors' views on important unmet needs, barriers and facilitators. Given the high use of Complementary Medicine (CM) by cancer survivors, the focus was Integrative Oncology (IO) where CM is integrated with conventional cancer healthcare.

**METHOD:** NICM conducted a cross-sectional national survey of 295 public and private healthcare organisations with cancer services. One senior staff member from each eligible organisation was invited to answer a paper/online questionnaire. Concurrently, purposive sampling of cancer survivors from Arabic, Vietnamese, Chinese and Anglo-European Australian backgrounds was used to recruit 33 participants for four focus group interviews and 121 respondents for an on-line survey. Triangulation mixed method analysis synthesised the results from the quantitative and qualitative data.

**RESULTS:** The national survey response rate was 93% (275/295), from which 71 (25%) provided IO services for a median duration of six years. IO was provided in a variety of settings - inpatient (52%), outpatient (53%), dedicated centre (35%) and home/residential care visits (4%). The Northern Territory was the only state/territory with no IO services. Compared to non-IO providers, organisations were more likely to be owned by a not-for-profit company (46%) or were government owned (38%) ( $p < 0.001$ ). Provision was restricted at most sites to a limited range of non-biologically based services, most commonly massage (73%), wellbeing (71%), and movement modalities (39%). Institutional policies and information regarding CM products and practitioner services were generally under-developed and inconsistent for IO and non-IO providers alike. The most important unmet need identified by providers was supportive care services, including IO. Cancer survivors emphasised that IO was not a 'luxury item', rather it was an important adjuvant for treatment side effects, co-morbidities, rehabilitation and quality of life. Four inter-related themes emerged - finance, logistics, information, and culture - as the barriers and facilitators to IO. The strongest convergence across the data was financial barriers. IO provision relied heavily upon patient payments, followed by philanthropy, and volunteer practitioners. Funding was the greatest barrier identified by 60% of non-IO providers. Out-of-pocket costs were a significant personal barrier to accessing CM or more CM. Views on funding solutions were more contentious. Other important barriers were lack of IO service provision, difficulties in referral pathways, healthcare professional attitudes, insufficient evidence, and uncertainty around patient demand, which services to provide and sustainable business models.

**CONCLUSION:** Australian organisations are increasingly providing IO services, signalling the need for clearer national guidance and policies. Discrepancies continue between what cancer survivors are doing or seeking, and the IO services they can access. Survivorship and wellness clinics are in urgent need of development. Coordinated strategic planning between all providers and insurers is required if the long-term needs of cancer survivors are to be adequately and equitably met.

**COLLABORATION:** NICM and the Centre for Health Research, Western Sydney University partnered with South West Sydney Local Health District and the registered charity, Oncology Massage Limited.

# EXECUTIVE SUMMARY

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Cancer remains a leading cause of mortality and morbidity, and increases to both cancer incidence and survival has resulted in growing numbers of cancer survivors accessing traditional and complementary medicines and therapies (CM).<sup>1,2</sup> Cancer survivors use CM for a variety of reasons that include managing treatment-related side effects and symptoms of cancers, enhancing the effectiveness of cancer treatment, prolonging life, improving quality of life and affirming self-efficacy.<sup>3,4</sup> Although the significant use of CM by cancer survivors is well documented, less is known about cancer survivors' views on integrating conventional cancer services with CM, the types of services they need, and their preferences for service delivery.<sup>5</sup>

The term integrative oncology (IO) evolved from integrative medicine (IM) and refers to the combining of CM interventions or services with conventional cancer care.<sup>6</sup> The integration of CM into Australian cancer services has been slow to gather momentum. NICM and the Centre for Health Research, Western Sydney University partnered with South West Sydney Local Health District and the registered charity, Oncology Massage Limited to gain further insight within this field. The aim of this study was to examine IO service provision and unmet needs across Australia, and identify barriers and facilitators to CM integration.

The study consisted of two parts;

- (i) A national cross-sectional survey of organisations providing cancer services, and
- (ii) Focus group interviews and an online survey with cancer survivors.

## 2016 NATIONAL SURVEY OF CANCER SERVICE ORGANISATIONS

A total of 295 healthcare organisations with a dedicated cancer service were identified with a very high, 93% (n=275), response rate providing a representative sample of cancer services across Australia. IO services were provided by 71 (25%) organisations, of which half had been introduced over the past six years. The IO services provided were predominantly massage (73%), wellbeing (71%), and movement modalities (39%).

Typically, one or two practitioners provided IO services, with limited availability. Funding of IO services varied, a contribution from the patient was the most common source of funding, followed by philanthropic contributions, volunteers, and lastly through the cancer service.

### Barriers and solutions to integrative oncology

The main barriers for not providing IO services included (i) lack of funding; (ii) uncertainty about which services to provide or how to set up services; (iii) low (perceived) patient demand; (iv) lack of staff interest; and (v) recruiting appropriately trained CM practitioners in regional areas. Commonly identified solutions to these barriers included (i) securing funding; (ii) addressing business models; and (iii) building stronger evidence. Views about how IO/CM should be funded were contentious and involved creating Medicare rebates, securing higher rebates from private health insurers, fundraising, and volunteer practitioners.

### Organisational policies

The implementation of national recommendations and institutional policies for CM practitioner services and use of CM products was inconsistent and not well developed for IO and non-IO providers alike. For some cancer centres, visiting

CM practitioners, referrals to CM practitioners, or patient-initiated CM product use were not permitted.

### **Key unmet service needs**

The most commonly reported unmet needs in respondents' regions were for ongoing cancer care following initial cancer treatment; for example, rehabilitation, survivorship or wellness services (28%) and palliative care services, either as an inpatient or at home (21%). Respondents also identified the need for IO services in their region.

## **CANCER SURVIVOR VIEWS**

Focus group interviews with cancer survivors (n=33) from Arabic, Vietnamese, Chinese and Anglo-European Australian backgrounds were undertaken and a further 121 cancer survivors completed the online survey. Two main themes were identified: "positive perceptions and experiences" and "barriers and unmet needs".

### **Positive perceptions and experiences**

Participants reported a range of positive experiences and perceived benefits of using CM throughout their cancer journey. This included the positive impact of CM on side effects and recovery, positive experiences with CM practitioners. Survivors emphasised that such services were not a 'luxury item' and an important component of cancer care. Hospital-based IO services had several perceived benefits, including CM therapists having more expert knowledge about cancer care, the benefits of having CM services close to the site of other cancer treatment, and lower costs compared to private services.

### **Barriers and unmet needs**

Structural barriers included lack of availability of IO services, difficulties in referral pathways, medical practitioner attitudes, the logistics of accessing care, and under-funding. Personal barriers for individuals and their family/carers were influenced by the severity of impairment and disability; attitudes, beliefs and knowledge about CM; and available personal resources (e.g. financial, time or transport).

## **DISCUSSION**

In line with previous research, the results from the community survey and interviews confirmed that many cancer survivors in Australia use CM and consult CM practitioners both during and after active cancer treatment.<sup>2,5,7</sup> None of the participants had used CM as an alternative to conventional cancer treatment. Instead, CM was used to augment their cancer treatment, increase their chances of survival, enhance their immune system, manage side effects, and improve quality of life. A substantial gap was observed between the use of CM products by cancer survivors and the paucity of IO services by cancer centres to guide appropriate use. In the absence of clear guidelines and increasing patient demand, cancer survivors may benefit from an IO medical consultation that aims to build positive therapeutic alliances and guide the safe and effective use of CM.<sup>8</sup>

Participants identified a wide range of complex interrelated barriers and solutions to IO service provision and access. The views expressed by participants emphasise the importance of access to IO services both during and after active treatment and ensuring it remains an integral part of rehabilitation and

long-term healthcare. Further guidance on the adoption of an IO approach by Australian cancer services can help deliver holistic patient-centred care whilst facilitating safer and more effective CM use by survivors throughout their cancer journey.<sup>9</sup>

## CONCLUSION

Australian healthcare organisations are increasingly providing IO services. There was evidence however of fragmented development, significant unmet needs for some patients, inequalities in access, and discrepancies between what cancer survivors are doing or seeking compared to the IO services they can access through their local cancer services.

Healthcare organisations signalled a need for more national policies and guidance on clinical governance and business models. Translating existing evidence, building further evidence and developing clinical guidelines may help. Coordinated strategic planning between all providers and insurers is required if the long-term needs of cancer survivors are to be adequately and equitably met.

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# DEFINITIONS AND ABBREVIATIONS

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**Aboriginal and Torres Strait Islander Peoples / Communities** is not abbreviated in the body of the document.

**AHPRA** Australian Health Practitioner Regulation Agency refers to the regulation of nonmedical acupuncturists.

**Biological based CM therapies** refer to naturally occurring substances such as herbs, vitamins, minerals, dietary supplements and medicinal foods.

**CALD** Culturally and Linguistically Diverse in Australia generally refers to peoples and communities that originate from countries not of Anglo-Saxons/ Celtic heritage.

**Cancer survivor** The broadest definition of this term is used throughout this report. Cancer survivor refers to any living person diagnosed with cancer, from the time of diagnosis, during and after treatment, whether in remission or terminal.

**CATAG** Council of Australia Therapeutic Advisory Groups provides a position statement for the use of Complementary and Alternative Medicines.

**CM** Complementary Medicine is an umbrella term that includes all traditional, complementary and alternative medicine. The term can be used to describe CM practitioners, therapies or products.

**COSA** Clinical Oncology Society of Australia.

**GP** General Practitioner.

**HREC** Human Research Ethics Committee refers to institutional ethics approval and governance.

**IM** Integrative Medicine refers to the combining of Complementary Medicine with conventional healthcare. The term can be used to describe IM practitioners, an IM team or IM services.

**Indigenous Australian** healing practices is used when distinguishing the traditional and contemporary healing practices of Aboriginal and Torres Strait Islander peoples and communities from the traditional medicine and indigenous healing practices originating from other countries.

**IO** Integrative Oncology is when integrative medicine is applied to the cancer care setting.

**Massage/touch therapies** refer to any style of CM massage or touch therapy NOT provided by a physiotherapist, osteopath or chiropractor (e.g. oncology massage, remedial massage, shiatsu, Bowen therapy, reflexology therapist). Lymphatic massage is also excluded unless it is provided by a CM practitioner.

**Movement modalities** refer to a range of CM exercise and movement modalities (e.g. yoga, tai chi, qigong, pilates, dance). Conventional exercise activities prescribed by an exercise physiologist or physiotherapist are excluded.

**NSW** New South Wales refers to the Australian state.

**OM** Oncology Massage refers to massage provided to cancer survivors by qualified massage therapists who have undertaken further training and certification for cancer care.

**OML** Oncology Massage Limited is a registered charity in Australia that provides education and certification for massage therapists.

**SSA** Site-Specific Approval is often an additional requirement alongside ethics approval at some institutions, such as public hospital settings.

**SWSLHD** South Western Sydney Local Health District is located in New South Wales, which covers seven Local Government Areas from Bankstown to Wingecarribee, has a population of approximately 820,000 people, and is responsible for public hospitals in Bankstown, Braeside, Bowral, Camden, Campbelltown, Fairfield and Liverpool.

**UK** United Kingdom.

**US** United States of America.

**Wellbeing services** refer to a range of CM services that support psychological wellbeing (e.g. art, music or pet therapy; and meditation, mindfulness or relaxation activities).

# 1 INTRODUCTION

---

## 1.1 BACKGROUND

At least 120,000 Australians are diagnosed with cancer every year. Cancer remains the leading cause of disease burden in Australia, accounting for about 19% of the total burden. With earlier detection and screening, and more effective treatment, five-year survivorship is now over 68%.<sup>[1]</sup> The pressure on an already strained health service, particularly for supportive care and ongoing surveillance, calls for changes and innovation in service delivery to adequately meet the needs of cancer survivors.<sup>[2, 3]</sup>

The significant use of traditional and complementary medicine (CM) by cancer survivors are well documented – prevalence of use and characteristics of users, motivators and barriers, and patient perceived outcomes and benefits. Australian cancer survivors have expressed preference to involve their doctors in decisions about CM use with and for oncology services to provide CM services.<sup>[4]</sup> As the incidence of cancer increases and survival time improves, the population accessing CM is also increasing. A recent meta-analysis of surveys describing CM use in adult cancer patients from Australia, Canada, Europe, New Zealand, and the United States (US) reported a rise from an estimated 25% in the 1970s and 1980s to more than 32% in the 1990s and to 49% after 2000.<sup>[5]</sup> In Australia, the prevalence of CM use by people with cancer has increased from 22% in 1996,<sup>[6]</sup> to 63% in 2008,<sup>[4]</sup> with an estimated 40% pooled prevalence rate for CM use between 1985 and 2009 in Australia and New Zealand.<sup>[5]</sup>

In general, the most commonly used CM include biological based CM therapies e.g. vitamins and minerals (50%), special diet and foods (23%), and Chinese herbal medicines (14%). Between 20 and 30% of respondents had used prayer or spiritual practices, meditation, imagery, and visualisation. Between 10 and 17% had used massage, acupuncture, and yoga. Cancer patients use CM for a variety of reasons including managing treatment-related side effects and symptoms of cancers, enhancing the effectiveness of cancer treatment, prolonging life, and improving their quality of life and self-efficacy.<sup>[7, 8]</sup> Cancer patients who do not use CM, cite barriers such as the cost and lack of time, fear and distrust, and lack of evidence as reasons for their choice.<sup>[9]</sup>

### 1.1.1 Evidence of CM therapies

There is an emerging evidence base of CM modalities to improve cancer symptoms and enhance quality of life.<sup>[10]</sup> Integrative oncology (IO) is a new evidence-based specialty that uses CM with conventional cancer treatment to enhance efficacy, symptom control, and to reduce patient distress. IO has been described as a focus on the role of herbs, vitamins and minerals, nutrition, acupuncture, meditation and other mind-body approaches including music therapy, touch therapies, and fitness therapies.<sup>[11]</sup>

Compared to countries such as the US and United Kingdom (UK), integration in Australia has been slow to gather momentum. In 2001, 70% of UK cancer centres provided at least one CM therapy with touch therapies being the most common.<sup>[12]</sup> Many of the major cancer centres in the US also offer CM alongside conventional treatment. However, a survey of 19 of the largest American centres found that integration was ad hoc and inconsistent within and across organisations.<sup>[13]</sup>

## 1.1.2 INTEGRATION OF CM WITHIN ONCOLOGY SERVICES

In response to the increasing use and demand for CM by cancer patients, interest in the implementation of IO services in Australia and abroad has developed. The 2005 Australian Senate Inquiry urged Australian cancer services to meet the unmet needs of their patients for IO services and provide CM alongside conventional cancer care.<sup>[14]</sup>

Two systematic studies have assessed the integration of CM with cancer services in Australia.<sup>[15, 16]</sup> The first, was a 2008 survey in New South Wales (NSW) examining the policies and provision of 43 public or privately owned cancer services.<sup>[16]</sup> Palliative care and paediatric cancer services were excluded. The findings revealed that few cancer services had formal policies about CM (14%) and eight (19%) of the services provided or prescribed a range of CM therapies. Funding of these services was provided in various ways including charging patients for use of the services, providing support by hospital funding and donations from charitable organisations. Further insight into the provision of IO services has since been informed by an Australian survey of 124 cancer services.<sup>[15]</sup> This study found only 11 (46%) services provided IO as part of their supportive care programs. Both surveys were limited by restricted inclusion criteria and suboptimal response rates. Questions remain about actual IO provision in Australia and the details regarding the types of service, policy environment, and key determinants influencing the provision of services.

Recent work by NICM researchers has identified many options and approaches to establishing IO services. Among services that have integrated CM with oncology, a diverse range of approaches to corporate governance and service delivery have been used.<sup>[17]</sup> The overarching aim of most IO services is to integrate and research a broad range of CM therapies that are patient centred, holistic, and individualised. Translating these aims into practice can be difficult due to a variety of reasons including uncertainty about evidence, mixed oncologist support, safety, and clinical governance. There may also be concerns about equity because the corporate governance and funding mechanisms can result in service delivery that is unaffordable to some patients. In addition, there may be ongoing challenges in managing patients who choose to use 'unendorsed' CM whilst undergoing cancer treatment at an IO centre.

Known barriers to providing IO include determining an appropriate service model and revenue structure;<sup>[18]</sup> concerns with ethical and legal issues such as regulations and credentialing;<sup>[19, 20]</sup> finding a common language between CM providers, conventional healthcare staff, and conventional physicians;<sup>[21, 22]</sup> identifying CM providers and integrating them into the system; and lack of education about CM.<sup>[23, 24]</sup> These barriers are common to the integration of CM in many settings but are compounded in cancer care where there is considerable concern about the possibility of adversely affecting chemotherapy or radiotherapy treatment.<sup>[20]</sup> Perhaps the most under-estimated challenge for IO services is how to create a truly integrative approach within a multidisciplinary team. The tendency for medical dominance may leave CM practitioners feeling unappreciated, marginalised, and disempowered.<sup>[24]</sup> This risk can be mitigated when therapists focus on targeted outcomes for CM such as reduced anxiety, better sleep, and reduced nausea.

## 1.1.3 Patient views of integrated CM services

The majority of the research undertaken in the oncology setting both in Australia and internationally, has focused on the prevalence of CM use,

motivators and barriers for use, patient perceived outcomes, and challenges with patient-clinician communication. Much less is known about patients' views on what the integration of conventional cancer services with CM might look like, the types of services they need, and preferences for service delivery. Even less is known about culturally and linguistically diverse (CALD) populations.

A qualitative study conducted focus groups with 18 patients receiving follow up cancer care.<sup>[25]</sup> The study identified that participants valued the self-determined nature of their decisions to use CM and saw it as an opportunity to contribute to their cancer treatment and to have some control over their disease. Participants talked about limited consultation time with their oncologists to discuss CM and acknowledged that many cancer health professionals lacked knowledge to advise them on CM or were dismissive. Various views were held about the co-location of CM and outpatient cancer therapy services, and perceived cost as a barrier to accessing CM, although they did not necessarily expect CM to be publicly funded. This initial study offers some insights into patients' views in an Australian context on the integration of CM with conventional cancer services. The generalisability of the findings was limited by a small sample of patients self-selected from a single oncology unit.

## 1.2 RATIONALE FOR THE STUDY

If CM is to be integrated with conventional cancer care services, there is a need to understand existing provision in different cancer settings, and with a more diverse cancer patient population so as to explore and incorporate their preferences and needs. Our partners, South Western Sydney Local Health District (SWSLHD) and Oncology Massage Ltd (OML) are aware of the trends in CM usage and recognise that there is a gap in contemporary cancer care that needs to be filled.

Existing cancer services in SWSLHD include wellness centres and plans are underway to expand the services and include CM modalities (e.g. Chinese medicine, tai chi, qi gong, and touch-based therapies including massage, exercise, and mind-body therapies) along with participating in clinical trials testing herbal medicines. The district serves a high proportion of patients from CALD backgrounds, particularly those speaking Arabic, Cantonese and Vietnamese as their first language, and patients from a wide range of socioeconomic backgrounds. There remains an important need to guide future development of the wellness centres in Camden and Liverpool by generating new evidence informed by the perspectives from health service managers and identification of patient's needs from an ethnically diverse population in SWSLHD.

OML is a registered charity that provides training and certification in oncology massage (OM). The charity attained Australian Skills Quality Authority (ASQA) accreditation for a Certificate IV and Diploma in Oncology Massage in 2013, achieving national recognition for the course that OML had been delivering for over 10 years. The organisation would benefit from more information about current OM service provision, barriers/facilitators, and unmet needs, to support OML's advocacy role in Australia, including possible directions for further research.

This research study will therefore expand upon and update pre-existing research about IO services in Australia by examining current CM provision in national cancer services and exploring patients' preferences and experiences

to the provision of CM in an integrated setting. In seeking the views of service providers and patients from English-speaking and CALD backgrounds, the results will inform the appropriate development of local services whilst providing valuable information for both state and national oncology service planning. It will be the first project to map IO service provision in both the public and private sectors across Australia.

### 1.3 STUDY AIM AND OBJECTIVES

The aim of this project was to work with the SWSLHD and our not-for-profit partner OML to examine CM in oncology healthcare services and identify barriers and facilitators to CM integration.

#### 1.3.1 Objectives

1. Conduct a national cross-sectional survey in 2016 to:
  - a. identify all organisations across Australia that provide specialised healthcare cancer services to patients of any age;
  - b. quantify the services they provide;
  - c. identify important unmet needs;
  - d. quantify IO service provision and policy; and
  - e. explore knowledge and attitudes towards OM.
2. Conduct focus group interviews and a community survey with cancer survivors to:
  - a. explore experiences, preferences, service requirements, and gaps and barriers to the provision of CM and its integration into cancer care services; and
  - b. include the views of CALD population groups that are under-represented in cancer research.

# NATIONAL CANCER SERVICES SURVEY

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The following chapter presents the study design, method and results from the 2016 national survey of cancer services.

## 2.1 AIM

This national survey aimed to identify all healthcare organisations across Australia that provide dedicated cancer services to patients of any age, the services they provide, and potential unmet needs, with a particular focus on IO service provision and policy.

### 2.1.1 Objectives

1. Identify all organisations across Australia that provide specialised healthcare cancer services to patients of any age
2. Quantify the services they provide
3. Identify important unmet needs
4. Quantify IO service provision and policy
5. Explore knowledge and attitudes towards OM

## 2.1 METHOD

### 2.1.1 Sample and recruitment

An extensive search strategy was implemented to ensure that all organisations with a dedicated healthcare cancer service in Australia were identified. Small businesses that ran clinics or consultation rooms for healthcare professionals, such as oncologists, radiologists, surgeons, allied health or CM practitioners, and those who only offered ad hoc health retreats, were excluded. This was because the sampling strategy would only reliably identify larger organisations and the survey questions were designed larger organisations not smaller clinics and consultation rooms.

## INCLUSION CRITERIA

- All organisations that had a dedicated healthcare cancer service
- Private health sector, not-for-profit and registered charities, and public health sector
- Adult, adolescent or children services
- Inpatient or outpatient services linked to a hospital, registered day hospital, or community based organisation
- Provides clinical care

## EXCLUSION CRITERIA

- Privately owned consultation rooms
- Businesses or organisations that only run ad hoc health retreats for cancer survivors

Organisations that only provide:

- General clinical services (e.g. medicine, surgery, palliative care or rehabilitation) and no dedicated cancer care services
- Physical activities, either in the class setting or individual sessions for cancer survivors (e.g. tai chi, yoga, Pilates)
- Support groups or counselling services for cancer survivors
- Information services for cancer survivors

## IDENTIFYING ELIGIBLE SERVICES AND RECRUITING PARTICIPANTS

In late 2015, the research team began shortlisting organisations that operate dedicated healthcare cancer services. The Australian Institute of Health Welfare Australian Hospitals Database 2013–14;<sup>[26]</sup> Hospital and Health; Hospitals and Aged Care Database;<sup>[27]</sup> Australian Health Directory;<sup>[28]</sup> and the Cancer Council Australia websites were used to create the initial shortlist (Appendix I).

This search was augmented with a second search to identify organisations that were located in community settings. Volunteers across Australia who were members of the research partner OML and familiar with their local and state IO services kindly assisted. Along with utilising their local knowledge, volunteers were given specific instructions for conducting searches on the Internet (Appendix II). Google and Bing search engines were set to the Australia region; the search terms included ‘Cancer retreat’, ‘Cancer therapy organisation’, ‘Cancer organisation massage support’, and ‘Cancer nonmedical cancer organisation’; searching ceased at the end of the fifth page unless a new organisation was identified, in which case the search was extended to the sixth page and so on, to a maximum of 10 pages. The two search engines tailored results to geographical location, so at least one volunteer per state conducted a search.

In addition, further services and sites were identified through conversations with industry experts from peak organisations (e.g. Cancer Nurses Society of Australia, Clinical Oncology Society of Australia (COASA)), integrated cancer care networks (e.g. Integrated Cancer Services Managers Group, Central Integrated Regional Cancer Service, Paediatric Integrated Cancer Service), collaborative groups (e.g. Complementary and Integrative Therapies Group, Western Australian Clinical Oncology Group), and managers and survey participants who provided information about affiliated sites, neighbouring catchment areas, and/or other locations. Following up on leads, recommendations, and referrals often snowballed into unearthing other eligible cancer services.

Due to the complex nature of healthcare organisations, identifying appropriate staff was often slow and involved liaising and networking with numerous people to verify specific details and to obtain further information to confirm inclusion/exclusion criteria. Initially, contacts with knowledge of the organisational structure were sought, such as the director or manager of the clinical service (e.g. Director of Nursing, Nurse Unit Manager, cancer care coordinator) or other staff member in a similar managerial capacity. Where necessary, further information about the organisation and/or applicable cancer services was obtained and verified via state and territory Cancer Councils, Cancer Council Australia, CanRefer Directory, Health Directory of Private Hospitals, organisational websites, Local Health District contacts/websites, and specific Google searches.

Once an organisation agreed to participate in the survey, it nominated a suitable staff member to answer the survey on its behalf and it provided this person’s contact details to the research team. While the research team primarily sought those in senior managerial positions, this procedure sometimes led to subsidiary managers and clinical staff being recommended and sourced. It is important to note, however, that those in senior managerial positions were not necessarily

more informed. In most instances, participants had adequate knowledge to complete the survey, and when necessary, could return to the electronic survey after clarifying answers to specific questions.

Having agreed to participate either via telephone or email, participants received a formal invitation by email that contained participant information, consent form, a PDF version of the survey, and a link to the electronic survey (Appendix III). The research team used a variety of proven methods to improve response rates.<sup>[29]</sup> Neither financial nor other incentive was offered to eligible organisations or individual participants. Non-responders received a follow-up reminder email at two weeks, six weeks, and then every three weeks thereafter. The research team also recontacted remaining non-responders in the final week of the survey.

### **2.1.2 Survey Questionnaire**

The research team designed a purpose-specific, self-administered questionnaire for the survey. Content and questions were based on a NSW survey instrument of CM practices and policies in cancer services<sup>[16]</sup> and a Scottish scoping study of OM services.<sup>[30]</sup>

The online and paper versions of the questionnaire were pilot-tested locally and modified accordingly. A questionnaire was chosen instead of interviews to allow respondents to gather information they may not know immediately or to pass the questionnaire onto another colleague who was better placed to answer some or all of the questions.

Participants could choose to complete the survey using their preferred format: online, electronic PDF, paper or structured telephone interview. The majority of the 52 questions were closed questions that were usually accompanied with a section for open-ended comments. Skip questions were used to improve relevance and minimise responder burden. The online questionnaire was administered through SurveyMonkey, using compulsory questions, skip logic, and random ordering of options, where appropriate.

The questionnaire collected information about the general features of the oncology service, such as geographical location and setting, ownership, and cancer services provided; important regional unmet needs; policies regarding CM practitioners and products; and attitudes towards and awareness of OM. Cancer services that provided CM services were asked further in-depth questions about these services, such as duration and location; number, types and characteristics of the CM practitioners; and related procedures and policies. See Appendix III to view a copy of the paper version of the questionnaire.

Wellbeing services, such as meditation, mindfulness and relaxation, were classified as an IO/CM service. Pastoral care was not considered part of IO/CM service provision, and as such, was outside the scope of this research project. The boundaries can be blurred, however, as CM wellbeing services may draw on religious philosophies and traditions, and spirituality (rather than religiousness) is considered to be a domain of 'holistic health'.<sup>[31, 32]</sup>

### **2.1.3 Data collection**

The survey was open from 1 May 2016 until 15 December 2016. All data was entered into SurveyMonkey, either directly by the respondent or by the research team. Data was then electronically exported for statistical analysis.

Respondents were able to return to their survey at any time during the data collection period. Investigators KT and JH were available to answer queries from respondents. The research team recontacted those respondents who reported that their cancer service was in the planning stages of developing and/or delivering a CM service before the closing date to determine if this prior status was still valid. The survey responses were updated accordingly.

KT reviewed the accuracy of selected questions from respondents throughout the data collection period. For example, where publicly available information about ownership of the organisation and cancers services provided could be externally verified. Every survey was checked to ensure that there was only one response per organisation and that respondents had not inadvertently selected an incorrect response to the skip question about service provision of CM. Errors to this question were possible for two reasons. First, there was the risk of double counting as some organisations providing CM services were co-located with other organisations and provided their CM services to the other organisation's patients. Second, there were a few instances where the respondent selected 'other' and then described the CM services they provided. This selection automatically skipped the rest of the CM questions. If either occurred, the respondents were contacted and asked to amend their survey responses. In instances where more than one staff answered the survey, the responses of the most senior person were kept.

#### **2.1.4 Data analysis**

Descriptive statistics detailing the counts and percentages was the primary statistical method used. Questions requiring inferential statistical analysis were determined a priori. Qualitative data from the open questions and comments were independently coded for content by two investigators (CS and JH)

Most of the analysis was undertaken using software SPSS V24.<sup>[33]</sup> Microsoft Office Excel was used to analyse and present the data for the geographical maps. A codebook dictionary was created in SPSS for use by the research team.

The denominator used for the survey response rate was the total number of eligible organisations. For skip questions, the number of respondents who were asked the question was used as the denominator. Many of the questions were compulsory, and instead, provided a 'don't know' option. Missing data included unanswered questions. There were no incomplete surveys.

#### **2.1.5 Ethics and disclosure**

Ethics approval was obtained from Western Sydney University Human Research Ethic Committee (HREC) (H11389) and the Joint University of Wollongong and Illawarra Shoalhaven Local Health District Health and Medical HREC (HREC/16/WGONG/178). The latter HREC was a NSW Lead HREC and recognised by the Interstate Mutual Acceptance program operating in Victoria, Queensland, and NSW.

Conflicting advice was given regarding the need for further HREC approvals and Site-Specific Approval (SSA) at the hospital, regional or state level. Initially, the team was advised that university HREC approval should suffice since the study posed negligible risk; however, the final decision would rest with the participating organisations. Correspondence with the Office for Health and Medical Research, NSW Ministry of Health, confirmed that approval from a 'Lead HREC' accredited by the Director General NSW Health was required for

this survey but could not confirm whether SSA was required from each Local Health District (LHD) or hospital. The final decision to obtain further HREC or SSA was made on a case-by-case basis. This meant that some hospitals did not participate in the survey as the resources required could not be justified to submit a full HREC application so as to obtain one completed survey.

HREC approval was, however, obtained from Calvary Health Care, Adelaide HREC (16-CHREC-E011). Site approval was obtained for St John of God hospitals (1004), Albury Wodonga Health (2016/344), Central Coast LHD (1116-117C), Illawarra Shoalhaven LHD (DT16-131481), Northern New South Wales LHD (G320), Murrumbidgee LHD (SSA/16/MLHD/43), and Western New South Wales and Far West LHDs (SSA/16/GWAHS/159).

The Participant Information sheet informed respondents that any identifying information was confidential and taking part in the survey confirmed consent. The names of cancer services and respondent's contact details were collected to enable further communication with the responder if there were queries regarding their response (consent was obtained during the survey to recontact a staff member). There was also the option to request a copy of the report. Specific assurance was given to some concerned organisations that results would not be presented at state or regional levels if this would enable identification of a specific service (e.g. tertiary children/adolescent cancer care services or remote services). The only exceptions would be publicly available information.

This project was funded through a 2016 Research Partnerships Program, Western Sydney University. Partner funding was obtained from OML, a registered charity that provides training to massage practitioners in Australia and internationally; and from SWSLHD. To ensure that the project was relevant to a broad range of stakeholders, the two partner organisations provided expertise and guidance to help improve the content validity of the survey questions and interpretation of the results. Neither partner had access to any confidential information about participating organisations.

## 2.2 RESULTS

### 2.2.1 Response rates

A total of 366 healthcare organisations were on the final shortlist, from which 295 met the inclusion/exclusion criteria and were invited to participate in the survey. Overall, the response rates were very high with 275 of the 295 eligible organisations (93.2%) completing the survey. Table 2.1 compares known characteristics of responders and non-responders.

Response rates differed by state/territory ranging from 66.7% to 100%; the highest response rates were from Tasmania, Queensland, and NSW (Fisher's Exact Test 15.8,  $p < 0.05$ ). There were no statistically significant differences in response rates according to the ownership of the organisation (Fisher's Exact Test 1.4,  $p = 0.5$ ), nor cancer service setting (Fisher's Exact Test 4.3,  $p = 0.1$ ).

Overall, the sample was representative of cancer services across Australia. However, results reported at the state/territory level for the Australian Capital Territory and Northern Territory should be interpreted with caution as both only had a few organisations (four and three respectively) with dedicated cancer care services and the lowest response rates.

## REASONS FOR NOT PARTICIPATING

Twenty of the eligible organisations across Australia did not participate in the survey. In most instances (n=14), either the director/manager of the organisation or the cancer service actively declined the invitation and no reason was given. Two staff who had been nominated by their organisation to answer the survey also declined; one was too busy and the other not interested. In four cases, participation in the survey was denied until individual hospital HREC approval was obtained. The decision was made not to apply for HREC approval as all four organisations were located in states with a high response rate (>0%). In three instances, there was no communication or response to telephone and email invitations.

## CHARACTERISTIC OF RESPONDERS

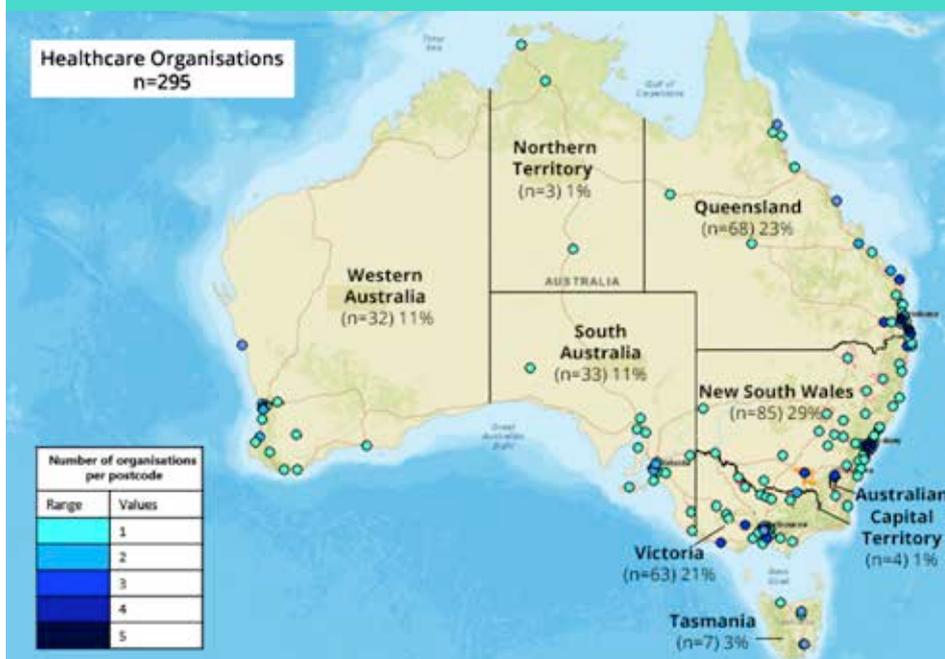
Most of the 275 responders (55.6%, n=153) reported their roles in the organisation were both a healthcare professional and administrator / manager in the organisation. The majority of healthcare professionals (49.5%, n=136) were known to have a nursing background, and virtually no oncologists (0.03%, n=7) answered the survey on behalf of their organisation. For 73 (26.5%) participants, their role was a healthcare professional only and the remaining 49 (17.8%) were in administration / management roles. No statistically significant

**TABLE 2.1** Location, ownership, setting and response rates

ELIGIBLE ORGANISATIONS	RESPONDER		NON-RESPONDER		ELIGIBLE		RESPONSE RATE <sup>a</sup>
	n	%	n	%	n	%	%
TOTAL	275	100.0	20	100.0	295	100.0	93.2
<b>LOCATION *</b>							
Australian Capital Territory	3	1.1	1	5.0	4	1.4	75.0
New South Wales	82	29.9	3	15.0	85	28.8	96.5
Northern Territory	2	0.7	1	5.0	3	1.0	66.7
Queensland	67	24.4	1	5.0	68	23.1	98.5
South Australia	28	10.2	5	25.0	33	11.2	84.8
Tasmania	7	2.4	0	0.0	7	2.4	100.0
Western Australia	28	10.2	4	20.0	32	10.8	87.5
Victoria	58	21.1	5	25.0	63	21.4	92.1
<b>OWNERSHIP</b>							
Government	136	49.4	12	60.0	148	50.2	92.5
Private limited company	78	28.4	6	30.0	84	28.4	92.9
Not-for-profit company / registered charity	61	22.2	2	10.0	63	21.4	96.8
<b>SERVICE SETTING</b>							
Hospital only (in-patient and/or out-patient)	199	72.4	19	95.0	218	73.9	92.5
Community only (out-patient)	13	4.7	0	0	13	4.4	100.0
Both Hospital and Community	63	22.9	1	5.0	64	21.7	98.4

\* Fisher's Exact Test 15.8, p<0.05 <sup>a</sup> refers to % across rows

**MAP 2.1 Organisations with specialised cancer services**



differences were found between the provision of CM or IM services by their organisation ( $\chi^2(2) = 5.6, p = 0.06$ ), nor the service setting - hospital, community or both ( $\chi^2(2) = 1.7, p = 0.8$ ).

### 2.2.2 Australian cancer healthcare services

#### LOCATION AND OWNERSHIP

The majority of cancer services were located in NSW followed by Queensland and Victoria and in the most populous areas (Table 2.1, Map 2.1). Half of the healthcare organisations (50.8%,  $n = 148$ ) were government owned and 84 (28.4%) were owned by a private limited company (Table 2.1). The remaining 63 organisations were listed as a not-for-profit company (21.7%), of which nine were registered charities.

Further detailed maps can be viewed in Appendix VI.

#### SERVICES PROVIDED AND SETTING

Participating organisations were asked which cancer services they provided and the settings in which they were provided (Table 2.2). Most organisations (69.5%;  $n = 191/275$ ) offered both specialised oncology services (e.g. chemotherapy, radiotherapy or surgery) and supportive cancer care services (e.g. allied health, survivorship clinics, wellness, IO). Given that participants may have different concepts and definitions for newly evolving terms such as wellness, survivorship and IO, the survey question asked about each type of service separately.

Some double counting of the supportive cancer service sub-categories was likely due to the inherent overlap between the services. Asking about specific sub-categories was revealing, however, wellness and survivorship services were not necessarily synonymous with IO services. Of the 72 organisations with

<b>TABLE 2.2 Cancer care services and settings</b>		
<b>CANCER SERVICES*</b>	<b>n</b>	<b>%</b>
SPECIALISED ONCOLOGY	256	93.9
Chemotherapy	213	77.5
Surgery	143	52.0
Radiotherapy	92	33.5
PALLIATIVE CARE	173	62.9
SUPPORTIVE CARE	209	76.0
Allied health	201	73.1
Wellness	72	26.2
Complementary medicine / Integrative oncology	71	25.8
Survivorship clinic	57	20.7
OTHER telehealth, on-line supportive services, regional paediatric shared care and regional outreach services	9	3.3
<b>NUMBER OF CANCER SERVICES / ORGANISATION</b>	<b>n</b>	<b>%</b>
1 type of service only	50	18.2
2 types of services	39	14.2
3 types of services	49	17.8
4 types of services	58	21.1
5 types of services	41	14.9
6 types of services	26	9.5
7 or more types of services	12	4.4
<b>SERVICE SETTING*</b>	<b>n</b>	<b>%</b>
HOSPITAL	262	95.3
Both in-patient beds and out-patient clinics	164	59.6
Only in-patient beds	11	4.0
Only out-patient clinics	87	31.6
COMMUNITY CLINIC OR CENTRE	76	27.6
HOME VISITS / RESIDENTIAL CARE VISITS	76	27.6

n=275 organisations (no missing data) \*More than one option for services provided and service setting was possible

wellness cancer services, only 41 (56.9%) also provided IO. Similarly, only 42.1% (n=24/57) of organisations with survivorship clinics also provided IO.

Other types of services not included as an option that a few respondents listed in the comments option included telehealth, online supportive services, regional paediatric shared care, and regional outreach services. This is not to say that other organisations were not providing these services since they were not directly asked.

While many privately owned cancer service providers (e.g. Icon Cancer Care, Genesis Cancer Care, and Radiation Oncology Centres) operate out of independent day hospitals, some of these practices were co-located on a larger hospital site. It is possible, however, that some respondents from the

larger organisation may have incorrectly included radiotherapy as a service provided by their hospital despite the fact that the service may be outsourced to a private provider.

Some respondents from private organisations providing only chemotherapy or radiotherapy were unsure about how to categorise their service setting – hospital or community. If the service was a registered day hospital, it was categorised as ‘Hospital setting: outpatient clinic or other room’. While some

**TABLE 2.3 Important unmet needs across Australia**

	n	%
<b>SPECIALIST ONCOLOGY SERVICES</b>	<b>64</b>	<b>30.9</b>
Breast clinic	5	2.4
Intravenous chemotherapy unit	6	2.9
Haematology	11	5.3
Oncologists	13	6.3
Paediatric / Adolescent cancer care	6	2.9
Palliative care (in-patient or home care)	43	20.8
Radiotherapy unit	16	7.7
Specialised cancer surgeons	8	3.9
Telehealth	5	2.4
Timely access	7	3.4
<b>NURSING RELATED SERVICES</b>	<b>76</b>	<b>36.7</b>
In-patient beds / more clinical care space	7	3.4
Cancer care training / education staff	6	2.9
Integrated services	35	16.9
Nursing staff and resources	18	8.7
Outreach / Home care	20	9.7
Nursing staff support	6	2.9
<b>SUPPORTIVE &amp; ALLIED HEALTH SERVICES</b>	<b>118</b>	<b>57.0</b>
Aboriginal health worker	2	1.0
Affordable access	24	11.6
Allied health (not specified)	43	20.8
Complementary Medicine services	19	9.2
Exercise programs / physiologists	5	2.4
Lymphedema services	6	2.9
Nutrition services / dietitians	10	4.8
Speech therapy	4	1.9
Psychosocial support services	59	28.5
Rehabilitation / Survivorship / Wellness services	59	28.5
Transport	6	2.9

n=207 respondents (missing data n=68)

Most respondents identified 1 or 2 important unmet needs

blurring of cancer service provision between private providers and hospitals may have occurred, this is very unlikely to apply to CM services. The smaller number of services made it logistically possible to cross-check those services that were co-located.

### 2.2.3 Unmet regional needs

Respondents were asked an open-ended question about the most important unmet needs in their region. The 207 responses were independently coded for content by CS and JH. The question encouraged respondents to list one or two most important unmet needs in point form. The occasional respondent used the comments section to list multiple unmet needs. All unmet needs were coded and counted; as such, the totals for each category add up to more than two unmet needs per respondent.

Respondents identified a wide range of unmet needs, which were categorised into three main groups: 1) services dependent upon specialist medical practitioners, 2) nursing-related services and resources, and 3) supportive and adjuvant cancer care services (Table 2.3).

Across all three categories, respondents identified services providing ongoing care following initial cancer treatment as the most important unmet need. They commonly identified rehabilitation, survivorship and wellness services, (28.5%, n=59) and palliative care services, either as an inpatient or at home (20.8%, n=43). The ongoing unmet needs of certain patient groups – breast and prostate cancer and those with lymphoedema complications – were also mentioned.

Three respondents explicitly stated there were no important unmet needs in their region. The question, however, was not compulsory and 48 respondents did not answer the question; perhaps, they too, could not identify any important unmet needs in their region. At least one respondent was “*Not really sure what is being sought by this question*”. South Australia had the lowest response rate followed by Victoria. No statistically significant differences were found between responders from the different states and territories and the three main categories of unmet need (Chi-square or 2-sided Fisher’s Exact Tests) Table 2.4.

Over half of the 207 respondents (57.0%, n=118) identified at least one important unmet need in the category relating to supportive and allied health services. Psycho-social support services was commonly listed (28.5%, n=59). Most who listed allied health did not specify the services or healthcare professionals (20.8%, n=43). Of those who did, nutrition, lymphoedema, exercise, speech therapy, and Aboriginal health were listed. Combined, 55 (26.6%) respondents listed allied health. A further 19 respondents (9.2%) identified CM services, including inpatient care, as one of the most important unmet needs in their region. Along with service provision, 24 respondents (11.6%) identified the need for equitable and affordable access to allied health, survivorship/wellness services or CM services as one of the most important unmet needs in their region.

Other respondents identified the unmet needs of specific population groups. Two respondents stated more Aboriginal health workers were needed in their region for culturally appropriate care. Others identified the unmet needs of CALD groups or economically disadvantaged groups. The unmet needs of specific age groups were also listed. Respondents identified paediatric and

TABLE 2.4 Categories of unmet need by location, setting and ownership of organisation									
ORGANISATIONS WITH CANCER SERVICES	SPECIALIST ONCOLOGY SERVICES		NURSING RELATED SERVICES & RESOURCES		SUPPORTIVE & ALLIED HEALTH SERVICES		SURVEY RESPONSE / RATE <sup>a</sup>		NATIONAL RESPONSE RATE <sup>b</sup>
	n	%	n	%	n	%	n	%	%
TOTAL	64	30.9	76	36.7	118	57.0	207	75.3	70.2
<b>LOCATION <sup>c</sup></b>									
Australian Capital Territory	2	1.0	0	0	2	1.0	3	100.0	75.0
New South Wales	24	11.6	24	11.6	31	15.0	82	80.5	77.6
Northern Territory	0	0.0	1	0.5	2	1.0	2	100.0	66.7
Queensland	11	5.3	19	9.2	29	14.0	67	79.1	77.9
South Australia	6	2.9	3	1.4	9	4.3	28	53.6	45.5
Tasmania	1	0.5	4	1.9	3	1.4	7	100.0	100.0
Western Australia	5	2.4	10	4.8	13	6.3	28	82.1	71.9
Victoria	10	4.8	15	7.2	29	14.0	58	65.5	60.3
<b>SERVICE SETTING <sup>c</sup></b>									
Hospital only (in- or out-patient)	39	18.8	51	24.6	86	41.5	136	73.4	67.0
Community only (out-patient)	3	1.4	6	2.9	6	2.9	78	84.6	84.6
Both Hospital and Community	17	8.2	19	9.2	26	12.6	61	79.4	78.1
<b>OWNERSHIP OF ORGANISATION <sup>c</sup></b>									
Government	34	16.4	44	21.3	63	30.4	199	80.1	73.6
Private limited company	17	8.2	12	5.8	27	13.0	13	64.1	59.5
Not-for-profit company / charity	8	3.9	20	9.7	28	13.5	63	78.7	76.2

a denominator n=275 (missing data n=68); b n=295 (missing data n=68, non-participants n=20)

Most respondents identified 1 or 2 important unmet needs

c p>0.05 Chi-square or 2-sided Fisher's Exact Tests

adolescent patients in rural and remote areas. Even well-resourced services were challenged by the unmet health and social needs of older patients in their region.

*"The service we provide is very comprehensive, but the difficulty in discharging elderly patients who have limited support is a significant issue."*

Along with the need for service development in general for rural and remote areas, respondents identified multiple challenges of cancer survivors living in these regions.

*"Rural patients don't do as well in cancer survivorship due to the difficulties associated with treatment access and their side effects, especially fatigue preventing them from pursuing ongoing management. Some can't face the travel or thought of being away from home in the first instance. Cost associated with seeking lengthy treatment is also prohibitive."*

*“The establishment and expansion of oncology services in the outer [city] areas and regional areas to provide consumers with the opportunity to receive treatment/care closer to where they live. Telehealth clinics, including the administration of chemotherapy via video link.”*

*“Rural and remote patients need special support when moving across into metropolitan settings. Some cancer services have more staff than a rural patient will see in a year. It is over whelming.”*

*“More innovative models of care to decrease travel time etc. for patients.”*

Issues other than the need for specific cancer services and healthcare professionals were also identified. Timeliness of access to acute and ongoing care was identified. Improving co-ordination and integration of cancer services was emphasised (16.9%, n=35), especially for *“complex patients and for social, economic, culturally diverse communities”* and patients requiring services from multiple sites and geographical locations. Solutions included providing more cancer care coordinators, using integrated electronic medical records, improving communication with primary healthcare providers and community services, telehealth and video consultations, and cross-referrals between the public and private health sectors to better manage demand and waiting lists. Some respondents from rural and remote areas highlighted more training, education, and support of staff, particularly nursing staff (3.4%, n=7).

#### **2.2.4 Integrative oncology services**

A quarter (25.8%, n=71) of the organisations surveyed confirmed that they provided integrative IO services (Table 2.5, Map 2.2). The median duration of service provision was six years, ranging from two months to 42 years, suggesting the number of services may have doubled in the past six years. For many, service development was incremental, reflecting changes in mainstream healthcare services’ attitudes towards IO services, pressure to provide evidence-informed therapies, and response to patient needs.

*“We used to be known for ‘alternative’ cancer care but in recent years have moved to more evidence-based and evidence-informed safe therapies.”*

*“We started as a small 2-hour hospital-based drop in for women with breast cancer. We have slowly and steadily developed the programs and services to be inclusive of complementary therapies”*

### **OWNERSHIP, LOCATION AND SETTINGS**

The research team asked only the 71 services currently providing IO at the time of the survey further in-depth questions regarding service provision and policy. Compared to non-IO providers, organisations were more likely to be owned by a not-for-profit company (46%) or were Government owned (38%) ( $\chi^2 (2) = 33.6$   $p < 0.001$ ). All states and territories, bar the Northern Territory, provided some type of IO (Table 2.5, Map 2.2).

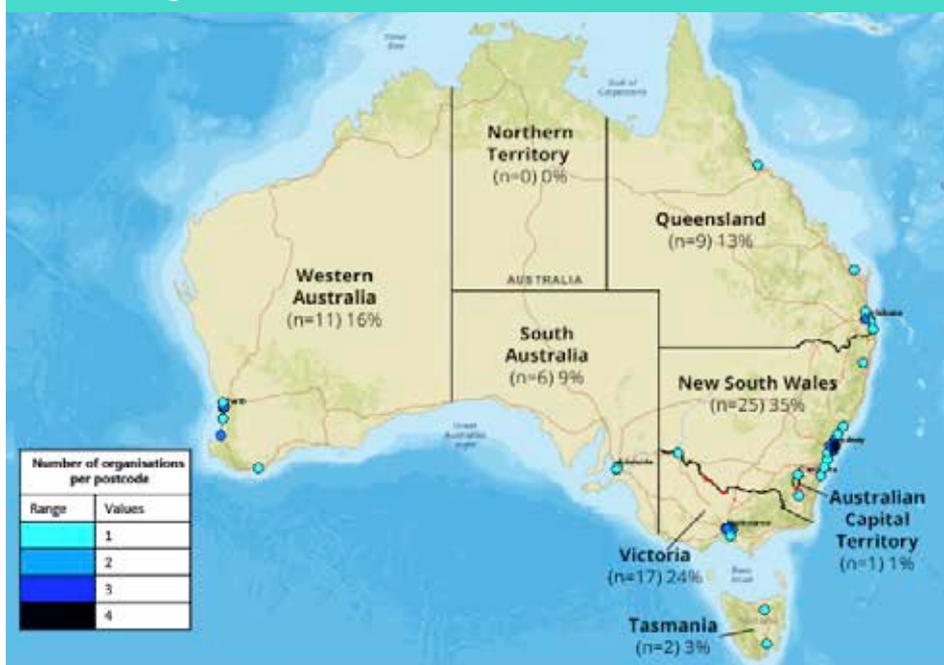
Similar to the sample for all cancer services, IO services were mostly provided in the inpatient and outpatient hospital settings (Table 2.6). Around one-third of these services were provided in a dedicated centre or clinic. No statistically significant difference was found between the proportion of services with or without a wellness centre or survivorship clinic and the likelihood of providing IO. The key difference between IO providers and non-providers was that only

**TABLE 2.5 Services providing Integrative Oncology (IO)**

CANCER SERVICES	IO / CM PROVIDED		NEVER PROVIDED		USED TO PROVIDE		PLAN TO PROVIDE		INFO / REFER*		TOTAL	
	n	%	n	%	n	%	n	%	n	%	n	%
TOTAL	71	25.8	165	60.0	16	5.8	12	4.4	11	4.0	275	100
<b>LOCATION</b>												
Australian Capital Territory	1	33.3	1	33.3	0	0.0	0	0.0	1	33.3	3	100
New South Wales	25	30.5	43	52.4	4	4.9	6	7.3	4	4.9	82	100
Northern Territory	0	0	2	100	0	0	0	0	0	0	2	100
Queensland	9	13.4	50	74.6	5	7.5	1	1.5	2	3.0	67	100
South Australia	6	21.4	19	67.9	2	7.1	0	0.0	1	3.6	28	100
Tasmania	2	28.6	2	28.6	3	42.9	0	0.0	0	0.0	7	100
Western Australia	11	39.3	11	39.3	1	3.6	2	7.1	3	10.7	28	100
Victoria	17	29.3	37	63.8	1	1.7	3	5.2	0	0	58	100
<b>OWNERSHIP</b>												
Government	27	19.9	8	5.9	89	65.4	8	5.9	4	2.9	136	100
Private limited company	11	14.1	6	7.7	55	70.5	3	3.8	3	3.8	78	100
Not-for-profit company / charity	33	54.1	2	3.3	21	34.4	1	1.6	4	6.6	61	100

\*Information given about, or active referrals to local IO/CM services

**MAP 2.2 Organisations with IO services**



Total number of healthcare organisations n=71

three services (4.2%) provided IO to patients at home or in residential care compared to 27.6% (n=76) for all cancer services.

A few variations of service provision by not-for-profit/charity owned organisations were also noted:

*“All the therapists have their own practices, some use their own clinics, some use the therapy rooms in our two centres, and some do home visits as required, for palliative people.”*

*“Services provided as needed, we can provide services to inpatient beds”*

*“Outpatient chairs are mainly used (no dedicated space is made for service providers to treat patients)”*

TABLE 2.6 Setting of IO services		
	n	%
Hospital setting: in-patient beds	37	52.1
Hospital setting: alongside other out-patient services	38	53.5
Hospital setting: a dedicated centre or clinic	25	35.2
Community setting: a dedicated centre of clinic	12	16.9
Community setting: not operated by the organisation	3	4.2
Home visits / residential care visits	3	4.2

n=71 organisations providing IO (no missing data)  
 Respondents could select more than one option

## TYPES OF SERVICES

IO services included a wide range of wellbeing services, massage, and movement modalities (Table 2.7). Less frequently provided were acupuncture and other traditional modalities. Overwhelmingly, biological-based CM therapies were not promoted. There were only four cancer services where natural health products (e.g. herbs, vitamins or minerals) could have been routinely prescribed by an IM or CM practitioner; formal advice from a pharmacist was available at nine services. None of the cancer services provided osteopathy and chiropractic services. It was common for more than one category or subcategory of IO services to be provided.

Fifty-two services offered massage/touch therapies, with OM (defined as massage provided by a certified OM therapist) available in 30 of these services. A wide range of other styles of massage and touch therapy were available. Wellbeing services were provided by 51 services comprising of art therapy, meditation, music therapy, and relaxation as the most common. Movement modalities were offered by 27 services with yoga and tai chi being the most frequently reported modalities. Ten services reported offering movement modalities delivered by either a physiotherapist (n=7) or exercise physiologist (n=3); nine of these were not included in the final count as the style is not classified as a CM.

## NUMBER OF PRACTITIONERS

The median number of practitioners ranged from one to 2.5 across the IO services provided (Table 2.7). There were wide variations between the services. For example, the number of massage therapists working in a service ranged from one to 11, with 18 services having only one practitioner. Wellbeing services were provided by up to 10 practitioners per service, with 13 services indicating one practitioner provided the service, and 11 services had two practitioners. Movement modalities were provided by up to 20 practitioners per service, with 11 services indicating they had one practitioner and 10 services had two practitioners.

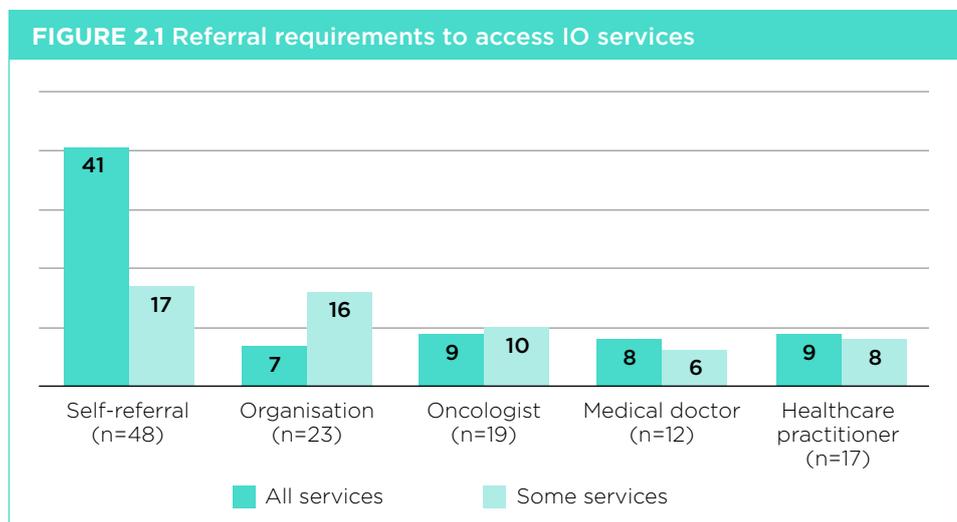
TABLE 2.7 Integrative Oncology (IO) service provision					
TYPE OF CM SERVICE	ORGANISATIONS PROVIDING EACH SERVICE		PRACTITIONERS PER SERVICE / IN AUSTRALIA		AVAILABILITY HOURS PER WEEK PER SERVICE
	n = 71	%	Median / Total		Median
<b>MASSAGE / TOUCH THERAPY</b>	52	73.2	2.5	250	12.0
Oncology Massage *	30	42.3	1	30	6.3
Massage (style not specified)	10	14.1			
Reflexology	13	18.3			
Therapeutic touch / Reiki	10	14.1			
Aromatherapy massage	4	5.6			
Relaxation massage	4	5.6			
Lymphatic massage	4	5.6			
Bowen therapy	3	4.2			
Hand & Foot, facial, head massage	3	4.2			
Kinesiology	2	2.8			
Indian head massage	2	2.8			
Shiatsu	1	1.4			
<b>MENTAL WELLBEING</b>	51	71.8	2	125	7.0
Art therapy	17	23.9			
Meditation	17	23.9			
Music therapy	13	18.3			
Relaxation	11	15.5			
Mindfulness	4	5.6			
Pet therapy	1	1.4			
<b>MOVEMENT MODALITIES</b>	28	39.4	2	78	3.0
Yoga	19	26.8			
Tai Chi	16	22.5			
Qigong	3	4.2			
Pilates	3	4.2			
Dance or movement	2	2.8			

\* an additional 9 were unsure if the therapists were also certified in Oncology Massage

TABLE 2.7 Integrative Oncology (IO) service provision					
TYPE OF CM SERVICE	ORGANISATIONS PROVIDING EACH SERVICE		PRACTITIONERS PER SERVICE / IN AUSTRALIA		AVAILABILITY HOURS PER WEEK PER SERVICE
	n = 71	%	Median / Total		Median
INTEGRATIVE MEDICINE (IM)	13	18.3	1	6	40.0
IM advice from a pharmacist	9	12.7			
IM consultation with a medical doctor	1	1.4			
IM referral	1	1.4			
BODY ALIGNMENT	2	2.8	1	4	3.0
Cranio-sacral	2	2.8			
Chiropractic	0	0.0			
Osteopathy	0	0.0			
OTHER COMPLEMENTARY MEDICINE	12	16.9	1	19	6.5
Acupuncture	9	12.7	1	13	6.0
Naturopathy	2	2.8			
Nutritional medicine (not a dietitian service)	1	1.4			
Chinese herbal medicine	0	0			
Ayurvedic (traditional Indian) medicine	0	0			
Indigenous Australian healing practices	0	0			

## AVAILABILITY AND ACCESS

Most CM services were provided on a fractional basis (Table 2.7). This included massage and wellbeing services, despite their greater provision the median availability was less than three days a week. IO was the exception, the median number of hours pharmacists or medical practitioners provided these services was 40 hours per week. The majority of services could be accessed through self-referrals, although some services required or encouraged a referral from a healthcare professional (Figure 2.1).



## FUNDING

Although the resourcing of IO services varied according to the modalities offered, in all cases it was mixed relying on a variety of sources (Figure 2.2). A contribution from the patient was the most common source of funding, followed by philanthropic contributions, volunteers, and lastly by the cancer service. Patients contributed towards the payment of services for all modalities (patient payments referred to any combination of out-of-pocket costs and rebates from either private health insurance or Medicare). The cancer service organisations contributed the most towards directly funding IO services provided by a hospital pharmacist or medical practitioner. Volunteers provided the greatest contribution to the delivery of wellbeing and massage services, the exception being massage that was provided by a certified OM therapist.

**FIGURE 2.2** Funding sources of IO services



\* Includes rebates to patient from private health insurance or Medicare.  
 Organisations often had multiple funding sources for practitioner services.  
 n = number of organisations.

## DUAL QUALIFICATIONS

Twenty of the cancer services (28.2%) indicated their IO/CM practitioners had dual qualifications. Several examples were given that included a nurse certified in OM and another who was also a naturopath, a medical practitioner with acupuncture qualifications, and an occupational therapist who trained as a music therapist. Of the remaining 51 cancer services, 26 (36.6%) reported their IO/CM practitioners did not hold dual qualifications, and 21 (29.6%) did not know the answer to this question (35.2%).

## MULTIDISCIPLINARY MEETINGS

Most cancer services held multidisciplinary team meetings or case conferences (83.1%, n=58) from which just under half (n=28) invited the IO/CM practitioners (or in one case, the coordinator of a large group of volunteers) to participate. Almost an equal number (n=27) indicated that these practitioners were not invited. The remaining four respondents did not know the answer to this question.

## SERVICE EVALUATION

Over half the cancer services providing IO services (64.8%, n=46) conducted some form of evaluation; patient surveys (52.1%, n=37) and feedback forms (43.7%, n=31) were the most common. Five services (7.0%) conducted clinical trials, 12 observational studies (16.9%), and nine (12.7%) ran clinical audits. Most services used more than one method; the most frequently used methods being a combination of patient survey and feedback form reported by 12 sites. Fifteen (21.1%) of the cancer services had no previous experience of conducting formal evaluations.

### 2.2.5 Integrative Oncology: barriers and solutions

The majority of organisations (68.4%, n=188) reported never providing IO and 16 (5.8%), used to provide IO (Table 2.5). As reasons for discontinuing, they cited difficulties with securing ongoing funding or a lack of interest once a key staff member left the organisation. Twelve organisations were planning to provide IO. A further 11 reported that instead of providing IO, either the service provided information about locally accredited CM practitioners or referred patients to IO cancer services, some were services co-located on the hospital grounds that were owned and operated by a separate organisation. Three services provided limited access to meditation, mindfulness or relaxation interventions delivered by a psychologist and these were not counted as providing IO.

The 204 non-providers gave multiple reasons for why their cancer services did not provide IO services (Table 2.8). The multiple-choice question about barriers was followed by an optional open-ended question where respondents were asked about potential solutions (Table 2.7). Sixty-five of the respondents also provided qualitative comments about barriers and 133 answered the question about solutions. The qualitative data was independently coded by investigators CS and JH for content. The results are summarised in Tables 2.8 under 'OTHER' barriers, and solutions are summarised in Table 2.9.

The most common reported barrier to providing CM services was a lack of funding (63.0%, n=123) (Table 2.8). Similarly, of the 130 respondents who identified solutions to providing CM, the most common was to address

**TABLE 2.8 Reasons for not providing complementary medicine (CM) services**

Lack of funding	123	60.3%
Low patient demand / awareness	65	31.9%
Unsure about which CM services to provide	64	31.4%
Unsure how to set up a CM service	55	27.1%
Lack of interest or support from oncologists	51	25.0%
Organisational policy does not support/allow CM	38	18.6%
Not enough evidence to support CM	22	10.8%
Management or Board directive	16	7.8%
OTHER: No champion or organisational interest	8	3.9%
OTHER: Unsure of patient demand	7	3.4%
OTHER: Recruiting CM practitioners	6	2.9%
OTHER: Affordability / high out-of-pocket costs	2	1.0%

Only respondents who reported their cancer service did not provide CM services were asked this question (n = 204)

More than one response was allowed

**TABLE 2.9 Solutions to help reduce barriers to providing CM services**

Address funding and business models	66	32.3%
Establish an evidence-base	64	31.3%
Staff education / training	35	17.1%
Guidance on clinical and/or business models	14	6.8%
Policy support	8	3.9%
Ensuring sufficient demand for service	6	2.9%
Attitude change of service providers	7	3.4%

Only respondents who reported their cancer service did not provide CM services were asked this question (n = 204)

More than one response was allowed

funding and business models (32.2%, n=66) or provide more guidance about clinical and/or business models (6.8%, n=14) (Table 2.9). How CM should be funded was more contentious. Some called for *“Medicare funding to support the use of appropriate complementary medicine.”* Others suggested higher rebates from private health insurers. Philanthropy, *“fundraising”* or finding CM practitioners *“that want to volunteer”* were also proposed.

A few respondents from the private health sector considered it was the responsibility of the *“public service to provide”* CM services. This view, however, was not always shared by those in the public health sector who stated that *“given the number of competing demands for resources within a public hospital”*, CM services *“would need to be patient/consumer-driven”* and patients could *“seek this if they wish to”* in the community rather than being *“provided from the public system”*. However, this raised the question of patient

affordability, and thus equity, as was highlighted by a respondent from a large publicly owned cancer service:

*“We are currently trying to develop integrative therapies in the centre. Sustainability and cost will always be a factor. We are in a demographically struggling area.”* (Administrator/ Manager and Healthcare professional from a public health sector hospital who only selected inadequate funding as a barrier)

For others, funding issues were often intertwined with other challenges such as providing value in healthcare and prioritising essential services. CM services were seen as a non-essential.

*“We are too busy complying with accreditation and providing the best possible known treatment services to our patients. I feel we are here to heal people not be airy fairy, there are plenty of places for that. I also feel these complementary treatments belittle what we are trying to achieve. But if they were paid by the Health Funds as inpatient services at great reward I would reconsider this.”* (Administrator/Manager from a private health sector hospital who selected inadequate funding and evidence as barriers)

*“Difficult, government authorities do not recognise complementary therapies as being essential in supporting cancer patients through cancer treatment and beyond. Grants are great but when the funding runs out the service has to cease in most cases. Retired complementary trained professionals may offer services free.”* (Administrator/Manager and Healthcare professional from a public health sector hospital who only selected inadequate funding as a barrier)

Although only 22 of the 204 respondents (10.8%) thought that inadequate evidence to support CM was a barrier (Table 2.8), building a stronger evidence-base was often seen as an important part of the solution (31.3%, n=64/130), and for some, it was paramount (Table 2.9).

*“Until there is adequate evidence to support significant objective benefit the other barriers are irrelevant. Oncologist support will only come with evidence.”* (Healthcare professional who selected inadequate funding, support from oncologists, and evidence as barriers)

*“If evidence supports better outcomes for patients when they receive complementary therapy, a business case could be made to include their services.”* (Healthcare professional who selected funding and evidence as barriers)

This was not to say that there is no evidence for CM, but rather, many require further scientific evaluation.

*“Complementary therapy” is a poor name. There are evidence-based therapies, therapies proven not to work or whose fundamental theories are disproven or physically impossible, and therapies incompletely examined. For many, the situation is the last mentioned.”* (Healthcare professional who only selected inadequate evidence as a barrier)

Along with “proven research”, respondents identified the need for more “detailed information about complementary medicines and the evidence

*regarding efficacy*”, *“in-service education*”, and *“information, assistance and education in setting up this service”*. *“Guidance from a well-established complementary service”* and *“leadership to champion”* was also seen as part of the solution to developing IO services.

Seven respondents stated in the comments section that patient demand was unknown (Table 2.8). Aside from research about efficacy and cost-effectiveness, a few respondents discussed the importance of also consulting patients:

*“Research as to what the patients would like us to consider and how we would fund it”* (Public hospital Administrator and Healthcare professional, who only selected inadequate funding as a barrier)

Six respondents commented that another barrier was challenges with recruiting CM practitioners (Table 2.8). For some regional/remote organisations, this reflected a difficulty in recruiting staff in general and others commented that the challenge was recruiting and credentialing appropriately trained practitioners. An unexpected comment from one regional hospital was the *“difficulty engaging with complimentary therapists who are willing to work with conventional treatments”*, as it is often assumed that the attitudes of conventional healthcare providers, rather than the CM providers, are the barrier to integration.

### **2.2.6 Complementary Medicine Policies**

The survey also explored the provision of policies and procedures. Recognition of national requirements and institutional policies influencing the provision of CM practitioner services and use of CM products were not well developed. Consistently, having no policy was a more frequent remark for the organisations that did not provide CM services.

The survey asked both CM providers (n=71) and non-CM providers (n=204) a series of questions about their organisation’s policies for visiting CM practitioners, referrals to CM practitioners outside the organisation, patient-initiated CM product use, documentation of CM product, availability of information for patients about CM, and whether these policies aligned with Council of Australia Therapeutic Advisory Groups (CATAG) recommendations. CM providers were also asked about their policies for appointing CM practitioners and documenting their services in the patient’s clinical records.

## **ORGANISATIONAL POLICIES FOR ONSITE CM PRACTITIONERS**

The 71 cancer services that provided CM services were asked about their organisation’s policies for engaging the services of CM practitioners. The three most common policy areas identified as ‘must have’ were confirmation of the practitioner’s credentials by the organisation, formal training about organisation protocols and procedures, and a criminal record and/or working with children check. Professional indemnity insurance and accreditation by a professional organisation were also important. The requirement for practitioners to be registered with the Australian Health Practitioner Regulation Agency (AHPRA) was slightly less important. Having a First Aid certificate was the only policy area that was not so essential to have in place (Table 2.10)

TABLE 2.10 Organisational policies for CM practitioners providing services on-site						
CANCER SERVICES PROVIDING CM (n = 71)	MUST HAVE	PREFERRED	OPTIONAL	NONE	DON'T KNOW	TOTAL
CONFIRMATION OF CREDENTIALS	54 76.1%	3 5.6%	4 4.3%	2 2.8%	8 11.3%	71 100%
FORMAL TRAINING ABOUT PROTOCOLS AND PROCEDURES	54 76.1%	3 5.6%	4 4.3%	2 2.8%	8 11.3%	71 100%
CRIMINAL RECORD OR WORKING WITH CHILDREN CHECK	50 70.4%	4 5.6%	1 1.4%	6 8.5%	10 14.1%	71 100%
ACCREDITED BY PROFESSIONAL ORGANISATION	43 60.6%	10 14.1%	5 7.0%	5 7.0%	8 11.3%	71 100%
PROFESSIONAL INDEMNITY INSURANCE	37 52.1%	12 16.9%	4 5.6%	4 5.6%	14 19.7%	71 100%
AHPRA* REGISTRATION	36 50.7%	10 14.1%	6 8.5%	11 15.5%	8 11.3%	71 100%
FIRST AID CERTIFICATE	22 31.0%	12 16.9%	10 14.1%	15 21.1%	12 16.9%	71 100%

\*AHPRA - Australian Health Practitioner Regulation Agency

## POLICIES FOR VISITING CM PRACTITIONERS AND CM REFERRALS

The majority of organisations had neither a formal credentialing policy for visiting CM practitioners (as opposed to CM practitioners who were routinely providing services), nor a scope of practice for these practitioners (Table 2.11).

The observed differences between IO and non-IO providers was largely explained by the significantly lower rates of policies from the non-IO providers (credentialing policy  $\chi^2(4) = 42.1, p < 0.000$ ; scope of practice policy  $\chi^2(4) = 32.7, p < 0.000$ ). For some organisations (10-13%), these decisions were made on a case-by-case basis; 21 (7.6%) organisations reported their policy was that visiting CM practitioners were not allowed to provide services onsite. The results were similar regarding policies for referrals to CM practitioners outside of the organisation, including a significant difference between IO providers and non-providers ( $\chi^2(4) = 25.3, p < 0.000$ ) (Table 2.11).

## POLICIES ON CLINICAL RECORDS

Of the 71 organisations that provided CM services, 42 (59.2%) used an integrated clinical record where the CM practitioners documented their services in the patient's clinical record. Seven (9.9%) of the organisations used a separate clinical record for CM services, and this was kept on site. Thirteen (18.3%) did not keep a clinical record of the CM services provided, instead, it was the responsibility of the CM practitioner to maintain their own clinical records for each patient (Table 2.12). Only IO providers were asked this question.

TABLE 2.11 Policies on visiting CM practitioners and patient initiated CM product use												
CANCER SERVICES (n = 275)	POLICY: 'YES' THERE IS A POLICY		POLICY: CASE BY CASE BASIS		POLICY: NOT PERMITTED		NO POLICY		DON'T KNOW		TOTAL	
	n	%	n	%	n	%	n	%	n	%	n	%
Credentialing policy for visiting CM practitioners*	55	20.0	29	10.5	21	7.6	107	38.9	63	22.9	275	100
IO providers	31	43.7	11	15.5	3	4.2	12	16.9	14	19.7	71	100
non-IO providers	24	11.8	18	8.8	18	8.8	95	46.6	49	24.0	204	100
A scope of practice for visiting CM practitioners*	36	13.1	35	12.7	21	7.6	118	42.9	65	23.6	275	100
IO providers	19	26.8	16	22.5	3	4.2	18	25.4	15	21.1	71	100
non-IO providers	17	8.3	19	9.3	18	8.8	100	49.0	50	24.5	204	100
Referrals CM practitioner outside the organisation*	14	5.1	46	16.7	14	5.1	151	54.9	46	16.7	275	100
IO providers	10	14.1	17	23.9	6	8.5	28	39.4	10	14.1	71	100
non-IO providers	4	2.0	29	14.2	8	3.9	123	60.3	36	17.6	204	100
Patient initiated CM product use	33	12.0	45	16.4	11	4.0	141	51.3	45	16.4	275	100
IO providers	12	16.9	9	12.7	5	7.0	33	46.5	13	18.3	71	100
non-IO providers	21	10.3	36	17.6	6	2.9	108	52.9	28	13.7	204	100
CM information for patients*	111	40.4	22	8.0	7	2.5	111	40.4	24	8.7	275	100
IO providers	43	60.6	6	8.5	3	4.2	15	21.1	5	7.0	71	100
non-IO providers	69	33.8	16	7.8	4	2.0	96	47.1	19	9.3	204	100

\*Statistically significant differences between IO providers and non-providers ( $\chi^2(4) > 18, p < 0.001$ )

## POLICIES ON CM PRODUCT USE

The survey asked all respondents (n=275) about their organisation's policy for CM product use. Half of the organisations (51.6%, n=142) did not have a formal policy on patient-initiated CM products such as herbs, vitamins and minerals; a further 45 (16.4%) did not know if there was a formal policy (Table 2.11). For 11 (4.0%) organisations, patient-initiated CM product use was not permitted. Unlike other CM policies, there was no significant difference between IO providers and non-providers regarding a policy on patient initiated CM product use ( $\chi^2(4) = 4.6, p=0.3$ ). However, in a different question about documenting CM product use, 19 (6.9%) reported that the organisation did not permit CM product use of any kind (Table 2.12). In this instance, IO providers were more likely not to permit CM product use of any kind ( $\chi^2(1) = 6.9, p < .01$ ). The discrepancy between the two responses may be explained by more respondents not knowing the answer to the question reported in Table 2.11.

Most organisations (86.5%, n=238) had a policy for documenting CM product use (Table 2.12). This included 19 organisations whose policy was not to allow

**TABLE 2.12 Policies on documenting herbs, vitamin and minerals (n=275)**

	n	%
All products (including self-initiated) are listed on the medication chart	79	28.7
IO providers (n=71)	17	23.9
Non-IO providers (n=204)	62	30.4
Only products approved by medical staff are listed on the medication chart other products are documented	88	32.3
IO providers (n=71)	25	35.2
Non-IO providers (n=204)	63	30.9
Product use is only documented in the clinical history	48	17.6
IO providers (n=71)	11	15.5
Non-IO providers (n=204)	37	18.1
Not applicable - patients are not permitted to use these products	19	6.9
IO providers (n=71)	10	14.1
Non-IO providers (n=204)	9	4.4
No specific policy	26	8.0
IO providers (n=71)	3	4.0
Non-IO providers (n=204)	23	11.2
Don't know	15	5.5
IO providers (n=71)	5	7.0
Non-IO providers (n=204)	10	4.9

Only respondents who reported their cancer service did not provide CM services were asked this question (n = 204)  
More than one response was allowed

CM product use, and thus, its use was not documented. Although the use of herbs, vitamins, and minerals were documented in the patient's clinical records by 215 (78.2%) organisations, only 79 (28.7%) organisations documented all CM product use, including patient initiated, on the medication chart; 88 (32.0%) organisations only documented those products approved by medical staff on the medication chart and all other product use was documented in the clinical history. The remaining 48 (17.6%) organisations documented all CM product use irrespective of who had initiated its use in the clinical history only. The survey found no difference between IO providers and non-providers and the likelihood of having a policy for documenting CM use ( $\chi^2(1) = 1.9, p=0.2$ ).

Fifty-six respondents provided further comments about policies and practices with obtaining a medication history and documenting CM products.

*"Patients are asked on initial consultation when a medical history is taken in the outpatient setting. If the patient discloses any information this will be recorded in the notes. Patients will also ask themselves and will be provided with advice from the oncologist/oncology pharmacist/oncology nurse. Patients are never told they cannot use herbs, vitamins/minerals the patient will only be advised if there is concern the medication may interact*

*with the cancer treatment or there is no evidence available to support the use of these treatments especially if very costly.”*

Quite a few respondents commented that their cancer service used a reconciliation medication chart to verify the patient’s current medications. One service stated that it used “a screening tool for new patients who fill in a Patient Self Reporting Health History that asks for a list of current medications including Vitamins/Herbal medications”. Among services that disclosed CM product use, quite a few commented that a consultation was then arranged with either a pharmacist or an oncologist. One service commented that any advice given about interactions, contraindications, and efficacy included checking databases such as the “Memorial Sloan Kettering Cancer Centre, the Australian Pharmaceutical Formulary and CAM-CANCER”.

Others, however, commented that not all patients are forthcoming even when they are asked about CM product use:

*“Anecdotally, patients have advised that they choose not to disclose alternate complimentary therapies.”*

*“It depends how honest the patient is and how much they perceive we need to know about what else they take. We encourage all patients to list complementary medicines in their own interest.”*

## HOSPITAL POLICY ALIGNMENT WITH NATIONAL CM GUIDELINES

Of the 262 respondents from registered hospitals, only 97 (37.0%) were aware of the CATAG, from which 35 indicated that their policies were aligned with the CATAG Position Statement for the use of Complementary and Alternative Medicines <sup>[34]</sup>, 21 reported that their service did not align, and 40 did not know. A hyper-link was included with the question so that respondents could immediately refer to the statement. Alignment with the CATAG position statement did not differ between IO providers and non-CM ( $\chi^2 (1) = 4.83$ ,  $p=0.08$ ).

### 2.2.7 Oncology massage attitudes, awareness and barriers

Overall, participating organisations indicated some awareness of evidence regarding potential benefits from OM. The majority thought that certified OM therapists were very likely to deliver a safe massage to cancer survivors. Participants indicated there are barriers to providing OM services, and the main barrier identified was a lack of funding.

Around half of the respondents were aware of evidence that OM can reduce pain and anxiety and one-third were aware of evidence that OM training can influence patient outcomes (Table 2.13). IO providers were more likely to indicate that OM can reduce pain and anxiety than non-providers ( $\chi^2 (1) 27.0$ ,  $p<.001$ ), and that OM training can influence patient outcomes ( $\chi^2 (1) 10.7$ ,  $p<0.01$ ).

The overwhelming majority of respondents indicated that a certified OM therapist was ‘very likely’ or ‘likely’ to deliver the safe massage (94.6%,  $n=262$ ). This was followed by 29% ( $n=79$ ) indicating that any massage therapist was ‘very likely’ or ‘likely’ to deliver safe massage, and another half thought that they would ‘possibly’ deliver safe massage to cancer survivors. Most

TABLE 2.13 Awareness of oncology massage evidence						
	YES		NO		DON'T KNOW	
RESPONSES (n = 275)	n	%	n	%	n	%
OM can reduce pain or anxiety**	149	53.8	43	15.5	85	30.7
IO providers (n=71)	59	79.7	5	6.8	10	13.5
Non-IO providers (n=204)	84	44.2	35	18.4	71	37.4
OM training can influence patient outcomes*	90	32.5	80	29.1	105	38.2
IO providers (n=71)	35	47.3	15	20.3	24	32.4
Non-IO providers (n=204)	51	26.8	64	33.7	75	39.5

\*p<0.01; \*\*p<0.001

respondents thought that healthcare professionals with no massage training, family members, and volunteers were far less likely to deliver a safe massage to cancer survivors (Table 2.14).

When asked whether there were any organisational barriers preventing the cancer service from providing massage by a certified OM therapist, 155 (56.4%) of respondents reported that there were barriers and 75 (27.3%) reported that there were no barriers. The remaining 45 (16.4%) respondents did not know whether there were any barriers. A lack of funding was the primary barrier identified by the 141 of the 155 respondents who reported there were barriers. Other reasons included difficulties with recruiting certified OM therapists, insufficient patient demand, a lack of support by other healthcare professionals, and inadequate space (Table 2.15).

Individual comments describing some of the barriers included:

*"we are in a rural/regional area and these therapies would be difficult to establish";*

TABLE 2.14 Views on the likelihood of delivering safe massage to cancer survivors						
RESPONSES (n = 275)	VERY LIKELY	LIKELY	POSSIBLY	UNLIKELY	VERY UNLIKELY	DON'T KNOW
Family member	1 (0.4%)	20 (7.3%)	118 (42.9%)	64 (23.3%)	64 (23.3%)	8 (2.9%)
Volunteer	2 (0.7%)	12 (4.3%)	89 (32.4%)	70 (25.5%)	90 (32.7%)	12 (4.4%)
Healthcare professional (no training)	0 (0%)	12 (4.4%)	83 (30.2%)	96 (34.9%)	70 (25.5%)	14 (5.1%)
Massage therapist (any style)	9 (3.3%)	70 (25.5%)	138 (50.2%)	26 (9.5%)	21 (7.6%)	11 (4.0%)
Certified OM therapist	216 (78.5%)	46 (16.7%)	9 (3.3%)	2 (0.7%)	1 (0.4%)	1 (0.4%)

The survey question generated a random order for the different provider options

TABLE 2.15 Organisational barriers to providing oncology massage		
Funding not available	141	89.7%
Unable to recruit certified OM therapist	26	16.8%
Low patient demand	21	13.5%
Doctors or allied health do not support OM	16	10.3%
Not enough space	17	10.9%
Other organisational barriers	9	6.4%

Only respondents who reported there was a barrier were asked this question (n = 155)

*“certain medical staff in the broader organisation are not supportive”;*

*“a lack of awareness about the benefits for people to advocate for such a service, and it is not prioritised in tight health budgets”;*

*“currently the barriers would be location, time and service providers”;* and

*“further research is needed to ensure patient safety/risk whilst undergoing cancer treatment, and there is no credentialing pathway”.*

# 3 INTEGRATIVE ONCOLOGY: CANCER SURVIVORS' EXPERIENCES AND VIEWS

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The following chapter presents the study design, method, and results from the focus group interviews and a supplementary community survey of cancer survivors.

## 3.1 AIM

The aim of this qualitative research was to explore the views of cancer survivors (including CALD population groups that are under-represented in cancer research) in relation to CM services with the view of informing IO service provision.

### 3.1.1 Objectives

Conduct focus group interviews and a community survey with cancer survivors to:

1. Explore experiences, preferences, service requirements, and gaps and barriers to the provision of CM and its integration into cancer care services.
2. Include the views of CALD population groups common to SWSLHD that are under-represented in cancer research.

## 3.2 METHOD

### 3.2.1 Design

The study employed qualitative methods - focus group interviews supplemented with an online survey - to examine cancer survivors' perceptions and experiences of CM use, decision-making processes, service delivery preferences, and enablers and barriers to accessing CM cancer care.

### 3.2.2 Participant recruitment

Three focus groups - Arabic, Chinese and Vietnamese Australian- were purposively sampled to include variable experiences with CM following cancer treatment and to represent common CALD groups in Western Sydney, the geographical area where the research was based. Participants were recruited through the distribution of information sheets in English, Arabic, Chinese, and Vietnamese by collaborating hospital clinics and CM services, including culturally specific cancer support services and a cancer wellness centre. Interviewees were offered \$25 gift card as a reimbursement for expenses.

Due to logistical reasons, other planned focus groups with Anglo-European cancer survivors (CM non-users and patients from regional areas) did not occur. Information regarding these population groups was then collected through a supplementary online survey for which participants were recruited through social media networks. This included creating a Facebook page that was used to advertise the survey via other Facebook networks including the National Breast Cancer Foundation, OML, and other natural therapies organisations (<https://www.facebook.com/integrativeoncologyaustraliaresearchstudy/>).

### 3.2.3 Procedure and instruments

The interviews were conducted to examine the subjective experience, meaning, and perceived consequences of CM use in the context of cancer. Two experienced interviewers used an "extended conversation" technique,<sup>[35, p. 96]</sup> in which the wording and formatting of questions is flexible to suit the

particular context and experience of the participants. Appendix IV provides an outline of the interview guide. Interpreters were used for the Vietnamese, Arabic, and Mandarin speaking groups. The interpreter for the Mandarin focus group was also accredited in Cantonese. Interpreters were asked to translate the actual wording of each participant's talk rather than summarising responses to capture the detail of participant accounts. A questionnaire was used to collect anonymous information about the demographic and cancer history of participants. All the interviews were audio-recorded and transcribed verbatim, with the resulting transcripts then read in conjunction with the audio recording to verify any errors in transcription.

The online survey was anonymous and consisted of 26 closed and open-ended questions examining participants' views on CM in the context of cancer (Appendix V). This included demographic and cancer history questions, whether participants had used CM services and therapies, the context of their use, where they would like to have received CM, and enablers and barriers using CM as part of their cancer care. The questionnaire was designed to collect data compatible with the topics discussed in the interviews.

Unlike many community/patient surveys, the focus of this survey was on CM services provided by CM practitioners rather than general CM use. Although prayer and spiritual practices are the most commonly used non-biological based CM therapies both in Australia and abroad,<sup>[4, 5, 36]</sup> in Australia, pastoral care is not considered part of IO service provision and, as such, was outside the scope of this research project. The boundaries can be blurred, however, as CM wellbeing services such as meditation and mindfulness may draw on religious philosophies and traditions, and spirituality (rather than religiousness) is considered to be a domain of 'holistic health'.<sup>[31, 32]</sup>

### **3.2.4 Ethics and disclosure**

HREC approval was granted by the Western Sydney University HREC (H11389) and the relevant local hospital HRECs (details are confidential to protect the anonymity of the participating groups). All participants gave specific consent.

### **3.2.5 Analysis**

The focus of the analysis was qualitative. The survey thematically analysed open-ended responses and interviews.<sup>[37]</sup> The style of analysis adopted was inductive with the development of themes being data driven rather than based on pre-existing research or hypotheses. A subset of the interviews was independently read and reread by two of the authors to identify first order concepts or codes, such as "benefits of CM for cancer patients", "negative experiences", and "practitioner attitudes". The entire data set was then coded using NVivo, a computer package that facilitates organization of coded qualitative data. All of the coded data was then read through independently by two of the authors. Codes were then grouped into higher order themes, a careful and recursive decision-making process which involved checking for emerging patterns, for variability and consistency, and making judgements about which codes were similar and dissimilar, leading to the development of a thematic map of the data with core themes and subthemes. Descriptive statistics were used to summarise information about the participants' characteristics, responses to the closed survey items, and frequencies of open-ended responses following coding.

### 3.3 RESULTS

In the final stage of analysis of the qualitative data, two core themes were identified “*positive perceptions and experiences*” and “*barriers and unmet needs*”; the latter had two interacting subthemes “*structural barriers*” and “*personal barriers*”.

In the presentation of the results below, the survey data reports the frequency of responses related to the core themes and subthemes that emerged from the qualitative analysis. The meaning and consequences of these themes draws on the qualitative analysis of the interviews and the open-ended survey items. Details of the cultural background of the participants are provided for longer quotes.

The majority of the survey questions were not compulsory; as such, response rates to questions ranged from 100% (n=121) down to 67% (n=84). Mostly, this was due to skipped questions throughout the survey with only 14 (12%) not completing the survey. Missing data is excluded from the denominators when calculating the percentage of responses to a question.

#### 3.3.1 Characteristics of participants

Thirty-three adults took part in one of the four focus group interviews (Table 3.1). The average age of the participants was 64 years (SD=8.7), the median number of years since diagnosis was six, ranging from four months to 30 years. The ethnicities of the four groups was Arabic, Vietnamese, Chinese, and Anglo-European Australia. Four of the participants in the Arabic focus group were carers of cancer survivors. The fifth focus group was intended to be an Anglo-Australian group with non-CM users. Only one participant attended. The interview schedule was modified, written consent was obtained, and a 45-minute one-to-one interview was then conducted.

One hundred and twenty-one participants completed the online survey (Table 3.2). The average age of survey participants was 60 (SD=11.1), and the median number of years since diagnosis was three and a half years, ranging from four months to 36.5 years.

**TABLE 3.1** Characteristics of focus group participants (n=33)

DEMOGRAPHICS		
Age (n=31: mean / SD)	64	8.7
Ethnicity	n	%
Arabic	11	33.0
Vietnamese	9	27.3
Chinese	7	21.2
Anglo-European	6	18.2
CANCER HISTORY		
Cancer survivors	29	
Years since cancer diagnosis (median /range)	6	0.3 - 30
Carers	4	

Most survey participants were of Anglo-European heritage and spoke English at home. Two respondents wrote that the cultural or ethnic group with which they identified was Aboriginal and Torres Strait Islander, two Maori, and two Samoan. The survey accidentally omitted a question on gender. Cancer diagnosis, however, demonstrates that at least 82 (68%) of the 121 respondents were female, most of which had been diagnosed with breast cancer (n=80/82).

Just under half (46%) of the respondents were currently engaged in either active treatment (e.g. surgery, chemotherapy or radiotherapy) or long-term treatment (e.g. hormone suppression medication, other medication, or rehabilitation), and 59% had received some form of treatment for their cancer

**TABLE 3.2 Characteristics of online survey participants (n=121)**

DEMOGRAPHICS	Mean	SD
Age	59.6	11.1
Country of Birth	n = 121	%
Australia (2 Aboriginal)	92	76.0
New Zealand (2 Maori, 2 Samoan)	6	5.0
Europe / United Kingdom	17	14.0
Africa	3	2.5
Asia	3	2.5
Languages spoken at home	n = 120	%
English	116	96.7
English and another language	4	3.3
CANCER HISTORY	Median	Range
Years since cancer diagnosis	3.6	0.3 - 36.5
Diagnosis	n = 121	%
Breast or gynaecological cancer	82	67.8
Haematological, bowel, skin or lung cancer	25	20.7
Prostate cancer	4	3.3
Other (includes those with multiple primary cancers)	10	8.3
Current treatment	n = 121	%
No treatment	65	53.7
Long-term treatment, including rehabilitation	46	38.0
Active treatment	10	8.3
Treatment in last 12 months*	n = 120	%
None	50	41.6
Surgery	38	31.6
Radiotherapy	31	25.8
Chemotherapy	26	21.6
Other: Medication	25	20.8
Other: rehabilitation, lymphatic massage, naturopathy	7	5.8

\*more than one response allowed

in the previous 12 months. The survey sample was biased towards English speaking Anglo-European Australians who were females with a diagnosis of breast cancer, and who were OM users (Table 3.2). This reflected the networks used to advertise and recruit participants.

### CM SERVICES AND PRODUCT USE

The majority of survey respondents (90%, 107/119) had used CM, including a range of CM modalities and/or products such as vitamins, minerals, and herbs (Table 3.3); 67% (n=22/33) of focus group respondents had used CM. CM had been used before their standard cancer treatment by 15% of the 96 survey respondents, at the same time by 46%, and after treatment by 78%. None of the respondents had used CM instead of, or as an alternate, to their standard cancer treatment.

None of the participants in the Arabic focus group said that they had experience with CM; specifically, everyone stated that they did not use any traditional healing practices as part of their cancer care. Consequently, most of the questions and responses during this interview were around the hypotheticals of using CM and where people would like to access information. These results are reported under the theme *barriers and unmet needs*.

**TABLE 3.3 Complementary Medicine use by on-line survey participants (n=121)**

CM use since cancer diagnosis	n = 116	%
Both CM modalities & products	74	63.8
Only CM modalities (no other CM products)	28	24.1
Only CM products	5	4.3
None	9	7.8
CM modalities commonly used since cancer diagnosis*	n = 116	%
Any type of massage or touch therapy	93	76.9
Oncology massage	73	60.3
Other massage/touch therapy	58	47.9
Mental wellbeing (e.g. meditation, art/music therapy)	61	50.4
Movement modalities (e.g. yoga, tai chi, massage)	41	33.9
Naturopathy or nutritional medicine	38	31.4
Acupuncture or Chinese medicine	17	14.0
Body Alignment (e.g. chiropractic, osteopathy, cranio-sacral)	15	12.4
Indigenous Australian healing practices	1	0.8
Other (e.g. Ayurvedic, Spiritual/prayer)	2	1.7
Timing of CM use*	n = 96	%
Before standard cancer treatment	14	14.6
During treatment	44	45.8
After treatment	75	78.1

\*more than one response allowed

### 3.3.2 Positive perceptions and experiences

Of the survey and focus group respondents who had used CM, they mostly reported positive experiences. The majority of survey respondents (95%, n=92/97) stated that they would recommend CM to others, and 92% (n=98/107) would consider using CM again.

#### POSITIVE IMPACT ON CANCER SURVIVAL

Several perceived benefits of CM were discussed. One was the belief that it could have a positive impact on cancer survival. This was reflected in the comment of a Vietnamese focus group participant who had used wheatgrass *“so the tumour – it remains the same. It didn’t develop more... Over time, I see my health start to get better”*. Another Vietnamese focus group participant said that *“the cancer in my lungs had developed and went up to the brain ... It was just terminal”*, but then he *“took Chinese medicine for one year and it stopped”*.

A Chinese focus group participant provided an account of the benefits of eating *“normal food, balanced food, good exercise”* combined with Chinese medicine, in *“fighting”* cancer:

*“The final result from this is your immune system becomes strong, balanced. Then you will get healthy and you have a chance that it will fight each other – the good guy fighting the bad guy. That’s the reason why sometimes some people who have cancer suddenly disappear.”* (Chinese)

*“It is very helpful to me and many of the people who also practise qi gong were diagnosed five or ten years ago and they are still living.”* (Chinese)

#### POSITIVE IMPACT ON SIDE-EFFECTS AND RECOVERY

Many participants gave accounts of using CM to *“enhance treatment and protect body against side effects of treatment”* or *“to improve my general health”* after treatment. This included the benefits of OM *“to improve my overall general health and to assist with managing lymphoedema”* and *“to assist my rehabilitation”*; hydrotherapy *“it’s good for the body, good for everything”*; vitamins *“to assist with side effects of chemotherapy induced menopause”*; meditation to *“reduce the painkillers”*; acupuncture to deal with *“pain on my legs”*; tai chi and yoga *“to make you feel a little bit more important and a little bit more active”*; and Chinese medicine to improve digestion *“after drinking the Chinese medicine, it really helped me with eating”*.

#### POSITIVE IMPACT ON CO-MORBIDITIES

CM was also used to deal with concurrent health problems that exist alongside cancer-related symptomatology, illustrated in the following account:

*“... But I found with the acupuncture and the massage in particular, apart from the side effects that you get from the traditional treatments – your chemotherapy, your radiation .... if you had any other ailments prior to cancer, they continue to exist throughout the whole cancer – I hate the word, but journey. And those supplementary therapies help with that as well as the other, because when you have got cancer, those other things suddenly seemed magnified.”* (Anglo-European)

## DOWNPLAYING NEGATIVE OUTCOMES

Not all outcomes from CM use were positive, however, and another participant described a perception of a social bias regarding CM outcomes within his community. Successes of CM were acclaimed and failures suppressed:

*“they kept very quiet. They never say they died because of this medicine.”*  
(Chinese)

## POSITIVE EXPERIENCES WITH CM PRACTITIONERS

Participants also reported positive experiences with CM practitioners, and emphasised their appreciation of CM care:

*“I haven’t tried anything else but the massage. I found it really relaxing especially the last time I went. That’s about a couple of weeks ago. I have a problem. I was tired. I wasn’t having any energy. I was really depressed and when she took me in for about 45 minutes, when I come out and I felt like, “God bless you. You’re here to help people.” It was so beautiful, and so relaxing, so good. So you come out and you think, “God, please help those ladies and help us to help others.”* (Anglo-European)

Participants commented that practitioners with appropriate training helped ensure quality care. Acupuncture practitioners were described as “so calm” and as having “that specific training with oncology”, which meant that “they have training and awareness of the whole thing” resulting in reports of “confidence” in the outcomes of CM. Others noted a difference in quality between OM offered at the hospital and those offered privately “the massages outside aren’t any good”.

## POSITIVE EXPERIENCES WITH INTEGRATING CM SERVICES

Respondents perceived hospital-based CM services as having several benefits, including IO/CM practitioners having more knowledge than practitioners in private practice, the benefits of having CM services close to the site of other cancer treatment, and low costs compared to private services:

*“I think to have it close by to where the other treatments are taking place helps, because I was able to go from radiation and then after I finished my treatment, then come up to the wellness centre and continue with whatever it was that I needed. Like on Tuesdays, I had the massage and Mondays was acupuncture and so on.”* (Anglo-European)

### 3.3.3 Barriers and unmet needs

Participants reported several unmet needs and barriers in relation to CM use in the context of their cancer care. Structural barriers included lack of availability of CM services, difficulties in referral pathways, medical practitioner attitudes, the logistics of accessing care, and the cost of care. Personal barriers for the individual and their family/carers were influenced by the severity of impairment and disability; attitudes, beliefs and knowledge about CM; and available personal resources (e.g. financial, time or transport). Only 13% (16/107) of the survey respondents reported that there were no barriers preventing them from using CM or using more CM.

## LACK OF AVAILABILITY OF CM SERVICES

Participants reported there were CM services that they would like to have used but could not. One of the reasons for this was availability of services, with 36% (n=39/107) of the survey respondents reporting that lack of availability either stopped them from using CM or from using more CM.

Two-thirds of the survey respondents (65%, n=70/107) wanted to access CM services across a range of service settings with 22 (21%) wanting to access CM at both inpatient and outpatient hospital settings; 23 (21%) following inpatient care, either as an outpatient or through their GP clinic; and 25 (23%) across the continuum of primary and secondary care services including nonmedical community settings. It was important that patients were made *“aware of therapies as an inpatient so that access can continue, or be used later when [the] patient is ready to access them. People have needs at different times.”* Some participants, however, preferred to access CM in nonmedical settings. Of the 43 (40%) survey respondents who selected a ‘community health centre’ as a preferred site, 10% of respondents only wanted to access CM services in nonmedical environments as *“Hospitals make you feel “you are sick” whereas [a community centre] can mean it is just “your time””*.

Overall, there was an apparent mismatch between where participants were accessing CM services and their preferences, particularly for hospital-based and medical services in general. The desire to access CM through the hospital (either as inpatient and/or outpatient) was reported by 64% (n=69/107) of the survey respondents. However, only 17% (n=16/95) had accessed CM in a hospital setting. Access via a medical practitioner in the community was also low with 14% (n=13/95) accessing CM through a GP clinic, and 26% (n=27/107) selecting this location. A better match was observed between respondents who wanted to access CM through a community health centre or private provider (45%; n=43/95) and those who did (42%; n=45/107). Informal settings, such as their house or a friend’s house, were also reported (19%, n=23/107) and 11 respondents stated in the open-ended comments section that they also accessed CM (that, for some, included a consultation with a naturopath) through the local pharmacy or health food store.

Regarding hospital-based CM services, several participants reported a limited mindset and expertise on the part of hospitals in the provision of CM services and the need for culturally appropriate CM services:

*“I think it should be better for each hospital have one [CM] department. You know why? Some time we went to the [hospital] – they got more Chinese patients. They know more knowledge about the Chinese medicine. Even we went to the [hospital] – they don’t know anything. They only have Western people.” (Chinese)*

If CM services were available through the hospital, they were described as *“often very booked”*, with *“demand far, far greater than the service that’s available”*. The time available for CM therapy sessions, when they were available, duration of treatment, and limits being placed on the total number of sessions, were also a focus of criticism:

*“It’s not fair to come here only once a fortnight or once in 20 days because you don’t get the benefit [of acupuncture] ... The massage therapist, half an*

*hour is not enough. You have people with limited mobility and the time that is taking to get into the room, to get undressed, you've got a questionnaire to fill out before the treatment and then after the treatment ... there is a limit on the number of times I can access oncology massage following my cancer treatment.” (Anglo-European)*

Others reported the absence of specific CM services or difficulties with finding CM practitioners knowledgeable in cancer care: *“I couldn't find a decent massage therapist who could work with this- still do remedial, as I have no secondaries or pain as such- but who understood cancer, scars, and lack of skin sensation”; “reflexology wasn't offered”; “it's hard to find suitably trained providers”.* These challenges were exacerbated for those living in regional/remote areas.

## DIFFICULTIES WITH REFERRAL PATHWAYS AND INFORMATION ABOUT CM

Even when hospitals were providing CM services, structural barriers, such as obtaining referrals and information about available CM services, remained an obstacle; however, *“once you come through that front door, you get that information. But it's getting through that front door, somebody telling you that it exists”.*

Participants reported frustration with their healthcare professionals not discussing CM options or being slow to refer, noting that the onus was on patients to question their healthcare professionals about CM options, which may subsequently disadvantage patients who were *“quiet”* and did not tend to question doctors or had less personal knowledge. Often, it was up to the participant to seek out information or find a poster or leaflet in the oncology department advertising hospital-based CM services rather than spoken about by doctors, to which one participant remarked *“I didn't see it”.*

Many participants talked about being referred straight to mainstream treatments, with a lack of consideration for nonmedical adjuvant therapies. Participants commented:

*“The doctor only said, “This tablet, this tablet,” and that's it!” (Arabic)*

*“He never mentioned any other support or any other alternative that we can do”. (Arabic)*

*“Doctors should be encouraged to use [CM] therapies for their patients in conjunction with their treatment not instead of, or as an after-thought.” (Survey)*

Another woman who had experienced hot flushes for five years following breast cancer treatment said:

*“But only a couple of months ago, [the doctor] goes ... “Why don't you try acupuncture?” And I thought, “Oh, great. Okay, something new.” But why wasn't it mentioned one and a half years ago? ... why did I have to get to breaking point to be told - look, what's available?” (Anglo-European)*

A disparity was found between how participants wanted to receive referrals to CM and obtain information about CM and what they had received. When the survey participants were asked: “How would you like to be referred to a

CM service", 63% (n=69/110) of respondents indicated they would prefer a referral via an oncologist or GP, with 22% (n=25/110) indicating self-referral as the method of choice. Yet of the 94 survey respondents who reported they had accessed CM services, only 47% of respondents reported that a medical doctor (either a specialist or GP) had made the referral or recommendation and 46% had self-referred.

While CM users were finding ways to access CM in the community without a GP or oncologist, there was a clear preference for referrals to come from this quarter as medical practitioners were held in a position of expertise: *"I also take the doctors opinion 'cause they have better knowledge"*. Other participants commented that GPs were better placed than specialists to distribute information and monitor CM use because they *"work with you like a family"* and patients had more frequent contact with GPs than their other medical practitioners. Participants gave accounts of wanting more information about CM from their GP *"even a little that's got one or two pages"*, *"there's a lack of information"*, and that the provision of information and referrals by GPs be supported by other channels as well.

Not all participants, however, expressed a preference for referral pathways from medical practitioners.

*"Either should be able to refer. Doctors should be encouraged to use therapies for their patients in conjunction with their treatment not instead of or as an after-thought. A patient should also be able to ring and make an appointment."* (Survey)

Other preferred information sources were via social workers and pharmacists; books written by CM therapists, magazines with diagrams or succinct information presented in a pamphlet; or *"through word of mouth from somebody who has been through the same or similar experience"*. Participants also reported the use of websites to source nutritional and vitamin supplements. However, information from the internet was generally viewed as unreliable. Other information sources included a support group run by nurses and a monk who was well known to a group of friends in the community. *"Word of mouth"*, or *"friends"* were also common sources, for example: *"A lot of people advised me..."*, *"Some people suggested..."*, *"Just this lady..."*.

The need for trusted, reliable information from a variety of sources was emphasised throughout as was highlighted by one survey participant who, when asked the question about preferences for accessing CM, commented that:

*"The where is not as important as knowing what is available - being informed - preferably by not relying on 1 source to provide information - so all the suggested venues [hospital, GP, community centre] would be appropriate to provide that information."* (Survey)

## ABSENCE OF MEDICAL PRACTITIONER SUPPORT

Participants identified ambivalent or negative attitudes from their healthcare professionals (particularly GPs and oncology specialists); conflicting advice; difficulties with doctor-patient communication, including disclosure of use; and they identified a lack of knowledge about CM and available CM services as barriers to accessing and using CM. In the survey, 13% (n=11/84) of respondents

selected “unsupportive healthcare practitioner / doctor” as a reason for not using CM or more CM. Such attitudes were at odds with the survey findings whereby virtually all respondents (98%, n=109/111) opted for wanting their oncology team to know that they were using CM therapies and 63% (n=69/110) preferred a referral from either their GP or oncologist.

Participants spoke about such experiences with medical practitioners. Some were ambivalent “*My oncology doctor tell me, “I don’t want to know”...*” whereas others advised their patients not to use a CM therapy as it may “*conflict*” with other concurrent cancer treatment, or in one case, “*cause cancers.*” This was despite patients attributing positive outcomes in their health and wellbeing to CM treatments. As one participant remarked through an interpreter:

*“The oncologist told her to stop when she’s on treatment, but actually, the instruction of this particular traditional Chinese medicine [is] that you don’t need to stop when receiving chemotherapy. Actually, it can help to minimise or to offset – diminish the side effects of chemotherapy.”* (Chinese)

Participants accounted for their experiences of negative and ambivalent attitudes of healthcare professionals by suggesting these practitioners were limited by the lack of evidence available for a CM. Some participants noted that although they were discouraged from CM due to a lack of evidence, this was the professional duty of the doctor:

*“They will not recommend anything [that] is not proved. And it is their duty and they’re professional”.* (Chinese)

Participants commented that greater government support for researching CM therapies for people living with cancer may help to address these barriers.

In addition to the lack of evidence, participants also spoke about the perceived professional and cultural divides between CM and mainstream medicine contributing to the attitudes of healthcare professionals. For example, one participant commented:

*“I think traditionally, there’s always been this thing between doctors and alternative therapy practitioners.”* (Anglo-European)

Another participant remarked:

*“Those who do receive education here in the Western world, they don’t have any faith in traditional Chinese medicine.”* (Chinese)

Although participants talked about their wish to freely discuss their CM use with their doctors, negative and ambivalent attitudes from healthcare professionals were reported to have an impact on patient disclosure of CM treatments; one participant only disclosed use after experiencing adverse cancer markers, saying:

*“The blood test index shows something not normal. The doctor said, “Honestly, tell me what you eat?” I have tried to keep quiet, but I said “it’s better open”.”* (Chinese)

More open discussion about CM use with their doctors was seen as a way to increase the doctor’s knowledge of CM therapies and their availability. One participant commented on the lack of doctor awareness of the CM therapies their patients were using, saying:

*"Maybe we're just waiting for chemo or anything, but actually in the meantime, we're taking other supplements, this sort of thing." (Chinese)*

## DIFFICULTIES ACCESSING CM CARE

Respondents identified the logistics of accessing CM care as another important barrier that often reflected a combination of both structural and personal barriers. Around two-thirds (69%, n=74/107) reported that they wanted to access CM services close to home. Logistics (e.g. no transport) and personal factors (e.g. too unwell or not enough time) accounted for 11% (n=11/84) and 6% (n=9/84) respectively of the reasons for not using any or more CM therapies. Logistics and personal factors may, in part, explain the reason why 23% (n=22/95) of survey respondents reported that they had accessed CM services at home.

*"Lack of energy is a big factor, making more appointments when you already have a lot of appointments puts me off. Having a massage therapist come to the house would be great!" (Survey)*

*"There was an extended period of time when I was certainly too ill to access anything that was not absolutely necessary." (Survey)*

Participants reported that structural barriers, such as difficulties in accessing CM that was distant from their home or not available at the hospital where they were actively being treated, were often compounded by personal barriers such as a lack of energy to seek further treatments and/or the consequences of travel on their health:

*"I would like to see a natural therapist, but as it is in another suburb, I haven't had the energy and keep putting it off. I may do it soon." (Survey)*

*"I just don't have the time at the moment, as I am in the middle of daily radiation and it takes me 1 1/2 hours to the cancer centre and 1 1/2 hours back. It's the travelling that wears me out, not the treatment." (Survey)*

*"Transport is a problem for me to try to get to her private practice. I can't do that. So, she's got to go without". (Arabic, carer)*

A few participants commented that "parking" at the clinical sites that offer CM was another structural barrier to access, with disability parking providing access for some. Having CM services close to public transport was offered as one solution; so too was community transport. Neither, however, completely resolved the challenges of managing personal health constraints and travelling to access CM services:

*"Interpreter: he said if it can be near the station. I think a lot of transport, I think, is an issue, isn't it? Interviewee: "As soon we can walk, we can go." (Arabic)*

*"I'm picked up at 6:30 in the morning. My appointment might not be till 10:00 because their drop off there is 8:00 ... their last pick up is at a certain time ... And you're exhausted at the end of the day." (Anglo-European)*

Other personal barriers, such as "Just too many health appointments", "Reiki, just unable to find the time", and logistical issues related to the timing of CM, were also reported by participants:

*"I would have used more yoga but it wasn't available at a time that suited and local classes were too intense. I also couldn't find a suitable meditation class so only managed to do this on a breast cancer retreat and then privately."*  
(Anglo-European)

These accounts demonstrate that some cancer survivors experience a variety of practical difficulties that prevent them from accessing CM care.

## COST OF CARE

Out-of-pocket costs were a significant personal barrier to accessing CM or more CM. In the survey, 82% (n=69/84) selected finance as an important obstacle, from which half reported it was the only obstacle. When asked who they thought should pay for all or some of the cost, structural solutions were most common: 86% (n=92/107) indicated Medicare and 48% (n=52) indicated private health insurance, and only 23% (n=25) thought the patient should pay for these services.

A variety of reasons were given as to why cost was a barrier to CM. Participants described the costs of their standard cancer treatment as considerable, with CM therapies "seen as a luxury" non-necessity item in comparison.

*"They are very expensive as an ongoing treatment given all the out of pocket expenses associated with cancer surgery."* (Survey)

*"Complimentary therapies are seen as a luxury and often expensive especially when income capacity is reduced due to illness."* (Survey)

The limits of private health insurance (high premiums and minimal rebates for CM) posed an additional cost barrier to accessing CM. Participants complained about the rebate amount received and the limitations placed on the number of sessions they were allowed:

*"We pay \$4,000 for the health fund - we only get such items - only \$200 [in total rebates for CM services]. How can we afford [CM]?"* (Chinese)

Some patients reported that they had searched overseas to find a better price for their CM:

*"I went back to China to bring capsules here ... it's much cheaper there."*  
(Chinese)

Not all participants, however, considered CM to be a luxury item and this was a reason for funding CM through Medicare. CM therapies were described as "not just feel-good stuff" but, rather, were "an essential part of recovery".

*"I myself struggle to pay for them [e.g. massage for lymphoedema] and they aren't a luxury item they are a necessity to minimize damage and should be part of the Medicare rebate, they aren't part complementary therapies but at present they are classed that way."* (Survey)

Other participants saw Medicare as a just reward for a lifetime of work and taxes, maintaining that the government should pay for CM through an appeal to rising social inequality:

*"I reckon the government should pay for it. Why shouldn't they? I mean the rich get richer, the poor get poorer. I mean it's lucky for some people who've*

*got – like me, I've got my life and personal accident insurance, but who else would have that?* (Anglo-English)

In circumstances where health coverage was inadequate to cover total costs, personal constraints associated with engaging in current cancer treatment made it difficult to “shop around” for the most affordable services or to pursue other ways of paying for CM such as accessing acupuncture from a medical practitioner:

*“If your operation [is] tomorrow, you no got time to look for the doctor? I don't think so.”* (Anglo-English)

Participants also emphasised the importance of the continuity of CM services for their effectiveness and, owing to the long recovery time following cancer treatment, the importance of ongoing funding from Medicare and the need for specialised funding arrangements for CM for cancer patients.

## 4 SUMMARY OF FINDINGS

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Over a nine-month period in 2016, researchers at NICM and the Centre for Health Research at Western Sydney University undertook a national cross-sectional survey of 295 healthcare organisations providing specialised cancer services and a mixed methods qualitative study of cancer survivors to examine IO service provision, and identify barriers and facilitators to CM integration.

The response rate to the national oncology services survey was very high with 93% of the eligible organisations from both public and private sectors completing the survey. Overall, the sample was representative of cancer services across Australia. The majority were located in the most populous parts of Australia, were hospital based inpatient or outpatient services, and provided a range of services – cancer treatment, supportive care and palliative care – for patients of all ages.

Thirty-three adults took part in one of the four focus group interviews (Arabic, Vietnamese, Chinese and Anglo-European Australia) and 121 participants completed the online survey. All the cancer survivors had used conventional medical treatment for their cancer. Aside from the Arabic focus group and nine survey participants, they had all used CM at some stage during their cancer journey.

### 4.1 CANCER SERVICE UNMET NEEDS

Key unmet needs identified by the cancer service respondents were the provision of ongoing care following initial cancer treatment, rehabilitation, survivorship, wellness services and palliative care services. This included 9% of respondents who specifically listed IO as an important unmet need in their region. Emphasis was also given to the ongoing unmet needs of patients and peoples including; (i) those diagnosed with breast or prostate cancer, (ii) provision of culturally appropriate care for Aboriginal and Torres Strait Islander and CALD groups (iii) the economically disadvantaged (iv) paediatric and adolescent patients in rural and remote areas, and (v) the health and social needs of older adults.

### 4.2 INTEGRATIVE ONCOLOGY SERVICE PROVISION

IO service provision was reported by 71 (25%) organisations and was located in all but one state and territory. The number of services had doubled over the last six years, a further 12 services were planning to provide IO, and 15 used to provide such services. Provision of the IO service was represented by a wide range of massage/touch therapies, wellbeing services, and movement modalities. Less frequently provided were acupuncture and other traditional modalities. Biological-based CM therapies interventions, chiropractic and osteopathy were not provided at all. A few organisations provided IO delivered by a medical practitioner or pharmacist, mostly offering professional advice only. All services were provided on a limited basis. Mostly patients could self-refer. Funding of IO services varied according to the modalities offered and included a patient contribution for all modalities.

### 4.3 BARRIERS AND SOLUTIONS TO INTEGRATIVE ONCOLOGY

Respondents offered many reasons for not providing services including funding, low (perceived) patient demand, lack of staff interest, unsure how to set up services, and unsure about which CM services to provide. They identified

the provision of funding and addressing business models as solutions to overcome these barriers. They also identified inadequate evidence to support CM as a barrier, and building a stronger evidence base was presented as an important solution.

#### 4.4 COMPLEMENTARY MEDICINE POLICY

Recognising national requirements and institutional policies that influence how CM practitioner services are provided and CM products used was not well developed. Policy provision was frequently inconsistent or non-existent. Having no policy in place was more frequent for the organisations that did not provide CM services. Most organisations had a policy for documenting CM product use, the majority doing so in the patient's clinical record, the medication chart or the clinical history.

#### 4.5 ONCOLOGY MESSAGE ATTITUDES, AWARENESS AND BARRIERS

There was some awareness of evidence regarding potential benefits from OM. The majority thought that certified OM therapists were very likely to deliver a safe massage to cancer survivors. Participants indicated there are barriers to providing OM services, and the main barrier identified was a lack of funding.

#### 4.6 CANCER SURVIVOR VIEWS

The research team identified two core themes from the interview data "*positive perceptions and experiences*" and "*barriers and unmet needs*", and the latter had two interacting subthemes: "*structural barriers*" and "*personal barriers*".

Participants mostly discussed the potential for CM to improve cancer survival, reduce side effects and manage comorbidities. Participants perceived hospital-based CM services to have several benefits, including IO/CM practitioners having more knowledge than practitioners in private practice, the benefits of having IO/CM services close to the site of other cancer treatment, and lower costs compared to private services.

Structural barriers included lack of availability of IO/CM services, difficulties in referral pathways, medical practitioner attitudes, the logistics of accessing care, and the cost of care. Personal barriers for the individual and their family/carers were influenced by the severity of impairment and disability; attitudes, beliefs and knowledge about CM; and available personal resources (e.g. financial, time or transport).

## 5 DISCUSSION

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The primary purpose of this study was to guide the development of existing and new IO services, and to inform policy, research and education infrastructure that is required to underpin these offerings. The results from the mixed methods design that explored the perspectives of both providers and users affirmed the importance of providing IO services across Australia. The study identified substantial unmet needs for ongoing supportive cancer care and barriers to providing IO services. As was inequitable access, that was exacerbated by geographical location, ethnicity, awareness of available services and ability to pay.

The Australian Senate report on the inquiry into services and treatment options for persons with cancer recommended, among other things that:

*“... in the best interests of cancer patients in Australia, there needed to be an integrative approach based on the models in the UK, the USA and other international centres.”<sup>[38]</sup>*

It is dubious to what extent these recommendations have been heeded and whether adequate resources and support have been provided to those organisations seeking to progress IO. Consistent with previous research, cancer survivors including CALD groups that are often underrepresented in cancer research, identified a range of potential benefits from CM use and the continuing need for improved integration with their mainstream cancer services<sup>[36, 39-41]</sup>. Indeed, since this report there is evidence of an exponential ongoing growth in IO, albeit in a limited capacity by many cancer services. IO service provision, however, remains patchy and organisational policy under-developed and inconsistent, signalling the need for stronger leadership and guidance.

The cross-sectional survey of healthcare organisations was the largest and most comprehensive of its kind to have been conducted in Australia<sup>[15, 16]</sup>, identifying 295 healthcare organisations with a dedicated oncology service. Even though the provision of IO by these services appears to have doubled over the past six years; most of the 275 surveyed organisations (74.2%) were yet to provide IO services. Encouragingly, 12 organisations were in the process of planning to provide. For 71 organisations that did, most provided IO services in hospital inpatient or outpatient settings. Access was, however, limited by availability and affordability. IO services were mostly provided on a part-time basis for a limited number of hours per week. Home visits were rarely provided. Demand often outstripped supply.

Services provision was restricted at most sites to a limited range of non-biological-based IO services. The most commonly provided services were massage/touch therapies, including OM provided by certified therapists, wellbeing services (e.g. relaxation/meditation, art, music and play therapy), movement modalities (e.g. yoga and tai chi), and then acupuncture. Aside from much lower rates of nutritional counselling and acupuncture, the types of CM services most commonly provided generally aligned with international examples of IO services<sup>[42]</sup> and national research on the prevalence of different CM therapies used by cancer survivors.<sup>[4]</sup> For biological based IO/CM therapies, however, there was an obvious mismatch between the low levels of service provision that included information and expert advice compared to the much higher use of biological based CM therapies by cancer survivors.<sup>[4, 36, 43, 44]</sup>

For the most part, IO services were poorly integrated with the other cancer services, tending to operate on the fringe. The gap between the idealised vision of IO and real-world practice is not unique to the Australian setting. A 2012 systematic review of 29 IO programs from the UK, North America and Europe also found the integration process with the conventional cancers services was often limited and organisational policy under-developed.<sup>[42]</sup>

Providers reported that insufficient evidence of safety and efficacy, and a lack of support or interest from oncologists or senior management, were barriers to service provision. Aside from a few strongly expressed views, neither were reported as the most important barrier. Overwhelmingly, the challenges with funding IO services followed by the need for more guidance on how to establish these services were the greatest reported obstacles. Existing IO services relied heavily on funding from patients and philanthropy, including volunteer CM practitioners. Out-of-pocket cost was a significant personal barrier for many cancer survivors seeking supportive care to help manage side effects and comorbidities, for rehabilitation, and to improve quality of life.

Cancer survivors clearly signalled the need for more financial support, a finding that contrasts with the only other directly comparable study of Australian cancer survivors in which focus group participants considered self-funding was acceptable.<sup>[41]</sup> Nevertheless, in both instances cancer survivors were pragmatic, recognising that a reason for the under-funding of IO/CM by health services, private health insurance, and Medicare was that these interventions are considered to be non-essential services, a luxury item – a view that was reiterated by health service participants. Yet the experience of cancer survivors suggests otherwise. The views expressed by participants in this study closely align with other research<sup>[36, 41, 45, 46]</sup> and emphasise the importance of being able to access IO/CM services both during and after active treatment and ensuring it remains an integral part rehabilitation and long-term healthcare.

Other obstacles preventing cancer survivors from accessing services included poor personal health, having to travel to services, and obtaining reliable information about available IO/CM services. In keeping with other research, the advantages of both hospital and community-based services were identified to support patient needs throughout their cancer journey.<sup>[41]</sup> The difficulties with finding suitably qualified practitioners (including medical practitioners) with appropriate experience and training in IO cancer care further supports the actions of organisations, such as OML and the Royal Australian College of General Practitioners (RACGP) IM Specific Interest Group, that are committed to specialised education and training suitable for this setting.

The challenges of meeting Australian population needs and inequalities in access for supportive cancer care are not unique to IO, and to some extent reflect the challenges with providing ongoing cancer care more generally.<sup>[3, 46-48]</sup> Overall, national survey respondents identified the need for ongoing care following initial cancer treatment, for some providers that included the need for more IO services, as the most important unmet need in their region.

As survival rates and prevalence continue to increase, so too will the demand for supportive, long-term care following initial cancer treatment. The World Health Organisation (WHO) recognises the significant role of CM in sustainable health systems.<sup>[49]</sup> Greater adoption of an IO approach by Australian cancer

services can help deliver holistic patient-centred care whilst facilitating safer and more effective IO/CM use.

## 5.1 POTENTIAL BENEFITS OF AN IO APPROACH

Consistent with other Australian research,<sup>[4, 36, 41, 43, 50]</sup> the focus group and community survey participants were using CM to augment their cancer treatment, increase their chances of survival, enhance their immune system, manage side effects, and improve quality of life. Participants also emphasised the importance of CM for managing comorbidities and as part of their ongoing supportive care and rehabilitation. As participants progressed through their cancer journey, their concurrent use of CM services and therapies increased. Less than one-fifth of the survey participants had used CM before commencing standard cancer treatment. The rate increased to nearly half during active treatment and continued to increase to over three quarters after active treatment.

Rather than historically being viewed from a scientific perspective as ‘unproven methods of treatment’, the rationale for CM use is steadily building stronger foundations in evidence.<sup>[51]</sup> An integrative approach to CM may improve patient outcomes through several possible mechanisms. These include the potential of improving the effectiveness of conventional treatments through agonistic adjuvant effects, managing side effects, and improving compliance.<sup>[52]</sup> For inpatients, IO approach has been shown to substantially reduce pain and anxiety, with bodywork and Chinese medicine therapies being the most effective for reducing pain.<sup>[53]</sup> High-quality evidence supports the role of acupuncture in reducing acute chemotherapy-induced nausea and vomiting, hot flushes, aromatase inhibitor induced pain, dysfunction in head and neck cancer patients, and sleep disturbance.<sup>[54-58]</sup> The physical and psychosocial benefits of yoga and tai chi have been demonstrated in a growing number of studies<sup>[59, 60]</sup>. The beneficial effects of meditation can support the recovery process of cancer survivors by improving anxiety, stress, sleep, and the immune system<sup>[61-63]</sup>. Massage therapy is associated with substantive improvement in cancer survivors’ symptom scores, reducing physical discomfort and fatigue, and improving mood disturbances.<sup>[64, 65]</sup> Cancer survivors who use CM experience a substantial individual psychological advantage, and this is also considered a main motivation for its use.<sup>[66]</sup> While this evidence exists, guidelines for the use of CM in the IO setting are only beginning to emerge and only sparse amounts of the existing CM evidence appears to have been integrated into conventional cancer care guidelines.

Botanicals and supplements continue to be the most controversial due to concerns over safety, especially regarding interactions with pharmaceuticals and contraindications.<sup>[67]</sup> Interactions can occur either by affecting the pharmacokinetics of chemotherapeutic drugs, most commonly by altering cytochrome P450 (CYP) metabolizing enzymes, or by antagonising (blocking) their mechanisms of action. This barrier to CM product use, however, may be over-emphasised. In a systematic review of botanical and supplements and drug interaction risk in cancer patients, of the 806 patients surveyed, 433 (53.7%) were reported to be taking combinations of supplements and drugs and 167 (20.7%) incidents of risk were identified for 60 patients (13.9%). The interactions however, were mainly theoretical and not supported by clinical data.<sup>[67]</sup> Nonetheless, even a theoretical risk warrants concern and the need for further research to determine whether the risks do indeed outweigh

the benefits. For example, high quality evidence is emerging in the use of probiotics,<sup>[68]</sup> cannabis,<sup>[69]</sup> and ginseng for cancer-related fatigue.<sup>[70]</sup> Decision making in this context is complex and cancer survivors may benefit from an IO consultations that aim to build positive therapeutic alliances and guide the safe and effective use of CM products.<sup>[71]</sup>

## 5.2 INTEGRATIVE ONCOLOGY SERVICES

As an emerging field, mapping of IO services in Australia and internationally has likely been hampered by the lack of clear definitions and the ad hoc manner in which these services have been integrated into existing cancer services. Notwithstanding these limitations, the substantially lower service provision across Australia compared to other comparable countries begs the question: to what extent have cancer care services heeded, or received adequate support and resources to activate the Australian Senate's recommendations to learn from progressive international IO models?<sup>[38]</sup>

Although mainstream healthcare professionals express concern about inadequate evidence of efficacy and safety, many CM users are satisfied that these therapies are meeting their expectations with few, if any, adverse effects.<sup>[4, 36]</sup> Results from the focus group interviews and community survey suggested that an IO approach was needed to help address a range of unmet needs regarding CM information, referral pathways, and access to safe and affordable services.

### 5.2.1 Growth of IO services in Australia

Results from the health service survey demonstrate that the number of organisations providing IO services was substantially higher than an earlier estimate of 10-19% of Australian hospital oncology departments in 2014.<sup>[15]</sup> The observed higher number and percentage may, in part, reflect different sampling frames and definitions of IO service provision. The 2014 survey identified half the number of hospitals with an oncology department and no community-based organisations were included. Excluding community-based organisations from the 2016 survey, however, would only reduce the estimate from 71 (26%) to 60 (23%), which remains over twice the 2014 rate. Of the 19% of hospitals identified as incorporating some CM in the 2014 survey, only 10% met the 2016 survey definition (i.e. provided CM services on a regular basis by employed or contracted CM practitioners). The remaining 9% would have been classified as non-IO providers in the 2016 survey, as they provided ad hoc or occasional CM programs through external providers such as the Cancer Council. Coupled with the 12 (4%) organisations that were currently planning to provide IO, the 2016 survey estimates remain substantially higher, demonstrating significant and ongoing growth of Australian IO services.

A number of factors has influenced growth in Australia. There is increasing acceptability and supply of CM and IM more generally and a growing number of IM services, IM professional bodies and IM education pathways.<sup>[72]</sup> The Australian Senate has explicitly recommended the adoption of IO models for supportive cancer care.<sup>[38]</sup> National celebrities and dignitaries acting as IO champions are another important influence. This includes a highly respected head and neck cancer surgeon who inspired the establishment of a comprehensive cancer centre associated within a renowned teaching hospital. The growth of such services increases pressure on other healthcare organisations seeking to maintain a 'market edge' and also paves the way for other

organisations to follow suit with less fear of retribution from certain factions of the medical community.

### 5.2.2 International comparisons

Despite this growth, Australian IO service provision would seem to be a lot lower than many other comparable countries. In the UK, an outstanding 70% of cancer centres in 2001 provided at least one CM therapy,<sup>[12]</sup> whereas the current rate in Australia is 26%. In 2009, the estimated mean number of UK cancer centres with a dedicated IO unit ranged from 2.2 per one million population in England to 5.0 in Northern Ireland.<sup>[73]</sup> Based on 2016 estimates, Australian service provision was substantially lower at around 1.5 IO units per one million population (37 dedicated clinics or centre; total population in Australia 24.4M<sup>[74]</sup>). A more recent 2013 European mapping survey of oncology centres and hospitals identified 47 of the 99 responding cancer centres provided IO.<sup>[75]</sup> The high rate may be an over-estimate of service provision as a convenience sampling frame was used; nonetheless, the results demonstrate IO is commonplace in many European countries. Rates for the US, Canada and New Zealand are yet to be reported; however, most of the National Cancer Institute designated comprehensive cancer centres in the US are said to provide IO.<sup>[42, 71]</sup>

Along with fewer Australian healthcare organisations providing IO services, those services offered a limited amount and range of therapies, with massage/touch therapies and wellbeing services being the most common. Only a handful of services provided biological based CM therapies or traditional medicine services. Although this choice of therapies appears to be most closely aligned with the UK,<sup>[12, 73]</sup> the IO units in the UK generally offer a wider range of therapies.<sup>[73]</sup> In a 2010 systematic review of US, UK, Canadian and German IO services, similar to Australia, massage/touch and wellbeing services were commonly provided; however, so too were nutrition counselling and acupuncture.<sup>[42]</sup> In the 2013 European survey of IO services, acupuncture (55%) was most commonly provided followed by homeopathy (40%) and Western herbal medicine (38%), and then other holistic medical systems such as Chinese medicine (36%) and Anthroposophical medicine (founded by Rudolf Steiner in the early 1900's in Germany) (21%).<sup>[75]</sup> Although it is not possible to accurately compare rates for nutrition counselling, as the definitions used could be different, the rate of acupuncture service provision in Australia was considerably lower at 12% and only 3% offered naturopathy services. Other traditional medical services relevant to the Australian setting, such as Chinese medicine and the healing practices of Aboriginal and Torres Strait Islander peoples, were not offered at all. Again, in contrast with Europe and the US, the 2016 Australian survey found negligible provision of IO services from medical practitioners or pharmacists.<sup>[42, 71]</sup>

## 5.3 UNMET INTEGRATIVE ONCOLOGY NEEDS

An apparent mismatch between patient preferences and health behaviours accentuates the discrepancies between IO service provision in Australia and many other comparable countries. Along with a general under-supply of IO services across many areas of Australia, the choice of CM therapies was mostly restricted to non-biological-based CM therapies. Virtually no traditional medicine (including practices that cancer survivors identified as important when delivering culturally appropriate services), biological-based CM therapies nor IO consultations with a medical practitioner were provided.

Affordability, geographical location and transport, knowledge and awareness of available IO services, and medical practitioners' attitudes and doctor-patient communication further limited access. The challenges of meeting patient needs for IO services were reflected in a wider unmet need for ongoing cancer care services following initial treatment and supportive care more generally. Combined, the results of previous research along with the findings from this study demonstrate the need for further integration of safe, effective and appropriate CM services.

### 5.3.1 Biological based CM and traditional medicine

In line with previous research, the results from the community survey and interviews confirmed that many cancer survivors in Australia use biological based CM therapies and consult traditional medical practitioners both during and after active cancer treatment.<sup>[4, 36, 41]</sup> Yet, virtually none of the IO services provided access to these therapies, nor consultations with either a traditional medicine practitioner (e.g. naturopath, Chinese medicine, Ayurvedic, indigenous Australian healer) who commonly prescribe these interventions nor an IO physician or pharmacist with expert knowledge of the field.

In 2008, an estimated 65% of Australian cancer survivors had used at least one form of CM during or after their active cancer treatment.<sup>[4]</sup> Although the rates of CM use are expected to have risen, the high rate of CM use (91%) in this 2016 community survey cannot be generalised, as a convenience sample was used that over-sampled women with breast cancer and OM users. Nonetheless, the rates of biological-based CM use align with those from more representative samples of Australian cancer survivors. In both the 2008 survey<sup>[4]</sup> and the current 2016 community survey, a high proportion (85% and 68% respectively) of the cancer survivors that used CM used biological based CM therapies. Both studies confirm significant use before, during, and after active cancer treatment. Most commonly used in the 2008 survey were nutritional supplements, special diets and foods, and Chinese or Western herbal medicines. Around 43% accessed some, or all, of these therapies through a CM practitioner.<sup>[4]</sup> These results are also consistent with the current survey results where 45% of respondents had consulted a naturopath, nutritionist, Chinese medicine practitioner or indigenous Australian healer.

The national survey that identified inconsistent organisational policies on CM product use, including patient initiated CM product use and the documentation of CM products further highlighted the mismatch between patient behaviour and service. This issue was identified for IO providers and non-providers alike, highlighting the need for clearer national guidelines and consensus. For hospital-based organisations, there is a CATAG position statement on the use of CM products.<sup>[34]</sup> It was concerning that less than half of the respondents from these organisations were aware of CATAG, from which over 41% did not know if their policies aligned with the recommendations and 21% stated their policies did not align. The CATAG position statement on CM product use in hospitals emphasises the importance of providing written information for patients, encouraging two-way discussions with patients about perceived benefits and risks, providing evidence-based advice with a focus on minimising risk, monitoring the effects of continuation or discontinuation and documenting any discontinuation in the discharge summary.<sup>[34]</sup> CATAG notes that hospitals cannot legally stop patient initiated CM product use, nor enforce the removal of CM products. The national survey found that around 4-5% of organisations had a contradictory policy that did not permit patient initiated CM product use

and this rate appeared to be higher for IO providers. The reason why more of the non-IO providers had a policy that did not permit CM product use, including patient initiated use compared to non-providers was unclear. It may reflect the large proportions in both groups that either had no specific policy, or the respondent did not know if there was a policy. Another explanation might be many of the IO providers require clear policies to ensure the acupuncturists for example, do not provide an unendorsed traditional Chinese herbal medicine service.

The reasons for such a low level of service provision for biological based IO services and variations between organisational policies was not explored in detail. This pithy issue continues to confound and warrants further research. Conflicting medical paradigms, insufficient evidence, and concerns about potential interactions with concurrent cancer treatment are likely explanations. Also likely is the lack of knowledge and suitably skilled healthcare professionals to provide this advice in an oncology setting,<sup>[76-79]</sup> along with the finding that many healthcare professionals and managers are not aware of existing recommendations.

### 5.3.2 IO medical practitioner consultations

The survey identified the need for more proactive guidance from informed medical practitioners about appropriate CM use. By default, the majority of cancer survivors are managing their own integration, yet they consistently state they want to discuss CM options with their medical practitioners and receive referrals to CM practitioners.<sup>[4, 41]</sup> Consistently, surveys of oncologists identify a lack of knowledge and education as major barriers.<sup>[76, 79, 80]</sup> The qualitative results from cancer survivors confirmed ongoing frustration about not receiving timely, informed recommendations from their treating doctors about CM therapies, particularly biological based CM therapies. Over half of cancer survivors are known to use CM in conjunction with conventional therapy<sup>[5]</sup> and want to discuss use with their doctors.<sup>[80]</sup>

The low rates of CM use disclosure to healthcare professionals are well recognised. One of the most common reasons is the 'doctor never asked'.<sup>[80]</sup> Communication may be further challenged by a lack of concordance between cancer survivors' and their oncologists' expectations of CM efficacy. For example, Korean oncologists anticipated that CM was mostly helpful for managing subjective symptoms and improve psychosocial outcomes whereas cancer survivors also anticipated physical benefits such as improved survival, immunity, and strength.<sup>[81]</sup> Poor doctor-patient communication and didactic anti-CM attitudes may result in cancer survivors choosing to use more CM, CM with higher risks of interactions, and on occasions even decline conventional treatment.<sup>[82, 83]</sup> The COSA position statement on CM use and the COSA guidelines for discussing CM<sup>[23, 84]</sup> are important first steps to help address this ongoing problem.

It may, however, be unrealistic to expect that oncologists will have the time or interest to completely inform themselves with the ever changing and growing evidence base for CM.<sup>[85, 86]</sup> Engaging medical practitioners who specialise in IO is commonly used by cancer services in other countries to help address this significant unmet need. A recent analysis of over 2000 IO consultations in a comprehensive cancer centre in the US found the most common reasons why cancer survivors sought an IO consultation with a medical doctor was to pursue a holistic integrative approach (34%) and/or to obtain expert advice on CM product use (34%) and nutrition (21%)<sup>[87]</sup>. Despite the growing trend

for IO consultations internationally, professional oncology bodies and cancer services in Australia have done little to actively build capacity to enable similar IO services to be delivered. It is, therefore, not surprising that the results from the national survey found that IO consultations with a medical practitioner or pharmacist were rarely provided.

### 5.3.3 Non-biological based CM services

The types of non-biological based CM most commonly provided by Australian IO services were massage/touch therapies and wellbeing services, followed by movement modalities and then acupuncture. Supply generally aligned with known patient choices in Australia.<sup>[4]</sup>

Important unmet needs for non-biological based CM services reflected limited availability and a lack of continuity of care across the different health service settings. Cancer survivors stated there was a need for ongoing treatments if users were to experience the full therapeutic benefits. They also emphasised the importance of accessing care across a range of settings, from hospital inpatient and outpatient settings to less formal community-based settings and home care. Results from the survey estimated that the total number of non-biological based CM practitioners working in Australian cancer services was less than 500. This number, coupled with the low median number of practitioners and hours of availability per service, further supports the claims from cancer survivors of under-provision, and that even when these services are provided, demand exceeds supply.

A reason for cancer survivors wanting to access these services through a hospital or IO clinic reflected the difficulty in finding CM practitioners knowledgeable in cancer care. Appropriate training is important, as was highlighted by the providers who thought that a certified OM therapist was much more likely to deliver safe massage compared to other massage therapists. Nevertheless, a large proportion of massage and touch therapy was delivered by non-certified therapists, suggesting there is indeed an ongoing need for further post-graduate training to ensure that the delivery of massage/touch therapies are optimised for the cancer setting.<sup>[88]</sup>

Compared to equivalent international examples of IO services,<sup>[75]</sup> the low level of acupuncture services was particularly surprising, given its safety profile and the growing evidence of effectiveness and inclusion in clinical practice guidelines for cancer care.<sup>[86]</sup> Granted, compared to the other non-biological based CM therapies, aside from acupressure and laser acupuncture, other commonly used techniques (e.g. needling, electro-acupuncture, moxibustion and cupping) are the more invasive. Clinical governance, however, is relatively straight forward as there are Medicare item numbers for medical acupuncture services provided by a suitably qualified medical doctor and nonmedical acupuncturists are regulated by AHPRA. This further supports the proposition that service provision of IO is driven by more than a desire to provide safe and effective services.

### 5.3.4 Under-served groups and inequalities in access

#### CALD GROUPS

This was the first study to explore the views of Australians with CALD backgrounds regarding their needs for IO cancer services. Other research has focused on health outcomes and cancer care needs more generally. However, in a series of focus groups with cancer survivors of Greek, Cantonese, or Mandarin speaking backgrounds, although questions about traditional

medicine were not asked, participants still talked about their unmet IO needs. Including difficulties with finding a traditional Chinese doctor in Sydney and reliable expert information to help them manage their cancer and side effects.<sup>[89]</sup> The only option was to return to China. The integration of Chinese medicine is widespread in Chinese cancer centres, enabling the building of clinical expertise and integration with Western medicine.<sup>[90]</sup> It should not be surprising that new immigrants would be aware of the types of IO services and expertise available in China.

In contrast, there appeared to be a lower awareness of CM and IO in the Arabic community that was sampled through the focus group. The reason is not clear. The observation might be a sampling artefact, as only 11 like-minded people in one focus group were asked. Prayer and spiritual practices are the most commonly used non-biological based CM therapies both in Australia and abroad,<sup>[4, 5, 36]</sup> and not asking about the use of prayer or other spiritual practices may partly explain the finding. Aside from prayer and spiritual healing, other CM use may be relatively uncommon.<sup>[91, 92]</sup> There is evidence, however, that traditional Islamic and Arabic plants are used for cancer care and general health.<sup>[93]</sup> Conversely, there is also evidence suggesting that many Arabic-Australians have uncritically embraced the Western medical model with community leaders expressing concerns about an over reliance on multiple prescription medications.<sup>[94]</sup> Although the interviewers specifically inquired about other traditional healing practices, there may still have been communication or cultural barriers.

The health behaviours, preferences and unmet cancer care needs of CALD groups and the role of IO warrants further in-depth attention. Recent evidence suggests that survival rates for many CALD cancer survivors are lower than Anglo-Australian, possibly due to delayed diagnosis.<sup>[95]</sup> English ability and knowledge of the health system are important contributors and have been found to be the strongest predictors of poor psychological and quality-of-life cancer outcomes.<sup>[96]</sup> After controlling for demographic and disease, CALD cancer survivors from any ethnic background had up to four time higher risks of depression and anxiety compared with their Australian-born Anglo counterparts;<sup>[96]</sup> they also experience higher unmet needs for information and help with a physical problem that persist several years after initial diagnosis.<sup>[95]</sup> There is good evidence that a range of CM interventions can improve mental health and wellbeing,<sup>[86]</sup> suggesting a potentially important role for IO in providing culturally appropriate, effective services.

## ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLES

The views and needs of cancer survivors who identify as Aboriginal and Torres Strait Islander were not assessed. The National Aboriginal and Torres Strait Islander Health Plan 2013-2023, acknowledges the traditional and contemporary healing practices of Aboriginal and Torres Strait Islander communities (bush medicine) and recommends that health services explore its role in providing holistic, culturally appropriate services. The use and potential value of the traditional and contemporary healing practices of Aboriginal and Torres Strait Islander communities (Bush Medicine) is under recognised, particularly in the cancer setting. Only one survey has been undertaken in Australia and was limited to 248 people in Queensland from which 19% of cancer survivors were using at least one CM therapy, 3% used bush medicine, and 3% consulted a

traditional healer.<sup>[44]</sup> Although these rates were lower than the national average, there was no comparison group to adjust for known confounders of CM use such as education, income, age and gender.

## REGIONAL AND REMOTE AUSTRALIA

It was not surprising that the cancer service survey identified significant unmet service needs in regional and remote Australia. The poorer health outcomes of cancer survivors living in regional and remote Australia and under-provision of cancer services are well documented.<sup>[97, 98]</sup> Survival rates are substantially lower, particularly for patients with cancers requiring tertiary care for better outcomes.<sup>[47]</sup> The establishment of the regional cancer centre (RCC) initiative in 2010 has focused on expanding chemotherapy and radiotherapy services into regional Australia and developing other models of care such as shared care with GPs, telehealth services, and cancer care coordinators.<sup>[47, 99]</sup> Despite these initiatives, the challenges with ensuring adequate service provision remain.

The under-provision of cancer services in regional and remote Australia was potentially even greater for IO service provision. Demand by cancer survivors may be equivalent, or even higher than their metropolitan counterparts. Some research suggests higher use of CM by the general population and greater provision of CM services in regional Australia.<sup>[100]</sup> However, a 2013 survey that investigated concurrent CM use during radiotherapy treatment found no significant difference between regional (45%) and metropolitan patients (47%).<sup>[36]</sup> The substantial concurrent use of CM with conventional cancer treatment confirmed by another survey in regional Queensland<sup>[43]</sup> Neither study, however, investigated the demand for CM services and consultations with CM practitioners. Consistently, the use of massage and wellbeing services was high. Regarding CM product use, it is unclear to what extent cancer survivors were self-prescribing, consulting CM practitioners or obtaining recommendations from pharmacists and medical practitioners.

### 5.3.5 Supportive and survivorship care

The challenges with providing IO services were reflected more generally in the challenges with providing ongoing care following initial cancer treatment. This was the most important unmet regional need that IO and non-IO providers alike identified. Respondents most often identified rehabilitation, survivorship and wellness services; psychosocial support services; and palliative care services, either as an inpatient or at home.

The ongoing unmet needs for supportive cancer care along with challenges, such as funding, are well documented in Australian and international health services research.<sup>[3, 46, 101]</sup> Qualitative comments from both providers and cancer survivors acknowledge the precedence that immediate cancer treatment has over ongoing care. Yet for many, the psychosocial impact and clinically significant distress from cancer and its treatment makes supportive services such as IO/CM more than just an add-on luxury service, they are essential for living well with cancer.

Survival rates will continue to increase, placing further demands on already stretched cancer services and threatening the sustainability of the current specialist-based care model.<sup>[46]</sup> The potential to reduce unmet needs through the co-ordinated delivery of multidisciplinary services signals the need for

more effectiveness research that evaluates models for supportive care.<sup>[3]</sup> Alternative models for providing ongoing care are urgently needed.<sup>[46]</sup> The role of IO warrants further exploration in this context. Cancer survivors use specialist-based follow-up care to monitor ongoing treatment, detect cancer recurrence, manage side effects of cancer treatment, facilitate rehabilitation, and support psychological wellbeing. Aside from the first two reasons for follow-up care, CM practitioners are well placed to meet cancer survivors' needs for supportive care. High patient demand for CM despite high out-of-pocket costs provides pragmatic evidence of its value. The holistic emphasis of the IO approach offers the potential to simultaneously address multiple issues and symptoms clusters. There is also the potential for IO services to provide cost effective supportive care through reductions in pharmaceutical use and the need for ongoing specialist-based care to manage multiple side effects and the sequelae of cancer.<sup>[102]</sup>

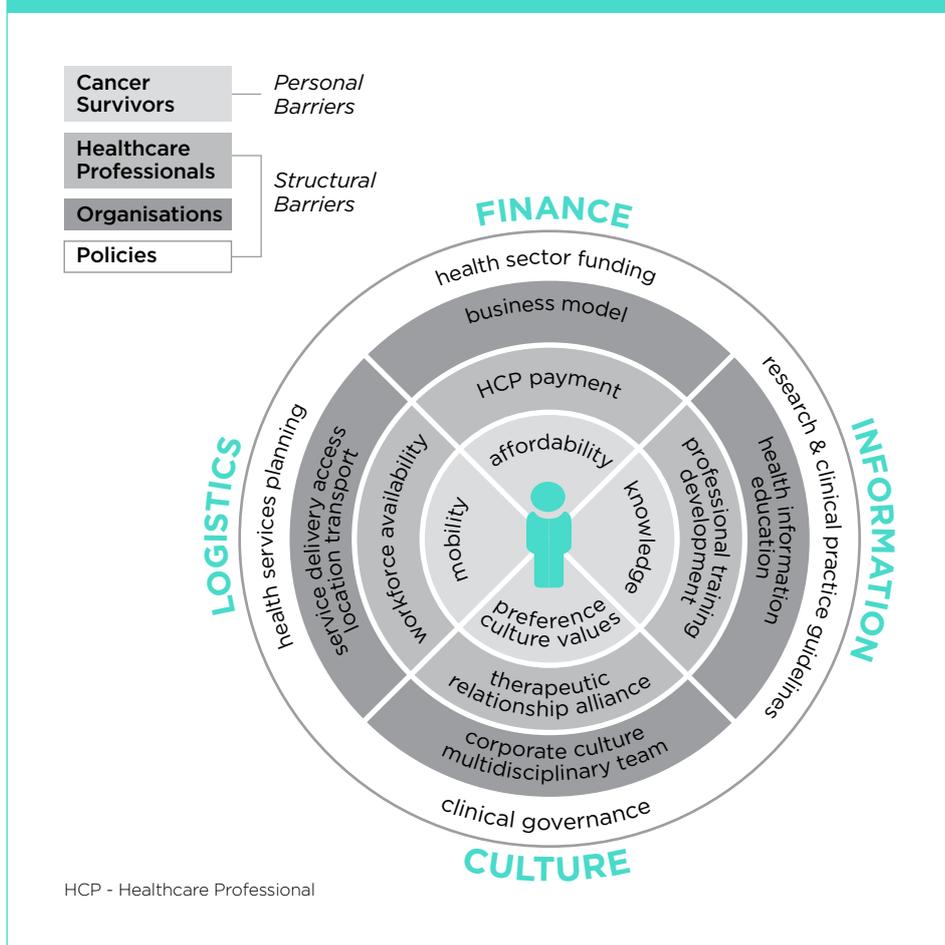
## 5.4 BARRIERS AND SOLUTIONS TO IO SERVICE DEVELOPMENT

Participants identified a wide range of complex interrelated barriers to IO service provision and access. The thematic analysis of the interviews and community survey identified two interrelated themes – ‘personal barriers’ and ‘structural barriers’. The quantitative and qualitative results from the national survey provided further insights, particularly regarding the structural barriers. A 2012 systematic review of IO programs determined the provision of IO services is influenced by a variety of factors such as evidence for safety and effectiveness, clinical experience, funding models, patient demand, and availability of practitioners. Organisational culture and logistical constraints of incorporating IO/CM were other important factors<sup>[42]</sup>. Specific to the Australian context, Grant et al. have published practical guidance for establishing an IO service that covers a broad range of topics – philosophy, structure, processes and evaluation.<sup>[103]</sup>

Using the principles of triangulation,<sup>[104]</sup> a patient-centred model is proposed that illustrates how the various barriers are interrelated (Figure 5.1). Evidence of convergence (agreement), complementary (additional) information, and dissonance (contradictions, discrepancies or disagreements) on the same theme were sought. Three levels of structural barriers – healthcare professionals, organisations and policies – are layered around the cancer survivor and their personal barriers. Four categories or subthemes were identified as applying to each level – finance, logistics, culture and information. The theme ‘personal barriers’ for example, utilisation of IO/CM services reflected the individual’s health and disability; their mobility and available social support; available economic resources; their knowledge and access to information about IO/CM; and their health beliefs, treatment preferences, culture and values.

Although the model draws directly on the research results pertaining to IO/CM, it has broader applications for understanding and improving healthcare delivery from the perspective of patients and providers. For example, a 2015 commissioned report by the Canadian Government proposes a similar conceptual framework that was developed by the Canadian Academy of Health Sciences to help transform their healthcare system and better address population health needs.<sup>[105, 106]</sup> Both models reflect the commonly used sociological levels of macro, meso and micro groupings when referring to those

**FIGURE 5.1 Patient-centred model of barriers and solutions to IO**



levels beyond the individual level. Figure 5.1, however, more clearly articulates the individual level (i.e. the cancer survivor) and proposes four categories (finance, logistics, culture and information) that apply across all the levels.

### 5.4.1 Finance

The strongest convergence (agreement) across all the data was the substantial financial barriers. The survey identified significant challenges with the funding and affordability of IO services at every level. In keeping with other Australian research,<sup>[41]</sup> out-of-pocket cost was a personal barrier for many non-CM users and users alike. For some, it was a motivator to purchase cheaper unregulated products from overseas. IO services often relied on volunteer CM practitioners or philanthropy to help fund their programs. Providers signalled the need for more guidance on business models, solutions for funding IO services and evidence that demonstrates value for money.

Views about how IO/CM should be funded were very contentious. Some participants stated it was the responsibility of the patient. Others thought the public health sector was responsible and should aim to reduce social inequalities. The need for higher rebates from private health insurers was also

signalled by both patients and providers. Although the sampling methods used to recruit cancer survivors limit the generalisability of the findings, the overall impression from the interviews was the need for more public funding. In contrast, results from another focus group with 18 cancer survivors in South Australia found the opposite.<sup>[41]</sup>

Comments from non-IO providers included the need for more evidence about potential benefits and demand to support a business case. Healthcare resource allocation reflects population need, the political and organisational context, and the moral principles underpinning the aims of the health service. For example, utilitarian principles aim to maximise the overall health of a society, whereas egalitarian principles seek to minimise inequalities between groups.<sup>[107]</sup> A systematic review of explicit decision criteria used in 'real-world' healthcare priority settings found that program effectiveness, budgetary impact/affordability, equity, number of beneficiaries, ability to access the program, cost-effectiveness/economic evidence, and the quality of the available evidence were the most commonly used criteria.<sup>[108]</sup> Pragmatic constraints, along with the political and organisational realities of the decision makers, were found to be balanced against the evidence for potential benefit and ethical considerations such as fairness and equity.<sup>[108]</sup>

In a systematic review of economic analyses of IO, the expert panel questioned whether integrating CM can be expected to lower healthcare costs.<sup>[109]</sup> CM is generally used as an add-on, rather than a substitute for conventional cancer treatment. The extra cost may be warranted, if for example, there is evidence that the CM intervention improves adherence to the treatment schedule. In this instance, there may also be additional costs for providing conventional cancer care. A comprehensive long-term assessment of the direct and indirect costs, and the specific and non-specific outcomes, should be undertaken. If an appropriate conventional treatment (either pharmacological or allied health) is not available, the panel recommended an incremental cost-effectiveness analysis.<sup>[109]</sup>

To some extent, the financial barriers preventing cancer survivors from accessing IO/CM are reflected more broadly in the funding policies for allied health in Australia. The untapped potential of allied health to deliver effective, efficient healthcare remains.<sup>[110]</sup> A reason for the under-funding of IO by health services, private health insurance, and Medicare that was suggested by both patients and providers was that CM interventions are considered a non-essential service, a luxury item. Yet, the experience of cancer survivors suggested otherwise; they emphasised the importance of accessing IO services during active treatment and the need for it to remain an integral part of their rehabilitation and long-term healthcare.

#### **5.4.2 Information**

Accessing reliable information and poor communication about the potential benefits and risks of IO/CM and the availability of high-quality services were important barriers that cancer survivors identified. Others were a lack of know-how about how to establish IO services and a paucity of evidence to support such services. Over half the respondents from the cancer service survey identified an absence, or were unaware of existing organisational IO/CM policies; were unaware of relevant national recommendations; or were unaware of OM evidence; thus, signalling the presence of various information barriers.

The high use of CM by cancer survivors in Australia<sup>[4]</sup> highlights the importance of ensuring access to reliable information and developing strategies to improve health literacy. A disparity was identified between what participants wanted, and where and how they ended up receiving information. Only 61% and 34% of the IO and non-IO cancer services respectively had a policy on CM information for patients. Participating cancer survivors claimed that often it was up to the patient to seek out information about IO/CM. In line with other research, participants were self-prescribing or obtaining information from lay sources such as friends and family. Whilst cancer survivors often appreciate this autonomy in decision-making,<sup>[41]</sup> results from both the interviews and community survey concur with other research to affirm that cancer survivors want to receive more information about therapeutic options and available services from their healthcare professionals and cancer services.<sup>[80]</sup> They also want their healthcare professionals to be informed about their CM use.

Qualitative comments from the national survey suggested that at least some cancer services proactively collect information from their patients about CM use. Indeed, most of the Australian organisations, IO providers and non-providers alike, had a policy for documenting CM product use in the clinical records. However, where this information was documented varied, only 32% documented all CM product use, including patient initiated CM, on the medication chart. Evidence of impaired information exchange between CM practitioners and other healthcare professionals was another finding. Less than half of the IO services invited CM practitioners to their multidisciplinary team meetings or case conferences and only 59% integrated the clinical notes of CM practitioners with the patient's official clinical records. Separating information about CM use from other medical information may increase the risk of adverse interactions and further impede doctor-patient communication, as there will be fewer prompts in the medical records to initiate a conversation about CM use and assess clinical response.

Oncologists commonly state their capacity to discuss CM use with their patients is limited by inadequate information.<sup>[76, 79]</sup> Cancer survivors seem to be aware of this knowledge gap. In keeping with other research,<sup>[41]</sup> the participating cancer survivors also thought that many of their healthcare professionals had insufficient knowledge to advise them on CM. Guidelines and position statements on discussing CM with patients may help build the therapeutic alliance and information exchange between relevant parties.<sup>[23, 84]</sup> Without further education and evidence-based clinical practice guidelines, however, healthcare professionals will be unable to engage in the informed discussions at the level that many of their patients are seeking.<sup>[80]</sup> Like their international counterparts, Australian oncologists would also like to receive more CM information and education.<sup>[11]</sup> Improved translation of existing information on the use, safety and effectiveness of CM therapies is therefore needed for lay persons and professionals alike.

### 5.4.3 Culture

The term 'culture' is used in this context to refer to the shared knowledge, belief, behaviour, attitudes, values, and practices of a group of people be they racial, religious, social, professional, or organisational. The most obvious examples of cultural barriers arising from the research came from the CALD focus group interviews. For some of these participants, the use of CM

reflected cultural norms and pride in their traditional knowledge. Respecting cultural diversity and providing culturally appropriate services required cancer healthcare professionals to change their mindset and provide IO services that more closely align with the traditional healing practices of the CALD groups they serve.

Less obvious cultural barriers that were identified included different conceptions of evidence and knowledge, patient-doctor communication, the marginalisation of CM practitioners, and the corporate culture and clinical governance of the health service.

Nondisclosure of CM use by cancer survivors continues to be a concerning issue with patient-doctor communication.<sup>[80, 82]</sup> Healthcare goals such as providing patient-centred care, shared decision-making, and building a therapeutic alliance are in stark contrast to what is often happening at the bedside. Importantly, a didactic anti-CM approach may even increase the likelihood that cancer survivors will decide to use CM as an alternative rather than an adjuvant to conventional cancer treatment.<sup>[82]</sup> In response, COSA has developed a guideline aimed at improving the quality of communication<sup>[84]</sup>.

Cancer survivors in the focus group interviews were aware of the philosophical differences between patients and doctors, stating that the negative or ambivalent attitudes of medical practitioners towards IO/CM was a function of their professional duty to only recommend scientifically proven interventions. Not surprisingly, conflicts of opinion were described regarding perceived benefits and risks that are reflected by critiques of the IO approach that argue the epistemological differences and lack of scientific evidence are significant barriers to integration.<sup>[112]</sup> Indeed, the potential direct and indirect risks of CM are a concern for many conventional healthcare professionals.<sup>[83]</sup> Direct risks include adverse effects from the intervention or interactions with cancer treatment. Indirect risks arise from the cultural differences, such as different medical paradigms and philosophical values that threaten to undermine the therapeutic relationship, and may even result in cancer survivors delaying or declining to use conventional treatment.<sup>[83]</sup> Having said this, the acceptance of CM by Australian oncologists appears to be increasing and the concern about risk is decreasing.<sup>[11, 113]</sup>

Given the high use of CM by cancer survivors in Australia and evidence of widespread unmet need, it was surprising that one-third of respondents in the national survey reported low patient demand was an important reason why their organisation did not provide IO services. This perceived low patient demand may, in part, reflect a broader ignorance and disinterest in providing services that oncologists or management consider to be non-essential or ineffective. Unfortunately, the perspectives of patients/users (and their representative organisations) are often belittled during the Australian health policy-making processes.<sup>[14]</sup> There is a preference for disease-related evidence, such as clinical outcomes and cost-effectiveness to take precedence over the personal lived experience of illness. Despite its high use and demand, IO/CM is no exception. A power imbalance appears to prevail where 'patients' are perceived as vulnerable and lacking competence; thus, any contrasting conceptions of evidence are downgraded during the decision-making process.<sup>[14]</sup> In response, terms such as preference-based medicine are increasingly being used to describe the optimal practice of evidence-based medicine.<sup>[15]</sup>

As the healthcare culture shifts from volume-based to patient-centric care, multidisciplinary teams have become a core component of cancer care and have been shown to improve clinical outcomes (including survival) for cancer patients and health service process outcomes.<sup>[116]</sup> The tendency for medical dominance within multidisciplinary teams is recognised in Australia and internationally,<sup>[117, 118]</sup> including IM teams.<sup>[24]</sup> The power imbalance experienced by CM practitioners is likened to that of nursing and allied health professionals.<sup>[119]</sup> Evidence pointing towards medical dominance in Australian IO services included not inviting CM practitioners to multidisciplinary team meetings and case conferences, not integrating the CM clinical records with the patient's clinical records, and inconsistent policies around patient-initiated CM and the documentation of CM product use.

Complex interactions, therefore, exist between cancer survivors and their various healthcare professionals that reflect established networks of power and leadership, which in turn, shapes policy, health service delivery, and its clinical governance. The challenges of changing corporate culture with well-established healthcare systems are well recognised.<sup>[120]</sup> More recently, it has been proposed that IO should be viewed as a 'merger' of different fields (cultures) of medicine. By identifying and understanding the professional and corporate cultures of the different healthcare providers, merger theories and strategies can be used to evaluate and facilitate successful integration.<sup>[121]</sup>

#### 5.4.4 Logistics

Logistical barriers and preferences for where IO services should be located were strongly influenced by individual circumstances of the cancer survivor. Current health status (in particular energy and mobility), social support, access to transport, distance to travel, and finding available time when undergoing active cancer treatment were all important personal barriers, some of which would change over time. Few IO services offered home visits for those too unwell to travel. Creating an ambiance conducive to healing, and was de-medicalised, was another consideration that prompted some cancer survivors to prefer community-based IO services. In keeping with other research, cancer survivors, therefore, held various views as to the co-location of IO alongside other outpatient cancer therapy services versus locating these services closer to home.<sup>[41]</sup>

The most obvious logical barrier facing many Australian cancer survivors, however, was the overall paucity of IO services in general, of which most were in major cities. Inequitable service provision for cancer survivors living in regional and remote Australia was further amplified.<sup>[99]</sup> The comment from one service provider in a regional area, who stated that it was difficult to recruit CM practitioners willing to work in an IO setting, was particularly interesting given the high ratio of CM practitioners to GPs in many rural regions of Australia.<sup>[100]</sup> Perhaps the higher use/availability of CM services in rural Australia compared to those living in urban areas<sup>[122]</sup> has created market forces that make working in a hospital setting less attractive for a variety of financial and cultural reasons discussed previously.

The additional logistical challenges and burden of accessing cancer care services when the health infrastructure is inadequate and access to healthcare providers is limited, cannot be under-estimated. The cancer journey requires survivors to navigate complex systems across primary and secondary services,

within both the public and private sectors. There is a need for improved vertical and horizontal integration and communication across the many health services that cancer survivors utilise at different stages of their journey. Although cancer survivors were happy to self-refer, the need for better communication and coordination between their healthcare providers was identified. Case studies of existing Australian IO services that are provided in a range of settings would provide greater insights and potential solutions to these logistical challenges.

## 5.5 STRENGTHS AND LIMITATIONS

The use of mixed methods, including surveys and focus groups, provided rich and robust data representing both providers and users of cancer healthcare services to address the study aims and objectives.

The national survey attained a very high response rate, thereby minimising the opportunity of non-response bias and increasing the generalisability of the findings. Methodological work and allowing sufficient time ensured the survey reached the person within the organisation best placed to complete the survey. The high response rate also indicates that, although the survey was long, this was an acceptable and efficient method for survey respondents to participate in the study. Managers/administrators and healthcare professionals with a nursing background were well represented in the survey. The views of specialist oncologists and CM practitioners, however, were under-represented and may have revealed other important information about barriers and facilitators of IO services. Although the acceptance of CM by Australian oncologists appears to be increasing,<sup>[111, 113]</sup> more information is needed about their views on providing IO services. Despite these limitations, compared to other Australian surveys the results have good internal and external validity due to the high response rate and coverage of the targeted sample of healthcare organisations providing specialised cancer services.

Although the national health service questionnaire was piloted, two questions were subsequently identified as unclear. Some respondents may have misinterpreted the question asking about important unmet needs in their region as some answers clearly referred to the organisation rather than regional needs. Other respondents commented they didn't understand the question. It was also possible that the respondent's perception of unmet need may have been influenced by the type of organisation in which they worked. The question about whether the organisation provided IO services may also have caused some confusion, as there was some crossover with what was considered a non-IO service. For some respondents, CM services that were provided within existing conventional allied health services (with no additional CM practitioners) were considered non-IO, whereas others thought this was an example of IO. For example, physiotherapy was often associated with movement modalities. There were also instances where therapies, such as mental wellbeing therapies (e.g. meditation and relaxation), were provided as part of psychology / psycho-oncology services. In addition, there were many occasions where volunteers provided a CM service to cancer patients (e.g. hand/foot massage), yet were not considered CM practitioners. This issue was proactively identified from reviewing all survey answers during data collection period. Participants were contacted to clarify their answers and had the opportunity to change their answers if indicated before the survey was closed. If no comment was made however, then such scenarios (either

alone or in combination) may have resulted in a slight under-estimation of IO service provision.

The qualitative methods used for the focus group interview enabled the research team to engage with, and explore the views of, CALD groups that are typically under-represented in Australian surveys of cancer survivors. It was important to provide a voice for the CALD communities utilising cancer services in the SWSLHD, and this was achieved with varying levels of success through representation from the Chinese, Vietnamese and Arabic communities. The focus groups successfully provided an acceptable method to capture the views of individuals who may have had lower levels of English literacy. Utilising a community translator enabled further engagement with the CALD groups. A larger number of focus groups with broader representation, including Aboriginal and Torres Strait Islander peoples (who are a significant population group in SWSLHD), residents from regional areas, and sub-groups of CM users and non-users, would further elucidate which barriers and unmet needs are common across all groups and those unique to specific community groups.

For various reasons, the number of Australian Anglo-Europeans was lower than planned. The community online survey of cancer survivors was introduced to embellish the qualitative results from the focus group interviews. It was anticipated that a survey written in English using the investigators' networks would reach Anglo-European Australians. As is the case for qualitative research methods, recruitment was not designed to be statistically representative of any population, instead, the purpose was to compare and contrast the different perspectives of participants. Adding the survey helped improve the overall diversity and representativeness of the combined characteristics of Australian cancer survivors who took part in either the community survey and focus groups.

The quantitative community survey results were presented in a mixed methods format to provide greater context to the qualitative results. Consequently, the quantitative data should be interpreted with caution. Statistics about participants' characteristics, the use of CM, and estimated unmet needs should not be extrapolated. The sample from the community survey was skewed to women who had a diagnosis of breast cancer and users of OM. This reflected the social media networks used to recruit participants to the community survey. As such, the survey sampled a significantly higher percentage of CM users than what is thought to be the rate in Australia<sup>[4]</sup>. However, even the CM users experienced substantial barriers to engagement with CM services. Furthermore, Australian cancers survivors with a diagnosis of breast cancer have been found to have the lowest levels of unmet supportive care needs<sup>[2]</sup>. Therefore, if anything, the survey was likely to have under-estimated rather than over-estimated unmet needs.

The under-representation of non-CM users overall (and conversely for Arabic-Australian CM users) highlights the importance of using different methodological approaches and recruitment strategies. The over-sampling of CM users in the community survey was, however, balanced by the inclusion of a much higher proportion of non-CM users in the focus groups. Nevertheless, more accounts about demands and barriers from non-CM users and Arabic-Australian CM users are needed to inform community and hospital service delivery and planning.

Finally, research bias is possible in the interpretation of qualitative data from cancer survivors. To minimise such risks, the qualitative research team undertaking the analysis was comprised of members with and without a background in IO/CM.

# 6 CONCLUSION AND RECOMMENDATIONS

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## 6.1 CONCLUSIONS

Organisations across Australia are increasingly providing IO services. Fragmented development, however, has resulted in significant unmet needs for some patients, inequalities in access, and discrepancies between what cancer survivors are doing or seeking and the IO services they are accessing through their local cancer services. Similar to allied health and supportive cancer care services in general, challenges with funding CM services and high out-of-pocket costs for patients were important barriers that exacerbated inequitable access, particularly for Australians in lower socioeconomic groups, including some CALD groups and Aboriginal and Torres Strait Islander peoples, and those living in many regional and remote areas. Healthcare organisations signalled a need for more guidance on clinical governance and business models. Building the evidence of CM and developing clinical guidelines may help. The findings from this study demonstrate, however, that the solutions are more complex than simply providing evidence-based IO services. The challenges with providing adjuvant services, such as IO, were reflected in the unmet needs across Australia for supportive cancer care services more generally and the increasing need for ongoing care following initial cancer treatment. Survivorship and wellness clinics are in urgent need of development. Strategic planning and policy guidance is urgently needed to help address these issues.

## 6.2 RECOMMENDATIONS FOR FURTHER RESEARCH

**6.2.1 NICM to undertake ongoing evaluation of IO service development in Australia** through partnerships with key local, state and national service providers, commissioners, and professional bodies.

Recommendations include:

- i. A survey of recipients of this report 12 months after publication to assess impact and usefulness, and to inform
- ii. Repeat the national survey in five years to assess progress in the scope of IO service provision in Australia, and explore barriers and facilitators to CM integration.

**6.2.2 Continue to build on the findings from this project that explore the views of under-represented cancer survivors**, particularly those with the highest risks of inequalities in health.

Recommendations include:

- i. participatory research designs and engagement with stakeholders during the planning of future research.
- ii. including Aboriginal and Torres Strait Islander peoples, low socio-economic status, and geographically remote communities as partners when undertaking further research.

**6.2.3 Undertake health services research that evaluates exemplar IO services in Australia to further inform IO service development** – corporate governance, clinical governance, funding structures, sustainable business models and clinical/economic outcomes. The perspectives of health commissioners, oncologists, and service providers should be part of this process.

#### **6.2.4 Undertake a comparative analysis of existing non-integrative and integrative oncology cancer supportive services.**

Recommendations include:

- i. Clarifying to what extent IO services are cost-effective and “*an essential part of recovery*” or whether CM is merely a luxury item and “*just feel-good stuff*”.
- ii. Develop appropriate methodologies to evaluate the patient outcomes and cost effectiveness of holistic IO provision and single intervention CM provision.

#### **6.2.5 Continue to build a stronger evidence-base for IO efficacy and safety at all stages of the cancer journey to inform clinical practice, guideline development, and policy.**

Recommendations include:

- i. The IO services identified in the survey consider collecting shared longitudinal data on patient reported outcomes for some or all of the CM therapies offered.
- ii. Studies relating to the safety of CM when used alongside conventional cancer treatment e.g. an active surveillance program similar to SONAR in Canada <sup>[123-125]</sup>.

### **6.3 RECOMMENDATIONS FOR SERVICE DEVELOPMENT**

**6.3.1 Design and provide high-quality, comprehensive cancer services with IO in mind.** Cancer service providers and commissioners should engage patient groups, professional bodies representing CM and IM practitioners, and institutions like NICM in both the planning and delivery of cancer services.

NICM could assist with the following:

- i. Further in-depth analysis of the national survey dataset to examine the characteristic of sustainable models of service delivery.
- ii. Qualitative and quantitative studies of nursing and other health professionals to identify facilitators and barriers and improve research translation.
- iii. Identify national health surveys of cancer patients where questions on CM use and demand may be included.
- iv. Examine how new models of care involving private health insurers and medical home fit in with other new innovative models, and the possibility of ongoing care.
- v. Investigate opportunities to disseminate the existing evidence base of IO to healthcare professionals, patients, carers, and the community.
- vi. Pilot translation clinics of non-biological based CM interventions for patients undergoing active treatment at cancer treatment centres.

**6.3.2 Identify and implement innovative funding mechanisms and strategies for organisational change management** aimed at improving equitable access for all patient groups seeking to benefit from IO.

Recommendations include:

- i. Explore options for sustainable funding streams for integrative and supportive therapies to be part of mainstream care.
- ii. Identify post-treatment programs in need of support from private healthcare funds and state organisations such as the PHNs and LHDs and the Commonwealth MBS.
- iii. Undertake corporate culture assessments to facilitate change management when merging/integrating different medical paradigms.

**6.3.3 For cancer services where it is not possible or appropriate to provide IO, ensure that all CM use is documented, CM information is available, and communication with treating CM practitioners is supported.**

Recommendations include:

- i. Training and education of conventional healthcare providers to support the appropriate use of CM, current evidence and safety, and improve translation of the CATAG position statement on CM use in hospitals, the COSA guidelines for discussing CM use, and the COSA position statement on the use of CM.
- ii. Establish direct referral pathways to appropriately trained CM practitioners.
- iii. Greater engagement with patient groups interest in IO/CM.

**6.3.4 Establish IO training, education, and orientation of CM practitioners** to support the safe and effective treatment when working with cancer survivors.

Recommendations include:

- i. Development of curricula for IO summarising the evidence base that is safe and effective.
- ii. Establish healthcare professional communication and referral channels with cancer healthcare providers and organisations.
- iii. Communicate evidence in sound bites to this community through mainstream media.

**6.3.5 Develop an Australian IO cancer services network** to facilitate information sharing, and a co-ordinated strategic approach to advocating for IO. Consideration should be given to establishing a professional development program in IO.

## 6.4 RECOMMENDATIONS FOR POLICY DEVELOPMENT

**6.4.1 Develop evidence-informed IO clinical guidelines** appropriate for the Australian healthcare setting, including clinical guidelines for CM therapists providing services within public health services. Along with conducting clinical trials, ensure the existing evidence base is better utilised to develop guidelines for CM use during different stages of the cancer patient journey.

**6.4.2 Establish nationally agreed position statements** that provide clearer guidance to cancer services about their CM policies (e.g. for CM product use, visiting CM practitioners, credentialing of CM staff, and the development of safety protocols). Ensure sufficient training is in place for organisational-wide awareness to effectively action these policies.

**6.4.3 Professional bodies representing CM and IM practitioners should encourage continuing professional development, training pathways, and certification in IO** to help ensure practitioners possess the necessary skills to work with cancer survivors throughout their cancer journey.

**6.4.4 Work with the COSA CAM group and other stakeholder groups to translate policy into practice.**

**6.4.5 Develop national strategies to support the meaningful use of big data** to ensure any electronic data from IO services, including patient outcomes, can be integrated with existing health information management systems and electronic health records.

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# APPENDIX I - CANCER SERVICES SEARCH STRATEGY

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Shortlisting of organisations that operate dedicated healthcare cancer services began in late 2015. The Australian Institute of Health Welfare, Australian Hospitals Database 2013-14 <sup>[26]</sup>; Hospital and Health, Hospitals and Aged Care Database <sup>[27]</sup>, Australian Health Directory <sup>[28]</sup> and the Cancer Council Australia websites were used to create the initial shortlist.

Each shortlisted hospital was screened for eligibility of oncology services and initial contact was made with each of the hospitals. The relevant healthcare professional responsible for managing oncology services in their department or cancer centre was contacted. Emails were sent to those not initially contactable by telephone. Initially, contacts with knowledge of the organisational structure were sought such as Director / Manager Oncology or Clinical Services, DON/NUM, Cancer Care Coordinator, or other staff member in a similar managerial capacity. However, once recruited, many managerial contacts were too busy to complete the survey. Therefore, where surveys were completed by those of a subordinate ranking (e.g. clinical nurse consultant, oncology nurse) this was due in part to the DON/NUM passing the survey directly onto subordinates for completion because of time pressures. In other instances, subordinate staff was the highest rank on site (e.g. in rural areas, those with smaller oncology networks / services, or where satellite/ outreach services were used) or certain subordinates (e.g. breast care nurse) were more likely to be exposed to CM services within the organisation and were recommended by senior managers.

Due to the complex nature of healthcare organisations, sometimes contacts were difficult to locate and/or secure and the process was very tedious, which involved liaison and networking with numerous people before the suitable contact was located. At times, the designated contact fell through and a new contact was recruited. While those who held managerial positions first and foremost in accordance with oncology services were primarily sought, this procedure sometimes led to subsidiary managers and staff members being recommended and sourced.

Please note that since it was often difficult to secure contacts, suitable participants who offered to complete the survey were graciously accepted and not turned away due to position and/or ranking. Importantly, this also applied to participants who completed more than one survey and were happy to represent other cancer services or sites that they were affiliated with. In most instances, participants had adequate knowledge to complete the survey, and where necessary, checked details with their superior / supervisor to obtain the correct information. It is important to note, however, that many participants in managerial positions (e.g. NUM) were not necessarily more informed about organisational policies than those in a lesser capacity.

In addition to hospitals and cancer services on the provisional shortlist, further services and sites were identified via interest and support from other alliances such as peak organisations (e.g. Cancer Nurses Society of Australia, Clinical Oncology Society of Australia), integrated cancer care networks (e.g. Integrated Cancer Services Managers Group, Central Integrated Regional Cancer Service, Paediatric Integrated Cancer Service), collaborative groups (e.g. Complementary and Integrative Therapies Group, Western Australian Clinical Oncology Group), or from participants who recommended colleagues at sister affiliated sites, neighbouring catchment areas, or other locations.

Following up on leads, recommendations, and referrals often snowballed into unearthing cancer services and/or sites not initially known to the researchers.

Where necessary, information about hospital and/or applicable oncology services was obtained and verified via state and territory Cancer Councils, Cancer Council Australia, CanRefer Directory, Health Directory of Private Hospitals, hospital websites, local health district contacts/websites, and relevant Google searches. In addition, contacting the hospital, cancer service, or participant directly (either by telephone or email) was regularly undertaken to determine and/or verify specific details or to obtain further information and/or elaboration regarding a response.

# APPENDIX II - AUGMENTED COMMUNITY SERVICES SEARCH STRATEGY

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## INSTRUCTIONS FOR CONDUCTING SEARCH FOR CANCER ORGANISATIONS IN THE COMMUNITY OFFERING HEALTHCARE SUPPORT TO CANCER PATIENTS.

We hope you can use your local knowledge and two search engines to find community organisations that are offering support to cancer patients.

*We are looking for any community-based cancer healthcare organisation, it doesn't matter if they offer conventional medical care only, complementary medicine care only, or a combination.*

### Who do we include and exclude?

Please refer to the examples on the first page of the EXCEL spreadsheet.

**If you are not sure**, include it with a comment and we can confirm later.

### **INCLUDE THESE SERVICES (must meet ALL of these criteria):**

1. an 'organisation' such as a not-for-profit organisation, registered charity, private company, or Government run organisation; AND
2. located in the community (i.e. not a hospital run service)
3. only for cancer survivors (and possibly their carers); AND
4. offers therapies provided by healthcare practitioners/therapists (may also offer other types of services e.g. social work, educational classes, support groups etc).

### **DO NOT INCLUDE ANY OF THE FOLLOWING SERVICES:**

1. also provides care for patients with other diseases (i.e. not a specialised cancer service - e.g. palliative care is also for patients with other diseases).
2. offers only physical activities, either in the class setting or individual sessions for cancer survivors e.g. Tai Chi, yoga, Pilates.
3. offers only support groups for cancer survivors.
4. offers only counselling services for cancer survivors.
5. provides only information for cancer survivors.
6. is an oncology service provided by an individual healthcare practitioner, or group of individuals such as a small business that is not an 'organisation' e.g. consultation rooms for a group of oncologists, or ad-hoc retreats run by a few practitioners. This is because the survey is designed for organisations, so many of the questions are not relevant for this group.

### Internet search strategy

Only conduct the search for Australian websites (see below for picture instructions).

Below are the search terms to use on both Google and Bing. You can also add your own search terms and you can open/explore webpages to look for cancer services.

**Cancer retreat**

**Cancer therapy organisation**

**Cancer organisation massage support**

**Cancer non-medical cancer organisation**

Stop searching at the end of the 5th page UNLESS a new organisation is identified, then continue to the 6th page. If a new organisation is identified on the 6th page, then continues to the 7th page and so on, to a maximum of 10 pages.

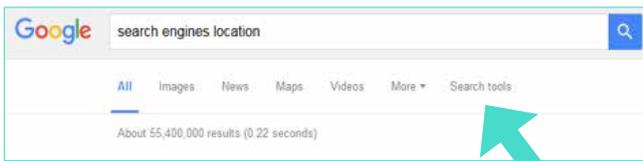
Record all the information you can on the Excel spreadsheet provided.

You do not need to contact the organisation at this stage.

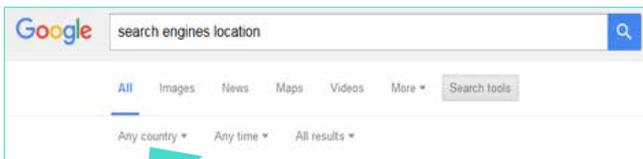
**How to set the country to Australia for the two search engines:**

**For Google:**

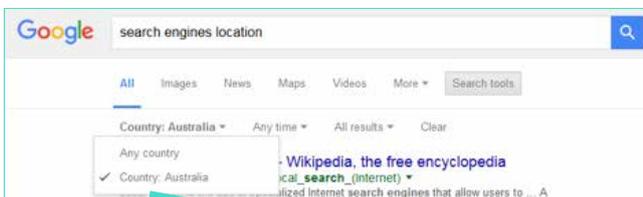
**1. Select Search tools**



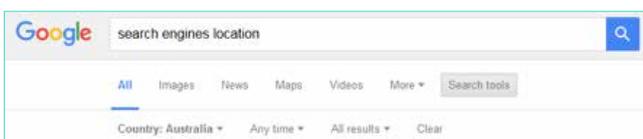
**2. Select Any country**



**3. Select Country Australia**

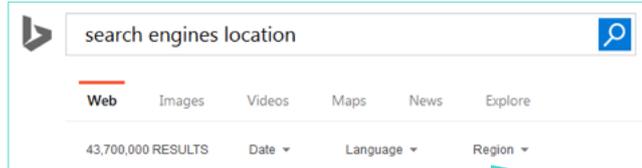


**4. The search page should now look like this:**

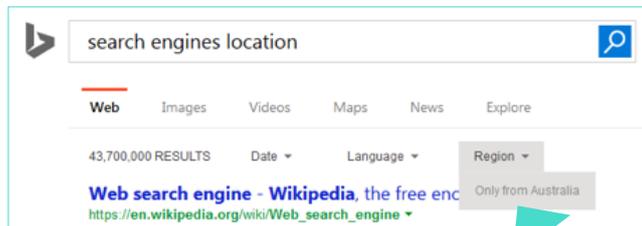


## For Bing:

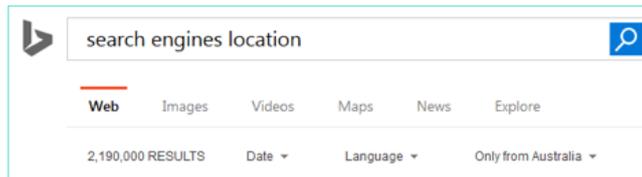
### 1. Select Region



### 2. Select Only from Australia



### 3. The search page should now look like this:



**GOOD LUCK AND THANK YOU SO MUCH FOR YOUR HELP 😊**

*from the research team - NICM, SWSLHD and Oncology Massage Ltd.*

# APPENDIX III – NATIONAL SURVEY DOCUMENTS

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Email invitation

Dear [NAME]

Thank you for your interest in this national survey to map oncology and cancer care health service provision across Australia.

The survey will take between 5-20 minutes depending on your responses. You may select your preferred format: online, electronic or paper PDF, or telephone interview. All reported results will be de-identified.

The short, self-administered survey seeks confidential information about your organisation, with a special focus on Complementary Medicine services and policies. Even if your organisation does not have any Complementary Medicine services, this information is still important.

Please use this secure SurveyMonkey link: <https://www.surveymonkey.com/r/2WQ8W5F>

SOME ORGANISATION SERVERS BLOCK THIS EMAIL LINK. If you are not directed to Survey Monkey you can use the uncorrupted link found in the word document or contact me.

You can go back and finish answering the survey at any time. There are skip questions, so you will only be asked relevant questions based on your previous responses.

A PDF copy is also attached if you prefer to complete the survey electronically. Please click on the appropriate boxes and comment areas to add your responses. Alternatively, you can print out the survey and complete the hard copy manually.

Please return completed PDF surveys to:

Fax: (02) 4620 3115

E-mail: [K.Templeman@westernsydney.edu.au](mailto:K.Templeman@westernsydney.edu.au)

You may also complete the survey via telephone and a suitable time can be arranged at your earliest convenience. Please contact me if this is your preferred option.

Attached is the participant information sheet outlining the HREC Ethic Committee approval.

This research has been funded through a Western Sydney University partnership grant with Oncology Massage Ltd and Western Sydney Local Health District.

If you require any further information, I will arrange a time to discuss any details and answer any questions you may have.

A courtesy e-mail will be sent to all participants in two weeks to follow up on any further queries.

If you have read this information and are happy to participate in this study, please click on the following link which will take you to the online survey (this signifies your consent). Please follow the prompts.

Please use this secure SurveyMonkey link: <https://www.surveymonkey.com/r/2WQ8W5F>

We greatly appreciate your participation and look forward to receiving your valued survey input at your earliest convenience.

With thanks and best wishes

Kate Templeman

**Dr Kate Templeman PhD (Med)**

Project Manager Oncology Partnership Program, NICM

M: 0466 518 666 | F: 02 4620 3115

E: [K.Templeman@westernsydney.edu.au](mailto:K.Templeman@westernsydney.edu.au)

The National Institute of Complementary Medicine

Western Sydney University | <http://www.nicm.edu.au>

Campbelltown Campus | Locked Bag 1797 | Penrith NSW 2751

# PARTICIPANT INFORMATION SHEET

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## Participant Information

You are invited to take part in a research study into complementary medicine service provision by Oncology Health Services across Australia. The study is being conducted by Professor Caroline Smith, Dr Jennifer Hunter, Professor Jane Ussher, and Professor Geoff Delaney at the National Institute of Complementary Medicine, Western Sydney University.

The study is funded through a partnership grant between Western Sydney University, Oncology Massage Ltd., and South Western Sydney Local Health District. The study has been approved by the Western Sydney University Human Research Ethics Committee (Approval number: H11389) and the Joint University of Wollongong and Illawarra Shoalhaven Local Health District Health and Medical HREC (HREC/16/WGONG/178).

The aim is to comprehensively map hospital and community-based oncology services and current provision of Complementary Medicine services in both public and private sectors across Australia, and to identify gaps and barriers to service provision. Even if your service does not offer any Complementary Medicine services, this is still important information.

The research will expand upon and update pre-existing research about Complementary Medicine service provision by Oncology Health Services across Australia. The results from this study will directly translate into informing service development and provide valuable information for both state and national oncology service planning.

The self-administered survey is being conducted online via SurveyMonkey, our preferred method for data accuracy and efficiency. Alternatively, a PDF copy of the survey is available to complete electronically, or the hard copy can be downloaded and completed manually. The survey may also be completed via telephone.

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Building 5 Campbelltown Campus  
Locked Bag 1797, PENRITH NSW 2751

T (02) 4620 3284

F (02) 4620 3291

[www.nicm.edu.au](http://www.nicm.edu.au)

All aspects of the study will be strictly confidential and only the investigators will have access to information on participants. All information will be de-identified and stored safely and securely (minimum retention period of five years) at Western Sydney University.

A report of the findings will be available to all participants and will also be submitted in an academic journal for publication. The names of individual participants will be de-identified in such reports. The name of your workplace will not be identified.

Participation in this study is entirely voluntary: you are not obliged to participate, and if you do participate you can withdraw at any time. Participants can exit at any time online, or choose not to return the electronic/hard copy. If you choose to withdraw, any information will be deleted securely from the University network; all hardcopies will be disposed of in official document destroying bins.

There are no foreseen risks as a result of participation in this research. Taking part in the survey signifies your consent.

If you require any further information, a time can be arranged at your earliest convenience to discuss any details and answer any questions you may have. If you would like to know more about the study, or wish to discuss the research further before deciding whether or not to participate, please feel free to contact the project manager or principal investigators Professor Caroline Smith or Dr Jennifer Hunter:

Professor Caroline Smith:

E-mail: [caroline.smith@westernsydney.edu.au](mailto:caroline.smith@westernsydney.edu.au)

Dr Jennifer Hunter:

E-mail: [jennifer.hunter@westernsydney.edu.au](mailto:jennifer.hunter@westernsydney.edu.au)

**Dr Kate Templeman (Project Manager):**

Tel: 0466 518 666

E-mail: [K.Templeman@westernsydney.edu.au](mailto:K.Templeman@westernsydney.edu.au)

If you have any complaints or concerns about the ethical conduct of this research you may contact the Ethics Committee through the Office of Research Services. Any issues raised will be treated in confidence and investigated fully, and you will be informed of the outcome.

Tel: (02) 4736 0229

Fax: (02) 4736 0013

E-mail: [humanethics@uws.edu.au](mailto:humanethics@uws.edu.au)

# INTEGRATIVE ONCOLOGY - NATIONAL SURVEY TO MAP COMPLEMENTARY MEDICINE OFFERED ALONGSIDE ONCOLOGY SERVICES IN AUSTRALIA

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The following definitions are provided for your information:

**Complementary Medicine** - any traditional or natural therapy/practice

**Examples of Complementary Medicine:** Oncology massage, Acupuncture; Herbal Medicine; Naturopathy; Chiropractic; Osteopathy; Massage; Therapeutic touch / Reiki; Aromatherapy; Meditation; Yoga or other movement therapy; Music or Art therapy

**Complementary Medicine Practitioner** - a health practitioner who provides a Complementary Medicine service

**Integrative Oncology (IO)** - combining Complementary Medicine with biomedicine in the oncology clinical setting

## 1. General information:

Organisation or hospital name:

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Cancer service name (if different to above):

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Post code:

---

Email address:

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## 2. Which would accurately describe your position in the organisation? (select ALL that apply)

I am in administration / management

I am a health care professional

Other (please specify)

---

THE FOLLOWING SECTION DESCRIBES THE PROVISION OF ONCOLOGY SERVICES

## 3. What type of organisation owns the oncology service? Please select one only.

Government

Limited Company

Small business

Not-for-profit organisation

Registered charity

Don't know

Other (please specify)

---

**4. Which of the following oncology services are provided (please select all that apply):**

- |   |  |
|---|--|
| <input type="checkbox"/> Chemotherapy           | <input type="checkbox"/> Supportive care and allied health |
| <input type="checkbox"/> Radiotherapy           | <input type="checkbox"/> Palliative oncology care          |
| <input type="checkbox"/> Surgery                | <input type="checkbox"/> Wellness                          |
| <input type="checkbox"/> Survivorship clinics   |  |
| <input type="checkbox"/> Other (please specify) |  |
- 
- 

**5. Where are these cancer services provided? (select ALL that apply)**

- Hospital setting: in-patient beds
  - Hospital setting: out-patient clinic or other room
  - Community setting: clinic or centre
  - Home visits / Residential Care visits
  - Other (please specify)
- 
- 

**6. Please list any important service gaps in cancer care in your district / region**

Most important unmet need

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Important unmet needs

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Comments

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**THIS NEXT SECTION FOCUSES ON COMPLEMENTARY MEDICINE SERVICES OFFERED THROUGH THE ONCOLOGY SERVICE**

**The following definitions are provided for your information**

**Complementary Medicine** – any traditional or natural therapy/practice e.g. oncology massage, acupuncture, naturopathy, chiropractic, osteopathy, therapeutic touch, reiki, aromatherapy, meditation, relaxation, yoga, tai chi, music or art therapy

**Integrative Medicine** – practitioners who combine evidence-based conventional Western Medicine with evidence-based Complementary Medicine

**7. Does your cancer service offer any Complementary Medicine or Integrative Medicine services?  
(select ONE only)**

- Yes (go to Q8)  No, we never have (go to Q41)
- No (go to Q41)  Don't know (go to Q41)
- No, not anymore (go to Q41)
- Other (e.g. planning to provide) ... (go to Q41)
- 
- 
- 

**WE WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT THE DIFFERENT TYPES OF  
COMPLEMENTARY MEDICINE AND/OR INTEGRATIVE MEDICINE YOUR SERVICE PROVIDES.**

**8. Where are these Complementary Medicine or Integrative Medicine services provided?  
(select ALL that apply)**

- Hospital setting: in-patient beds
- Hospital setting: alongside other out-patient services
- Hospital setting: a dedicated centre or clinic
- Community setting: a dedicated clinic or centre
- Community setting: not operated by our organisation
- Home visits / Residential Care visits
- Other settings: (please specify)
- 
- 
- 

**9. Approximately how long has your cancer service been providing these services?**

Years \_\_\_\_\_ Months \_\_\_\_\_

Comments \_\_\_\_\_

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**WHICH OF THE FOLLOWING COMPLEMENTARY MEDICINE SERVICES ARE PROVIDED  
THROUGH THE ONCOLOGY SERVICE?**

**10. Oncology massage** *(provided by a certified oncology massage therapist)*

	Yes	No	Don't know
Oncology massage therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

---

<b>11. Massage / Touch therapy</b>	Yes	No	Don't know
Massage therapy any style	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reflexology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Aromatherapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Therapeutic touch / Reiki	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>12. Body alignment</b>	Yes	No	Don't know
Chiropractic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Osteopathy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cranio-Sacral Therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>13. Exercise / Movement</b>	Yes	No	Don't know
Yoga	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tai Chi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Qigong	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dance or Movement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>14. Acupuncture</b>	Yes	No	Don't know
Acupuncture	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**15. Integrative medicine (IM) (defined as conventional medicine combined with evidence-based Complementary Medicine)**

	Yes	No	Don't know
IM consultations (e.g. a medical doctor who may recommend or prescribe)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
IM advice (e.g. pharmacist advice about drug interactions)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>16. Mental Wellbeing</b>	Yes	No	Don't know
Relaxation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Meditation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Music therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Art therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)			

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**17. Other Complementary Medicine services**

	Yes	No	Don't know
Acupuncture	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chinese Herbal Medicine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ayurvedic Medicine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Naturopathy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Indigenous healing practices	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nutritional Medicine (not a dietitian service)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)			

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NONE of the above  GO TO Q41

**HOW ARE THE COMPLEMENTARY MEDICINE SERVICES FUNDED? YOU ONLY NEED TO ANSWER FOR THOSE SERVICES PROVIDED BY YOUR ORGANISATION**

**18. Massage provided by a certified oncology massage therapist**

- Don't know
  - Patient (*includes rebates to patient from private health insurance or Medicare*)
  - Organisation / Hospital
  - Donations / Fundraising
  - Volunteers provide free service
- Other (please specify)
- 
- 

**19. Massage therapy (other) and Touch therapy**

- Don't know
  - Patient (*includes rebates to patient from private health insurance or Medicare*)
  - Organisation / Hospital
  - Donations / Fundraising
  - Volunteers provide free service
- Other (please specify)
- 
- 

**20. Body alignment services**

- Don't know
- Patient (*includes rebates to patient from private health insurance or Medicare*)
- Organisation / Hospital
- Donations / Fundraising
- Volunteers provide free service

Other (please specify)

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**21. Exercise/movement services**

Don't know

Donations / Fundraising

Patient (*includes rebates to patient from private health insurance or Medicare*)

Volunteers provide free service

Organisation / Hospital

Other (please specify)

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**22. Acupuncture services**

Don't know

Donations / Fundraising

Patient (*includes rebates to patient from private health insurance or Medicare*)

Volunteers provide free service

Organisation / Hospital

Other (please specify)

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**23. Integrative medicine services**

Don't know

Donations / Fundraising

Patient (*includes rebates to patient from private health insurance or Medicare*)

Volunteers provide free service

Organisation / Hospital

Other (please specify)

---

---

**24. Mental wellbeing services**

Don't know

Donations / Fundraising

Patient (*includes rebates to patient from private health insurance or Medicare*)

Volunteers provide free service

Organisation / Hospital

Other (please specify)

---

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**25. Other Complementary Medicine services**

- Don't know
- Patient *(includes rebates to patient from private health insurance or Medicare)*
- Organisation / Hospital
- Donations / Fundraising
- Volunteers provide free service

Other (please specify)

---



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**Practitioners providing the following services**

	Number Practitioners	Don't know	Hours / week service is available	Don't know
<b>26. Oncology massage</b>	<input type="text"/>	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>
<b>27. Massage (other) or touch therapy</b>	<input type="text"/>	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>
<b>28. Body Alignment</b>	<input type="text"/>	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>
<b>29. Exercise / movement therapy</b>	<input type="text"/>	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>
<b>30. Acupuncture</b>	<input type="text"/>	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>
<b>31. Integrative Medicine</b>	<input type="text"/>	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>
<b>32. Mental Wellbeing</b>	<input type="text"/>	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>
<b>33. Other Complementary Medicine</b>	<input type="text"/>	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>

**34. Do your Complementary Medicine practitioners need to meet any of the following requirements?**

	Must have	Preferred	Optional	No	Don't know
Criminal Record or Working with Children Check	<input type="checkbox"/>				
First-aid certificate	<input type="checkbox"/>				
Credentials confirmed by your organisation	<input type="checkbox"/>				
Accredited by a professional association	<input type="checkbox"/>				
AHPRA registration (e.g. doctor, nurse, dietitian, psychologist, Chinese medicine, osteopath, chiropractor)	<input type="checkbox"/>				
Professional indemnity insurance	<input type="checkbox"/>				
Formal training about the organisation's procedures and protocols	<input type="checkbox"/>				

Comments:

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**35. Do any of your Complementary Medicine practitioners have dual qualifications as a biomedical trained practitioner?** (e.g. Massage Therapists is also a Physiotherapist; Yoga instructor is also an Exercise Physiologist; Acupuncturist is also a Doctor; Nutritional Therapist is also a Dietitian)

Don't know

No

Yes, please provide details:

---

---

---

**36. Do your Complementary Medicine practitioners participate in multidisciplinary team meetings or case conferences? (select ONE only)**

Don't know

No

Yes, please provide details:

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**37. How are Complementary Medicine practitioner services documented? (select ALL that apply)**

Don't know

A shared online clinical record within the organisation

A shared paper based clinical record within the organisation

A separate record that is not integrated with the patient's clinical records but kept on-site

A separate record that the Complementary Medicine practitioner maintains and owns

Other (please specify)

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**38. Who can access or use the Complementary Medicine service? (Please select ALL that apply)**

All cancer patients

Some cancer patients please specify

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Family members and carers of oncology patients

Staff

General Public

Other (please specify)

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**39. Do patients need a referral to access the Complementary Medicine services? (select ALL that apply)**

	ALL services	SOME services
NO referral is required, self-referrals are accepted	<input type="checkbox"/>	<input type="checkbox"/>
YES internal referral from within the organisation	<input type="checkbox"/>	<input type="checkbox"/>
YES referral from an oncologist	<input type="checkbox"/>	<input type="checkbox"/>
YES referral from any medical doctor	<input type="checkbox"/>	<input type="checkbox"/>
YES referral from any healthcare practitioner	<input type="checkbox"/>	<input type="checkbox"/>
DON'T KNOW	<input type="checkbox"/>	<input type="checkbox"/>

Comments:

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**40. Which of the following methods are used to evaluate your Complementary Medicine services? (select ALL that apply)**

- Don't know
  - None, we do not formally evaluate our services
  - Patient survey
  - Written Patient feedback form
  - Practitioner or organisation initiated clinical audit
  - Observational studies
  - Clinical trials
  - Other (please specify)
- 
- 

**NOW GO TO QUESTION 43**

**THE FOLLOWING TWO QUESTIONS ARE FOR CANCER SERVICES THAT DO NOT PROVIDE COMPLEMENTARY MEDICINE SERVICES**

**41. What are the reasons for not providing Complementary Medicine services? Please indicate ALL that apply.**

- Organisational policy does not support or allow Complementary Medicine use
- Standards set for complementary medicine to fit within the acute care setting
- No interest or support from oncologists
- Management directive
- No patient awareness or demand
- Lack of funding

Other (please specify) \_\_\_\_\_  
 \_\_\_\_\_

**42. What solutions can you identify to help reduce some of these barriers?**

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**THE REMAINING QUESTIONS APPLY TO ALL SERVICES**

**THIS SECTION ASKS ABOUT YOUR ORGANISATION'S GENERAL POLICIES FOR COMPLEMENTARY MEDICINE**

**43. Does your organisation have the following in place?**

	YES	NO	Decision is made on a CASE by CASE basis	NOT APPLICABLE this is never allowed	DON'T KNOW
Credentialing policy for visiting Complementary Medicine practitioners	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Scope of practice for visiting Complementary Medicine practitioners	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Policy for referrals to Complementary Medicine practitioners outside the organisation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Policy on patient initiated herbs, vitamins and minerals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complementary Medicine information available for patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**44. How are herbs, vitamins and minerals documented in the patient's clinical record? (select ONE only)**

- Not applicable - patients are not permitted to use these products
- ALL products (including self-initiated) are listed on the medication chart.
- ONLY products approved by medical staff are listed on the medication chart. Other product use is documented in the clinical history.
- Product use is ONLY documented in the clinical history.
- Don't know
- Other, please specify \_\_\_\_\_

**45. Have you heard of the Council of Australian Therapeutic Advisory Groups (CATAG)?**

- Yes
- No (GO TO Q47)
- Not applicable, we are not a hospital organisation (GO TO Q47)

**46. If yes, then thinking about your organisation and CATAG's Position Statement for the use of Complementary and Alternative Medicines, 2015?**

[http://www.catag.org.au/wp-content/uploads/2012/08/150518\\_CAM-Position-statement-final.pdf](http://www.catag.org.au/wp-content/uploads/2012/08/150518_CAM-Position-statement-final.pdf)

Our policies are aligned with this CATAG statement

- Yes
- No

Comments:

---

**THE FOLLOWING SECTION RELATES TO ONCOLOGY MESSAGE**

**DEFINITION:** Oncology massage is massage delivered by a trained, certified oncology massage therapist.

**47. In your opinion, who is likely to deliver safe massage to cancer \* patients/survivors?**

	Very Likely	Likely	Possibly	Unlikely	Very Unlikely	Don't know
Family member or friend	<input type="checkbox"/>					
Volunteer	<input type="checkbox"/>					
Health Practitioner (with no massage training)	<input type="checkbox"/>					
Massage therapist (any style)	<input type="checkbox"/>					
Certified oncology massage therapist	<input type="checkbox"/>					

**48. Is your cancer service aware of any evidence demonstrating that the training of the person delivering massage influences cancer patient outcomes?**

- Yes
- No
- Don't Know

**49. Is your cancer service aware of any evidence demonstrating that oncology massage can reduce pain or anxiety in cancer patients?**

- Yes
- No
- Don't Know

**50. Are there any barriers to providing oncology massage in your organisation?**

(i.e. provided by a certified oncology massage therapist)

- No (GO TO Q52)
- Don't know (GO TO Q52)
- Yes

**51. If yes, what are the barriers? (Select ALL that apply)**

- Doctors or allied health do not support or advocate oncology massage
- Funding not available for oncology massage
- Unable to recruit oncology massage therapists
- Low patient demand for oncology massage
- Don't know
- Other - (please specify)

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**52. Do you have any further comments?**

e.g. patient needs, challenges, lessons learnt, future plans for services

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**53. Who can we contact if we need to clarify any questions?**

Name

---

Email Address

---

Phone number

---

**54. To receive a copy of the results**

Please provide postal or email details (if different to above)

---

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**THANK YOU VERY MUCH FOR YOUR ASSISTANCE.**

# APPENDIX IV – FOCUS GROUP

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## FOCUS GROUP PARTICIPANT DETAILS

1. What is your current age? (in years)
2. What is your current postcode?
3. What is your country of birth?
4. With which ethnic or cultural group do you identify?  
(e.g. Anglo-Australian, Chinese)
5. Which language do you speak at home?
6. What type of cancer were you diagnosed with?
7. What stage of treatment are you in currently? (Please circle)
  - a. Active treatment
  - b. Long-term treatment
  - c. No treatment
  - d. Other (please specify)
8. Active treatment / Long-term treatment / No treatment
9. How long ago were you diagnosed with cancer?  
Years:            Months:

## INTERVIEW GUIDE

### CM USE

10. What kinds of CM have you heard about?
11. What CM have you used? Which ones, why?
12. Regarding your cancer - did you use CM in addition to conventional medical care or instead of conventional treatment? Which ones, why?
13. Have you used CM for other reasons now or in the past?
14. Have you benefited from using CM or know other people who have benefited?
15. Would you consider starting/continuing to use CMs in the future? Which ones, why?

### CM DECISION MAKING

1. What influences your decision to use CM?
2. Has anyone recommended you use CM? Who, which ones, why?  
Did you accept their advice?
3. If a doctor recommended CM, would you use it?
4. If a nurse or other health care practitioner recommended CM, would you use it?

5. What about friends or family members?
6. What about community leaders?

## CM DELIVERY

1. What are your thoughts about coordinating CMs with conventional care?
2. What role would you want and/or expect the following members of your treating team to have in terms of CMs? Oncologist, GP, nurse, psychologist, physio etc
3. Would you expect them to refer you, recommend it, provide information, talk about CM?
4. Where would you like to access CM? Whilst an inpatient, attending outpatient department, at the GP clinic, in a community centre, close to home?
5. Where would you prefer CM services to be provided?

## CM FUNDING

1. Who should pay for CM?
2. Do you think it should be an “extra” that you pay for, that private health insurance should pay for, or funded through the public health system?

## CM INFORMATION

1. Where do you get information about CM?
2. What information sources do you trust?
3. What further information do you need?
4. What are the best formats – verbal, written (which language), internet

## CM BARRIERS

1. What is stopping you from using CM or using more CM? Which ones?
2. Availability?
3. Financial?
4. Logistical? E.g. too far, no transport etc
5. Personal? E.g. too sick, not enough energy or motivation?
6. Health practitioners unsupportive?
7. Family or friends unsupportive?

# APPENDIX V – COMMUNITY SURVEY

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As part of the Integrative oncology in Australia - Exploring Unmet Needs and Service Provision Study being conducted by Western Sydney University we are interested in your experiences of complementary medicine and therapies. People who have undergone treatment for cancer are invited to take part in this study.

The study has been approved by the University of Western Sydney Human Research Ethics Committee (Study ref: H11389)

## INSTRUCTIONS

Taking part in the study is voluntary. Information you provide is confidential.

The survey will take about 15-20 minutes to complete.

Please do not exit the survey before completing as you cannot return to the incomplete parts after exiting.

Use the previous and next buttons at the bottom of each page to move between pages. If you have any questions, please contact us on: Tel: 02 4620 XXXX; Email: XXXXXX

Your participation in this study is greatly appreciated.

## THESE QUESTIONS ARE ABOUT YOU AND YOUR EXPERIENCE OF CANCER

1. What is your current age?
2. What is your current postcode?
3. What is your country of birth?
4. With which ethnic or cultural group do you identify?  
(e.g. Anglo-Australian, Chinese)
5. What language do you speak at home?
6. What type of cancer were you diagnosed with?
7. What stage of treatment are you in currently?
  - a) Active treatment
  - b) Long-term treatment
  - c) No treatment
  - d) Other (please specify)
8. How long ago were you diagnosed with cancer? Years/Months
9. Which of the following have you used/had in the last 12 months for your cancer treatment?
  - a) Radiotherapy
  - b) Chemotherapy
  - c) Surgery

- d) Other cancer treatment medicines (e.g. tamoxifen)
- e) None

**THESE QUESTIONS ARE ABOUT YOUR EXPERIENCE OF COMPLEMENTARY THERAPIES SINCE YOUR DIAGNOSIS WITH CANCER**

10. Please select any of the following therapies that you have used either during your cancer treatment or to help with your recovery?

- a) Oncology massage
- b) Other massage therapy
- c) Reflexology
- d) Aromatherapy
- e) Therapeutic touch / Reiki
- f) Chiropractic
- g) Osteopathy
- h) Cranio-sacral
- i) Yoga
- j) Tai Chi
- k) Qi Gong
- l) Relaxation
- m) Meditation
- n) Music therapy
- o) Acupuncture
- p) Chinese medicine
- q) Ayurvedic medicine
- r) Naturopathy
- s) Indigenous Australian Medicine
- t) Nutritional medicine
- u) Other (please explain)

11. Please indicate whether you selected any of the therapies in the previous question.

**IF YES GO TO Q13; IF NO GO TO Q12**

12. Have you used any vitamins, minerals, herbs, fish oil, probiotics, or other natural health products either during your cancer treatment or to help with your cancer recovery? Y/N

**IF YES GO TO Q18; IF NO GO TO Q22**

13. Have you used any vitamins, minerals, herbs, fish oil, probiotics, or other natural health products either during your cancer treatment or to help with your cancer recovery? Y/N

14. Who recommended you use these complementary therapies or natural health products? Please select all that apply.
- a) A doctor from the hospital or oncology service
  - b) A nurse or another practitioner working in the hospital
  - c) A General Practitioner (GP)
  - d) A pharmacist
  - e) A natural health practitioner
  - f) Friend or family member
  - g) I decided to use them
  - h) Other (please explain)
15. Where did you access these complementary therapies or natural health products?
- a) The hospital or oncology clinic
  - b) General practice clinic or medical centre
  - c) Health clinic
  - d) In a community centre or hall
  - e) At a friend's house
  - f) In my house
  - g) Other (please explain)
16. In what way did you use natural health products?
17. Would you recommend any of these complementary therapies or natural health products to a friend in a similar situation? Please explain why.

### GO TO Q22

18. Who recommended you use these natural health products? Please select all that apply.
- a) A doctor from the hospital or oncology service
  - b) A nurse or another practitioner working in the hospital
  - c) A General Practitioner (GP)
  - d) A pharmacist
  - e) A natural health practitioner
  - f) Friend or family member
  - g) I decided to use them
  - h) Other (please explain)
19. Where did you access these natural health products?
- a) The hospital or oncology clinic
  - b) General practice clinic or medical centre
  - c) Health clinic
  - d) In a community centre or hall

- e) At a friend's house
- f) In my house
- g) Other (please explain)

20. In what way did you use these natural health products?

21. Would you recommend any of these natural health products to a friend in a similar situation? Please explain why.

### GO TO Q23

22. If you haven't used any of the complementary therapies or natural health products listed previously, why not?

23. Are there complementary therapies you wanted to use but couldn't? If so, why not?

24. Would you consider using complementary therapies in the future? Which ones and why/why not?

25. Do you think oncology services should offer complementary therapies?  
Y/N

If so, what services and where?

26. Where would you like to access complementary therapies?

- a) Whilst an in-patient
- b) Attending an out-patient department
- c) GP clinic
- d) Community centre
- e) Close to home
- f) Other (please specify below)

Please explain your preferences.

27. How would you like to be referred to a complementary therapy service?

- a) Through an oncologist or GP
- b) Through self-referral
- c) Other (please explain)

28. Would you want your oncology team to know you are using complementary therapies?

29. Who do you think should pay for complementary therapies?

- a) Medicare
- b) Private health insurance
- c) Person funds

Please explain your preferences

30. What is stopping you from using complementary therapies or using more complementary therapies?

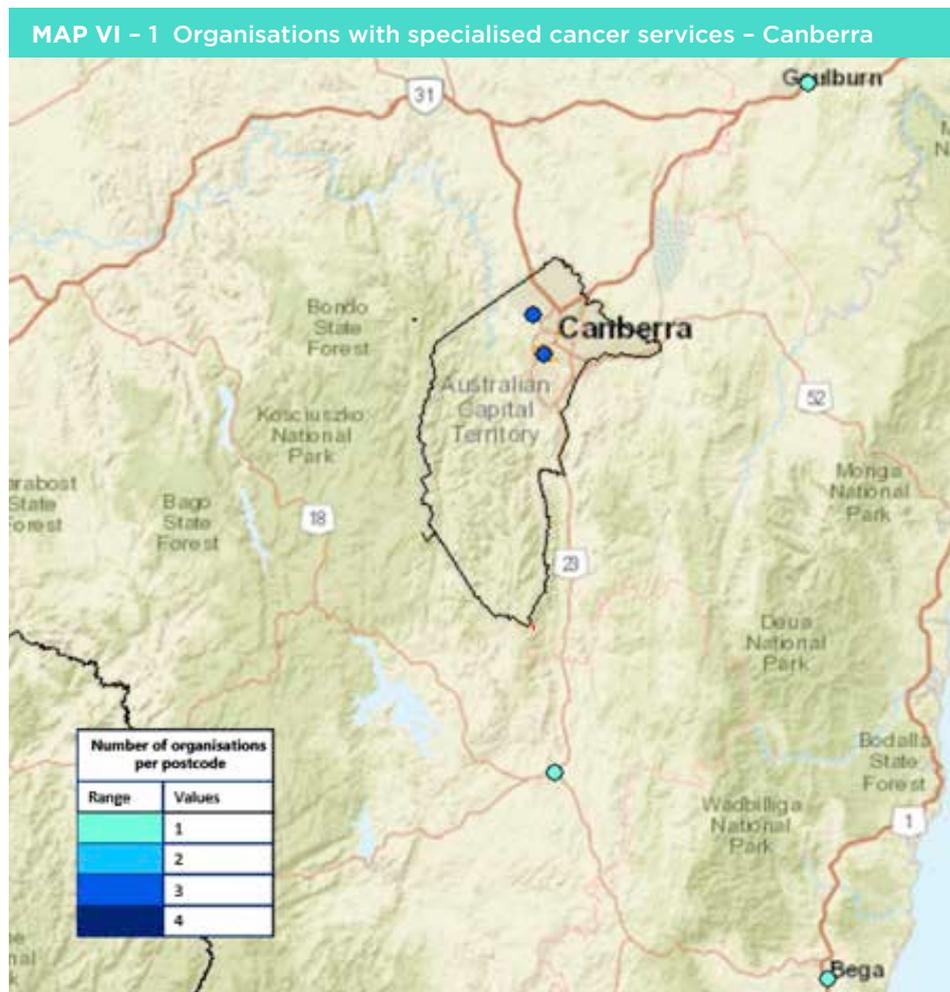
- a) Availability
- b) Finance
- c) Logistics e.g. no transport
- d) Person e.g. too sick
- e) Health practitioner / doctor unsupportive
- f) Family or friends unsupportive

Please explain

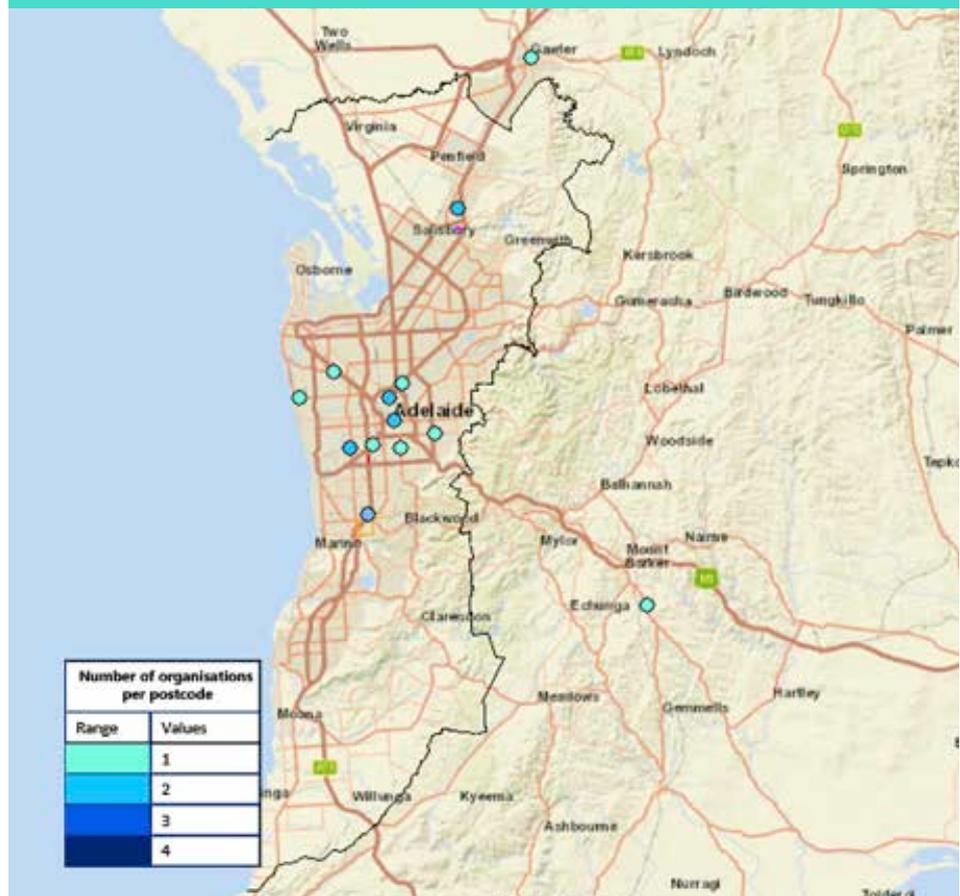
**THANK YOU FOR COMPLETING THIS SURVEY**

# APPENDIX VI – MAPS

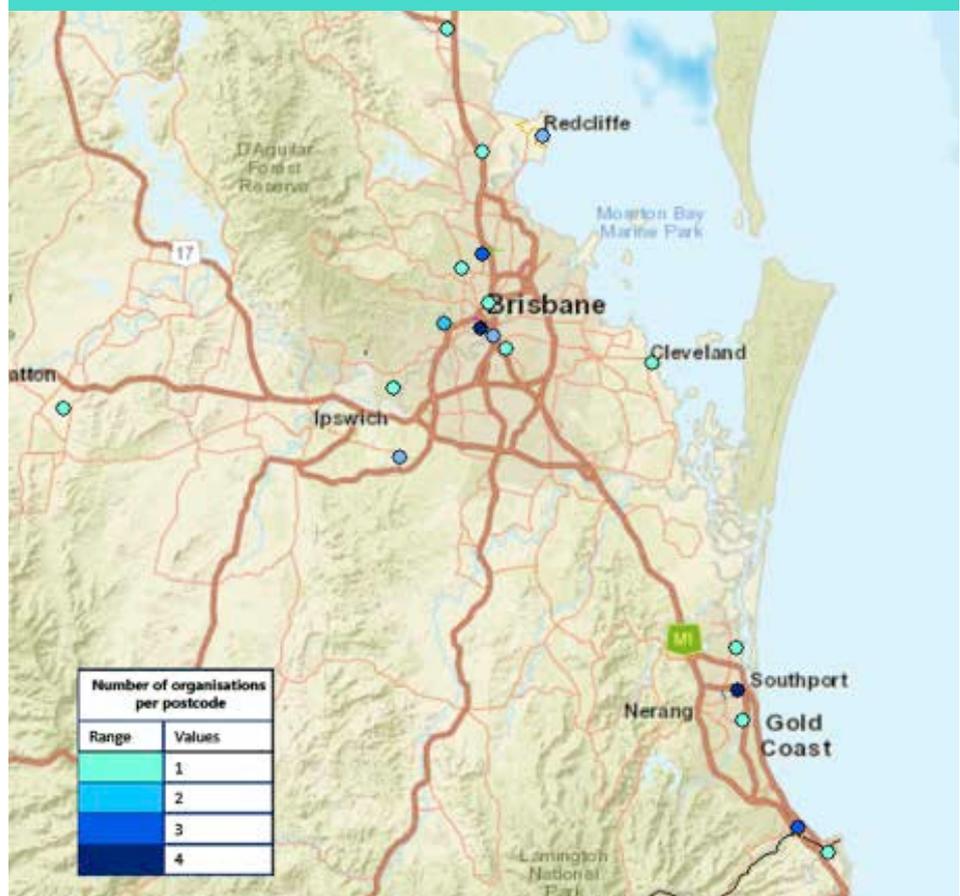
The following maps for each Australian capital city and their surrounding area are derived from the data used to generate Map 2.1. The dots are placed according to the postcode area, not the exact location of the organisations.



MAP VI - 2 Organisations with specialised cancer services – Adelaide



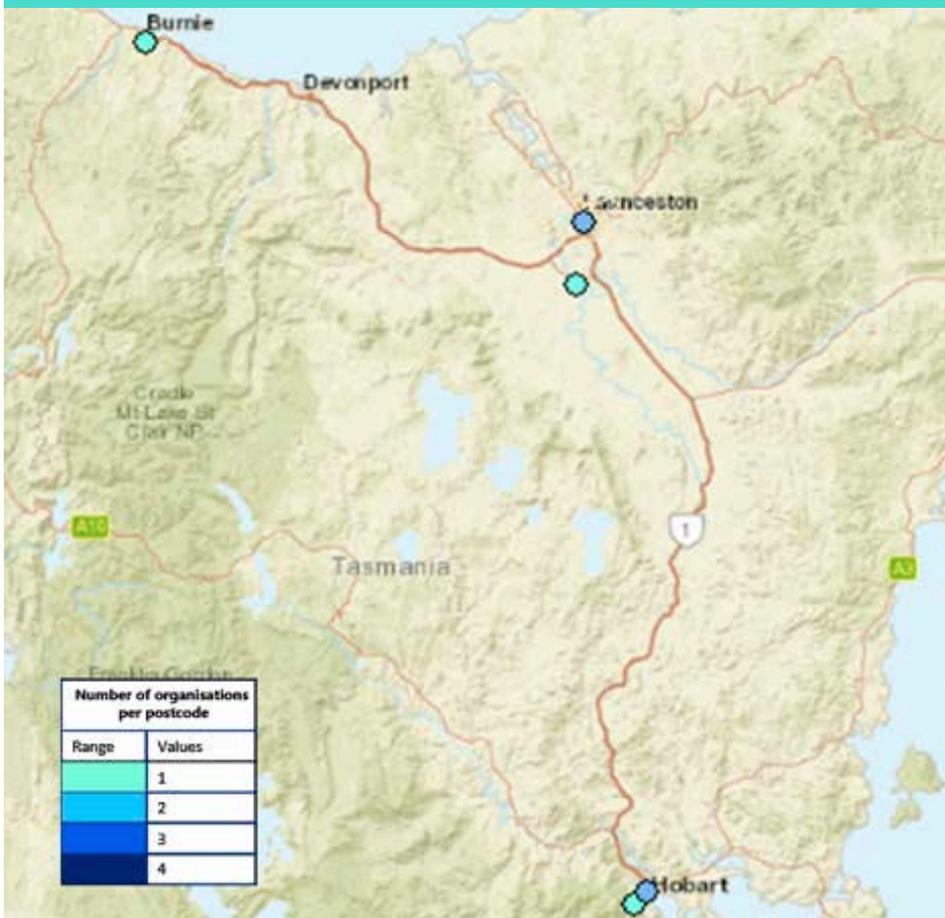
MAP VI - 3 Organisations with specialised cancer services – Brisbane



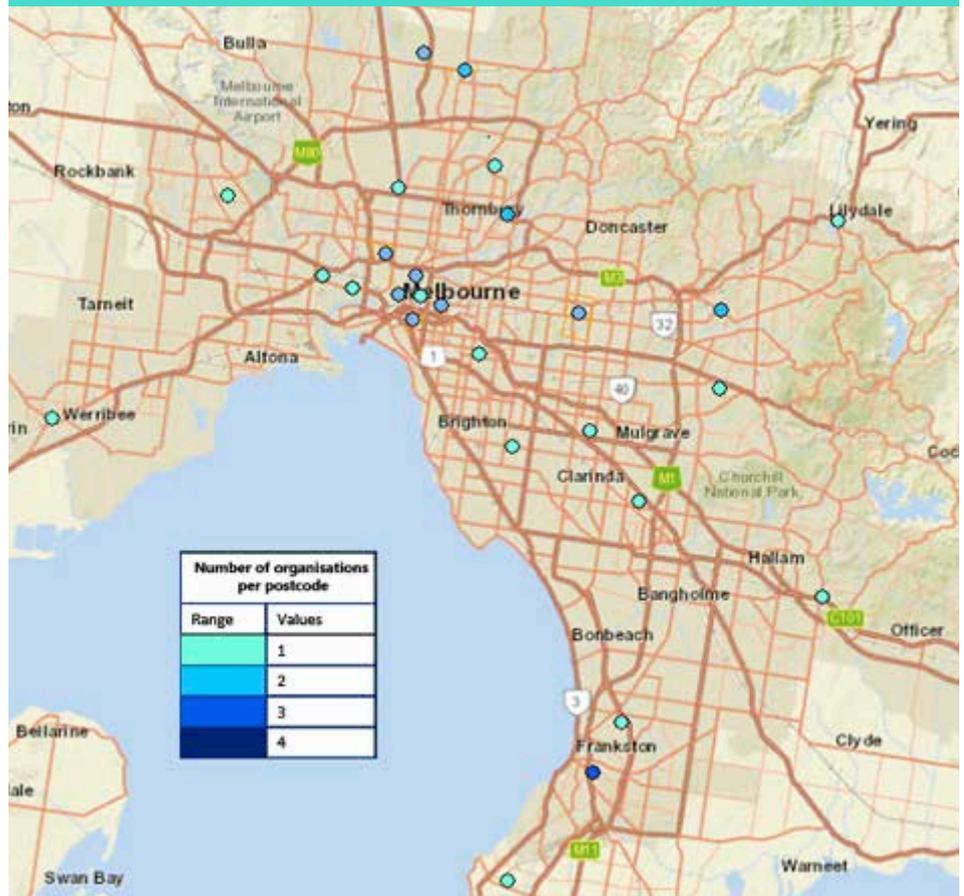
MAP VI - 4 Organisations with specialised cancer services - Darwin



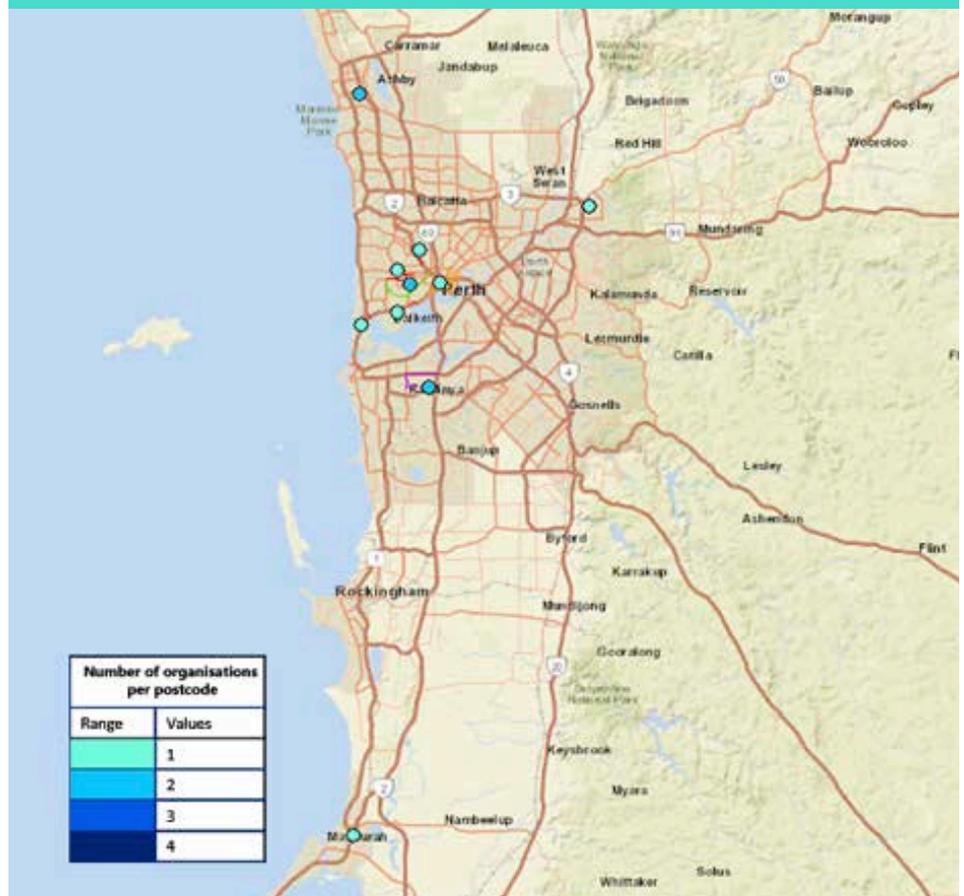
MAP VI - 5 Organisations with specialised cancer services - Hobart



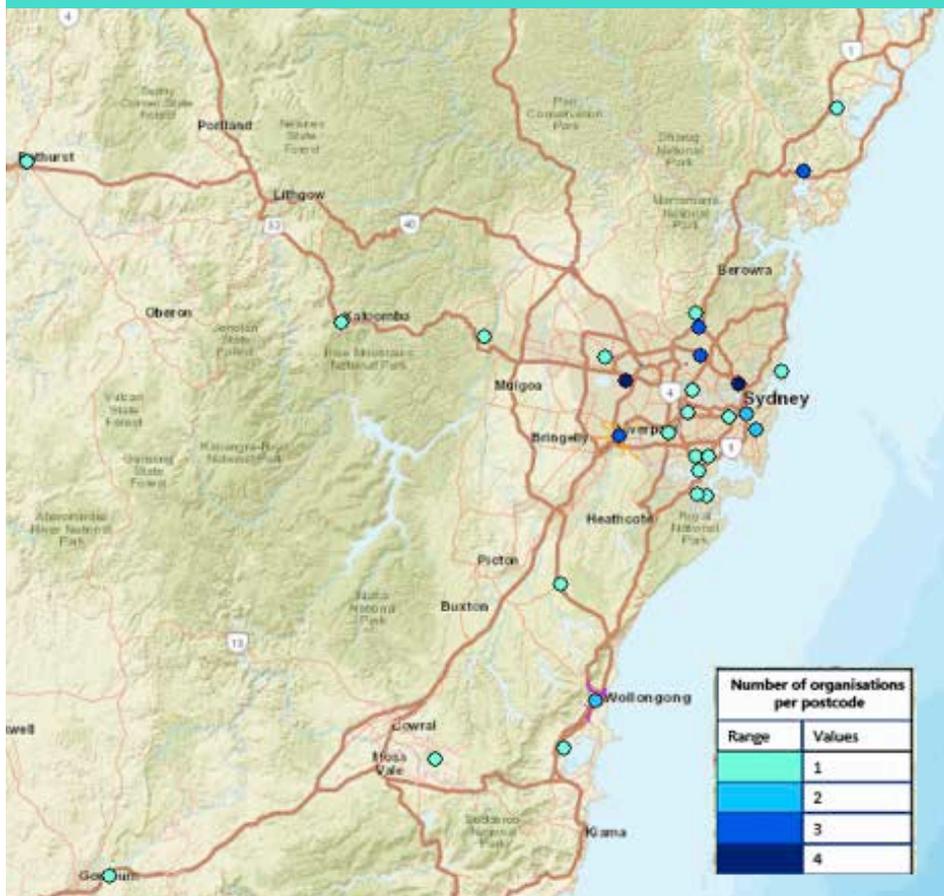
MAP VI - 6 Organisations with specialised cancer services - Melbourne



MAP VI - 7 Organisations with specialised cancer services - Perth



MAP VI – 8 Organisations with specialised cancer services – Sydney







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