The Winston Churchill Memorial Trust of Australia

Report by

Christine Scott

2011 Churchill Fellow

The Dr Dorothea Sandars and Irene Lee Churchill Fellowship to study the integration of complementary and supportive therapies with conventional medical care for people with cancer – USA, UK

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Signed: Dated: 05.02.2012
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Acknowledgements

I sincerely thank the late Dr Dorothea Sandars and Ms Irene Lee for generously supporting my Fellowship, and the Winston Churchill Memorial Trust for providing the opportunity of a lifetime.

To my colleagues at Austin Health in Melbourne who work tirelessly to bring the dream of the Olivia Newton-John Cancer and Wellness Centre to fruition, and to Olivia herself for her vision and commitment to making cancer care more responsive to the breadth of patients' needs.

To Jason Payne and Amanda Hordern who supported my Fellowship application and Molly Carlile whose experience as a 2008 Churchill Fellow provided inspiration as well as encouragement through the selection process.

To the many experts in the UK and USA who met with me and took the time to share their experience and knowledge.

To my family and friends – particularly my husband Gil Brown for encouraging me every step of the way, to Sheila Hirst for helpful comments on the first draft of this report and to Lister for keeping me company while writing it!

Finally to those who may experience a cancer diagnosis in the future, I hope that this piece of work will make a positive contribution to the experience of cancer care, and provide a greater range of options to support mind, body and soul.
Executive summary

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Mont Albert, Vic 3127 Centre
M: 0413 605 415 Austin Health
Heidelberg, Vic 3084

*The Dr Dorothea Sandars and Irene Lee Churchill Fellowship to study the integration of complementary and supportive therapies with conventional medical care for people with cancer, visiting cancer services in the United Kingdom and the United States of America.*

Highlights

- Meeting leading experts in the field of integrative oncology and establishing lines of communication to support information sharing in the future
- Seeing the impact of the NHS peer review program in driving regional and local policy development in complementary therapy
- The opportunity to compare and contrast different models of integrated cancer care
- Witnessing the passion of champions in the field and their dedication to make complementary and supportive therapies more accessible to patients and carers

Conclusions

- high level policy grounded in the evidence base gives credence to the role of complementary and supportive therapies in cancer care and drives service development and integration
- some form of regulatory system is required in Australia to establish standards of professional practice in complementary therapies, and to safeguard the public
- sustainable funding streams are required to support the provision of evidence-based complementary therapies
- those services where complementary and supportive therapies were better integrated had:
  - organisational commitment reflected in organisational structures and policies
  - strong clinical leadership
  - a values base that creates a culture within the organisation of staff commitment and patient empowerment
  - an integrated team approach supported by a clear model and a strong identity that is consistently reinforced
  - a research program in place be it small scale local level research or nationally funded collaborative research
  - a commitment to consumer involvement in service planning and improvement
  - a program of professional education which exposes mainstream health professionals to the benefits of complementary and supportive therapies
  - a program to upskill complementary therapists in the specific needs of people with cancer
  - access to extensive web-based resources for patients, families, staff and external users

Dissemination & implementation

- Present findings at National and State cancer care conferences and meetings
- Distribute this report to local, national and international stakeholders
- Seek opportunities to discuss findings with state and national government departments
- Pursue opportunities for national collaboration with other cancer centres involved in development and delivery of complementary and supportive therapies
## Program

<table>
<thead>
<tr>
<th>Date and Location</th>
<th>Meetings</th>
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| **14th October 2011**  
Charing Cross Hospital  
Imperial Health Trust, London | Dr Sarah Partridge, Clinical Oncologist,  
Rumi Peynovska, Hypnotherapist,  
Miranda Roger, Manager, MacMillan Information Centre,  
Tatyana Guveli - MacMillan information Lead for the Trust |
| **14th October 2011**  
St Marys Paddington  
Imperial Health Trust, London | Jenny Pettrak, Lead Clinical Psychologist |
| **14th and 17th October 2011**  
Maggie’s Centre, London | Bernie Byrne, Centre Head |
| **17th October 2011**  
Kings College Hospital  
Kings Health Partners &  
St Thomas’ Hospital  
Guys and Thomas’ Foundation Trust, London | Catherine Dale, Programme Manager, Patient Centred Care  
Anne Duffy, Head of Nursing, Cancer and Palliative Care, KCH  
Chiara DeBiase, Manager, MacMillan Information & Support Centre  
Barbara van der Merwe, Manager and Information Coordinator, Dimbleby Cancer Centre |
| **18th October 2011**  
University College London Hospitals | Emily Freemantle, General Manager, Haematology  
Hilary Plant, Macmillan project manager, UCLH cancer centre  
Alison Donaldson, narrative writer employed by Macmillan  
Elaine Charlesworth, Head, Complementary therapies UCLH |
| **19th October 2011**  
Guy’s Hospital  
St Thomas’ Hospital  
Guys and Thomas’ Foundation Trust, London | Dr Fran Woodard, Director of Transformation and Cancer Programme  
Rebecca Brennan, Physiotherapist, Breast Unit  
Nicola Peat, Physiotherapist, Clinical Specialist Oncology  
Kirsten Holt, Occupational Therapist, Clinical Specialist Oncology  
Jason Pawluk – Quality & Productivity Lead |
| **20th October 2011**  
London Hospital for Integrated Medicine,  
University College London Hospitals | Chris Perrin, Head nurse  
Dr Sosie Kassab, Integrative Medicine Specialist & Homeopath  
Margaret Patsias, Natural Healer |
| **21st October 2011**  
Royal Marsden Hospital (Chelsea), London | Dr Theresa Wiseman, Lead for Health Service Research, Nursing, Rehabilitation and QA  
Dr Isabel White, Clinical Research Fellow in Psychosexual Practice  
Nicki Murtagh, Head of Therapies  
Lesley Edwards, Lead Psychologist  
Natalie Doyle, Nurse Consultant, Living with and beyond Cancer  
Sheila Murphy, PALS service  
Jeannie Dyer, Complementary Therapy Lead |

Continued...
<table>
<thead>
<tr>
<th>Date</th>
<th>Location</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>24th-25th October 2011</td>
<td>Yorkshire Cancer Centre St James Institute of Oncology, St James University Hospital, Leeds</td>
<td>Krystina Kowslovska, Lead Cancer Nurse, Supportive Care Sarah Catesby, Head, Psycho-oncology Vicki James, Enhancing Patient Experience Sadie Smith, Manager, Robert Ogden Macmillan Centre Lorraine Buckingham, Complementary Therapist Josie Sharp, Information Nurse Specialist Tom Mansell, Information &amp; Supportive Care Project Officer Nicola Rawston, Acupuncturist</td>
</tr>
<tr>
<td>27th-28th October 2011</td>
<td>The Christie Manchester</td>
<td>Dr Peter Mackereth, Clinical Nurse Specialist, Complementary Therapies, and members of the complementary therapy team</td>
</tr>
<tr>
<td>2nd November 2011</td>
<td>Cancer Treatment Centers of America - Eastern Region Philadelphia, USA</td>
<td>John M. McNeil, President &amp; CEO Rev. Dr. Michael Barry, Director of Pastoral Care Kristen McQuaid, Talent Manager Harry Buchman, Director of New Patient Experience Dr Anthony Perre, Medical Director of New Patient Intake Jeff Sklar, Director of Chiropractic Services Dr Shayma Kazmi, Medical Oncologist Aminah Keats, Naturopathic Doctor Fran Reichel, Deputy Vice President, Oncology Patient Services Kristin Mullen, Vice President, Patient Care Services Benita Stevens, Gina Smith, Oncology Rehabilitation Services</td>
</tr>
<tr>
<td>7th-8th November 2011</td>
<td>Memorial Sloan Kettering Cancer Center, New York, USA</td>
<td>Dr Barrie Cassileth, Chief, Integrative Medicine Service Prof. David Kissane, Jimmie C. Holland Chair in Psycho-oncology, Department of Psychiatry &amp; Behavioral Sciences Karen Popkin, Music therapist</td>
</tr>
<tr>
<td>9th – 12th November</td>
<td>Cleveland, Ohio, USA</td>
<td>Society for Integrative Oncology Eighth International Conference</td>
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<tr>
<td>14th-17th November</td>
<td>M.D. Anderson Cancer Center Houston, Texas, USA</td>
<td>Integrative Medicine Observer Program Professor Lorenzo Cohen, Director A/Professor Richard Lee, Medical Director &amp; Integrative Medicine team</td>
</tr>
<tr>
<td>22nd November 2011</td>
<td>Sheri and Les Biller Center Department of Supportive Care Medicine City of Hope Cancer Center Los Angeles, USA</td>
<td>Dr Matt Loscalzo, Director, Supportive medicine Linda Klein, Manager of Operations, Sheri &amp; Les Biller Center Annette Mercurio, Director of Programs Diane Morrison, Manager, Social Work Lina Mayorga, Program evaluator/health educator Bridget Marshall, Visitor Services Associate Virginia Christman, Chaplain</td>
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**Introduction**

With an estimated 114,000 new cases of cancer diagnosed in Australia in 2010, and a figure of one in two Australians being diagnosed with cancer by the age of 85, cancer is a disease that impacts on virtually all Australians in some way\(^1\).

What is encouraging is that advances in early diagnosis and treatment have improved survival rates with more than 60% of cancer patients surviving at least five years after diagnosis. This represents an increase in survival rate for many common cancers of 30 per cent in the past two decades.

We know that Australians are big users of complementary therapies. A survey conducted in 2004 estimated that approximately 52% of the Australian population used complementary medicines and that 26% consulted practitioners of complementary medicine. It was estimated that this represented out of pocket spending of $1.8 billion\(^2\).

People living with cancer and their families are increasingly seeking to improve their wellness through sourcing a range of activities that promote health and wellbeing. A 2005 study of Australians with cancer found that for all cancers, 17% of patients were using at least one form of complementary or alternative medicine\(^3\).

We should not be surprised by these figures. The effects of cancer and its treatment can have a significant impact on the individual and their families. For example, studies of psychological distress in cancer patients have shown that 25-30% of patients experience raised levels of emotional distress (e.g. Zabora et al 2001)\(^4\).

The benefits of the provision of supportive care (such as those services provided by social workers & psychologists) to patients is well documented and has a positive impact on patients by reducing levels of anxiety, depression, mood disorders, nausea, vomiting and pain, and increasing the patient's knowledge of their disease and treatment (NBOCC and NCCI 2003)\(^5\).

The benefits of complementary therapy are less clear and have become a topic which stimulates much debate, especially as people with cancer can be vulnerable to false claims about their efficacy. However, there is a growing body of evidence to support some complementary therapies in reducing symptoms and side effects associated with cancer and its treatment. In recognition of this, the 2005 Australian Senate Community Affairs Committee Enquiry\(^6\) into the delivery of cancer services, recommended that where quality of life can be improved by complementary methods, these should be made more accessible within the states and territories.

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With the development of comprehensive cancer centres in Australia such as the Olivia Newton-John Cancer and Wellness Centre (ONJWC) in Victoria, there is increasing recognition that a more holistic approach to cancer care needs to be adopted. This approach combines the very best of medical care and research with supportive care and a range of complementary therapies that are aimed at improving the well-being of patients and families. These may include massage, meditation, counselling, reflexology, nutritional advice and support groups. This integration of complementary and supportive therapies with traditional medical care is known as integrative oncology or integrative medicine.

It is important at this point to emphasise that my study, and indeed the therapies that will be integrated into patient care at the ONJCWC will only be those that are complementary to mainstream medical care and not alternative or in place of medical care. Unsafe or unproven practices that have the potential to put the patient at risk are not under consideration. Such approaches are generally referred to as “alternative therapies”. The inclusive term complementary and alternative medicine is commonly used in this area, but readers will note that I am careful to always use only the term complementary therapy to clearly indicate the focus of this endeavour.

In my role as Manager, Wellness and Supportive Care in cancer services at Austin Health, my responsibilities extend to planning for the range of therapies that will be provided in the Wellness Centre of the Olivia Newton-John Cancer and Wellness Centre. My Churchill Fellowship enabled me to visit overseas cancer services and cancer centres to investigate how they had integrated complementary and supportive therapies into their care of people with cancer. I was particularly interested to see:

- the range of therapies available
- models of service delivery and staffing
- the evidence for their efficacy in the cancer setting
- strategies to facilitate integration with medical care including training and education
- the content of policies to ensure therapies are delivered safely and by appropriately qualified individuals
- methods for evaluating the effects of complementary and supportive therapies on quality of life & symptom relief

My experience of the UK and the USA was quite different and this is reflected in the structure of this report. The report opens with the lessons learnt and observations from the visits made in the UK, and secondly with those made during the USA visits. The emphasis in the report is on complementary therapies – a reflection of this being the area where the greatest learning opportunities existed.
The UK experience
In describing my experiences in the UK I will firstly describe complementary therapies, and secondly supportive therapies.

Complementary therapies in the UK - National level strategy
For good integration of complementary therapies to occur into mainstream cancer care, one of the most fundamental requirements is having sound governance in place to ensure that the highest standards of care are being provided by those who are appropriately qualified to provide them. So I was interested to discover that most of the services I visited were either in the process of developing policies on complementary therapies, or had recently completed them. I soon learnt that this was being driven by high level strategies in the National Health Service, and by a recently introduced voluntary regulatory body for complementary therapies.

Regulation of complementary therapies in the UK
As we have come to recognise in Australia, the complementary healthcare industry in the UK is diverse with a range of different membership bodies representing the various disciplines involved. In an unregulated industry such as this, it can be extremely difficult to verify the qualifications and experience held by therapists without seeking advice from a number of parties, which can be very time-consuming. In the UK a voluntary regulatory body was established in 2008 with Government funding and support. The function of the Complementary and Natural Healthcare Council (CNHC) is to enhance public protection by setting standards for registration with CNHC. To achieve registration recognised by CNHC, professional groups must demonstrate that the training provided to their members meets the National Occupational Standards and the core curriculum for the profession/discipline concerned (or the equivalent through experience). The Department of Health has recommended that, where CNHC registers the professional discipline in question, patients should consult with someone who is CNHC registered.

Professional groups currently regulated include Bowen Therapy, Hypnotherapy, Massage Therapy, Microsystems Acupuncture, Naturopathy, Reflexology, Shiatsu, Sports and Remedial Therapy and Yoga Therapy. In 2011, the register was due to open to practitioners of Reiki.

Whilst the emergence of the CNHC may be an important first step in safeguarding the public by accrediting practitioners and their qualifications, it does not provide evidence that a practitioner will be qualified to provide their particular discipline to patients within specific disease groups such as cancer. Mandating membership of this body was seen by some service providers as unnecessary if the individual practitioner was able to show other evidence of membership of an appropriate professional body together with a number of years’ experience in the community.

National level strategy
The organisation and practice of complementary and supportive therapies in the UK has been strongly influenced in recent years by a number of other national initiatives. Amongst the most influential is the National Institute for Health and Clinical Excellence (NICE) Guidance for Supportive and Palliative Care (2004). NICE provides guidance for the NHS on the most effective ways to treat diseases such as cancer. Amongst the recommendations made were that complementary therapies provided in NHS facilities be provided safely by trained practitioners who are sufficiently aware of clinical problems and psychological issues with which patients with cancer can present.

7 National Cancer Action Team - National Cancer Peer Review Programme. Evidence Guide for: Complementary Therapies Network

The peer review program is one of the key mechanisms employed by the National Cancer Action Team (NCAT) to promote quality of clinical teams and facilitate national benchmarking of cancer services delivery in the UK. The national peer review program measures for complementary therapy\textsuperscript{9}, are based on the NICE recommendations and have as their focus the clinical governance requirements for practitioners providing complementary therapies on NHS premises.

The measures include those for Network (regional) level and local (individual service) level. Examples of policies that were shared with me included:

- at network level - the South East and South West London Cancer Networks Criteria for complementary therapists (2011)
- at a local level the Dimbleby Cancer Care complementary therapies operational policy (2011).

**Network (regional) policy on complementary therapies**

This is inclusive of the criteria for practitioners providing services on NHS premises and covers the requirements for employed staff and volunteers. Of interest is the requirement of practitioners to provide written information for patients which states that their therapy is not an alternative method of tumour reduction to the conventional therapies (surgery, radiotherapy, chemotherapy etc.). Other criteria include: clearance (e.g. possession of professional indemnity insurance), qualifications, written informed consent.

Interestingly, the policy is also inclusive of practitioners whose names may be cited within patient information provided by a health service (implying endorsement of their service). In addition to the above criteria, the network require these individuals to also demonstrate the compliance of any equipment and materials used with relevant occupational health and safety standards.

**Local policy on complementary therapies**

In addition to maintaining a register of all endorsed practitioners including their relevant registration numbers with approved national bodies, the local policies were generally inclusive of the content described in Table 1 (below). Policies viewed were informed by the peer review measures and by the National Occupational Standards for complementary therapies. These are not unique to cancer and are developed and published by Skills for Health\textsuperscript{10,11} (the skills council for all health employers including the NHS).

**Management and governance of complementary therapy services in the NHS**

A variety of management/organisational models were encountered. Some services had appointed a Lead Complementary Therapist with responsibility for all aspects of management of the paid and volunteer complementary therapy (CT) staff. At the Royal Marsden this role is situated within the therapy services (extended allied health) division. The Dimbleby Centre has a CT coordinator reporting through the Dimbleby Cancer Care Manager to the lead cancer nurse. At The Christie, a clinical nurse specialist in complementary therapies manages the CT service, reporting through the nurse lead for clinical support services.

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\textsuperscript{10} \url{http://www.grcct.org/main/index.php?option=com_content&view=article&id=61&Itemid=68} Accessed Dec 27th 2011

\textsuperscript{11} \url{http://www.skillsforhealth.org.uk/} Accessed Dec 27th 2011
<table>
<thead>
<tr>
<th>Component</th>
<th>Descriptor</th>
</tr>
</thead>
</table>
| Rationale and principles        | Background & brief review of literature  
                                | Definitions  
                                | Qualifications to Practice  
                                | Competencies  
                                | Principles |
| Service provision               | Referral criteria  
                                | Patient access  
                                | Information provided to patients  
                                | Complementary therapies available  
                                | Benefits of complementary therapies (evidence) |
| Professional practice           | Management of complementary therapy service  
                                | Policy and Guidance Framework (OH&S, compliance with local health service staff policies) |
| Service delivery                | Informed consent  
                                | Confidentiality  
                                | Documentation  
                                | Data collection  
                                | Outcome measurement  
                                | Clinical audit & research  
                                | Equipment & materials  
                                | Treatment guidance |
| Complementary therapy guidelines| Guidelines for specific therapies provided |
| Complementary therapies for non-patients (staff and carers) | Guidelines |

**Table 1. Local health service policy on complementary therapies**

**Funding for complementary therapies**

The same issues face the funding of complementary therapy staff in the NHS as they do here in Australia, with many posts being funded through philanthropic organisations, charitable events or donations, short-term research funding or other revenue (for example the Christie in Manchester raises considerable revenue through its Integrative Therapies Training Unit). Posts that were Government funded, tended to be within well-established programs in which a limited set of evidence based complementary therapies had been provided over many years e.g. Royal Marsden, Dimbleby Centre, University College London Hospital.

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12 the peer review measure recommends that patients should be provided with a written consent form confirming that they have received appropriate information about the service they are to receive and have agreed to the therapy. In practice, if the therapy being provided has met with Network criteria (as stated in their policies), then verbal consent alone may be deemed sufficient.

13 there are no peer review measures around documentation but most services had developed standard complementary therapy referral and assessment forms and many kept their own patient records. There did not appear to be consistent documentation of CT’s in the patients’ central medical record.

14 The Christie has developed an Excel-based data collection system to capture: referral source, patient gender, indication for referral (anxiety, distress, pain etc.), tumour stream, CT provided and by whom, length of consultation, physical issues, patient feedback (free text).

15 although most Centres were not actively collecting outcome measures, the following tool was recommended by several services: MYCaW - Measure Yourself Concerns and Wellbeing: an individualised questionnaire for evaluating outcome in cancer support care that includes complementary therapies.
**Raising revenue from patient fees**

Almost exclusively the complementary and supportive therapy services observed in the UK were free of charge to patients and carers. At the Royal Marsden, a fee of £12 per 15 minutes is charged to private patients for massage. This may also occur in other situations, but wasn’t always canvassed by the author.

**Range of therapies offered**

The ‘core’ therapies offered in NHS settings were:

- Massage
- Aromatherapy
- Reflexology
- Relaxation and/or stress management (group-based)

The following therapies were provided in some, but not all centres:

- Acupuncture
- Hypnotherapy or autogenic training
- Art therapy
- Music therapy
- Reiki
- Natural healing
- Indian Head Massage.

Anecdotally, it appeared that the most popular complementary therapy with patients was reflexology or foot massage. There was speculation from staff that this might have been because it was readily accessible and didn’t require patients to remove clothing. True reflexology (based on the principle of reflex points which relate to all parts of the body), was infrequently provided – more often it was a professionally delivered foot massage.

**Service delivery models**

Table 2 describes a number of different service delivery models observed in the NHS hospitals. This is not an exhaustive list, but provides some options for consideration.

**Extension of existing roles**

Of interest to us here in Australia was the broadening of a number of traditional allied health and nursing roles to a more holistic role, combining existing skills with qualifications in a range of complementary therapies. While allied health and nurses are already overstretched in their “traditional” roles, this model does provide some options in relation to extension of existing, paid roles.

**Staffing/resourcing of complementary therapies – paid staff vs. volunteers**

A number of different models of resourcing of complementary therapists were observed. Most involved a mix of paid and volunteer staff (or students). These models were generally driven by the lack of availability of funds for paid staff, or by the availability of philanthropic or charitable monies for paid positions. What is interesting is how each model differs in its detail.

**Paid staff only**

The Royal Marsden Hospital employs paid staff only. There is a Lead Complementary Therapist who has been in post for 19 years and 6 part time massage therapists (equivalent to 2 EFT) across their 2 sites (Sutton and Chelsea). There is also a music therapist and art therapist. While all positions are paid, some are funded through philanthropy or charitable trusts. A strong view was held at the Marsden that complementary therapists had the same expectations placed on them as any other professional staff (get a professional qualification, undertake continuing professional education, work hard) and as such they should be remunerated as any other health professional. The benefits of this model included that the complementary
therapists were considered as an integral part of the multi-disciplinary team and that the same standards of professionalism could be expected of them as of any member of the team.

<table>
<thead>
<tr>
<th>Model</th>
<th>Characteristics</th>
<th>Hospital site(^{16})</th>
</tr>
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</table>
| Complementary therapist integrated into inpatient and outpatient settings | • highly visible in surgical, oncology wards and day oncology  
• welcomed into the ward environment  
• dressed in white clinical uniforms  
• have access to patient medical record  
• inter-professional referral and patient self-referral  
• most popular treatment given is foot massage and/or reflexology | • The Christie  
• Royal Marsden  
• UCLH                                                  |
| Immediate support on request               | • responsive to need wherever it occurs e.g. chemotherapy patient with high levels of anxiety or needle phobia, or ward patient with high level of distress | • The Christie CALM project\(^{17}\)  
• Proposed in the new Macmillan Cancer Centre at UCLH |
| On request/by appointment                  | • based in unit with dedicated rooms for treatments  
• primarily serviced out-patients  
• receptionist/admin role in place to make appointments  
• may be combined with ‘on request’ service to wards and day oncology | • Dimbleby Centre  
• Robert Ogden Macmillan Centre, Leeds |
| Drop-in clinic                             | • Twice a week open clinic from 4pm-7pm  
• just turn up and receive treatment from a complementary therapist (either a staff member or a trained volunteer)  
• Acupuncture and smoking cessation is available from 4-5pm  
• complementary therapies from 5-6pm  
• relaxation class from 6-7pm | • The Christie |
| Medical outpatient clinic model            | • GP or medical specialist referral required  
• integrative medicine assessment  
• 5 follow-up appointments with Dr Kassab (for homeopathy and other interventions)  
• up to 8 sessions of complementary or supportive therapies to relieve symptoms or manage side effects of treatment | • London Hospital for Integrated Medicine  
- Dr Sosie Kassab (Integrative Medicine Specialist) |
| Outreach First Aid                         | • Provided by clinical nurse specialists and other nursing staff (and volunteers where appropriate) trained in basic therapy skills to assist distressed patients | • Proposed in the new Macmillan Cancer Centre at UCLH |

\(^{16}\) list not exhaustive  
\(^{17}\) CALM project (charitable funded) is based in the Radiotherapy service and provides complementary therapies including hypnosis to patients exhibiting anxiety, panic and phobias related to challenging procedures such as cannulation, MRI scans & treatments involving facial masks
**Mixed model – paid staff and volunteers**

**London Hospital for Integrated Medicine** - most of the complementary therapy staff are health professionals (nurses and allied health) with additional qualifications in a complementary therapy. In addition to performing their ‘traditional’ roles, their scope of practice is extended to provide a more holistic range of interventions. For example:

- The senior Occupational Therapist who is trained to Masters’ level has undertaken additional training and is competent to conduct autogenic training, relaxation, anxiety management, runs the chronic fatigue service and has been instrumental in the establishment of a new service for insomnia.
- One of the medical staff is a trained medical and clinical hypnotherapist.
- The volunteer manager in the Trust is an aromatherapist.
- The physiotherapy service also offers acupuncture.

To supplement the services available and to extend the breadth of what they can offer to patients, some volunteer therapists are also ‘employed’ and provide art therapy, psychotherapy, healing, reflexology and massage. Experienced (paid) staff provide supervision, support and education to volunteer therapists. Potential benefits to the volunteer therapists include the teaching and experience provided and supervised access to a population who are sicker than they’d see in the community.

Some volunteers may become employees as funds and new positions become available.

**The Christie Hospital, Manchester** – A complementary therapy team is headed by an experienced individual who is a senior nurse with additional qualifications in a range of complementary therapies. A team of 6.7 EFT therapists is supplemented by up to 13 volunteer therapists. Most of the paid positions are funded through charitable or philanthropic sources.

As funds become available (average time was reported to be 9 months), complementary therapists working in a volunteer capacity are interviewed for a paid position. Some are in positions that are part-funded and part-voluntary. Due to funding constraints, complementary therapists are paid less than the ‘market rate’, but this appears to be a generally accepted position given the other benefits provided by working in this setting. Volunteer therapists are supervised by experienced paid staff and get discounted rates to attend an extensive range of continuing professional development courses held in the Integrative Therapies Training Unit.

**University College London Hospital** has an established complementary therapy service that has been running for 18 years and has a paid staff of 3.2 EFT including a head of complementary therapies. They provide predominantly aromatherapy, massage, Reiki and reflexology. Volunteer complementary therapists are used, but only in the Radiotherapy department. Volunteers are credentialed and supervised and required to work to the same standards as paid staff. The separation of the volunteer staff into the Radiotherapy service is considered to make this “mixed model” more workable, as the volunteers are less distributed, and paid staff do not perform the same roles in the same area.

At the **Dimbleby Centre** (based at St Thomas’ Hospital but servicing the Guy’s and St.Thomas’ hospitals) a team of 5EFT paid staff (supported by 1.5EFT administration staff) provide aromatherapy, massage, reflexology, group stress management and relaxation. This is supplemented by the use of volunteer therapists (currently 2 but has been up to 9) who provide a service of massage and reflexology for staff only. The investment in a service for staff is considered worthwhile on the basis that they go on to recommend complementary therapies to patients and carers.
Predominantly volunteer-provided complementary therapies

Robert Ogden Macmillan Centre at St James Hospital, Leeds ‘employs’ 60-70 volunteers of whom 23 provide complementary and supportive therapies. The Centre is located on the hospital site at some distance from the new Oncology Centre and operates as an information and resource centre in addition to providing complementary therapies. The Macmillan Information Centre at Robert Ogden has a manager, an information nurse specialist, an information officer, 2 part-time hair loss support workers, a supportive care administration coordinator and a part-time secretary.

Most of the complementary therapies are provided by volunteers under the supervision of an experienced complementary therapist who has a part-time paid role within the Hospital’s Oncology Unit and a voluntary role within the Robert Ogden Centre. The majority of volunteers are therapists - qualified to diploma level - who are undertaking advanced training in their discipline at a local training institution. They provide reflexology, Indian head massage, seated massage and aromatherapy. There are also 2 volunteer counsellors.

Education programs

Programs aimed at education of health professionals and complementary therapists were provided at the Marsden and The Christie. The Integrative Therapies Training Unit at The Christie warrants a special mention. An extensive range of conferences, courses and programs are offered throughout the year, including the opportunity to gain a ‘post graduate diploma’ awarded by the Unit itself. Examples of diploma packages include aromatherapy and cancer care, clinical reflexology, relaxation and creative imagery interventions and adapting complementary therapies for cancer care. Study days include acupressure for complementary therapists, hypnotherapy and acupuncture for acupuncturists working in hospice environments. Course fees help to fund the complementary therapy service provided at The Christie. The full list of courses is available at: http://www.christie.nhs.uk/media/98311/Brochure.pdf

Supportive therapies in the UK

Psycho-oncology and other supportive services

While most attention was given to complementary therapies, I also had the opportunity to observe models of psychological support for people with cancer, particularly in the UK. The NICE Guidance for Supportive and Palliative Care (2004) identified psychological and emotional issues as areas of significant unmet need. A four-level model of professional psychological assessment and intervention was recommended to be implemented in each Cancer Network (see Table 3). In this model, professional psychological support at Levels 1 and 2 should, in the first instance, be provided by health and social care professionals directly responsible for the care of people with cancer. More severe psychological distress (Levels 3 and 4) should be managed by a variety of psychological specialists, including counsellors, mental health nurses, clinical and health psychologists, psychotherapists and liaison psychiatrists.

Informed by the NICE Guidance, the national peer review measures for psychological support have challenged cancer services to demonstrate provision of supportive care within this 4-tiered framework. At Network (regional) level, there is the requirement for a single named lead for psychological support (psychologist or psychiatrist).

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Table 3  NICE four-tier model of psychological support in cancer care.

<table>
<thead>
<tr>
<th>Level</th>
<th>Group</th>
<th>Assessment</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>All Health and Social Care Professionals</td>
<td>Recognition of Psychological Needs</td>
<td>Effective information giving, compassionate communication and General Psychological Support</td>
</tr>
<tr>
<td>2</td>
<td>Health and Social Care Professionals with additional experience</td>
<td>Screening of Psychological Distress</td>
<td>Psychological techniques such as Problem Solving</td>
</tr>
<tr>
<td>3</td>
<td>Trained and accredited Professionals</td>
<td>Assessment of Psychological Distress and Diagnosis of some Psychopathology</td>
<td>Counselling and specific psychological interventions such as anxiety management and solution-focused therapy, delivered according to an explicit theoretical framework</td>
</tr>
<tr>
<td>4</td>
<td>Mental Health Specialists</td>
<td>Diagnosis of Psychopathology</td>
<td>Specialist psychological and psychiatric interventions such as psychotherapy, including cognitive behavioural therapy (CBT)</td>
</tr>
</tbody>
</table>

This position chairs a network expert group across the network that oversees implementation of the measures including:

- Screening of cancer patients and carers by level 1 and level 2 staff
- Training and professional support for level 2 (non-psychological) practitioners (note that the measures require all multidisciplinary cancer care meetings to have at least one health professional trained to level 2 present to identify referrals)
- Induction program for level 3 practitioners who come from a non-cancer background
- Referral guidelines for health professionals
- Development of psychological support section of local cancer services directories

In addition, the measures require Networks to undergo a service needs assessment. This is expressed as the difference between a baseline service mapping of current services, and a service specification (*the quantifiable amount of service provision that is required to support cancer and palliative care psychological needs in the network*). A service development strategy (updated every 3 years) is then developed describing how the network plans to implement the required service as described in the service specification. This includes a training and education strategy.

At Imperial College Healthcare Trust, London, the Manager of Clinical Psychology (who is also the Psychology Lead for the network) shared the Network guidelines for referral to clinical psychology and counselling for adults with cancer.
These clearly state the expected process for:

- Screening patients for distress
- Indicators for referral
- The range of services provided
- The process for making a referral (including explanation of the triage process)

At the St James Oncology Unit in Leeds, the lead Clinical Psychologist shared details of the locality referral protocol & guidelines (they are part of the Yorkshire Cancer Network), and the training program developed for level 2 health professionals (predominantly nurses). The program is provided for three days over a three month period and also includes four individual and one group supervision sessions. It aims to train CNS level nurses to:

- Assess & screen for general psychological well-being at key points in pathway
- Offer supportive interventions & advice, provide psycho-educational and problem solving techniques
- Ensure that physical health care is delivered in a way that minimises psychological; distress and trauma
- Access regular supervision & training

Note that as a pre-requisite, those undertaking the programme must be a clinical nurse specialist and have undertaken an advanced communication skills 3 day course and have a knowledge of cancer, its treatment and palliative care.

**Holistic Needs Assessment (HNA)**

Many of the health services visited were in the process of implementing a holistic needs assessment (in Australia this is more commonly referred to as the supportive care needs assessment). This is also in response to the NICE guidance (2004) which recommended that the psychological well-being of patients and carers should be explicitly assessed at key points in the patient pathway - including around the time of diagnosis, during treatment, as treatment ends and at the time of recurrence. Health professionals trained to a level 2 are identified as having the skills required to screen for anxiety and distress. The Nurse Consultant (Living with and Beyond Cancer), has responsibility for introducing the HNA at the Royal Marsden Hospital. The aim is to screen every patient throughout the care pathway using a modified version of the Distress Thermometer\(^{19}\). The modifications made by the team include a re-naming of the tool to “Concerns thermometer” – a term considered more acceptable by patients.

**Advanced communication skills**

Again, in accordance with the NICE Supportive and Palliative Care Guidance (2004), a national communication skills training programme has been developed for the NHS by leaders in the field and has received support from Cancer Research UK and Marie Curie Cancer Care. The program is known as “Connected” and is managed by a team based at NCAT and delivered through the local cancer networks. The training courses are offered over three days and teach advanced communication skills to senior cancer health professionals working with patients in England. These individuals then become trainers in their own organisations.

Information and Resource Centres
A number of information centres were visited. Some were integrated into the cancer service area, while others were in adjacent buildings. They included:

- Charing Cross Hospital Macmillan Information Centre
- King's College Hospital Macmillan Information & Support Centre
- Dimbleby Information Centre, St Thomas’ Hospital
- University College London Hospitals, Macmillan Information & Support Centre
- Patient Advice and Liaison Service (PALS) and Patient Information Service, Royal Marsden Hospital
- Robert Ogden Macmillan Centre, St James’ University Hospital Leeds
- Cancer Information Centre, The Christie, Manchester.

All centres were staffed by health professionals supported by volunteers. Macmillan have provided funding to establish a number of the centres – generally this is for an initial period of 3 years, after which funding is taken over by the health service in which the Centre has been established. The Macmillan service is confidential, and operated around a “drop-in” philosophy, working only with what the patient wants to know at the time. Nothing is documented about the nature of the intervention and no identifiable demographic details are taken from the patient/carer. The information specialist will follow up patients’ queries with members of the cancer care team but only when the patient authorises them to do so. The confidential nature of the service is considered essential to the integrity of the service in enabling those affected by cancer to approach the service with absolute confidence. The following are key points about the Macmillan Centres:

- At minimum the Centres are staffed by one full time cancer information specialist (dependent on service volumes and budget)- nurse or allied health by background, and volunteers
- Some were only open for limited hours – organised around out-patient clinic times with bookable appointments to meet with information specialist
- All Centres provided access to a computer and printer. Computer access was generally allowed for patients and carers to access e-mail accounts. Cancer information access only available through established portals to ensure only reliable information sourced.
- Volunteers roles varied but included:
  - meet and greet, make a cup of tea
  - offering a brochure about the service to all new in patients and day patients in chemotherapy and radiotherapy
  - provide “first line” of information and support, especially around Government benefits
  - refer on to information specialist as required
  - stocking and ordering of materials
- Volunteer training was not standardised but generally comprised around 4-6 sessions including what is cancer, talking to people with cancer, information provision, know your boundaries. Training was sometimes supplemented by structured observation and by the training program offered to volunteers within the host organisation.
- Macmillan have guidelines for recruitment of volunteers including a ‘2 year rule’ – indicating that volunteers who have had a cancer experience themselves must be a

20 The Macmillan charity was founded in 1911 and is a source of support for people affected by cancer and their carers, families and communities. They also fund nurses and other specialist health care professionals and build cancer care centres.

http://www.macmillan.org.uk/Aboutus/WhatWeDo/What_we_do.aspx
minimum of 2 years post-bereavement or post-treatment (including oral hormone treatments)

**Information and information prescriptions**

All the Centres stock the full range of literature published by Macmillan and other cancer charities. This is supplemented by information on local services. A source of key information on conditions, services and care, *Information Prescriptions* (IP) are a recent innovation that is being trialled in Centres across England. IPs tell patients and carers about their condition and treatment options, support services available, benefits support and local and national self help and support groups. It also tells patients where to find out more information, with contact details and website addresses that they might find useful. An initiative of NCAT, information prescriptions draw from patient information pulled together from a wide range of cancer charities including Macmillan Cancer Support, Cancer Research UK, the Prostate Cancer Charity, Breast Cancer Care and Breakthrough Breast Cancer. All the information has been approved by NHS clinicians and patients for inclusion into the National cancer patient information pathways.

IP’s can be dispensed `on the spot’ either from the patient’s own PC, or from the local information centre. They can be downloaded in a variety of formats, including verbal, booklets, leaflets and via an interactive Information prescription system. With the patient’s consent they can be sent via email (direct to the patient, carer or an appropriate information centre), or by post.

**Some observations on information centres** –

- A number of Centres were located at a distance from the hospital services from which they “draw” their customers. While this could be seen as an advantage (a non-hospital environment), the distance was generally acknowledged as a barrier to reaching the target population. In some settings this had resulted in the establishment of more than one cancer information service, sometimes run by different organisations e.g. one run under the auspices of the local cancer network or a cancer charity, another run by Macmillan.
- Most identified the need to have a reason to bring patients to the Centre, or to coax them across the threshold. Volunteers helped with this, as did organised morning teas or events around particular topics, or simply having access to the internet and a printer
- Relationship building between the Cancer Information Specialist and the Cancer Nurse Specialists was critical to patients being referred to the Centres
- Promotion of the information service by the Information Specialist through attendance at multidisciplinary meetings and presentations at in-services for cancer care teams was seen as essential
- A model of nurse (CNS) induction in the information centre was seen as a positive move towards integration of the Centre into the patient pathway

**Support groups**

Often linked to the information centres and to the role of the Clinical Nurse Specialists, support groups in the UK appeared very active. The Cancer Network structure within the UK offers an opportunity for patients and carers to access a greater range of support groups within a geographical area, and provides a critical mass for low incidence cancers. At the Dimbleby Centre in Central London there was a support group for most of the main cancers – most meeting monthly in the middle of the day. All of the groups are professionally led, with some being co-facilitated by members of the psychological support or information service team. The Robert Ogden Macmillan Centre in Leeds provided a meeting place for a range of support groups.

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22 [http://www.nhs.uk/ipg/Pages/IPStart.aspx](http://www.nhs.uk/ipg/Pages/IPStart.aspx) accessed on 17th January 2012
Look Good, Feel Better and Living with Cancer programs were also widely offered.

**Of special note...**

In this final section of the report on the UK experience, I have included a number of observations that have not been mentioned elsewhere, but which are important in the discussion around how complementary and supportive therapies become integrated into mainstream care.

**Consumer engagement**

Reflecting one of the key principles of the UK’s strategy for cancer which is to put the patient or service user at the heart of the public services using the principle of “no decision about me without me”, I saw a number of examples of initiatives aimed at giving patients this voice. The VIVA program at St. James’ in Leeds (Voices, Information, Volunteers, Arts and Environment) was one such example. The program has initiated the Leeds Cancer Partnership Group with a membership comprising staff, patients, carers and ex-patients. The aim is to establish 2-way communication between cancer services and their customers and focuses on aspects of service requiring improvement and on new program proposals.

Experience based co-design (EBCD) is a new methodology which places the patient experience at the centre of service development. There are two components to EBCD - a user-centred orientation which adopts a narrative storytelling approach with patients who have experienced cancer care, and a collaborative change process involving staff and patients which allows staff to ‘see the person in the patient’ and respond to the issues they raise in a constructive manner to improve services. This was particularly evident in the renovated Day Oncology Centre at Guy’s Hospital in London, where many design features including art works and poetry that were the product of an artist and a poet in residence, and the configuration of clinical areas had been directed by the EBCD process.

I also saw evidence of a similar movement in the US. At the City of Hope in LA, the Patient and family advisory council comprised 20-25 members, co-chaired by a cancer survivor and the director of supportive care programs. The group has assisted with development of orientation program, process improvement ‘targets’ and reducing waiting times for chemotherapy. People are recruited to the advisory through articles in newsletters, letters to physicians seeking suitable candidates and through support groups.

**The Maggie’s Centre model**

The Fellowship trip would not have been complete without a visit to the Maggie’s Centre in London. Maggie’s is a unique model of psychosocial support. Their vision is to “transform the way that people live with cancer.... We want everyone in the UK who is affected by cancer to have access to our high quality, evidence based psychological, emotional and informational support”.

Consistent with the Maggie’s philosophy, the Centre is an architecturally designed orange cube in a garden setting situated in the grounds of Charing Cross Hospital – deliberately not integrated with the hospital.

All Maggie’s Centres are built with sensitivity to how the physical environment can affect individual well-being. The London Centre has a very contemporary feel with polished concrete floors and a number of different open-plan spaces. The “hub” of the Centre is the kitchen space with a brightly coloured bench, open shelving and a casual kitchen table. Some informal quiet

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24 [http://www.maggiescentres.org/about/our_purpose_vision.html](http://www.maggiescentres.org/about/our_purpose_vision.html) accessed on January 17th 2012
spaces are created with the clever use of book shelves and rugs, and the seating is boldly coloured, modern but comfortable. There is a sense of “bringing the outdoors indoors” with greenery visible at every turn, and sheltered outdoor spaces in which to find sanctuary.

The core program and philosophy at Maggie’s program is one of support which includes practical information, psychological and emotional support, stress and distress management and help to make choices to live differently. The manager stressed the value of the psychological approach which starts from the minute someone works through door and is greeted by a staff member. The focus is on normalisation of feelings and responses, and most people visiting the Centre are offered at least one appointment with the resident psychologist. There is a guiding principle of self-empowerment, with the Maggie’s staff helping people to set small achievable goals and using their knowledge of the healthcare system to help people find a solution. In this context, complementary therapies such as massage are considered to be an intervention (which has its place) but users are encouraged not to become dependent on them.

The organic nature of the group programs was emphasised. They vary the program according to the needs of their users and prefer to run courses rather than support groups as they are better attended. One example is the “where now?” course which runs for 6 weeks and people can join at any time. Following the success of this group, a “where now” graduate group has been established.

The US experience

Following two weeks of virtual immersion within the NHS, I was ready to experience health care in the USA, where all the facilities I visited were owned and operated by the private sector. Within this system most services are provided on a fee for service basis in which the hospitals and/or the doctors are funded by payments from patients and insurance plans.

Most of the Centres selected were major standalone cancer centres with significant integrative medicine programs with a strong research profile in the field. Because of the diversity of the models experienced, I have chosen to organise this section by each organisation visited, and to highlight key points of interest.

Integrative Medicine Service, Memorial Sloan Kettering Cancer Center, New York

MSKCC is one of the world’s best known cancer centres in the world – spread across 40 buildings in New York City. The Integrative Medicine Service (IMS) is located at the Bendheim Center – a converted bank building a couple of blocks from the main in-patient building. The IMS offers acupuncture, massage, meditation, music therapy, nutrition, advice on herbal supplements, yoga and a range of fitness classes. The service is well-known for its “About herbs” website which provides current and objective information for oncologists and health professionals on constituents, adverse effects and potential benefits of herbs and botanicals.

The visit centred around a consultation with the Director, Barrie Cassileth PhD, about establishing an integrative oncology service. The following is a summary of her advice:

**Service establishment**

- Make a strong start with therapies where the benefits are well documented e.g. music therapy - everything you provide has to be rationale and evidence-based
- Be clear about the expected endpoints and communicate up front that “these therapies do not shrink tumours”
- Establish the service before getting into research and always collaborate with senior oncology staff
- Structure of the program needs to sit within the oncologists’ conceptual framework e.g. structured around clinical/research/education & training
- Presentations to ‘faculty’ or Grand Rounds by senior person in Integrative Oncology help to raise profile and provide evidence based information
• Describe what you're **not** doing more than what you are doing e.g. NOT Reiki. This provides confidence

**Professional standards**

• Make sure massage therapists have training with oncology patients
• Is good to have complementary therapists who have Western medicine background e.g. nurses, physios, etc.
• Advises against naturopathy, chiropractors and homeopathy
• Acupuncture – don’t ever see patients because they're interested – get staff to refer them.

**Outcome measures and research**

• Start by collaborating with existing trials/research. Find a research question important to you and which is beneficial politically and clinically e.g. acupuncture and pain management
• Bring in additional people to do research e.g. a biostatistician
• Publish in medical literature not the integrative medicine literature
• Measuring outcomes: Record what patients and family members say and use that. Also nurses on the floor – ask them to report what they observed in patients. It helps to engage them
• Use internationally recognised Quality of Life tools

**Funding and revenue generation**

• You will need to seek funds internally and through philanthropy.
• People will value service if you charge for it - do some things in groups to make charges lower e.g. community acupuncture group program – 6 patients at a time
• Make services available to patients, staff and carers
• Pay your staff - can’t have volunteers do work of professional people

**M.D. Anderson Cancer Centre (University of Texas)**

I attended the 4 day **observer program in integrative oncology**. MDA is the largest free standing cancer centre in the world, providing cancer care for approximately 33,000 new cancer patients per annum. This is virtually 10 times the number of new cancer patients treated at the Austin Hospital. There are 17,000 employees and a volunteer corps of 1300. With its clever trademarked buy-line “making cancer history”, MDA is one of 40 National Cancer Institute-designated comprehensive cancer centres in the US and has ranked as one of the top two hospitals for cancer care in the USA for 20 years. They have an impressive program of patient care, research, education and cancer prevention programs.

Of interest is that MDA have recently re-badged their program from *Place…of wellness*, to Integrative Medicine Center. This was explained by the medical director as better reflecting the evidence-based nature of the program and that it makes use of all available therapeutic approaches and providers to achieve optimal health and healing. Their model aims to provide benefits in quality of life, improved functional status and recovery from cancer and cancer treatment, reduction in recurrence and increased survival.

A medical referral is required to the integrative medicine (IM) consultation service where the patient will be assessed by an integrative oncology specialist. Most of the individual therapies offered e.g. acupuncture and massage, require a medical referral (but not necessarily via integrative oncology) and are provide only evidence-based interventions. The group programs do not require a medical referral.

**Steps to achieving an integrated approach**

Factors which contributed to the integrated approach that were observed here included:

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25 US News and World Report “America’s Best Hospitals”
• Leadership of the Integrative Medicine Program provided by a dual team of Professor/Director and a Medical Director (Assistant Professor). The Director, Professor Lorenzo Cohen, is a founding member of the Society for Integrative Oncology and his research focus is on the biobehavioural effects of complementary therapies. A/Professor Richard Lee is a medical doctor qualified in oncology/haematology and palliative care who has also studied Traditional Chinese Medicine with an emphasis on acupuncture.
• They have a clearly defined model of IM which is promoted by the entire team and used in all their presentations.
• There are three clear components to the IM program
  1. the clinical program which comprises group and individual therapies including: acupuncture, oncology massage, music therapy, meditation, nutrition, mind-spirit programs e.g. aromatherapy & self-massage, centering prayer, music for relaxation, yoga, physical programs e.g. Pilates, Feldenkrais, support groups, social activities including laughter yoga, expressive arts, singing groups
  2. the research program which is focused on
     ▪ the bio-behavioural effects of mind/body-based interventions,
     ▪ the anti-cancer potential of natural animal or plant compounds such as dietary supplements, vitamins and herbal remedies
     ▪ acupuncture to treat some common cancer treatment related side effects including pain, xerostomia, nausea and others
     ▪ examining traditional Chinese medicine (TCM) for cancer. There is a collaboration with Fudan University, Cancer Hospital, Shanghai
  3. the education program for patients, carers, and internal and external health professional audience including:
     ▪ monthly education series for staff and faculty including lecture series with invited speakers, research club & complementary and integrative medicine courses designed to provide an overview of a the major therapies offered
     ▪ an annual integrative medicine oncology training conference for licensed acupuncturists, massage therapists and yoga teachers on evidence-based cancer care
     ▪ clinical rotations in IM are offered to medical students and medical residents
     ▪ MDA’s own Complementary and Integrative Medicine Education Resources (CIMER) website (consumer and health professional versions) providing educational resources on complementary medicine. Includes access to the Natural Medicines Comprehensive Database (NMCD) (an interactive resource for information on herbs, dietary supplements, alternative systems of medicine, vitamin and mineral ingredients of currently available natural medicines).
     ▪ significant range of patient education resources are available in multiple modalities
     ▪ regular classes for patients and caregivers on “high demand” topics run regularly and are free of charge. These include new patient orientation, bowel management, cancer fatigue, side effects, diabetes and cancer, ask the expert (in a given tumour stream or on a topic such as pain management, fertility)
     ▪ PIKNIC series (Partners In Knowledge News In Cancer) – regular lunchtime program provided by MDA staff, and organised by volunteer services. Covers topics such as depression, lifestyle management, life after cancer etc.
     ▪ Regular Caregivers programs called “I’ve got feelings too”
Other features of the MDA program that contributed to their integrated model included:

- there is a weekly team meeting of the IM clinic team to discuss cases
- a newsletter with a research focus is attached to the monthly IM program that is circulated widely
- myMDAnderson patient website enables patients to log in and view their personal health record including test results to which they have access, schedule appointments, get directions and exchange secure messages with their care team

Cancer Treatment Centers of America - Eastern Region, Philadelphia

The main observations from this visit were about the application of a different model of integrative medicine, and an underpinning business model that drove a strong work culture and ethic.

CTCA is a private, for-profit operator of cancer treatment hospitals providing an integrative approach to cancer treatment. There are 4 CTCA’s across America and a fifth is due to open in September 2012. The approach brings together the standard medical disciplines (surgery, chemotherapy, radiotherapy) with a range of complementary treatments under their model of ‘patient empowered care’ (PEC). At every turn the empowered patient checklist is prominently displayed asking patients “have we addressed all your concerns”, “have we fully explained your treatment to you?” “have you asked us how we can improve your quality of life?”.

The core treating team in PEC comprises a medical oncologist, a naturopathic physician, a nutritionist and care manager. Further support is provided by an extended medical and supportive care team – physical therapist, occupational therapist, speech and language therapist, massage, acupuncture, chiropractor, pain management, Reiki, spiritual support, psychoneuroimmunology (mind body medicine team), psychiatry. The role of the naturopathic doctor is to manage side effects, to provide immune support, to prescribe natural supplements to help conventional therapy work better and to advise on drug and herb interaction.

The core PEC team work in a multidisciplinary manner within the same physical location – meaning that the patient can stay in one room while the core team carry out their multidisciplinary assessments sequentially. The initial assessment period is 72 hours after which the patient and family are presented with a treatment plan, and they decide whether they will proceed.

Patients attending the Centre mostly have stage 3 or 4 disease and on average have been to 3 facilities before finding their way here. The average distance travelled to attend the hospital is 300-500 miles.

There is a strong focus on the values of CTCA as an organisation, and it is these (hope, joy and pride) together with a commitment to the integrative approach that guide recruitment of all staff. All employees are referred to as ‘stakeholders’ – on the basis that if you treat people like owners they’ll make decisions in the best interests of the organisation. Employees are expected to adopt lean six sigma thinking – the best practice methodology for business improvement – and to come up with creative solutions to help patients and improve performance. There’s an annual performance related bonus which is based on how departments and individuals did in meeting their annual goals.

And an emphasis on organisational culture is driven by their trademarked Mother Standard® of care, meaning their “entire focus is driven by ... the kind of care we would want for our own family members”.

Integrative medicine program, City of Hope Cancer Center, Los Angeles

City of Hope occupies a park-like campus north-east of Los Angeles, in the lee of the San Gabriel mountains, and is one of the National Cancer Institute’s designated Comprehensive Cancer Centers.

Led by multidisciplinary teams of professionals and volunteers, the Sheri & Les Biller Patient and Family Resource Center is the main focus for the integrative medicine program at the City of Hope. It was opened in 2008 and provides a ‘hub’ for supportive care connections to all 80 health professionals in supportive care. These include patient navigators, pain management specialists, psychiatrists, psychologists, social workers, spiritual care providers, healing arts workshops, peer support groups, health information, Positive Image Center, complementary medicine, nutrition education. The Center occupies prime real estate at the front of hospital and is designed to send a message of compassionate care from the moment the patient enters the hospital.

The services provided here come within the domain of the Department of Supportive Care (SC) Medicine which is led by Professor Matt Loscalzo. Established three years ago, Professor Loscalzo’s model has challenged traditional boundaries between health professional groups by seeking to work in a more integrated manner. At the heart of this is the pursuit of patient-centred care rather than profession-centred care (the distinction here being that patient needs determine the way that health professionals provide services, rather than services provided being dictated by historical models and boundaries between disciplines).

A twice-daily patient orientation class is held in the Center for new patients and carers as part of their first appointment (there are 50 new pts per day on average). 10 facilitators have been trained, and the content standardised to include tour of the facility, resources available, how to talk to your doctor, taking notes, advanced directives, hand hygiene. All new employees also come through as part of their orientation to the organisation.

Matt Loscalzo and team are well known on the international stage for their electronic supportive care screening program “Support screen” available on touchscreens in out-patient areas. Working closely with patients and carers, the questions and response options have been developed through extensive consumer consultation and are tailored for each clinic or tumour stream. Their research has shown that the initial screen is most effective if conducted on the second visit when patients are less stressed than at time of initial diagnosis. This screening process is one of the entry points for referral to the range of supportive care services available through the Sheri & Les Biller Patient and Family Resource Center.

Of interest to observe was the new role of health program evaluator/health educator which is seen as vital to supporting the development of new programs that meet patient and family needs, and in collecting data on the programs already running, to demonstrate viability and effectiveness. Key features of the role:

- Conducts regular needs assessment on specific patient groups resulting in more tailored approaches e.g. a new class developed “problem solving, coping and communication” – content includes advanced directives, holding difficult conversations, and how to ask for help when you need it.
- Every program gets evaluated with data collected weekly or daily. Data useful when preparing grant applications. They are able to claim that their programs are 95% effective e.g. breathing and meditation, yoga.
- Provide a “ballot box” at exit to group room to return evaluations
- All introductory slides for a presentation must state that evaluation is part of the process
Eighth International Conference of Society for Integrative Oncology Annual Conference
I was able to time my Fellowship to attend this conference in Cleveland, Ohio. Apart from the value of networking with 300 participants from around the world, three key themes emerged from the conference to inform the Fellowship. These were:

**What it takes to get a sustainable integrative medicine program off the ground**
A number of presentations and discussion sessions explored this topic. Commonly mentioned were the following:
1. Achieving physician buy-in: multidisciplinary co-ordination, tolerance for supportive and complementary therapies
2. Development of academic and research programs to support training in supportive oncology and development of research
3. Financial support from Government and the community

**A variety of interventions or models for consideration and further exploration**
- **CAMEO** complementary medicine education and outcomes – Lynda Balneaves’ work on development of training and information about complementary and alternative medicine for health care providers and patients through a collaboration between University of British Columbia school of nursing and British Columbia Cancer agency.
- **Reiki** outcome evaluation – elegant and replicable study of Reiki for cancer patients by Dr Jun Mao and Kimberley Fleischer (Reiki Master and Masters in education) from University of Pennsylvania

**Psychoneuroimmunology**
It is becoming possible to measure the biobehavioural impact of complementary and supportive therapies on the individual – thus providing the possibility of objective evidence of the impact of mind-body therapies. Psychoneuroimmunology investigates the relationships between behaviour, psychosocial factors, the nervous, endocrine, and immune systems, and disease. Examples included Barbara Andersen’s study\(^{26}\) that reported a relationship between a stress reduction program for breast cancer patients and improved T cell immunity. Jeffery Dusek’s work at the Penny George Institute\(^{27}\) is investigating whether mind/body therapies can be explored through gene expression, with the goal to find whether there are some genes that help us identify who will benefit from certain interventions.

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\(^{26}\) Andersen, B. Ohio State University  
\(^{27}\) Dusek, J.A. Director of Research, Abbott NorthWestern Hospital, Penny George Institute for Health and Healing.
Conclusions

The fellowship exposed me to a wide range of experiences and ideas. It reminded me that we are all struggling to provide the best possible care to patients, often within unsuitable accommodation, on a shoestring budget or with minimal resources. I was inspired by many of the people I met – some for their vision, some for their clinical expertise, many for their passion. It was impossible to overlook the influence of the ground-breaking work being conducted within the NHS – specifically its national cancer peer review program. It was clear that these evidence-based measures were a very significant driver of practice improvement and change. There must be a role for national and state government agencies in Australia to establish and incentivise good practice care in complementary therapies, but for this to happen there has to be mechanism to agree on what constitutes good practice in the Australian context. Starting in the same place as the NHS - with governance principles around the employment of complementary therapists - may be a good place to start.

The aim of the fellowship was specifically to inform the integration of complementary and supportive therapies with conventional cancer care. It made me reconsider what integration entails. I observed that the most effective models of integrated care were underpinned by some or all of the following:

- high level policy based on the evidence base to give credence to the role of complementary and supportive therapies and drive service development and integration
- a regulatory system to establish standards of professional practice in complementary therapies, and to safeguard the public
- sustainable funding streams
- organisational commitment with appropriate organisational structures and policies
- strong clinical leadership
- an integrated medicine team with a strong identity and a values base that creates a culture within the organisation of patient empowerment and staff commitment
- a model that clearly depicts the services involved in an integrated approach, and their relationships
- integration of research into clinical practice, commencing with internal collaborations
- a commitment to consumer involvement in service planning and improvement, and to good customer service (similar to the motion of patient empowered care)
- a program of professional education to upskill complementary therapists in the specific needs of people with cancer
- access to extensive web-based resources for patients, families, staff and external users

I was particularly drawn to models in which complementary therapies were integrated with supportive care (generally provided by allied health professionals and specialist nurses) to create an integrated care approach. This saw complementary therapists working as members of an extended multidisciplinary cancer care team alongside medical staff, allied health professionals and nurses to enhance outcomes and add value to the patient experience. It also provided opportunity for allied health professionals and nursing staff with additional qualifications in a complementary therapy e.g. massage, to extend their scope of practice.

In the USA, the term “integrative medicine or integrative oncology” has been adopted in Centres where there is combined medical and integrative therapies leadership and a strong research profile. One of these Centers had recently changed its name from Place…of wellness to Integrative Medicine Center – a move thought to better reflect the stature of the service and its commitment to evidence based care. This is something to consider as the program within the Olivia Newton-John Cancer and Wellness Centre (ONJCWC) matures.
Those integrated services that were well-established and enjoyed a good reputation were generally structured around the three traditional functions of a teaching hospital – clinical service delivery, education (patients, health professionals, complementary therapists) and research.

The culture of an organisation is driven by well-articulated values which are at the core of the service provided, and reflected in the way the service is experienced by patients and families. I was struck by the commitment of the staff at The Cancer Treatment Centers of America to the core values of that organisation (hope, joy, pride), and to their dedication to the model of patient empowered care and the mother standard. Without a doubt it is easier to implement such things in a private organisation, particularly where financial incentives exist for performance consistent with organisational goals. However the principle of establishing and living by a set of shared values which enhance patient care, is something we can take from this example.

I have learnt that we are on the right track in the development of the wellness program for the ONJCWC (and indeed with other Centres around Australia) with some of the above factors already in place. Oncology massage (which will lead our new suite of complementary therapies) was available almost everywhere I visited on the Fellowship, and in some places had been safely provided for almost 20 years. I hope this will provide a greater level of confidence to those that remain concerned about the potential risks of introducing new modalities such as these. The approach we are adopting that will result in the up-skilling of already qualified massage therapists to be competent to meet the needs of people with cancer, was internationally endorsed and is a model we should continue as we introduce other complementary therapies.

Except in the USA which has a ‘user-pays’ system, health services struggled to fund complementary therapy services. In this less-than-ideal situation, some services have ‘employed’ volunteer complementary therapists to supplement the work of those therapists who are in the few paid positions. I encountered a variety of opinions on this mixed model – from those who were stringently against it, to those who actively embraced it. I came home with a more moderate view than I left with – I observed that a mixed model could work in circumstances where the same standards of practice are expected from volunteers as they are from paid staff, where volunteer-provided services are provided in one location with strict supervision from trained (paid) staff and where the volunteers enabled a breadth of service to be provided that might not otherwise have been possible e.g. in providing massage to carers and staff. Carers are often the forgotten ones in great need of therapies to help them manage their anxiety and distress, and staff who have experienced the benefits of complementary therapies are more likely to recommend them to patients, which in turn assists in the establishment and uptake of new services.
**Recommendations**

**At a national and/or state-wide level**
- Lobby for the development of a regulatory body for complementary therapies in health care (similar to the CNHC) to provide a consistent regulatory framework to guide health services
- Develop national or state-wide guidelines on complementary therapies in the health care setting - commencing with clinical governance requirements that should be applied to complementary therapies being provided to cancer patients within public health services
- Work with government and non-government agencies to promote the role of evidence based integrative and supportive therapies as part of mainstream cancer care, and to establish sustainable funding streams
- Establish a collaborative of national cancer service providers with an interest in developing integrative medicine programs

**Organisational level**
- Develop a strong model for wellness and supportive care which can be visually depicted and which becomes the reference point for the organisation and the people who work within it
- Consider introduction of an integrated care program which brings together supportive care providers and complementary therapists within the same governance structure. This will create an extended multidisciplinary cancer care team which can offer patients and families an increased breadth of options and evidence-based approaches
- Develop a culture within the service which is based on a set of values developed by patients, carers and staff
- Develop a detailed business model and service plan for the ONJCWC wellness and supportive care program.
- Identify potential funding sources for all or part of the service and make application for funds
- Take steps to ensure mechanisms for consumer advice and feedback are in place, and become part of standard practice in service development, implementation and evaluation
- Establish a program structure around the three components of clinical service delivery, education (patients, health professionals, complementary therapists) and research
- Develop local policies on the provision of complementary therapies within an organisation or institution. These should include:
  - Service rationale, service objectives, therapists’ regulation and registration, scope of work, professional practice, service delivery (including informed consent, documentation and data collection), referral and assessment, record keeping & data collection
- Develop an organisational position on the use of volunteer therapists and develop policies to support this
- Collect data to inform current and future service provision and configuration. Data to include demographics, cancer type, indication for intervention, treatment provided, service provider, location & duration of treatment, outcome measure

**Clinical service delivery**
- Build an integrative program around evidence-based treatments that will be provided on a 1:1 and a group basis
- In collaboration with patient and carers, develop and implement new models of service delivery to meet a range of needs in a variety of settings e.g. the outreach first aid model of stress management, a ward-based or day centre based massage service, new patient orientation programs and ‘ask the expert’ sessions (in a given tumour stream or on a topic such as pain management, fertility)
- Develop an extended carer program based on evidence and on consultation with carers
• Evaluate therapies and programs and develop an evidence base by:
  o Identifying appropriate program evaluation and outcome measurement tools which are internationally recognised
  o Making evaluation a key component of all programs offered
  o Collecting feedback from patients, carers and staff and using it to make the case for new services and further funding

• Consider models which enable paid and volunteer complementary therapy staff to contribute to the supportive therapies program. These might include:
  o Developing a business model for external practitioners to provide therapies within the wellness centre
  o Using volunteer therapists who meet credentialing standards to provide complementary therapies such as massage to staff and carers

• Maximise application of skills of existing health professionals by identifying those people with additional qualifications and assess suitability for role extension and implications for scope of practice

Education
Health professionals:
• Establish a professional development program in integrated medicine, drawing on internal and invited speakers with expertise in the field. Record these presentations and make available through an updated and expanded website
• Consider opportunities to become an education provider for complementary therapists and others wishing to upgrade skills to become oncology service providers
• Establish orientation/education for junior medical staff, students of allied health professions and nursing and all new staff to cancer services
• Expand communication skills training for staff by drawing on the skills of internal experts and training additional “trainers”

Patients:
• Consider an orientation session (face to face and/or on-line) for all new patients
• Further develop wellness and supportive care website to supplement programs offered, linking to other reputable sites. Take opportunity to provide podcasts and other items for download
• Develop written and web-based information for patients and families about complementary therapies

Research:
• Look for internal opportunities to collaborate or add value to existing research or trials
• Seek opportunities to demonstrate the value of particular complementary therapies e.g. in relieving stress during stressful procedures such as MRI and radiotherapy of the head and neck
• Establish lines of communication with established researchers in the field, and create opportunities for collaboration
• Seek opportunities for collaborations with other established researchers (nationally and internationally) in the field