SUPPORTIVE CARE CONFERENCE
2011

Supportive cancer care into the future – sustaining, surviving and growing

PROGRAM & ABSTRACT BOOK

Monday 11 July 2011
Hilton on the Park
192 Wellington Parade, East Melbourne
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Chairs’ Welcome

As joint chair of the Conference Committee we would like to welcome you to the second Victorian Integrated Cancer Services Supportive Care Conference (ICS SCC), with the theme of “Supportive cancer care into the future – sustaining, surviving, and growing”.

Building on the success of the inaugural conference in 2009, where over 250 people attended, the committee has worked with determination and enthusiasm to help make this event an enormous success and a truly memorable occasion.

The Integrated Cancer Services are a Department of Health, Victoria initiative whose aim is to support the provision of an integrated approach to service delivery, which focuses on delivering the right treatment and support to patients, as early as possible in their cancer journey.

This important state wide supportive cancer care conference has been organised by the nine Victorian ICS and aims to:

1. build on the outcomes of the inaugural SCC conference with exploration of sustainable implementation of supportive care practice
2. focus on the specific supportive care and resilience building needs associated with people affected by cancer including survivorship and adolescents and young adults
3. consider models that will shape the future of supportive cancer care provision
4. promote the voice of people affected by cancer in the provision of supportive care

We hope you find the program innovative, exciting and rich in content, and appealing to a wide range of professionals working at many different levels and within many cultural contexts as part of multidisciplinary cancer care, such as:

- supportive cancer care clinicians
- ICS staff
- health service managers
- consumer representatives
- palliative care and pastoral care workers

The program will be delivered through engaging plenary sessions, workshops and concurrent sessions on the one day. We welcome your participation at this exciting event and hope you enjoy the professional development and networking opportunities.

Philippa Hartney
Joint Chair Conference Committee

Kylie Halsall
Joint Chair Conference Committee
Invited Speakers

Dr Carrie Lethborg

Clinical Leader, Cancer Social Work Coordinator Psycho-social Care – Cancer Services, St Vincent’s Hospital

Dr Carrie Lethborg is a psycho-oncology clinician, researcher and educator with over 20 years experience. She holds the positions of Clinical Leader, Cancer Social Work and Coordinator Psycho-social Care – Cancer Services at St Vincent’s Hospital in Melbourne as well as honorary appointments at Peter MacCallum Cancer Centre and at the University of Melbourne. She is Chair of the Western and Central Melbourne Integrated Cancer Service – Supportive Care Advisory Group, Deputy Chair of the Victorian Co-operative Oncology Groups’ Psycho-Oncology Committee and is an executive member of the State Government Advisory group for cancer survivorship, Oncology Social Work Australia, Australian Psychoncology Society, Cancer Social Work Victoria and the Clinical Advisory Group for the Western and Central Melbourne Integrated Cancer Service.

Dr Lethborg is currently completing an NH&MRC and Victorian Cancer Agency funded Post Doctoral study trialling a Meaning and Purpose based therapy in an advanced cancer population. She is widely published in peer review journals and text books as well as producing an award winning children’s book for children with a parent with cancer. She is the recipient of multiple awards including the Emerging Leader award for Catholic Health Australia, the Award for Excellence for social work research, the Premier’s Excellence Award for Improving Cancer Care in Victoria (2009), the International AOSW Naomi Stearns award (2009).

Professor Suzanne Chambers

Professor of Preventative Health and Director for ASI (Area of Strategic Investment) for Chronic Disease Prevention, Griffith Health Institute, Griffith University.

Professor Suzanne Chambers is the Professor of Preventative Health at Griffith University and Scientific Advisor in Psycho-Oncology for Cancer Council Queensland. Suzanne has worked in oncology since 1989 and over that time has undertaken the development of a broad range of cancer support services and led research into breast, gynaecological and prostate cancer, cancer nursing and physician education, peer support in cancer, supportive care interventions, patient decision making and patient education.

Professor Chambers’ current research projects include:

- The ProsCan Program: Patterns of care and health-related outcomes for men newly diagnosed with prostate cancer in Queensland.
- The ProsCan Program: Development and evaluation of a new support program for men diagnosed with prostate cancer.
- ProsCan for CouplesTM: a supportive care intervention that targets the specific challenges couples experience at diagnosis of localised prostate cancer and after radical prostatectomy.
- Beating the Blues after Cancer: A Community Based Approach to Improving the Psychosocial Health of People with Cancer and their Carers.
- Improving Outcomes for Men with Advanced Prostate Cancer.

Professor Susan Sawyer

Director, Centre for Adolescent Health, Royal Children’s Hospital and Chairman, Victorian Adolescent and Young Adult Cancer Committee, DOH

A paediatrician by training, Professor Sawyer holds the inaugural chair of Adolescent Health within the Department of Paediatrics at the University of Melbourne and has helped define the field of adolescent
health within Australia and increasingly internationally.

In various leadership roles, Professor Sawyer has influenced the development of adolescent health into a widely accepted multidisciplinary area of practice. This is most evident by her appointment in 2005 as the inaugural Chair of Adolescent Health at The University of Melbourne, the first chair of adolescent health in Australia.

Professor Sawyer was the inaugural chairman of the Royal Australasian College of Physicians’ Adolescent Health Committee, is a past president of the International Chapter of the North American Society of Adolescent Medicine and was Chairman of the Scientific Committee for the 9th World Congress on Adolescent Health in 2009 in Malaysia, a meeting held only every 4 years. She is the subject of a personal profile in the Lancet. She is a member of the Technical Steering Committee for the Child and Adolescent Health Department at the World Health Organisation, Geneva, an advisory committee to the WHO.

**Dr Bruce Rumbold**

*Deputy Director of the Palliative Care Unit, La Trobe University*

Dr Bruce Rumbold holds postgraduate qualifications in physics, pastoral care and health social science, and has published in all three fields. His longstanding interest in palliative care began with doctoral work in England in the mid-seventies, and has continued throughout palliative care’s period of development in Australia. The health promoting model employed by the La Trobe University Palliative Care Unit, with its emphasis on social and spiritual care, is particularly congenial to his interests in pastoral care, spirituality and public health.

Before taking up his present fulltime position at La Trobe University, Bruce was from 1986-2002 the foundation Professor of Pastoral Studies at Whitley College Theological School, developing and teaching ministry and pastoral care programs accredited by the Melbourne College of Divinity. At La Trobe he teaches in the School of Public Health and is Director of the Palliative Care Unit within that School. Currently he is finalising work, as a co-editor with Mark Cobb (UK) and Christina Puchalski (USA), for a comprehensive textbook “Spirituality and Healthcare” that will be published by Oxford University Press, Oxford, toward the end of this year.

In 2003 he was elected as a member of the International Academy for Practical Theology. He was from 2004-7 Secretary of the International Council for Pastoral Care and Counselling, a body that connects nearly fifty national pastoral care associations worldwide. He was awarded an Order of Australia Medal for services to pastoral and palliative care, particularly as an educator, on Australia Day 2005.

**Ms Meg Rynderman**

*Volunteer with the Australian Cancer Survivorship Centre (ACSC)*

Meg Rynderman generously volunteers her time one to two days a week at Australian Cancer Survivorship Centre (ACSC). Meg is a survivor of recurrent Hodgkin disease. Treatment for her disease included radiotherapy, high dose chemotherapy and stem cell transplant. Meg also volunteers for Cancer Council Victoria’s Cancer Connect program.

Meg’s 17-year cancer journey has instilled in her a passion that other cancer survivors should be offered more appropriate support and follow-up care than she experienced in her early years and that cancer should no longer be seen as a one-off incident, but rather a whole-of-life health issue.

Meg is a Governor of Bialik College in Hawthorn and has a background in family business.
Conference Program
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<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>9.00 am</td>
<td>Conference Registration</td>
<td>Main Foyer</td>
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<td>9.00 am</td>
<td>Registration, Tea &amp; Coffee</td>
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<td>9.45 am</td>
<td><strong>Morning Plenary Session</strong></td>
<td>Ballroom 3</td>
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<td><strong>Chairs: Phillipa Hartney &amp; Sanchia Aranda</strong></td>
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<tr>
<td>9.45 am</td>
<td>Conference opening and welcome to ICS SCC 2011</td>
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<td>10.00 am</td>
<td>Unfair care – time to face the supportive care needs of the underserved with cancer</td>
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<td></td>
<td>Dr Carrie Lethborg</td>
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<td>10.30 am</td>
<td>Factors that influence access to psychosocial care: What happened with translation?</td>
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<td></td>
<td>Professor Suzanne Chambers</td>
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<td>11.00 am</td>
<td>Questions</td>
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<td>11.15 am</td>
<td><strong>Morning tea &amp; poster viewing</strong></td>
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<td>11.15 am</td>
<td>Morning tea &amp; poster viewing</td>
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<tr>
<td>11.45 am</td>
<td><strong>Morning Concurrent Sessions</strong></td>
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<td><strong>Concurrent Session 1: Workshop – Adolescent and Young Adult Cancer</strong></td>
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<td><strong>Chair: Jane Williamson</strong></td>
<td>Delacombe Room</td>
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<tr>
<td>11.45 am</td>
<td>Identifying and addressing the supportive care needs of Adolescents and Young Adults with cancer. This workshop will provide an opportunity to review healthy adolescent development, and then focus on what ‘Adolescent Friendly’ health services look like.</td>
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<td>Facilitator - Professor Susan Sawyer</td>
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<tr>
<td>11.45 am</td>
<td><strong>Concurrent Sessions 2-4: Seminars</strong></td>
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<td>Session 2. Implementing change in cancer and palliative care</td>
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<td><em>Chairs: Michelle McKinnnie &amp; Robyn Moylan</em></td>
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<td>Huntingfield Room</td>
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<td>End of Life Care: Implementing the Liverpool Care Pathway across four oncology in-patient sites</td>
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<td>Di Saward</td>
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<td>12.05 pm</td>
<td>Many a slip twist the trial and the rollout - Pathway for Improving the Care of the Dying 'PICD' an integrated end of life care pathway</td>
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<td></td>
<td>Dr Michael Franco</td>
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<tr>
<td>12.25 pm</td>
<td>Strategies to support sustainable supportive care screening</td>
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<td></td>
<td>Christine Scott</td>
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<tr>
<td>12.00 pm</td>
<td>Lunch &amp; poster viewing</td>
<td>Main Foyer</td>
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<td>12.45 pm</td>
<td><strong>Lunch &amp; poster viewing</strong></td>
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<td>2.00 pm</td>
<td><strong>Plenary Session - SCCV Resource Launch</strong></td>
<td>Ballroom 3</td>
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<td><strong>Chairs: Canon Alan Nichols</strong></td>
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<tr>
<td>2.00 pm</td>
<td>Ribbon cutting and launch of the SCCV resources</td>
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<td>Hon Minister David Davis MP - Minister for Health</td>
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### 2.20 pm - 3.40 pm: Afternoon Concurrent Sessions

**Concurrent Session 5: Workshop – Sustainability of supportive care identification**

**Chairs:** Kylie Halsall & Cathie Pigott  
**Delacombe Room**

#### 2.20 pm

**Implementing psychosocial care: challenges and solutions.** This round table discussion will provide participants with the opportunity to discuss their experiences in the implementation of distress screening and psychosocial care pathways.  
**Facilitator - Professor Suzanne Chambers**

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### Concurrent Sessions 6-8: Seminars

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<thead>
<tr>
<th>Session 6. Screening in specific patient populations</th>
<th>Session 7. Multidisciplinary education and communication</th>
<th>Session 8. Adolescent and Young Adults and Family Communication</th>
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<tr>
<td><em>Chairs: Robyn McIntyre &amp; Bridget Wislang</em></td>
<td><em>Chair: Kaye Matthews &amp; Narelle Wadsworth</em></td>
<td><em>Chair: Kathy Simons &amp; Mirella Matthews</em></td>
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<tr>
<td>Huntingfield Room</td>
<td>Ballroom 3</td>
<td>Stradbroke Room</td>
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<tr>
<th>2.20 pm</th>
<th>Developing Professional Linkages Across the Loddon Mallee Region to Facilitate Sustainable Supportive Cancer Care</th>
<th>Consumer perspectives on adolescent-friendly care</th>
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<td><em>Dr Sarah Kofoed</em></td>
<td><em>Rosalind Deacon</em></td>
<td><em>Dr Sarah Drew</em></td>
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<th>2.40 pm</th>
<th>Supportive Care Screening in Elderly Cancer Patients: why focus on this population, and how do we measure our success?</th>
<th>The development, implementation, and evaluation of an evidence based education program to guide family meetings in the oncology setting</th>
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<tr>
<td><em>Jenny Donnelly</em></td>
<td><em>June Savva</em></td>
<td><em>Melinda Williams.</em></td>
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<tr>
<th>3.00 pm</th>
<th>Sexual and hormonal quality of life differences between clinical subgroups of men commencing radiotherapy for prostate cancer</th>
<th>Innovative electronic system enhances supportive care communication</th>
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<tbody>
<tr>
<td><em>Karla Gough</em></td>
<td><em>Melinda Williams.</em></td>
<td><em>Dr Sarah Drew</em></td>
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<tr>
<th>3.20 pm</th>
<th>Innovations in supportive care practice: the Brain Tumour Support Officer at Austin Health</th>
<th>Vicarious trauma in oncology social work: a team response</th>
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<tbody>
<tr>
<td><em>Dianne Legge</em></td>
<td><em>Alison Hocking</em></td>
<td><em>Margaret Hjorth</em></td>
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### 3.40 pm - 4.00 pm: Afternoon tea & poster viewing

**Main Foyer**

**3.40 pm**  
Afternoon tea & poster viewing

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### 4.00 pm - 5.10 pm: Afternoon Plenary Session

**Ballroom 3**

**Chairs:** Phillipa Hartney & Sanchia Aranda

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<th>Asking the questions about spirituality</th>
<th><strong>Dr Bruce Rumbold</strong></th>
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<td>4.30 pm</td>
<td>Supportive care from the perspective of a survivor - does it really happen?</td>
<td><strong>Ms Meg Rynderman</strong></td>
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<tr>
<td>5.00 pm</td>
<td>Close of ICS SCC 2011</td>
<td><strong>Phillipa Hartney</strong></td>
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### 5.15 pm - 6.00 pm: SCCV Video Resource Viewing & Post Conference Drinks

**Stradbroke Foyer**

**Chair:** Sanchia Aranda

| 5.15 pm | Demonstration of the SCCV video resources and post conference drinks | **Sanchia Aranda** |
Oral Presentation Abstracts
Session 2: Implementing change in cancer and palliative care

End of life care: implementing the Liverpool Care Pathway across four oncology in-patient sites

Di Saward, Project Coordinator, Cancer Specific End of Life Care Project, Peter MacCallum Cancer Centre; Dr Odette Spruyt, Director, Pain and Palliative Care, Peter MacCallum Cancer Centre; Dr Brian Le, Head of Unit, Palliative Care, Royal Melbourne Hospital; Dr Maria Coperchini, Director Palliative Care, Western Health; Katy Weare, Cancer Services Manager, Royal Women’s Hospital

Objective:
The Liverpool Care Pathway (LCP) is an evidence based framework which guides patient care in the last few days of life; it enables the multidisciplinary team members to think holistically about the care of their patients at this important time. In 2010, the Western & Central Melbourne Integrated Cancer Service (WCMICS) funded an end of life care project across 4 collaborating institutions. The aim of the project was to improve nursing, medical and allied health staff confidence and documentation in the care of dying patients.

Method:
An initial retrospective audit was conducted at each site to provide the baseline comparator information of documented end of life care. These audits identified gaps in documentation which directed the educational needs for the project. Version 12 of the LCP was minimally adapted to local hospital formats and piloted at each site. Each site was registered with the Marie Curie Palliative Care Institute in Liverpool allowing for ongoing support and benchmarking beyond the life of this project. Evidence indicates that the introduction and sustainability of change in health care settings is a complex process. One recognized strategy is to develop nurse champions in clinical areas of interest. A nurse champion was identified on each unit and acted as the “change agent”, where she educated on the specifics of the pathway, preparing the area for LCP implementation.

Many a slip twixt the trial and the rollout - Pathway for Improving the Care of the Dying ‘PICD’ an integrated end of life care pathway

Dr Michael Franco, Medical Oncologist and Palliative Medicine Physician; Christine Mooney, Palliative Care Nurse Consultant; Gabrielle O’Connor, Palliative Care Nurse Consultant (Manager); A/Prof Kate Jackson, Director Supportive and Palliative Care; Dr Leeroy William, Palliative Medicine Specialist; Ben Evans, Palliative Care Consultant Nurse; Kaye Walsh, Palliative Care Consultant Nurse; Pam Hosking, Palliative Care Consultant Nurse; Peter Poon, Palliative Medicine Specialist

Objective:
Development and rollout of an end of life (EOL) integrated care pathway (ICP) in a tertiary referral hospital on general medical and oncology wards.

Method:
At Southern Health PICD was developed in 2007 and trialled for 2 months in the general medical unit. PICD’s major domains are comfort measures, communication, support for psychological/spiritual/cultural issues, written information for families and care after death. PICD consists of 2 forms, one predominantly medical and the second a revised nursing care plan, both being part of the patients standard medical record.

Results:
Following a successful 2 month pilot, PICD became part of general medicine’s quality assurance program to be managed by the unit with advice from the Supportive and Palliative Care Unit (SPCU). An audit at 12 months showed the gains made had clearly fallen back.

Discussion:
It was realised the initial success was dependant on SPCU individuals, predominantly the 0.5EFT project officer (CM), a position not funded on an ongoing basis. A new model needed to be developed to make PICD sustainable:

• Individual units taking responsibility for PICD in their unit
• Nurse champions in each unit
• A large nursing education program (to date 270 nurses trained)
• Regular medical presentations as the junior medical staff change
• Developing a DVD to enable online training with SPCU doing the initial training and subsequent advice and support.

Implications
For a successful and sustainable EOL ICP in general hospitals, individual units must take clinical ownership. It is also vital ongoing funding for education and support is available.

Strategies to support sustainable supportive care screening

Christine Scott, Manager, Wellness & Supportive Care, Cancer Services, Austin Health; Helen Longton, Cancer Quality Project Manager, Austin Health; Sue Oldfield, Team Leader, Oncology Social Work, Austin Health

Objective:
To sustain progress made during a pilot program to introduce routine supportive care (SC) screening in cancer services at Austin Health.

Method:
Sustainability strategies were implemented during the pilot program e.g. strong governance, consumer consultation, a tiered approach to education and regular progress reporting. In the sustainability phase a team was employed to embed screening as routine practice in selected patients in 3 areas of oncology. This occurred in the context of establishing the Wellness model for the Olivia Newton-John Cancer and Wellness Centre (ONJWC).

Results:
6 months into the 12-month sustainability phase, screening rates have increased in 2 areas [Radiation Oncology: 64% (pilot) 73% (sustainability), Day Oncology: 77% (pilot) 88% (sustainability)]. In the oncology wards, a baseline has been established (27% eligible patients screened). The sustainability team continued nurse education and screener training (pilot phase 40+ trained, sustainability phase, 29). Improvements in staff knowledge of SC is being evaluated. SC screening has been integrated into a proposed model for Wellness and SC in the ONJCWC.

**Discussion:**
Sustainable improvements in screening rates have been made in 2 areas. These outcomes cannot yet be attributed to any particular sustainability strategy. Barriers to screening in the oncology wards are being explored. Longer term sustainability will require alternative, nonperson dependent solutions. The SC screening program has influenced the model for Wellness and SC.

**Implications**
Sustainable change may require a range of planned strategies. An effective SC screening program can become a driver for an integrated model of wellness and supportive care.
**Session 3: Providing Supportive Care; Real life experiences**

**Living with cancer: enabling leisure participation**

**Sarah Shipp**, Occupational Therapist; **Dr Carol McKinstry**, Senior Lecturer La Trobe University; **Elizabeth Pearson**, Chief Occupational Therapist Peter MacCallum Cancer Centre; **Jenni Bourke**, Occupational Therapist Peter MacCallum Cancer Centre

**Objective:**
The aim of the current study was to gain an understanding of the cancer experience in relation to leisure participation.

**Method:**
A narrative methodology was utilised to explore the experiences of four men living with colorectal cancer, focusing on how cancer altered their engagement in leisure activities and the role that leisure played during the stages of their cancer experience. Data were analysed to create participant stories and common themes conceptualised using the Canadian Model of Occupational Performance.

**Results:**
Participants typically stopped active and community-based leisure pursuits while they were receiving active treatment and resumed their preferred leisure activities progressively after treatment. A variety of environmental and personal factors impacted on leisure participation, more commonly restricting rather than enabling participation in leisure during cancer. Leisure was described as important and meaningful by all participants during all phases of their cancer experience.

**Discussion:**
While there has been very little interest in researching how leisure is impacted on by cancer diagnosis and treatment, quality of life is influenced by the resumption of meaningful leisure in the treatment and post-treatment phase.

**Implications**
While the study’s limitations in size and scope restrict the ability to generalise the results to the wider population of cancer survivors, the research provides some insight into men’s lived experience of colorectal cancer and associated changes in leisure participation. The findings reinforce the importance of further research into understanding cancer’s impact on enabling leisure participation and quality of life for cancer survivors.

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**Application of Lean Thinking Methodology: prescription of nutritional supplements as medication by dietitians**

**Mary Anne Silvers**, Manager of Dietetics, Monash Medical Centre, Southern Health; **Anne M Gordon**, Clinical Dietitian, Chemotherapy Day Unit, Monash Medical Centre, Southern Health; **Rubina Raja**, Clinical Dietitian, Monash Medical Centre; **Mary Kate Inkster**, Dietitian, Monash Medical Centre, Southern Health; **Jessica McDonald**, Dietitian, Monash Medical Centre, Southern Health

**Objective:**
To develop and implement a model of practice, in which Oncology Unit Dietitians are given prescribing privileges to chart nutritional supplements on patients’ medication charts.

**Method:**
Direct observation and value stream mapping were used according to the Lean Thinking Methodology application. This method identified all aspects of time spent in the current procedure of prescribing Nutritional Supplements As Medication (NSAM). A detailed root cause analysis of identified issues was undertaken, followed by the development of an implementation plan.

**Results:**
Identified problems: 1) Ordering process was complicated and not linear; 2) Delay in patient receiving NSAM (2.8 days, range 0-23 days); 3) 60% repeat requests by the dietitian for NSAM. To overcome these identified problems an implementation plan was developed which included: 1) Submission to the Medical Executive Committee to seek prescribing privileges for dietitians; 2) Dietetic competency training and credentialing; 3) Communication strategy; 4) Development of prescribing and administering procedures; 5) Ward education. Dietetic prescribing privileges were granted and implementation is presently been addressed. Evaluation of this change in dietetic practice will be undertaken.

**Discussion:**
Application of Lean Thinking Methodology enabled Dietitians to clearly examine systematically, delays, risks and inefficiencies with our current process of ordering NSAM. It led to a plan of action to improve quality of care to patients and reduce waste in our health care setting by timely and appropriate commencement of NSAM.

**Implications**
Transferring prescribing privileges for oral nutritional supplements to Dietitians, highlights the importance of nutrition as an integral part of patient’s treatment plan. NSAM is effective in attenuating deterioration in nutritional status.

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**Mentoring for lymphoedema therapists in the NEMICS region**

**Judith Purbrick**, Senior Physiotherapist Mercy Health Lymphoedema Clinic

**Objective:**
To provide a formal mentoring program for 12 months to newly trained lymphoedema therapists in the NEMICS region. To assist the professional development of these therapists so that new skills can be consolidated, the network of lymphoedema therapists strengthened and workforce retention promoted. To provide training in mentee/mentor relationships for all participants. To develop skills amongst mentees that facilitates the assumption of
a mentoring role to in the future.

**Method:**
There was voluntary recruitment of mentees from eligible therapists in the NEMICS region. Mentors are lymphoedema therapists with a minimum of five years experience. All applicants completed preliminary worksheets and were matched according to the goals they had identified. Applicants attended a training session in early 2011 conducted by a psychologist and were supplied with a resource pack. Pairs have committed to meet on 6 to 8 occasions during 2011.

**Results:**
Process outcomes are on target. The program will conclude in November 2011 when impact and final outcomes will be collated.

**Discussion:**
Mentoring is reported to be beneficial to professionals at every career stage, enhancing job satisfaction and provision of quality services. The relational process brings benefits to both mentor and mentee. It is anticipated that this program will assist with the support of solo practitioners while they are implementing new skills.

**Implications**
To discover whether a mentoring program supports practice amongst newly trained therapists and to consider if this could be an effective strategy for promoting workforce retention in a documented area of workforce need.
Session 4: Consumer Involvement

Working together to better service the community of people living with cancer

Amanda Spillare, Cancer Support Group Coordinator, Cancer Council Victoria; Lea Marshall, Cancer Service Improvement Coordinator, GICS; Robyn McIntyre, Cancer Service Improvement Coordinator, GICS

Objective:
To pilot a collaborative model between Cancer Council Victoria (CCV) and a regional ICS to better service the community of people living with cancer in regional areas.

Method:
In 2009, CCV and Grampians Integrated Cancer Service decided to work together to bring a number of community forums to the Grampians community. These forums focused on the service gap areas of Advanced Cancer (When Cancer Won’t Go Away forums) and Cancer Survivorship (Life after Cancer Forums) and were funded through the RACV. Ballarat and Horsham were the original pilot sites.

Results:
This presentation will outline the process undertaken to develop the ongoing collaboration, the key points to what has made the partnership work, and insights learned from the process. Participant outcomes will be outlined including several other unexpected benefits from this community development approach, including the development of:
- The Maryborough Cancer Support Group
- Multiple collaborations with other ICS throughout the state using a similar model
- The consumer advisory committee – Grampians Region

Discussion:
Collaboration is a term often spoken about, yet the true notion of collaboration can be difficult to achieve, sustain and do well. What has made this process unique from other initiatives was that we embraced the true notion of partnership by engaging local stakeholders and consumers to participate in the process.

Implications
This model is a great example of how working together helps reduce costs, avoids duplication, and better services our community. "If everyone is moving forward together, then success takes care of itself." (Henry Ford)

Engaging cancer patients and their carers: a change process

Anthony Love, Professor of Psychology, University of Ballarat; Eleanor Whitehead, Manager, Grampians Integrated Cancer Services; Laura Maher, Liversage, Research Assistant, University of Ballarat; Michael Coleman, Project Officer, Grampians Integrated Cancer Services; Helen Wade, Executive Officer, Central Highlands Primary Care Partnership

Objective:
To consider how strategies used to engage cancer patients and their carers in the Grampians region have acted as a process of change for consumers and services.

Method:
Adopting an action research framework, GICS Community Engagement Task Group produced a four-faceted approach to promoting participation. GICS, together with the University of Ballarat and the Central Highlands Primary Care Partnership, held Forums throughout the Grampians region, inviting consumers to share their experiences of Services. Individual interviews and focus groups were also conducted. Thirdly a workshop on consumer advocacy was conducted. The final focus involved inviting support group members and others to join GICS committees.

Results:
Forums, interviews, and focus groups publicised the work of GICS and raised awareness about the client-focussed care model and participation; 207 people contributed to the activities, and over 50 individual interviews were conducted. A full Report is available from GICS. Here, the positive aspects of services received in the Grampians region, and aspects seen as needing improvement are presented. Participants’ feedback on their involvement is also reviewed. Outcomes of the advocacy workshop, for delegates and GICS, are summarised.

Discussion:
The benefits of community participation for both participants and services are presented and proposals for ensuring sustained change are offered. Key lessons learned from the efforts to foster consumer participation in cancer care in the Grampians region are presented and directions for further development are summarised.

Implications
Implementing strategies for promoting consumer engagement offers potential benefits to services, health care professionals, and those affected by the cancer journey.

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Training consumer volunteers for the LMICS Swan Hill Cancer Resource Centre

Glenys Smith, Cancer Systems Improvement Officer, LMICS; Rachael Hamilton-Keene, Data, Quality, Projects and Research Coordinator, LMICS; Philippa Hartney, Strategic Manager, LMICS; Nicole Johnson, Research Assistant, LMICS

Objective:
To establish a training program that suitably prepares and educates volunteers, providing them with a satisfactory level of knowledge, skill and confidence to perform the role of cancer support volunteer at the LMICS Swan Hill Cancer Resource Centre (the Centre); To train community members so they are suitably prepared for the role of cancer support volunteer at the Centre; To establish an ongoing mentoring program (formal and informal) for cancer support volunteers.
**Method:**
Community volunteers were provided with two days of training in order to prepare them for the role as Centre volunteers. Volunteers were asked to complete quantitative evaluation forms to rate the usefulness and suitability of the training program.

**Results:**
Evaluation showed a very high rate of satisfaction with the training sessions, with volunteers agreeing that the training provided them with the knowledge, skills and confidence required to perform the role. Subsequently, volunteers have been successfully performing these roles now for several months.

**Discussion:**
Overall, the success of volunteers in these roles has further engaged the Swan Hill community with many other community members and organisations becoming further involved. For example, a group of Swan Hill business people has raised funding in order to develop a healing garden around the Centre.

**Implications**
Providing the skills to a team of community members, along with ongoing mentoring and support, enhances engagement of the entire community. This has a significant impact on sustainability, with ongoing success of this initiative being supported by engendering community ownership.
Supportive care screening in elderly cancer patients: why focus on this population, and how do we measure our success?

**Jenny Donnelly**, Supportive Care Project Coordinator, Hume RICS; **Jenny O’Connor**, Cancer Care Coordinator, CCOAC Project, Hume RICS; **Christopher Steer**, Lead Clinician CCOAC Project, Border Medical Oncology

**Objective:**
This project aimed to use existing service infrastructure to meet the supportive care needs of cancer patients over 70.

**Method:**
The CCOAC project, implemented by Hume RICS with funding from Cancer Australia in 2010, sought to do two things:

- improve care coordination and supportive care for elderly cancer patients in the Hume region through implementing a screening tool specifically developed for cancer patients over 70 years of age.
- develop a system of referral to appropriate supportive care providers particularly aged care and community based providers.

**Results:**
It evaluated the effectiveness of the screening through a combination of surveys measuring quality of life; unmet supportive care needs; the effectiveness of the care coordination provided; and some economic analysis.

**Discussion:**
There is a lack of screening for the supportive care needs of elderly patients in routine clinical practice. (refer COSA audit). We know however that:

- there is a high rate of geriatric issues in patients over the age of 70 e.g. co-morbidities, cognitive impairment, need for support for activities of daily living.
- the population is ageing

Studies of geriatric assessment-guided intervention have shown a survival benefit in elderly oncology patients.

**Implications**
Is there added value for elderly patients in having a more specific screening tool?

Sexual and hormonal quality of life differences between clinical subgroups of men commencing radiotherapy for prostate cancer

**Karla Gough**, Senior Research Officer, Department of Nursing and Supportive Care Research, Peter MacCallum Cancer Centre; **Kerryann Lotfi-Jam**, PhD Candidate/Researcher, Department of Nursing and Supportive Care Research, Peter MacCallum Cancer Centre; **Kathryn Schubach**, Registered Nurse, Uro Oncology Service, Peter MacCallum Cancer Centre; **Sanchia Aranda**, Director of Cancer Services and Information, Cancer Institute NSW; **Paul Dudgeon**, Associate Professor, Psychological Sciences,
**Objective:**

Men commencing radiotherapy for prostate cancer may have had previous treatments (radical prostatectomy, androgen deprivation therapy) or no prior treatment, reflecting important clinical differences. This study examined health-related quality of life (HRQoL) (sexual, hormonal) in these clinical subgroups before radiotherapy and associations between HRQoL and psychological morbidity (anxiety, depression).

**Method:**

332 men commencing radiotherapy with curative intent completed baseline questionnaires including the Hospital Anxiety and Depression Scale and Expanded Prostate Cancer Index Composite (EPIC-26) measuring HRQoL.

**Results:**

Medium-sized associations were observed between prior treatment-based subgroups and most items comprising EPIC-26 sexual and hormonal domains (all p<.05). A greater proportion of the ADT (92%) and prostatectomy (80%) subgroups reported poor sexual functioning compared to the no prior treatment subgroup (53%). Further, a greater proportion of the ADT subgroup indicated hot flushes and lack of energy were a problem (69% and 51% respectively) compared to the prostatectomy and no prior treatment subgroups (approximately 5% and 20% in both subgroups respectively). Poorer sexual HRQoL was associated with elevated levels of depression (rho=-.27), whereas poorer hormonal HRQoL was associated with elevated levels of anxiety and depression (rho=-.42 and -.55 respectively).

**Discussion:**

Sexual and hormonal HRQoL differs between clinical subgroups commencing radiotherapy. Poorer function in these domains shows medium- to large-sized associations with psychological morbidity.

**Implications**

Alongside previous research demonstrating robust relationships between pre-treatment functioning (physical and psychological) and longer-term psychosocial outcomes in cancer patients, these findings suggest the need for early assessment and management of domain specific impairments and psychological morbidity, particularly among those who have undergone prior treatments.

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**Innovations in supportive care practice: the Brain Tumour Support Officer at Austin Health**

*Dianne Legge, Brain Tumour Support Officer, Austin Health*

**Objective:**

Receiving the diagnosis of a primary malignant brain tumour is a challenging and difficult process for patients and families. Since 2008, Austin Health has had a dedicated Brain Tumour Support Officer to address some of the supportive care needs of people and families affected by this diagnosis. This presentation will discuss the benefits, challenges and learnings about establishing, maintaining and sustaining this unique tumour specific service.

**Method:**

The model of care has been designed to enable patients and families to be supported through their healthcare journey from the point of diagnosis, through to their treatment and beyond. The service focuses on 4 strategies: Inform, Resource, Acknowledge and Support.

**Results:**

During 2010, over 150 families accessed the service, with more than 75% on multiple occasions. Support methods are a combination of education, practical problem solving, referral & direct phone or face-to-face support.

**Discussion:**

The Brain Tumour Support Officer and its model of service is now firmly embedded as part of the Austin Health Wellness and Supportive Care program. These patients and families are well supported and resourced as a result. However, the challenge of providing adequate and targeted supportive care for patients and families in their own regional community remains.

**Implications**

The next challenge is to create a sustainable model of support, one that has the potential to extend out beyond the metropolitan health services to reach patients and families in their own communities by helping resource the health professionals and services they access during this difficult and challenging illness.
Session 7: Multidisciplinary education and communication

Developing professional linkages across the Loddon Mallee region to facilitate sustainable supportive cancer care

Rosalind Deacon, Senior Clinician Physiotherapist Bendigo Health; Rachael Hamilton-Keene, Data, Quality, Projects and Research Coordinator, LMICS Bendigo; Andrea Shaw, Multidisciplinary Cancer Care Development Coordinator, LMICS Bendigo

Objective:
To improve the educational and networking opportunities of allied health and nursing clinicians in the Loddon Mallee Region and in doing so improve the supportive care and allied health needs of cancer patients in the region.

Method:
We established the Loddon Mallee Allied Health Oncology Special Interest Group (LMAHOSIG) in 2009 and have bimonthly meetings video conferenced across the region. To date we have had involvement with clinicians in the public and private sectors from Mildura, Robinvale, Ouyen, Swan Hill, Echuca and Bendigo.

Results:
The meetings have been evaluated using the appropriately adapted LMICS survey form using a 5 point scale with 1 meaning strongly disagree and 5 meaning strongly agree. Over the 2 years we have regularly achieved a 4 or 5 rating for the vast majority of the questions with over 90% of respondents finding their learning needs have been met.

Discussion:
The paper will discuss the importance of this networking and professional development opportunity to enhance the supportive care needs of patients in our region. Since the advent of the meeting we have had noted increases in phone calls and emails amongst the clinicians in our region. The next step is to incorporate therapeutic communication and psychosocial support competencies as core skill components.

Implications
Regardless of staff movement, the value of a regular meeting such as this means we can encourage links across the region and upskill new staff whilst supporting all clinicians involved. Sharing our knowledge makes for sustainable practices and optimises patient outcomes.

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The development, implementation, and evaluation of an evidence based education program to guide family meetings in the oncology setting

June Savva, Clinical Dietitian, Monash Medical Centre, Moorabbin Campus, Southern Health; Vicki McLeod, Oncology Nurse Practitioner Candidate, Monash Medical Centre, Moorabbin Campus, Southern Health

Objective:
To promote efficient, effective and collaborative communication and decision making between patients, their caregivers and clinicians in the oncology setting through the development and evaluation of
- a communication skills training workshop to promote treating team competencies in conducting family meetings
- facilitator and multidisciplinary clinical practice guidelines
- participant self-efficacy and satisfaction

Method:
- Review the literatures’ empirical evidence and current best practice methods for communication skills training
- Develop formalised meeting procedures, resources and etiquette to guide clinicians in preparing, conducting and evaluating family meetings
- Develop, evaluate and pilot a communication skills workshop incorporating interactive role play using professional actors as simulated patients, discussion and feedback for several clinical scenarios

Results:
This workshop builds on a project previously initiated by the oncology team to develop a formalised multidisciplinary family meeting model. The next step is to incorporate therapeutic communication and psychosocial support competencies as core skill components.

Discussion:
Research is lacking on the serviceability of family meetings and specific guidelines for clinical practice in the oncology setting. Health care professionals receive minimal or no preparation to conduct family meetings. This project addresses all five domains of supportive care and aligns with the strategic directions for supportive care for optimizing patient care by improving communication skills to competently conduct family meetings.

Implications
The workshop can potentially be translated into a training module road show for interdisciplinary oncology units to conduct an evidence based model that effectively addresses patient supportive care needs by promoting clinician confidence and competency in patient centred communication skills.

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Innovative electronic system enhances supportive care communication

Melinda Williams, BSWRICS Supportive Care Project Manager

Objective:
In 2006 the CANMAP database was implemented by Barwon South Western Regional Integrated Cancer Service to coordinate their Cancer Tumour Stream Multidisciplinary Meetings (MDM).
The collated data from these meetings demonstrated that only 5% of patients were recommended for any type of supportive care intervention. Therefore the objective was to develop the database further to promote discussion around supportive care needs of patients and improve referrals to the supportive care team.

**Method:**
In 2009 an advisory supportive care team was formed to guide the development of new sections within the database encompassing information, resources and supportive care. The existing template on the database was adapted to collect information and data specific to supportive care.

**Results:**
A Supportive Care MDM commenced and to date has presented 195 patients. Data has been collected on patients supportive care needs, stage of journey and referral pathways.

**Discussion:**
The database has facilitated a sustainable way of communicating and recording case discussions around the supportive care needs of patients and families. It has promoted early supportive care interventions and enhanced accountability of follow up by clinicians.

**Implications**
Outcomes have included the ability to communicate the recommendations made by the supportive care team to other health practitioners in real time. The database has enabled supportive care discussion to be sent electronically to the digital medical record and/or printed out as a hard copy for clinician’s records. This provides evidence of timely follow up of the supportive care needs of the patient ensuring that clinicians are following best clinical practice.

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**Vicarious trauma in oncology social work: a team response**

_Lynette Joubert_, Associate Professor, School of Health Sciences, University of Melbourne; _Alison Hocking_, Manager, Social Work Department, Peter MacCallum Cancer Centre

**Objective:**
Little is known about the negative impacts for social workers working in oncology, on their quality of life (physical, psychological and relationship domains) as a result of possible vicarious trauma experienced in their work context. The aim of this study was to explore the experience of a team of 15 social workers working at the Peter MacCallum Cancer Centre and to suggest a team approach to management of vicarious trauma experienced by social workers.

**Method:**
A mixed methodology was used. Social workers completed the Traumatic Stress Institute Belief Scale (TSIBS) (Revision and Pearlman, 1996). The quantitative data was both descriptively and inferentially analysed. Three focus group discussions were held using Pearlman’s (1999) model of vicarious traumatisation ie self capacity, ego resources, psychological needs and cognitive schemas and imagery. The thematic content was analysed for recurring and dominant themes.

**Discussion:**
The results describe the prevalence and nature of vicarious trauma experienced by oncology social workers. Of significance is the informal team approach developed by the team at Peter MacCallum to support, and sustain social workers in their personal and professional growth. We suggest a translational model grounded in their experience.

**Implications**
Identification of applicable supports and systems to assist the self-care of frontline staff who work with cancer patients and families aids to sustain the supportive care provided in oncology settings.
Consumer perspectives on adolescent-friendly cancer care

**Dr Sarah Drew**, Adolescent and Young Adult Services Improvement Officer and Youth Cancer Network Project Officer, Children’s Cancer Centre, RCH; **Sharon DeGraves**, Nurse Unit Manager, Children’s Cancer Centre, Monash Medical Centre; **Dr Maria McCarthy**, Director, Psychosocial Services, Children’s Cancer Centre, Royal Children’s Hospital; **Tamara Bugge**, Research Assistant, Murdoch Children Research Institute; **Dr Lisa Orme**, Medical Director, OnTrac, Peter MacCallum Cancer Institute, and Clinical Director, Victorian and Tasmanian Youth Cancer Project

**Objective:**
Worldwide, cancer services are moving to establish new approaches to the clinical care of adolescents in an attempt to better meet their specific needs. In 2010 the Children’s Cancer Centre at The Royal Children’s Hospital Melbourne surveyed patients to gain adolescent consumer perspectives on: 1) the provision of an appropriate clinical environment, and 2) the delivery of effective supportive care.

**Method:**
A web-based survey sought quantitative and qualitative responses from patients (12-18 yrs). Quantitative data was analysed via descriptive statistics with cross-tabulation. Qualitative data was analysed via thematic analysis.

**Results:**
Participants (n=29) were largely positive about the quality of their healthcare experiences. However, 55% reported they had not had confidentiality explained to them, and 55% indicated there was not a member of the healthcare team with whom they felt comfortable discussing personal issues. 34% reported dissatisfaction with a lack of age-appropriate activities in treatment locations. 73% stated they would like to meet other adolescents with cancer while in hospital and that they would like an adolescent-only clinic provided within the Day Oncology Unit.

**Discussion:**
This data provides a good starting point for service-improvement initiatives. Time alone in consultations and doctor-patient confidentiality are cornerstones of adolescent-friendly practice; data suggests significant effort is needed to prepare patients and practitioners to embrace these practices.

**Implications**
Ethics approval necessitated onerous recruitment strategies, distancing consumers rather than engaging them actively in sharing their perspectives. PICS has appointed an AYA Cancer Services Improvement Officer to facilitate adolescent-related initiatives at RCH and Monash Medical Centre.

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Utilising commercially available software to develop customised roadmaps for patients and their caregivers: a quality management project

**Chris Williams**, Clinical Services Improvement Coordinator, Paediatric Integrated Cancer Service.; **Jane Williamson**, Program Manager, Paediatric Integrated Cancer Service; **Nadine Stacey**, Director, Clinical Operations, Royal Childrens Hospital; **Francoise Mechinaud**, BMT Physician, Royal Childrens Hospital

**Objective:**
To provide a validated, flexible, easy to read summary of treatment information to patients and their families dealing with a cancer diagnosis.

**Method:**
A working group was formed to drive the project. A literature review, national and international benchmarking was undertaken. The use of a commercially available task and scheduling software was utilised. Document controlled templates are being developed for inputting data for all 74 current protocols available. Multi-disciplinary input and validation of roadmaps will occur to ensure accuracy and integrity of each document. Standard operating procedures created govern the use of roadmaps and secure document control. A pilot of eight patients has been conducted since late 2010 to test the software.

**Results:**
The literature review and benchmarking showed wide variation in the complexity of the information shared and how it is provided. The pilot test indicates the software and programmed templates are easily modified to generate individual treatment summaries. The final product is in a simple calendar format. Input and validation of each roadmap began in February 2011 and will be complete by June 2011 to enable clinical rollout thereafter.

**Discussion:**
The potential outcomes from this project for increasing consumer participation are significant, as this initiative was the single biggest priority in a document submitted to the Department of Health from the Children’s Cancer Centre Parent’s Advisory Group for improving supportive care services.

**Implications**
Improved communication, greater levels of consumer participation, improved adherence to clinical trials and reduced levels of stress and anxiety for patients and their families.

Who’s following up on the follow up? Unmet service needs of survivors of childhood cancer and their parents

**Dr Sarah Drew**, Adolescent and Young Adult Services Improvement Officer and Youth Cancer Network Project Officer, Children’s Cancer Centre, RCH; **Dr Maria McCarthy**, Director, Psychosocial Services, Children’s Cancer Centre,
Objective: ‘Optimising health and wellbeing after treatment for cancer’ was a pilot study funded by the Victorian Cancer Agency, investigating psychosocial wellbeing, healthcare usage and unmet needs of survivors of childhood cancer and their parents.

Method: Semi-structured interviews were conducted with parents (n=36) of children who were aged 0-14 at diagnosis, and currently 3-5 years post-treatment. Individual interviews were also conducted with adolescents (n=21). The sample included: a range of cancer diagnoses; male and female patients; and metropolitan and regional families. Data saturation was achieved. Thematic and case study analyses were applied.

Results: Participants spoke predominantly about on-treatment experiences and disruption to family life and psychosocial wellbeing: often reporting that experiences with cancer were ‘not over’ in spite of significant time passing since treatment completion. Many reported ongoing psychosocial and emotional issues. Participants had limited understandings of why they were returning for follow-up care and were often unclear about long-term healthcare planning. Frustration with communication associated with follow-up care was reported. Young people seldom had a significant role in healthcare communication.

Discussion: A key message from this research is the importance of making post-treatment clinical and psychosocial care pathways clearer to survivors and their families as they transition off active treatment.

Implications: Findings from this study have implications for the refinement of short- and long-term follow up services in paediatric cancer care, particularly in relation to improving communication and long-term health planning. More structured follow-up via the recently established PICS Long-term Follow-up Program should allow these issues to be addressed.

Objective: To develop an information resource package to facilitate an improved experience for patients and carers receiving radiotherapy in the Grampians region.

Method: Develop a radiotherapy information package for all radiotherapy patients as a mechanism to dispel myths and relieve anxieties. Develop an associated education package for regional health professionals with consistent, accurate information. In consultation with consumers, health professionals and stakeholders.

Results: Package, including DVD, successfully produced and given routinely to all patients at planning appointment since October 2010. Feedback indicates the information provided reduces anxiety/concerns therefore improving patient experience and outcomes. Three education workshops delivered in the past 12 months to inpatient and community nurses locally and within the region.

Discussion: The package has successfully been rolled out to the region. Educational sessions for health professionals were well attended and positive feedback received, leading to stronger working relationships with the regional services. One of the inadvertent outcomes of the pilot has been the value of the DVD, initially targeted to patients, as an information resource for health professionals. Post completion of the pilot, the package has become sustainable requiring only minor updates as any details change.

Implications: The package has been a change agent as it provided the opportunity to reflect on nursing practice, improve pathways and ultimately influence positive patient outcomes. Availability of a sustainable education package for service providers.
Poster Presentation Abstracts
1. Malnutrition Screening Tool trial in St. Vincent’s Day Oncology

Katherine Kidd, Dietitian

Objective:
Malnutrition is common in cancer patients and may reduce treatment response and quality of life. Patients attending St Vincent’s Day Oncology for chemotherapy treatment do not routinely undergo a nutrition screen. Dietitians identified that referrals from Day Oncology were inconsistent and delayed, with referrals often made when patients were well into treatment and already malnourished.

Objectives: To trial the validated Malnutrition Screening Tool (MST) in Day Oncology to identify patients at risk of malnutrition and improve dietitian referrals.

Method:
Nurses were asked to complete the MST on all patients receiving chemotherapy for a one month period in 2010. Patients identified at nutrition risk underwent a nutrition assessment. The oncology database provided information on the number of patients receiving chemotherapy.

Results:
During the month prior to the trial 91 patients received chemotherapy and 4% were referred to the dietitian. During the trial period 76 patients received chemotherapy of which 28(37%) had the MST completed. Of these, 10(36%) were identified at risk of malnutrition. All 10 were assessed by the dietitian and 100% were found to need nutrition intervention due to poor nutritional status.

Discussion:
Greater than 1/3 of patients screened using the MST were identified at risk of malnutrition generating appropriate referral to the dietitian.

Implications
Implications for practice: Early nutrition screening should continue in Day Oncology. Strategies to remove barriers to routine nutrition screening require further investigation.

2. Consumer consultation - supportive care for patients with cancer at Mercy Hospital for Women

Marja Steur, Project Officer

Objective:
To investigate supportive care needs and providers for patients with cancer at Mercy Hospital for Women before implementing a supportive care screening process.

Method:
We consulted with fourteen people affected by cancer, of varying ages, ethnicities, domiciles and stages of disease and treatment, mostly by telephone interviews. A few consumers attended a focus group meeting. People were asked “What were the things you most needed support with?” and “What support was the most important/useful?”

Results:
- Most people expressed satisfaction with services provided at Mercy Hospital for Women
- Most people talked about their need for information
- Many people expressed a need to have a sense of personal control
- Many people alluded to the need to be recognised as an individual
- Everyone acknowledged the support they received from family and friends
- Many people mentioned a desire to talk with someone who had been in the same situation
- A range of support services was described

Discussion:
The general themes that surfaced in this consultation reflect the psychological needs of autonomy, competence and relatedness as described in Self-Determination Theory.

Implications
Patient resources being considered as a result of the findings include an information leaflet about relaxation/meditation, and a support group at the hospital. The consultation findings will also be used to prepare a staff training programme. Furthermore it is expected that the success of this relatively small consultation will encourage other areas within Mercy Hospital for Women to seek consumer participation.

3. Discussions of Chronic Myeloid Leukaemia and Imatinib adherence with patients and health professionals

Simon Wu, Medical Student, The University of Melbourne; Desmond Chee, Medical Student, The University of Melbourne; Anna Ugalde, Researcher, Peter MacCallum Cancer Centre; Phyllis Butow, NHMRC Principal Research Fellow and Chair of Psycho-Oncology Co-operative Research Group, University of Sydney; John F Seymour, Head of Haematology, Peter MacCallum Cancer Centre; Penelope Schofield, NHMRC Research Fellow, Peter MacCallum Cancer Centre

Objective:
Imatinib adherence is critical to good medical outcomes in chronic myeloid leukaemia (CML) patients. Research indicates that adherence is sub-optimal and limited data are available surrounding patient and health professional perspectives on the issue.

Method:
Sixteen CML patients currently prescribed imatinib therapy and ten health professionals, comprising of haematologists, nurses
and pharmacists involved in the treatment process were recruited at a specialist cancer centre in Melbourne, Australia. Semi-structured qualitative interviews were recorded, transcribed and analysed for themes using interpretive phenomenological analysis methodology.

Results:
Eleven out of the sixteen patients reported nonadherence to imatinib to some extent over the duration of their treatment. Reasons included not knowing how to deal with adverse events, forgetfulness, and complacency following a period of sustained disease control. Patients utilised a range of techniques to maintain adherence. At present, unless blood test results indicate a sub-optimal response to treatment, health professionals rely on the patients’ reports of adherence behaviour to guide discussion about adherence and treatment decisions.

Discussion:
Adherence issues persist through the treatment period, from short-term adverse drug events to long-term chronic management. Patient strategies to combat poor adherence are variable and are largely self-initiated. Health professionals rely on patient report and professional judgement to detect true adherence in CML patients.

Implications
This study indicates that novel intervention strategies are needed to enhance adherence and disease control. Ideally, strategies should be tailored to support patients with initial drug management issues and facilitate ongoing monitoring of treatment.

4. Transitional care for the haematology patient
Bianca Hopkins, Haematology Nurse Coordinator; Andrew Wei, Haematologist, Alfred Health; Michelle Gold, Palliative Care Consultant, Alfred Health; Katrina Lewis, Nurse Unit Manager, Alfred Health

Objective:
The project aims to develop and pilot a haematology supportive care plan form for haematology patients transitioning into palliative care.

Method:
A working group was established to develop the form and guide the project. The patient care plan is to be discussed and completed with all haematology patients deemed appropriate for palliation. Patient and staff surveys were developed for the purpose of feedback and evaluation.

Results:
The pilot commenced March 1 2011 and is in progress to date. There will be results available at the six month interval.

Discussion:
Patients with a haematological malignancy present a particular challenge in the period of transition into palliative care. It has become a significant challenge to manage haematology patients with no formal care plan documented when patients still require haematology medical interventions, such as blood product support and febrile neutropenia management. The care plan form addresses the re-definition of goals and parameters of treatment. Anecdotal evidence tells us patients lack a good understanding of the modification of there management when there is an unclear line between haematology and palliative care management of their care. A patient information booklet titled: ‘Haematology-Palliative Care: Working together to support your care’ has been developed to improve patient’s understanding surrounding these issues.

Implications
The form and booklet aim to formalise current practice where patients reach the need for palliative care involvement, and in turn will improve patient outcomes by ensuring redefined treatment goals and new measures of comfort are well communicated between haematology and palliative care.

5. Supportive care screening pilot at Peninsula Health
Bernadette McCormack, Cancer Service Improvement Coordinator, SMICS; Sue Liersch, Cancer Service Improvement Manager, SMICS; Tracey Tobias, Operations Director, Medicine and ICU, Peninsula Health; Carmel O’Kane, Nurse Unit Manager, Oncology Day Unit, Peninsula Health; Jennie Riley, Dietician, Peninsula Health; Anna Ryan, Speech Pathologist, Peninsula Health; Louisa Whitwam, Social Worker, Peninsula Health; David Steinberg, Physiotherapist, Peninsula Health; Sue Davies, Occupational Therapist/Lymphoedema Consultant, Peninsula Health; Raelene Rees, Palliative Care Consultant, Peninsula Health; Fiona Lee, Oncology Day Unit Registered Nurse, Peninsula Health

Objective:
To pilot an agreed supportive care screening tool to identify the needs of all new patients attending the Oncology Day Units (ODU) at Frankston and Rosebud Hospitals.

Method:
A multidisciplinary working group was established to develop the tool and guide the project. All new patients were screened at their first contact for chemotherapy treatment and then rescreened 3 months later. 31 patients were screened using the screening tool which included the NCCN Distress Thermometer and Problem Checklist© and key allied health questions. Evaluation included patient and staff surveys and screening tool data analysis.

Results:
Seventy four percent of patients scored significant distress(≥4) at initial screening compared to 44% at re-screening. Multiple supportive care needs were identified by patients: the most common were nervousness, worry, fears and sadness. Fatigue, sleep and eating were the most significant physical problems at initial screening and re-screening. Over 55% of patients were at either high or moderate risk of malnutrition. Nearly all patients...
surveyed agreed that the screening tool was understandable and strongly agreed that they felt comfortable answering questions.

**Discussion:**
The project has demonstrated the usefulness of a supportive care screening tool in the ODU setting. The project findings reflect existing evidence about supportive care and the role screening has in identifying patient needs at an early stage.

**Implications**
A supportive care screening tool is currently in the process of being implemented as standard practice in Peninsula Health's ODUs.

6. Supportive care in the Loddon Mallee region – a regional framework

**Robyn Moylan, Supportive Care Manager; Rachael Hamilton-Keene, Data, Quality, Projects and Research Coordinator; Philippa Hartney, Strategic Manager**

**Objective:**
Victoria’s Cancer Action Plan 2008-2011 directed the Integrated Cancer Services to develop a Supportive Care Strategic Plan specific to their region. The objective was to develop and implement a supportive care strategic plan for the Loddon Mallee Region (LMR) including a focus on introducing supportive care screening into routine practice.

**Method:**
Loddon Mallee Integrated Cancer Service (LMICS) introduced the concept of supportive care with site visits to the Loddon Mallee health services. Strategies were identified which were linked to the four strategic directions outlined in the document Providing optimal cancer care – supportive care policy for Victoria.

**Results:**
The plan was developed in two parts.
1. LMICS Supportive Care Strategic Plan 2010-2012
2. LMICS Community Participation Plan 2010-2012
LMICS chose to develop a plan specific to consumer participation to demonstrate the importance of involving consumers in supportive care.

**Discussion:**
LMICS had face to face contact with the health services initially to provide information about supportive care. This was reinforced and developed at subsequent meetings as an engagement process to promote sustainability of the screening process. Supportive Care Screening Implementation Steering Committees have been formed throughout the region, and they include health care professionals and consumers.

**Implications**
This project demonstrates the importance of engaging regional health services in change processes. This process has resulted in uptake of the supportive care screening, which will ensure sustainability. The screening process will identify issues that impact compliance with treatment and quality outcomes.

7. How can routine, supportive care screening help to increase the 5 year survival rate?

**Delwyn Morgan, Project Officer for Supportive Care Screening**

**Objective:**
To explore how supportive care screening can help to increase the 5 year survival rate. The Victoria Cancer Action Plan (VCAP) has set the goal of increasing the 5 year survival rate from cancer to 74% by 2015. This is indeed a challenge as the anticipated 5 year survival rate by 2015, based on current projections, is 67%. One way VCAP aims to achieve this goal is by investing in supporting and empowering patients and carers throughout their cancer journey.

**Method:**
Distress thermometer is a simple way of screening for psychosocial distress for those with a diagnosis of cancer. A total of 84 patients were screened over a 16 week pilot period, across Eastern Health using the NCCN Distress Thermometer and Problem checklist, during 2010. Patient feedback was obtained with phone interviews from 38 patients, to assess their experience with the screening process.

**Results:**
The feedback highlighted how supportive care can not only empower patients and their carers’, but also provided examples of how screening for needs can help to increase the five year survival rate to 74% by 2015.

**Discussion:**
When planning the appropriate action and referral, clinicians are encouraged to consider the individual needs of the patient, and to tailor the response accordingly. Patient satisfaction was very positive, and revealed that patients not only welcomed the opportunity to discuss their personal issues, but also helped them to feel supported and empowered.

**Implications**
When the benefits of screening for supportive care needs are taken into consideration, it can be seen that incorporating supportive care screening into routine, everyday practice is highly recommended.

8. Resources are needed for supportive care screening to be sustainable and allow appropriate responses to any needs identified
Objective: Providing supportive care requires resources. We aimed to determine: 1) the number of supportive care needs of lung cancer outpatients at two WCMICS sites not currently performing supportive care screening; 2) how many are currently being addressed; 3) the capacity to continue screening and respond to identified needs.

Method: A cross-sectional supportive care survey of lung cancer outpatients attending RMH and WH was performed over 4 months, followed by a medical record audit and survey of medical, nursing and allied health staff about resources.

Results: Multiple supportive care issues were identified in 89 patients but were rarely documented in the medical record. 63% of patients had dyspnoea, 64% fatigue, 45% pain, 28% symptoms of depression and 38% anxiety. Fifty-four percent had at least one functional issue. Forty percent of patients indicated they wanted help with at least one issue. Of the unit doctors given the survey, 64% said it altered their practice. Most referrals made during the study period were a direct result of the survey. A staff member with the time to perform screening in outpatients could not be identified at either site. Allied health services existed for inpatients but were limited or non-existent for outpatients.

Discussion: We confirm that lung cancer outpatients have multiple unidentified supportive care needs and highlight gaps in ambulatory care allied health services.

Implications
Supportive care screening can only be sustained and valuable if an adequate workforce to perform screening and respond to needs is instituted, particularly in ambulatory care.
Objective:
To develop and pilot an agreed supportive care screening tool in the Haematology Oncology Centre (HOC) at Alfred Health.

Method:
A multidisciplinary working group was established to develop the tool and guide the project. All new patients were screened at first contact for chemotherapy treatment. Patient and staff surveys were conducted to seek feedback on the project.

Results:
Fifty new patients were screened using the screening tool including the NCCN Distress Thermometer and Problem Checklist and key allied health questions. Sixty percent of patients scored significant distress (≥4). Multiple supportive care needs were identified by patients; the most common were fear, nervousness and worry, and loss of interest in usual activities. Fatigue, sleep and pain were the most significant physical problems. Over 50% of patients were at either high or moderate risk of malnutrition at their initial chemotherapy appointment. The results of the pilot indicated that the greatest demand for referrals was to dietetics and occupational therapy. Nearly all patients surveyed agreed that the screening tool was understandable and strongly agreed that they felt comfortable in answering the questions (90%).

Discussion:
The project has demonstrated the usefulness of a supportive care screening tool in the HOC setting. The project findings reflect existing evidence about supportive care and the role screening has in identifying patient needs at an early stage.

Implications
From the findings of the pilot a supportive care screening tool has now been implemented as part of routine practice in HOC.

11. Functional decline in patients with advanced stage non-small lung cancer (NSCLC)

Andrew Murnane, Exercise Physiologist, Peter MacCallum Cancer Centre; A/Prof Meenir Krishnasamy, Director, Cancer Nursing Practice and Research, Peter MacCallum Cancer Centre; A/Prof Linda Denhe, Head of Physiotherapy, The University of Melbourne; Catherine Granger, PhD Candidate, The University of Melbourne; Dr Linda Mileshkin, Medical Oncologist, Peter MacCallum Cancer Centre

Objective:
Patients with advanced NSCLC decline physically over time. This study aimed to quantify the physical function and health-related quality of life (HRQoL) of patients with advanced NSCLC.

Method:
A descriptive cohort study was performed. Patients with stage III and IV NSCLC were recruited. HRQoL and functional status data were collected using the EORTC QLQ-C30, the 6-minute walk distance (6MWD) and timed up and go test (TUG). Preliminary results are presented.

Results:
36 patients with a mean age of 62 years (18 males) had a mean 6MWD at baseline of 416.7m, significantly lower than predicted for age, sex and height (562.6m). This significantly declined from baseline to 2 months (n=22) by a mean of 35.8m (95%CI: 14.7 to 56.9; p=0.02), with a significant decline from baseline to 4 months (n=16) of 53.8m (95%CI: 17.3 to 90.4; p=0.007). Time taken to complete the TUG increased (worsened) significantly from baseline (mean 7.7 seconds) by a mean 0.83 seconds (95%CI: 0.56 to 1.11; p<0.05) at 2 months (n=22) and a mean of 1.04 seconds (95%CI: 0.7 to 1.39; p<0.05) at 4 months (n=16). Despite the decline in physical function, self-reported global HRQoL had a non significant improvement from baseline to 2 months, followed by a decline in global HRQoL from 2 to 4 months.

Discussion:
Patients with advanced NSCLC have clinically significant lowered physical function at commencement of treatment. Function continues to decline significantly over time, despite improvements in self-reported HRQoL from baseline to 2 months.

Implications
Future interventional studies are needed to address this issue.

12. A network approach to sustainable supportive care screening: NEMICS case study

Mirela Matthews, Quality and Projects Manager NEMICS; Kathy Simons, NEMICS Manager

Objective:
Barriers to implementing supportive care in routine cancer care are well documented and can not be ignored if we are serious about routine supportive care screening for all cancer patients. This paper outlines NEMICS’ strategies for enabling its health services to implement sustainable supportive care screening practice. The results of the screening projects in 2010 will also be presented.

Method:
Strategies: (1) short-term resources for health services to change their practice; (2) create opportunities to learn about supportive care; (3) obtain commitment from CEOs; (4) facilitate a network of key supportive care implementation personnel across NEMICS.

Results:
By November 2010 three out of four health services developed and implemented models of supportive care screening. A total of 97 clinicians were educated in screening and 450 staff attended general in-services. During the data collection period 333 patients were screened. The models were acceptable to patients and staff but there was some variation in integrating the screening practice in all units.

Discussion:
Through the network approach NEMICS enabled its member
health services to develop and implement supportive care screening in units where most cancer patients are treated. It is too early to judge if the screening practice is sustainable as the projects in health services are still funded by NEMICS. However, several strategies, which will be discussed further, will be used to indicate the potential for sustainability of screening.

**Implications**
Synchronising implementation efforts through a network is a stepping stone to sustainable practice that will take time to achieve.

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**13. Northern Health (NH) supportive care screening - an eLearning Package**

*Clare Poker, Northern Health Supportive Care Project Officer; Hugh Burch, Northern Health Nemics Service Improvement Facilitator*

**Objective:**
Meeting the challenge of sustainable Supportive Care Screening education in a time limited workplace.

**Method:**
The Supportive Care elearning (SCE) package is available on the NH intranet site complimenting established methods for workforce training at NH. SCE is evidenced based and developed in collaboration with NH Education, Quality and Safety/Injury Prevention Units and the Supportive Care Project Team. SCE packages completed by clinicians over a ten week period from September 2010 were examined to measure number completed, assessment score, workforce discipline and designated workplace.

**Results:**
Twenty seven staff completed the SCE package. Disciplines included Nurses n=22(81%), Social Work n=3(11%) and Allied Health n=2(7.4%). Designated workplaces included Day Oncology n=10(37%), Specialist Nurses from Breast Care, Colorectal, Palliative Care, Education and Administration n=9(33%), Registered Nurses from Medical/Surgical Wards n=3(11%), Social Workers n=3(11%) and Allied Health n=2(7%). Staff worked in Inpatients n=15(55%), Outpatients n=9(33%) All Day Oncology staff were nurses. Day Oncology Nurses n=10(100%) completed SCE packages. The assessment pass mark was 80%. Range 82 – 100%. Average score 93.07%.

**Discussion:**
Discipline and designated workplace numbers are predominately nurse orientated as reflected in the larger NH workforce. Uptake of SCE indicates acceptance of the VCAP screening mandate and eLearning generally. The assessment was designed to reinforce learning which supports the high achieving scores. Qualitative evaluation of the SCE package is required.

**Implications**
Accessible; Mirrors established work practices; Lends to Evaluation; Records professional learning credits; Technology future based.

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**14. Screening for supportive care needs at commencement of cancer treatment**

*Helen Longton, Quality/Project Officer, Cancer Services, Austin Health; Kelly Mills, Supportive Care Project Officer, Wellness and Supportive Care Program, Cancer Services, Austin Health*

**Objective:**
To implement a sustainable process for routine validated screening for the supportive care needs of patients commencing chemotherapy and radiation therapy.

**Method:**
Clinicians and consumers evaluated the available screening tools. Action and referral pathways were identified to address needs raised. A multidisciplinary team of staff were trained. Supportive care screening was implemented at commencement of cancer treatment in day oncology, radiation oncology and cancer wards for a 16-week pilot period.

**Results:**
220 patients were screened using the patient-administered NCCN Distress Thermometer (DT). A significant number of patients (38%) indicated moderate to severe distress (scores ≥4), with the majority of patients (62%) indicating mild distress (scores < 4). Patients on the Wards indicated more distress (4.0) than patients in Day Oncology (3.3) or Radiation Oncology (2.6). Most problems indicated were from the physical (50%) and emotional (41%) domains. A referral for further supportive care follow-up was offered to 41% of screened patients, and accepted by 30% patients screened.

**Discussion:**
Training of multidisciplinary staff enabled successful incorporation of screening into routine patient care. Most clinicians reported that it improved rapport with patients, and allowed identification of problems possibly not otherwise detected. Most patients surveyed reported the DT helped communicate their needs with staff, appreciated the opportunity to discuss issues, and would be happy to repeat the screening.

**Implications**
Local demonstration of successful screening warrants efforts to sustain the screening model used and expand it to include all cancer patients admitted to the oncology wards and palliative care unit. Introducing repeat screening points will also be introduced.

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**15. Referral patterns and client attendance to the Northern Health oncology psychologist: implications for supportive**
**care screening**

**Dr Hunter Mulcare**, Psychologist - Oncology Department Northern Health

**Objective:**
The development of strong referral pathways and identification of under-referred patient groups present a challenge in meeting patients’ supportive care needs. Referrals to the oncology psychologist were examined to identify which patients are more likely to be referred and attend therapy.

**Method:**
Referrals to the psychology service since it began in March 2010 were categorised according to clinical characteristics and number of sessions attended.

**Results:**
Sixty-six patients were referred, 18 (27.3%) declined to attend and one was referred on. Average age was 53.6 years (SD = 13.4), 53 (80.3%) were female and five (7.6%) were family members. Breast cancer patients were most frequently referred (40, 60.6%), followed by Gastro-Intestinal cancer patients (13, 19.7%); the two tumour groups predominantly treated at Northern Health. Breast patients were predominantly referred by Breast Cancer Nurses (27, 69.2%) and Medical Oncologists (5, 12.8%). For non-breast patients, 48.1% (13) of referrals came from nurses and 25.9% (7) from Medical Oncologists. Non-attending patients did not differ in terms of tumour type, family member, gender, or age.

**Discussion:**
The over-representation of breast cancer patients referred results from regular Supportive Care Screening by Breast Cancer Nurses rather than a lack of distress in non-breast cancer patients. One in four patients declined therapy; the data gives no clues to reasons for nonattendance. While referrals to psychology come from a range of professionals, higher rates are obtained when there is a screening point that is consistent and part of routine cancer care.

**Implications**
A consistent and regular supportive care screening point maximises referrals to psychology.

**16. Chemotherapy Day Unit: development of a supportive care screening tool**

**Anne M Gordon**, Dietitian, Chemotherapy Day Unit, Monash Medical Centre, Southern Health; **Emily Mead**, Acting Nursing Unit Manager, Chemotherapy Day Unit, Monash Medical Centre, Southern Health; **Kate Bourne**, Social Worker, Chemotherapy Day Unit, Monash Medical Centre, Southern Health

**Objective:**
To develop and pilot a Supportive Care Screening Tool (SCST) which identifies the needs of patients admitted to the Chemotherapy Day Unit (CDU) at Monash Medical Centre (MMC)- Moorabbin Campus.

**Method:**
Implementation of SCSTs be considered across inpatient and outpatient settings. Given patients nutritional status can vary greatly between chemotherapy treatments, using MST as a screening tool is ideal for monitoring potential nutrition related issues.

**Results:**
A literature review was undertaken of current SCSTs. A screening tool was developed which incorporated the five domains of supportive care. Specific validated tools employed were: Distress Thermometer and Problem Checklist and Malnutrition Screening Tool (MST). New admissions to CDU from October 2009 to April 2010, who consented to participate in the pilot were provided with the self administered SCST prior to treatment. Evaluation surveys were self administered to patients and staff.

**Discussion:**
Evaluation by way of pre and post questionnaires has shown consumer confidence up from 9% to 71%, and when compared to a random selection of the same number of consumers who did not attend the program, the number of home deaths was greater,
18. Utilising commercially available software to develop customised roadmaps for patients and their caregivers: a quality management project

**Objective:**
To provide a validated, flexible, easy to read summary of treatment information to patients and their families dealing with a cancer diagnosis.

**Method:**
A working group was formed to drive the project. A literature review, national and international benchmarking was undertaken. The use of a commercially available task and scheduling software was utilised. Document controlled templates are being developed for inputting data for all 74 current protocols available. Multi-disciplinary input and validation of roadmaps will occur to ensure accuracy and integrity of each document. Standard operating procedures created govern the use of roadmaps and secure document control. A pilot of eight patients has been conducted since late 2010 to test the software.

**Results:**
The literature review and benchmarking showed wide variation in the complexity of the information shared and how it is provided. The pilot test indicates the software and programmed templates are easily modified to generate individual treatment summaries. The final product is in a simple calendar format. Input and validation of each roadmap began in February 2011 and will be complete by June 2011 to enable clinical rollout thereafter.

**Discussion:**
The potential outcomes from this project for increasing consumer participation are significant, as this initiative was the single biggest priority in a document submitted to the Department of Health from the Children’s Cancer Centre Parent’s Advisory Group for improving supportive care services.

**Implications:**
Improved communication, greater levels of consumer participation, improved adherence to clinical trials and reduced levels of stress and anxiety for patients and their families.

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19. The psychosocial impact of haematopoietic stem cell transplantation on relative donors

**Objective:**
The objective of the present study was to explore the psychosocial impact of Peripheral Blood Stem Cell transplantation donation before, during and after donation, and to gain insight into donors’ experience of the preparation for and procedures associated with donation.

**Method:**
Participants were 11 males and 8 females, with a mean age of 52.4 (SD =9.85) years, who had donated their blood stem cells to a relative at the Alfred Hospital in the last three years. Data were collected via face-to-face interviews, telephone interviews, and a questionnaire.

**Results:**
Results revealed that the psychosocial impact of donation was influenced by the interactions between factors such as pragmatic aspects of the donation process, family dynamics, and the perceived adequacy of preparation for donation and emotional support.

**Discussion:**
The psychosocial impact of the donation experience was found to be influenced by issues such as preparation for donation, emotional experiences at different time-points and pragmatic aspects of donation. Participants also offered various suggestions for the improvement of practical and emotional support provided by The Alfred.

**Implications:**
There were implications for the provision of information and supportive care services to stem cell donors. Pre-donation support.
Information about the donation process should be offered well in advance to the potential donor and support provided for those who opt to self-inject. Post-donation follow-up. Follow-up in the form of telephone communication or a letter should be carried out for all donors, regardless of the donation outcome. Forming a donor support group could also facilitate improved contact between donors undergoing similar experiences.

20. A collaborative model of palliative care

Teresa Arnold, Project Manager

Objective:
The Integrated Palliative Care Service Model (IPCSM) project sought to develop and plan implementation of a sustainable model of palliative care between a primary care service and specialist palliative care service, with integrated systems and coordinated care across both organisations, underpinned by a memorandum of understanding.

Method:
The IPCSM project was driven by the Project Management Body of Knowledge (PMBoK) and included literature review, focus group workshops and survey of nurse perception of competence in palliative care. Methods supporting IPCSM project implementation included process management, information analysis and synthesis, change management and futures planning.

Results:
A collaborative model of palliative care emerged from the IPCSM project, together with implementation plans for the collaborative model of palliative care and costed palliative care nurse education. Other deliverables included a resources manual (tools, protocols and templates) to support model implementation and a memorandum of understanding between the primary care and specialist palliative care services.

Discussion:
Referral triggers used by both the primary care and specialist palliative care services were central to the collaborative model of palliative care. Tools using existing reporting data were developed to facilitate systems integration and coordinated care. Nurse education focussed on assessment of complexity of care required, pain management and advance care planning.

Implications
To ‘sustain beyond the project’, the collaborative model of palliative care and nurse education implementation plans covered eighteen months and adopted principles including collaboration, change management, continuous quality improvement, clinical governance and risk management. Implementation phases covered: prepare, introduce, prime, implement, maintain and improve, sustain and finalisation and close.
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