



## **CONFERENCE HIGHLIGHTS**

### **2012 Cancer Care Coordination Conference: Towards New Horizons**

**6–7 March 2012**

Novotel, St Kilda, Melbourne

## INTRODUCTION

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As the peak national body representing health professionals whose main work is cancer control, the Clinical Oncological Society of Australia (COSA) has identified cancer care coordination as a priority issue of concern to its members. Workshops conducted by COSA in 2006,<sup>1</sup> 2007<sup>2,3</sup> and 2009<sup>4</sup> have facilitated in defining not only the issues, purpose and expected outcomes of cancer care coordination in Australia but have also improved understanding of the contribution of cancer care coordinators improving outcomes for people with cancer in Australia. COSA leads the way in providing a forum for discussion about the contribution of Cancer Care Coordinators to cancer control, and strategies needed to facilitate development of this role.

In 2010, with input from delegates at the Cancer Care Coordination Conference COSA formalised the structure of the Interest Group Steering Committee to focus on three key areas, Education & Conference, Communication & Networking, Research<sup>5</sup>. The new structure has facilitated a mechanism to progress work in these key areas<sup>6</sup>.

Two national conferences on cancer care coordination were held (2008 and 2010). These conferences contributed to setting an agenda for ongoing development of the cancer care coordinator role and provided an important forum for discussion about the evidence base underpinning care coordination interventions.

The 2012 national cancer care coordination conference, *Towards New Horizons* aimed to provide delegates with the insights into key issues and tools to support their practice. This report provides highlights from the third national conference on cancer care coordination held on 6–7 March 2012. The conference was attended by 257 participants from across Australia and New Zealand (see Appendix I for a list of conference delegates).

Presentations from the conference will be made available on the COSA website at <http://www.cosa.org.au/Home.htm>.

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<sup>1</sup> Clinical Oncological Society of Australia. Care Coordination workshop report, 2006.

<http://www.cosa.org.au/File/Reports/CCC%20workshop%20report%20-%20Palm%20Consulting%20Feb%202007%20.pdf>

<sup>2</sup> Clinical Oncological Society of Australia. Care Coordination workshop report, 2007.

<http://www.cosa.org.au/File/publications/COSAcarecoordinationworkshopJAN08.pdf>

<sup>3</sup> Evans A on behalf of the Clinical Oncological Society of Australia. Care Coordination Workshop Report. Cancer Forum 2008;32(1):49–54.

<sup>4</sup> Clinical Oncological Society of Australia. Cancer Care Coordination workshop report, 2009.

<sup>5</sup> COSA members can access information about the COSA Cancer Care Coordination Interest Group via the COSA members area <http://www.cosa.org.au/MembersArea/InterestGroups/CCCoordination.htm>

<sup>6</sup> COSA members can access information on the cancer Care coordination Executive Committee via the COSA members area [http://www.cosa.org.au/cosa\\_assets/files/Members%20Area/Cancer%20Care%20Coordination/Copy%20of%20CCC\\_Executive\\_SteeringGroupsMembers\\_v2.pdf](http://www.cosa.org.au/cosa_assets/files/Members%20Area/Cancer%20Care%20Coordination/Copy%20of%20CCC_Executive_SteeringGroupsMembers_v2.pdf)

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The 2012 national cancer care coordination conference “Towards New Horizons” underlined the emerging issues and health care challenges for cancer care coordinators working in an ever changing health care environment. The presentations highlighted a range of tools to support care coordination practice. The conference also illustrated the enormous progress that has been made in the field of cancer care coordination in recent years.

Key messages arising from the conference presentations and discussions are summarised below.

### Keynote Presentations

#### *Dr Helen Zorbas*

Dr Helen Zorbas, Chief Executive Officer, Cancer Australia in her opening address set the scene on the current trends in cancer incidence in Australia. She reported on significant health and systems reform currently underway which will impact at all levels of cancer care- the individual, the service and systems levels.

She noted that a National Audit of multidisciplinary cancer centres in Australia found:

- 65% of hospitals did not have MDTs in the five cancers surveyed (breast, lung, gynaecological, colorectal and prostate)
- 18% of patients were not informed of their case being discussed at a MDT
- Treatment plans were not recorded for ¼ cancer patients
- 30% did not communicate treatment plans with GPs

Dr Zorbas said effective care coordination is a system wide responsibility and there is not one band-aid solution – called a care coordinator. Cancer Australia recognises the need to ensure the care coordinators role is not seen in isolation of the need for a supportive environment.

#### *Professor Emma Ream*

The conference keynote speaker, Professor Emma Ream, Kings College London, spoke about the cancer trends in the United Kingdom and issues relating to cancer care, survivorship and support that mirror those in the Australian setting. Her presentation also explained how patient and carer burden are compounded by:

- existing co – morbidities
- complex treatment regimes
- treatments now being given in an ambulatory care setting
- much greater emphasis on self- management.

Professor Ream introduced her research work (Cancer Action Team, 2007; National Cancer Action Team, 2011) and the holistic needs assessment at Kings College London. Her research focus on the informal carers (family and friends) was reviewed highlighting the major role they play supporting the cancer patient. In the United Kingdom, holistic needs assessments are now being introduced into the clinical setting to identify patients and the carer needs across the patient journey including in survivorship and end of life care. Her presentation was directed towards how best to undertake holistic needs assessments and provided examples of tools

that can be used in the process. In concluding she reflected on how a consistent approach to assessment data collection can be best fed back to multidisciplinary teams and to guide treatment decision-making.

Although the United Kingdom does not have designated cancer care coordinator roles, Professor Ream noted that cancer care coordinators are ideally placed to undertake holistic needs assessment of both patients and carers to ensure that treatments and care decisions remain patient focused.

## **Coordinated Care of the Elderly**

In a highly engaging session, medical oncologist Dr Christopher Steer, Border Oncology Wodonga, provided valuable guidance to delegates around the suitable assessment of the elderly cancer patient. He outlined the fundamental questions and documentation recommended to review an older person with cancer. These should include:

- existing comorbidities.
- activities of daily living in a formal way (ADLs and IADLs).
- depression/anxiety
- polypharmacy issues or perform a detailed drug interaction check.
- cognitive function
- QOL markers prospectively in routine practice
- Formal nutritional assessment.

Key messages from Dr Kheng Soo, (geriatric oncology trainee) were that ageing is an individual process and people can vary dramatically in the physical, psychological and social functioning. Some research indicates that a comprehensive geriatric assessment is more sensitive than a physical judgement in detecting problems, although research in this area is limited.

The important elements to better support elderly patients were outlined by the session presenters, Jane Phillips, North Coast Cancer Institute, Janette Prouse, Royal Adelaide Hospital and Jenny O'Connor, Border Health were. These included:

- Geriatric assessment tools can identify unmet needs in a timely manner and a geriatric oncology service within a medical oncology department can assist patients and clinicians to make insightful and collaborative treatment decisions
- Telephone administered VES –13 assessment tool:
  - Are quick & easy to administer
  - Have potential for under reporting of function
  - Are being self-administered as the Royal Adelaide Hospital Screening Tool (Modified CGA), taking 30 minutes for patients to self-complete (has minimal cognitive assessment item and pending validation)
- Geriatric home care interventions can improve survival of advanced cancer patients.
- Improving links and service co-ordination with the primary health sector (including GP's) improves patient and carer outcomes.

## Workshops

Three concurrent workshops were offered during the program.

### *Evidence based Co-Design Workshop*

Professor Emma Ream, assisted by Marion Strong, facilitated an Evidence based Co Design Workshop. This form of participatory action research is an innovative method aimed at identifying and implementing service improvements. The workshop was an excellent introduction to the origins, processes and the value of applying the user focus design process to enhance the cancer patient experience.

### *Future Research Workshop*

The Future Research Workshop led by Professor Patsy Yates provided an outline of the critical elements of a research study which included related examples of research activities. There were opportunities to discuss some proposed research topics relevant to cancer care coordinators and provided insight for those considering a research project.

The take home messages for Cancer Care Coordinators were:

- Think about a problem and clearly define your question (the hardest part is conceptualising and clarifying the problem)
- Importance of consumer involvement in projects
- Literature search is vital, key question to consider is “What will my research add to the existing body of knowledge?”
- Ask the help of a librarian in the literature search process
- A pilot study can shed important learnings before taking on the larger project
- Peer review of the research project is critical (e.g. ethics applications, consent forms)
- Develop collaborations with other researchers
- Don’t be afraid to email an author of an article you have read
- In the lead up to ethics submissions talk to and get to know research governance at your work place, get a copy of someone else’s submission for guidance
- Statisticians have an important role to play, such as determining the necessary sample size and add credibility to the application.
- Don’t develop a new instrument or tool - there are plenty of validated tools around

### *Mindfulness and Meditation at Work*

Jane Gray facilitated a workshop on Mindfulness and Meditation at Work. The workshop offered care coordinators insight into important meditation techniques that can be used for personal benefit or an understanding to recommend meditation as a support mechanism for their patients. The workshop was well attended and illustrated a need to offer approaches that have a positive effect on health and wellbeing for health professionals to not only prevent and heal burnout but also strengthen the capacity to care.

## Concurrent Streams – Oral Abstracts

Presentations from a number of participants highlighted the considerable work being done in areas of professional practice, research, evaluation and supportive care. The end of conference evaluation identified that participants valued the opportunities to share their ongoing research and projects and to learn from others across the country.

Some of the tools and strategies profiled included:

- health professionals' and patients' attitudes to multidisciplinary cancer meetings (MDM): qualitative analysis ( Bianca Devitt VIC)
- streamlining the referral pathway for patients with suspected colorectal malignancy – a model for optimising coordination of cancer services (Jan Stilberc WA)
- cancer care coordinator/clinical nurse consultant: a model of advanced practice nursing (Carla Thamm QLD)
- cancer care coordinator takes on nursing research and winds: developing research skills at the coal face (Sonia Khatri NSW)
- a formative evaluation of nurse cancer care coordinators: building a platform for ongoing evaluation and development (Louise Freijser VIC)
- putting the CCC in to CCC – supporting communication, coordination and data collection for Cancer Care Coordinators (Marion Strong QLD)
- keeping an eye on upper GI; oesophagogastric cancer care coordination in South Australia (Jeff Bull SA)

## Survivorship

Another key theme of the conference was raising awareness of survivorship issues and how best our Australian leaders in health care can define a comprehensive order of management for post treatment care of cancer patients. Professor Michael Jefford from the Peter MacCallum Cancer Centre, opened the session with an informative presentation on setting the scene on his UK experience with United Kingdom's National Cancer Survivorship Initiative (NCSI).

Professor Bogda Koczwara followed with a talk on the United States model and her participation in a Washington DC Workshop, called the "Essential Elements Meeting" supported through the Lance Armstrong Foundation. The US is taking a national approach in defining the essential elements of survivorship care. The workshop outcome resulted in defining the essential elements of survivorship service into three tiers:

- Tier 1. Health practitioners must provide direct access or referral to the five elements of care.
- Tier 2. Defined the high-need elements where in the medical setting all professionals should provide direct access,
- Tier 3. Health professionals should strive to provide access or referral to care.  
<http://www.livestrong.org/pdfs/3-0/EssentialElementsBrief>

Professor Koczwara expressed the need in Australia to define a national policy for Survivorship Care in Australia with some key questions to be considered. These include:

- National policy versus centres of excellence?
- What are the Essential Elements in Australia? Same or different?
- What does drive care? Reimbursement vs. other drivers.
- Advocacy in Australia versus United States model – similar or different?
- What needs money? What needs change of philosophy?

Todd Harper, CEO Cancer Council Victoria and Professor Emma Ream joined the presenters in a dynamic panel discussion on the broad approaches to dealing with Survivorship Care in Australia. There was support for further discussion at a national level to define a course of action.

The remaining two presenters provided models of a nurse led survivorship. One in a clinical setting in a major teaching hospital (Amanda Robertson) and the other was a cancer care coordination led survivorship intervention at Nambour Hospital reported by Jacinta Elks. An important message from the Nambour Hospital program evaluation was the need for up skilling nursing staff who deliver active treatment to enable them to confidently broach topic of survivorship.

## **Indigenous Health**

Aboriginal and Torres Strait Islander suffer a disproportionate burden of illness and death from cancer. Understanding and meeting their needs are essential to improving cancer screening, diagnosis and treatment outcomes for this marginal group. The session on Indigenous Health provided cancer care coordinators valuable information to build their knowledge and communication skills in an effort to meeting unmet needs for this group of patients.

Veronica Saunders (Cancer Council NSW) opened the session with an outline of the Aboriginal Patterns of Care Study. This study aims to understand the current gaps in cancer treatment and diagnosis, through exploring reasons for increased death rate from cancer of Aboriginal people in NSW. Early results indicate that that some of the barriers to treatment are:

- stigma association with having a diagnosis of cancer (defer diagnosis and treatment)
- financial burden of cost of treatment
- lack of transport services to attend treatment centre
- isolation when away from family and community
- loneliness when away from family (aboriginal health care worker important for support)

A need to understand cultural practises and learning the “lingo’ to communicate with aboriginal peoples was highlighted in the work being undertaken in Queensland and South Australia. Ali Drummonds (Queensland Health) presented information on the Queensland Health Service resource ‘Sorry News, Sad Business’ a valuable guideline to assist health professionals working with Aboriginal or Torres Strait Islander communities. [http://www.health.qld.gov.au/atsihealth/documents/sorry\\_business.pdf](http://www.health.qld.gov.au/atsihealth/documents/sorry_business.pdf)

Josie Owens and Carolyn Selby have been appointed as Care Coordinator for Aboriginal and Torres Strait Islander Health in South Australia. The complexities of care associated with Aboriginal and Torres Strait Islander peoples undergoing cancer treatments reflect that reported in other states. Josie and Carolyn have addressed some of the issues by providing information and training sessions to health professionals and administrative staff to better

coordinate patient care. They continue to identify and address training needs and are working to strengthen links with Aboriginal Community groups and Aboriginal Community Controlled Health Services in South Australia.

## **Adolescent & Young Adults (AYA)**

Participants were introduced to the ground breaking national initiatives developed and being developed to support adolescent and young adults with cancer. Since 2008 with funding from the Youth Cancer Network Program, substantial achievements have been made in seven key areas. Pandora Patterson (CanTeen) summarised the projects:

- National AYA Cancer Network
- AYA Cancer Clinical Practice Guidelines and Protocols
- Increasing AYA Cancer Clinical Research
- Adolescent and Young Adult Oncology Education Program
- National Minimum Dataset
- AYA Cancer Services Web Portal
- AYA Psychosocial Assessment and Care Process

Presenters Kate Thompson and Sharon Bowering provided a snapshot on various ways AYA care processes and the psychosocial tools are being implemented in Victoria, Tasmania and South Australia.

Key messages throughout the session were:

- States differ in how they are implementing the assessment and models of care
- It is important that cancer care coordinators know delivery treatment models in their own jurisdiction
  - In some states there is local application, e.g. South Australia
  - In Victoria & Tasmania there is a broad supportive care policy and they have established a state-wide AYA cancer service

## **Where are we now?**

In this final session, Professor Patsy Yates, COSA Chair of the Cancer Care Coordination Interest Group thanked COSA for recognising the importance of the Cancer Care Coordinator role to patient outcomes and supporting the work of the committees. Since the 2010 Cancer Care Coordination Conference the four members of the Executive have lead working committees to focus on three key areas, research, education and communication.

COSA has provided a small grant to support a review of the literature on outcome measures for Cancer Care Coordination. The review is in its final stages of preparation and will be ready for publication in the next few months. The review will be used to guide the development of a larger piece of work to develop and recommend measures for evaluating cancer care coordination activities.

Douglas Bellamy, Chair of the Education & Conference Committee thanked his committee and the support of the delegates who contributed to the success of the conference. He thanked COSA and sponsors for supporting the only national educational event held for cancer care



coordinators and emphasised the value of participating in such a group in terms of professional development.

Violet Platt the Director of Nursing representative in the COSA Cancer Care Coordination Executive committee much-admired the commitment to professional growth of health professionals' working as cancer care coordinators across the country. There is clearly a need to work together in developing strategies to further develop the role particularly in view of the proposed federal government's activity based funding. The funding framework needs to consider the services performed by cancer care coordinators' in public hospitals.

Jacinta Elks (Networking & Communication Committee) illustrated how to access the cancer care coordination contacts database through the members' area of the COSA website. Launched in June 2011 the database continues to provide an excellent networking tool. It provides information on the care coordinator's work contact details, the coordinator's specialty area of care and also any new resources or service improvement initiatives. Cancer Care Coordinators can have their details added to the contacts database by emailing through to COSA at [coordinator@cancer.org.au](mailto:coordinator@cancer.org.au).

**'The Coordinator'** Newsletter aims to showcase activities and projects being undertaken by care coordinators across the country. This newsletter is the next step in a strategy to foster and facilitate communication and networking amongst all Australian Cancer Care Coordinators. Feedback and ideas are essential to continue to make improvements and progress the goals of the working group and warmly encourage delegates to complete the evaluation and email suggestions to committee members.

Patsy Yates led a discussion about future directions for the Cancer Care Coordinator Group and invited delegates to provide feedback on priorities in the conference evaluation. She noted that the Executive Committee would meet in coming months to develop its priorities for work over the coming 12 months, including plans for future conferences.

## **Conference Award Winners**

Congratulations to the winners of the oral presentations and poster session:

- Professional Practice – Bianca Devitt
- Research, Evaluation and Development – Rebecca Keating QLD
- Supportive Care – Elisabeth Coyne QLD
- Poster – Julie Thompson

## **Next Steps**

Based on the feedback from the conference evaluation there is support for COSA to continue to lead a Cancer Care Coordination Conference every two years and provide a forum for a professional development day each alternate year. COSA will investigate opportunities to run the conference and professional development days concurrently with other professional groups such as the CNSA.

COSA will continue to work with the Cancer Care Coordination Executive and the Education & Conference Committee to further these objectives.

## Program

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### Monday, 5 March 2012

5:00 - 6:30PM      **Registration, Poster Session and Welcome**  
Welcome to Country, Wurundjeri tribe

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### Tuesday, 6 March 2012

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9:00 – 9:30AM      **Official Welcome**  
**Marie Malica**, Executive Officer, COSA  
**Official Opening**  
**Patsy Yates**, Professor of Nursing, Queensland University of Technology  
**Opening Keynote**  
**Helen Zorbas**, CEO, Cancer Australia

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9:30 - 10:30AM      **Conference Keynote**  
**Emma Ream**, Professor of Supportive Care, Florence Nightingale School of Nursing and Midwifery, King's College London, UK  
Evolving Perspective of Coordinated Care    *abs#001*

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**10:30AM**              **Morning Tea and Poster viewing**

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11:00 - 12:30PM      **Coordinated Care for the Elderly**  
*Chair: Robyn Sharman*

    11:00am      **Christopher Steer** - Coordinated care for elderly patients with cancer. A medical oncologists' perspective    *abs#002*

    11:15am      **Wee Kheng Soo** - Geriatric Principles in the Cancer Treatment of the Elderly    *abs#003*

    11:30am      **Janette Prouse** - Royal Adelaide Geriatric Oncology Service - What do we do and how do we do it    *abs#004*

    11:40am      **Jane Phillips** - A collaborative initiative to better support people 70 and up referred to a Regional Cancer Centre: The key elements and the lessons learnt    *abs#005*

    11:50am      **Jenny O'Connor** - Coordinated Care for the Elderly – presenting the art of the possible. Supportive Care Screening - the Community Context    *abs#006*

    12:00PM      **Discussion Panel**  
*Session sponsored by Cancer Council NSW*

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**12:30 – 1:30PM**      **Lunch and Poster viewing**  
**Talking tables 1.00 – 1.30pm**

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1:30 - 3:00 PM

## Workshops

### Workshop 1 - Evidence Based Co-Design

**Emma Ream & Marion Strong**

*Experience Based Co-Design: An innovative method to identify and bring about service developments abs#007*

### Workshop 2 - Future Research

**Patsy Yates**

*Research Workshop abs#008*

### Workshop 3 - Caring for Ourselves

**Jane Gray**

*Mindfulness and Meditation at Work abs#009*

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3:00PM

Afternoon tea and Poster viewing

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3:30 - 5:00 PM

Abstracts – 3 concurrent streams

#### Stream 1

#### Professional Practice

*Chair: Marcia Fleet*

3:30pm

**Bianca Devitt** - Health professionals' and patients' attitudes to multidisciplinary cancer meetings (MDMs): a qualitative analysis *abs#010*

3:45pm

**Chris Williams** - Utilising commercially available software to develop a customised roadmap for coordinating the care of children with cancer *abs#011*

4:00pm

**Jan Stiberc** - Streamlining the referral pathway for patients with suspected colorectal malignancy-a model for optimising coordination of cancer services *abs#012*

4:15pm

**Carla Thamm** - Cancer Care Coordinator/Clinical Nurse Consultant: A model of advanced practice nursing *abs#013*

4:30pm

**Jeff Bull** - Keeping an Eye on Upper GI; Oesophagogastric Cancer Care Coordination in South Australia *abs#014*

4:45pm

**Kathryn Nattress** - Ensuring fertility preservation is an integral component of care coordination for women with gynaecological malignancy *abs#015*

## Wednesday, 7 March 2012

8:00 - 9:30AM

### Survivorship

*Chair: Violet Platt*

8:00am

**Michael Jefford**

The UK experience on survivorship concerns *abs#028*

8:20am	<b>Bogda Koczwara</b> The standards of survivorship care – the US model and what it may mean for Australia <i>abs#029</i>
8:40am	<b>Amanda Robertson</b> A nurse led cancer survivorship clinic <i>abs#030</i>
8:50am	<b>Jacinta Elks</b> Survivorship Intervention – A Cancer Care Coordination Initiative <i>abs#031</i>
9:00am	<b>Discussion Panel : “What can be achieved working as a network and how we can progress better management of cancer survivors.”</b> <b>Todd Harper</b> , CEO of Cancer Council Victoria, will join the discussion
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9:30 - 10:30AM	<b>Indigenous Health</b> <i>Chair: Louise Underhill</i>
9:30am	<b>Veronica Saunders</b> Aboriginal Patterns of Cancer Care (APOCC) & its Implications <i>abs#032</i>
9:50am	<b>Ali Drummond</b> Aboriginal and Torres Strait Islander Cultural Capability in contemporary health practices associated with dying and death <i>abs#033</i>
10:10am	<b>Josie Owens and Carolyn Selby</b> Aboriginal and Torres Strait Islanders patients with cancer: Stories, Issues and Outcomes <i>abs#034</i>
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<b>10:30AM</b>	<b>Morning Tea and Poster viewing</b>
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11:00 - 12:30PM	<b>"I'm the only one under 60 in the waiting room!"</b> <i>Chair: Jacinta Elks</i> <b>Pandora Patterson, Kate Thompson and Sharon Bowering</b> "I'm the only one under 60 in the waiting room!" - Aged based screening tools & assessment measures to provide best practice supported care for Adolescents & Young Adults <i>abs#035</i>
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<b>12:30 – 1:15PM</b>	<b>Lunch and Poster viewing</b> <b>Talking tables 12.45 – 1.15pm</b>
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1:15 – 1:20 PM	<b>Announcements of Awards</b>
1:20 - 2:00 PM	<b>Where are we now?</b> <i>Chair: Patsy Yates</i> Douglas Bellamy – Education and Conference

Jacinta Elks – Networking and Communication  
Patsy Yates – Research  
Violet Platt – Nurse Leaders

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2:00 – 2:15PM

**Conference Close**

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