

Measuring Cancer Care

A National Breast Cancer Centre Workshop

33rd Annual Scientific Meeting of the Clinical Oncological Society of Australia

Melbourne Exhibition and Convention Centre
Thursday 30 November 2006



The National Breast Cancer Centre (NBCC) hosted a breakfast session during the 33rd Annual Scientific Meeting of the Clinical Oncological Society of Australia in November 2006 to promote a consistent national approach to data collection, monitoring and reporting across all cancers using exploratory work in breast and ovarian cancer as the basis for discussion. The session was well attended with representatives from Cancer Australia, The Cancer Council Australia, Australian Association of Cancer Registries, the Royal Australasian College of Surgeons, State/Territory Cancer bodies including Cancer Institute NSW, the Cancer and Palliative Care Section of the Department of Human Services in Victoria, Queensland Health and other key stakeholders.

This report reflects the issues explored and consensus opinion of participants at the workshop, and identifies approaches to achieving a nationally consistent approach to the measurement of cancer care in Australia.

Workshop overview

The workshop was facilitated by Dr Norman Swan with short presentations made by:

- Dr Helen Zorbas, Director, National Breast Cancer Centre
- Professor David Currow, CEO, Cancer Australia
- Dr Paul Jelfs, Chair, Australian Association of Cancer Registries
- Mr Andrew Spillane, Breast Section, Royal Australasian College of Surgeons.

Key discussion points

Background

- Presentations summarised:
 - *the reasons for data collection*: to review outcomes, measure best practice and review trends for the purposes of forward planning
 - *the types of data currently being collected at a population and clinical level*: incidence, mortality, survival, tumour-specific data, clinical treatment data
 - *the different groups engaged in data collection processes*: registries, state/territory cancer groups, professional colleges, sub-speciality groups, area health services, hospitals, government, non-government organisations, individual clinicians.
- The current variation in approaches, data collection systems and data sets was highlighted. It was emphasised that, even with data managers in place, current data sets are not complete.
- Specific experience in inconsistencies found in breast and ovarian cancer systems were acknowledged to be typical of the broader cancer spectrum.

Challenges

A number of challenges were identified in achieving national consistency in data collection and reporting for cancer:

- poor investment in central data collection to date
- registries act as passive recipients of data instead of active data collectors, in part due to state-/territory-based legislative requirements
- funders and health planners may not prioritise the need for data
- the complexity of the health system
- lack of infrastructure to support a range of data collections, including stage-based reporting, effectiveness of current and emerging technologies, and toxicity data
- lack of support for clinicians to undertake data entry into hospital and other databases, especially within the private system
- barriers associated with identity management, including differing regulations dependent on how data will be used
- lack of coordination of effort, with developments and advances in one jurisdiction not widely disseminated.

Enablers

- Build services around patients and outcomes.
- Secure long-term financial investment at a national level.
- Justify expenditure by demonstrating the net benefit of data collection, matching the national picture with information for individuals that demonstrates they are receiving quality care.
- Identify benefits for the clinicians, eg by linking data collection to the multidisciplinary team.
- Promote information flow from the clinical setting to registries and back to the community.
- Identify the cases for which data collection is important, recognising that it may not be necessary to collect data for all cases but rather for a representative sample.
- Identify appropriate levers and incentives to encourage participation in data collection initiatives.
- Build data collection systems around synoptic reporting to provide a standardised and consistent approach.
- Identify and fund required resources, including IT infrastructure and data managers across both public and private settings.
- Involve IT workforce to develop workable solutions, eg how to get around firewalls.

Long-term goals

- Integrate data collection into the clinical care pathway.
- Achieve national consistency between registries.
- Gain buy-in from funders and clinicians.
- Work out what is affordable, eg start with synoptic reports to develop minimum data sets and determine periodicity for review.
- Look beyond clinical outcomes, eg include psychosocial outcomes.

Next steps

- NBCC, Australian Association of Cancer Registries and Cancer Australia to hold a round table discussion between jurisdictions, including public and private representation and consumers, to review strengths and weaknesses of current systems and to gain consensus on priorities.
- NBCC to pilot minimum data sets for breast and ovarian cancer, with a view to providing a model for other cancers.