

# Welcome Address & Facilitating Knowledge Exchange and Transfer: A Patient Perspective

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## Acknowledgement

**We wish to acknowledge the traditional owners of the land we are meeting on, the Ngunnawal people. We respect their continuing culture and the unique contribution they make to the life of this area.**

## Welcome

- **Welcome to our 13<sup>th</sup> Health Outcomes Conference**
- **Welcome to our speakers and participants**
- **Welcome to our international guests Prof Neil Aaronson and Prof Suzy Skevington**

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## Thanks and Welcome

- **To our Sponsors**
  - **Office for an Ageing Australia; Mental Health and Suicide Prevention Program; Palliative Care Section; Asthma, Arthritis and Branch Support Section of the Department of Health and Ageing**
  - **Eli Lilly Australia Pty Ltd**
  - **The Pharmaceutical Alliance**
  - **Community Care Branch and Veterans and Veterans' Families Counselling Service of the Department of Veterans' Affairs**
  - **The Motor Accidents Authority of NSW**

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## Thanks

### To our co-conveners and conference secretariat staff

- Centre for Advances in Epidemiology and Information Technology, The Canberra Hospital and the School of Clinical Medicine, Medical School, ANU College of Medicine and Health Sciences, The Australian National University
- To Astoria Barr, Elizabeth Rodgers and Marina Roseby

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## Knowledge Exchange & Transfer: A Patient Perspective

- Example: Surgical intervention for early stage breast cancer
- Need for patient to make timely decisions concerning lumpectomy or mastectomy
- Biopsies, mammograms, clinical advice – how best can patients digest this information?

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## Some Barriers

- Language and jargon of medical reports (cancer stage, type, tumour grade, hormone receptor status, nodal status)
- Speed with which decisions need be made
- Currency of information available in publications provided - guides, brochures, web, practice guidelines (e.g. 2001-2005)

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## Some Barriers

- Patient's understanding of the pros and cons of alternative treatments (e.g. web forums)
- 'Weighting' of relevant pieces of information (biopsy status, family history)
- Obtaining necessary information (e.g. re breast reconstruction; or further tests to clarify decisions)

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## Challenges for Patients

**Knowing the important questions to ask!**

**Example: Initial Biopsy Lobular Breast Cancer**

Stage 1, 2cm, Tumour Grade 1 - Score 1/9, No Signs  
Nodal Involvement, Hormone Positive, Unicentric

Selects: Lumpectomy vs. Mastectomy

**Example: Post Lumpectomy Biopsy**

Stage 2, 4cm, Tumour Grade 3- Score 8/9, Nodal  
Involvement (2), Hormone Positive, Unicentric but  
with satellite deposits, Margins not clear

Consequence: Follow up Mastectomy

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## Some Questions To Ask?

With the benefit of hindsight?! :

- How often do women who have lumpectomies proceed to further surgery including mastectomy ? (33-40%)
- How accurate are initial biopsy findings in relation to the follow up biopsy once the lump is removed?
- Recurrence rates by type of cancer, same and contra lateral breast
- Is there some other form of assessment that could be undertaken to further clarify matters (e.g. MRI— to further assess spread or to ascertain whether tumour is multicentric?)
- NBCC – provides good lists of questions but these issues are not included

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## Conclusion: Aids for Decision Making

- Patient friendly 'plain English' summaries of reports?
- Easy access to updated information – folio vs. hard bound publications, updates on web site?
- Online tools as for adjuvant therapy for cancer? Helpful to assess the range of factors to be considered?
- Continuing and further assessment of patient's experiences, perceptions and satisfaction with care (Cancer Australia, Cancer Voices Australia)

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