

How to get started and where to look for consumer assistance?

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Who can be a consumer?

- Patient, carer, family member or survivor with experience of a health issue
- Capable consumers
 - developed knowledge from their experience
 - able to represent the views of others



Types of consumers

- Individuals with personal experience and motivation
 - Prior experience in consumer engagement not needed
 - Helpful for focus groups, working groups
- Expert consumers - high-level expertise
 - participate on organisational boards, advisory committees, major projects

Why involve consumers in research?

- **ensures issues important to consumers are identified and prioritised**
- different perspective
- help disseminate research results into broader community
- help translate research findings into clinical practice
- help implement research findings within health service delivery
- essential requirement of grant applications, accreditation, reporting

How consumers can be involved in research

- Identifying research priorities
 - Planning and design of research
 - Assisting with the conduct of research
 - Improving participant information, surveys, questionnaires
 - Contributing to the evaluation of research results
 - Disseminating research findings
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- Not simply recruiting patients as participants in clinical trials

Finding consumers for research

- Ask patients and families from your clinical practice
- Ask colleagues, nursing and allied health staff to contribute names
- Advertise for volunteers
- Approach relevant research and consumer groups and organisations
 - Cancer Cooperative Trials Groups
 - Cancer Australia
 - Cancer Voices
 - Breast Cancer Network Australia
 - Consumer Health Forum
- Hospital consumer groups

Involving consumers in research

- **Include consumers from the very beginning**
- Involve at least two consumers
- Cultivate environment where consumers feel valued and equal
- Make meetings 'user friendly', avoid jargon and acronyms
- Provide training and support from the beginning
 - Expectations
 - Knowledge - research, cancer, trial design
 - Meeting and teleconference etiquette
- Ensure facilities, venue choices, meeting times are appropriate and accessible

Some examples from my research



The iTool Study: A web-based tool to help oncologists estimate and explain survival time to patients with advanced cancer

- Oncologist estimates expected survival time for an individual patient
- iTool calculates worst-case, typical and best-case scenarios



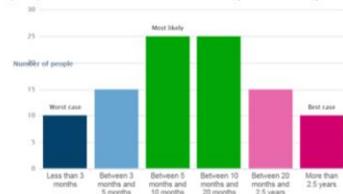
If we imagine 100 people in exactly the same situation, then we'd expect:

- the 5 to 10 who did best would live longer than **3 years**
- the 5 to 10 who did worst would die within **3 months**
- the middle 50 would live **6 months to 2 years**.

This also means that

- half the people would live longer than **12 months** and
- half the people would live less than **12 months**.

Cancer is very unpredictable. Sometimes that unpredictability acts in your favour



Print for patient and relatives, copy sent to GP and referring doctors

The iTool Study

- Consumer identified priority for research
- Patients with advanced breast and prostate cancers invited to join clinicians in trial steering committee
 - Concept and Protocol development
 - 1 page summary of individual prognostic information
 - Patient information and questionnaires
 - Development of website
 - Co-investigators on successful grant application
 - Participation in teleconferences during progress of study

“Scanxiety” in people with advanced cancer

- Anxiety around the time of CT scans identified as a problem by patients, term trending on social media
- Consumer involvement to improve our understanding of the problem
 - Focus groups with patients
 - Patient Questionnaire
 - piloted by small group of patients
 - distributed in outpatient clinics and via BCNA online review and survey group
 - Qualitative study - interviews with patients with different levels of anxiety
- Ultimate aim to develop an intervention study

Melatonin for sleep disturbance in women with early breast cancer

- Problem identified from my clinical practice
- Concept presented to Breast Cancer Trials
- Consumer advisory panel (CAP) assisted with protocol, participant information, patient diary and questionnaires
 - Plain language, burden on participants
- Study considered by SAC (consumer members)
- Successful discretionary funding application
- Trial opening soon

Management of genitourinary symptoms in women on endocrine therapy for early breast cancer

- Common problem
- Topical vaginal oestrogens helpful in general post-menopausal population but safety and efficacy in ER+ breast cancer population uncertain
- Concept presented to Breast Cancer Trials
 - Consumer (CAP) views on willingness of women to trial vaginal oestrogens
 - Working group with members of CAP to develop protocol for pilot study
- Planned focus group to develop patient questionnaire
 - Most bothersome symptom, frequency and severity of symptoms
 - Views of women with breast cancer to treatment options
- Aim for large randomised trial if feasibility study successful

Helping researchers to work with consumers

- Lack of training for clinicians and researchers in how to involve consumers in research
 - esp difficult for lab researchers and those not in direct patient contact
- Useful Resources
 - Cancer Australia consumer involvement toolkit
 - NHMRC Guidelines for consumer involvement
 - Australian Clinical Trials

Thank you for your attention