The Psycho-oncology Co-operative Research Group (PoCoG)

Quality of Life Office

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& PoCoG Executive

PoCoG

- One of 13 national cancer co-operative trials groups
- Funded by Cancer Australia and Cancer Institute NSW
- Based at the School of Psychology, University of Sydney
- Free membership
PoCoG’s Mission

• To improve the outcomes of:
  • patients experiencing a diagnosis of cancer,
  • their families
  • and carers

• through evaluation of psychosocial and supportive care interventions

PoCoG’s Aims

1. To bring together researchers, clinicians, health care professionals and consumers with an interest in psycho-oncology to foster collaboration and the exchange of ideas.

2. To develop large-scale, multi-centre psycho-oncology studies of clinical relevance and importance which would be hard for any one team to mount.

3. To develop formal links with cancer co-operative clinical trial groups to facilitate psycho-oncology sub-studies.

4. To promote psycho-oncology research and support emerging new researchers in this area.
Quality of Life Office - Goals

- Foster HRQoL research in collaboration with other co-operative trials groups and PoCoG members
- Develop methodological research
- Develop HRQoL resources
- Support the transfer of evidence about HRQoL into clinical practice

Quality of Life Office - Operation

- Staff:
  - Project Manager: Dr Tim Luckett
  - Visiting Scholar: A/Prof Madeleine King (Centre for Health Economics Research Evaluation [CHERE], UTS)
  - Research Assistant: Rachel Zordan

- Advisory Group
Cancer Australia Chair in Cancer Quality of Life

Position description -

- develop a program of research in cancer quality of life;
- create networks with the national co-operative clinical trials groups in Australia to foster HRQoL sub-studies, with a particular focus on achieving consistency in the HRQoL measures used across trials groups, where appropriate;
- provide support to development of protocols, process for assessing HRQoL in cancer patients and their carers, and encouraging the initiation of sub-studies on HRQoL issues in new and existing cancer clinical trials;
- create networks with organisations, locally and globally, involved with quality of life research;
- liaise with PoCoG and trials statisticians to develop standardised strategies for analysis of HRQoL data;
- mentor junior researchers in the area, initially through co-supervision of research higher degree students.

Quality of Life Office Resource Library

- HRQoL questionnaires and other PROMs
  - Sample instruments (with acknowledgment of copyright and adherence to copyright laws)
  - Key references (validity, reliability, sensitivity, responsiveness)
  - Scoring instructions / users’ manuals
  - Interpretation guidelines
  - Reference and normative values
Quality of Life Office Resource Library

- **Key publications**
  - Measurement, analysis, interpretation and reporting
  - HRQoL by cancer type

- **Online Resources**
  - Frequently Asked Questions (FAQs)
  - Links to online resources
  - Suggested reading
  - Protocol templates
  - Position paper on guidelines
  - Database of measures

Frequently Asked Questions - Overview

- **What is HRQoL and why should I measure it?**
  - What is health-related quality of life?
  - Why include HRQoL as an endpoint in my clinical trial?
  - Where does HRQoL sit within the family of ‘patient reported outcomes’?
  - Where can I get more information about HRQoL issues?

- **How do I measure HRQoL?**
  - How is HRQoL typically measured?
  - Which questionnaire should I use to measure HRQoL?
  - Where can I get hold of HRQoL questionnaires to use in my research?
  - How often should I measure HRQoL in my clinical trial?
  - Can I ask caregivers or health professionals about patient HRQoL?
  - Practical issues for clinical trials managers
  - Measuring symptom burden
  - Measuring psychological distress
  - Measuring stress response and adaptation
  - The EORTC suite of HRQoL measures
  - The FACIT suite of HRQoL measures
  - EORTC and FACIT compared
FAQs – Overview cont.

- How do I analyse, interpret and report HRQoL data?
  - How do I analyse and interpret HRQoL data?
  - How do I report HRQoL data from my study?
  - Why is missing HRQoL data such a problem and what can I do about it?

- Issues specific to various cancer groups
  - Measuring quality of life in children
  - Measuring the quality of life of caregivers
  - Measuring quality of life at the end of life
  - Chemotherapy and quality of life
  - Breast cancer and quality of life
  - Gastrointestinal cancer and quality of life
  - Gynaecological cancer and quality of life
  - Leukaemia and lymphoma and quality of life
  - Lung cancer and quality of life
  - Melanoma and quality of life
  - Neurological cancer and quality of life
  - Sarcoma and quality of life
  - Testicular cancer and quality of life
  - Etc

FAQ - Which questionnaire should I use to assess the HRQoL of cancer patients in my study?

- Should I use a general or disease-specific questionnaire?
- Does my questionnaire cover all the ‘domains’ that matter?
- How will the questionnaire be administered?
- Will my questionnaire be sensitive or responsive enough to show an effect?
- What sort of response options would it be best to use?
  - Dichotomous choice
  - Ordered categorical scale
  - Visual Analogue Scale (VAS)
- What sort of recall period would suit my purposes?
- Will my questionnaire be too burdensome for patients and research staff?
- Does my questionnaire enable me to generate an overall score, and does this matter?
- Will my questionnaire be valid and reliable for use with my patient groups?
  - Will my questionnaire be suitable for the cultures and language groups I’ll encounter?
- How available is my questionnaire and the information I’ll need to use it?
- What should I do if I can’t find a questionnaire that suits my purpose?
- Can I use a single-item, global rating scale?
Advisory services

- Choice of measures – e.g.
  - RCTs
    - Merkel cell carcinoma (Trans-Tasman Radiation Oncology Group [TROG])
    - 6 x drug trials (Palliative Care Clinical Studies Collaborative [PaCCSC])
  - Prospective cohort studies
    - Head and neck cancer (Royal North Shore Hospital)
    - Lung cancer (Gold Coast Hospital)
- Psychometric properties of questionnaires
- Help with analysis and interpretation of data
- Revised HRQoL guidelines for TROG

Research program – potential categories

- Intervention studies with HRQoL as a primary or secondary outcome (pharmaceutical, psychological, exercise, etc.);
- Intervention studies which examine clinical use of HRQoL questionnaires to improve process and outcomes of care;
- Descriptive studies in which HRQoL is an outcome (e.g., models of care; different cancer groups)
- Methodological research (e.g., cross-cultural interpretation; response shift; responsiveness);
- Studies exploring consumer definitions of HRQoL and important differences in scores;
- Studies examining ways to get HRQoL evidence into practice.
Research program - NHMRC round, 2008

- Does palliative chemotherapy improve symptom control in women with recurrent ovarian cancer?
- Understanding the psychosocial sequelae of surviving testicular cancer
- Improving psychosocial outcomes for cancer patients: A RCT
- Quality of life outcomes and cost effectiveness of pelvic exenteration for people with advanced rectal cancer
- Psychological morbidity, unmet needs, quality of life and patterns of care in migrant cancer patients
- Development and valuation of cancer-specific multi-attribute health states for use in economic evaluation

Quality of Life Office:

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Please share your ideas …

- Resources the Quality of Life Office might offer?
- Research priorities in HRQoL?