Psycho-oncology Co-operative Research Group (PoCoG): A New ‘Quality of Life Office’ to Support Australian Cancer Clinical Trials

Abstract:

Background: Along with survival, health-related quality of life (HRQOL) is now mandated as the most important outcome in cancer clinical trials. However, the measurement, analysis and interpretation of HRQOL outcomes are often of inadequate quality to inform clinical practice. The patient reported nature of HRQOL data places special demands on trial design and methodology.

A New Initiative: Over the past year, the Psycho-oncology Co-operative Research Group (PoCoG) has been developing a Quality of Life Office to support appropriate, valid, rigorous and patient-centred HRQOL assessment by the national clinical trials groups and PoCoG members. Infrastructure funding has been provided by Cancer Australia and the Cancer Institute NSW. The Office is currently establishing:

- a resource library containing relevant questionnaires (with manuals, interpretation guidelines and references) and HRQOL-related literature
- a website with FAQs and relevant links
- guidelines about a range of HRQOL-related issues
- support in developing the HRQOL component of protocols and analysing and interpreting HRQOL data
- a program of research, including collaborations with the national clinical trials groups.

These activities will be supported by the creation of the Cancer Australia Chair in Cancer Quality of Life.

Management and Operation: Daily operations of the Quality of Life Office are supported by a project manager, Dr Tim Luckett, working collaboratively with visiting scholar Dr Madeleine King and the PoCoG staff and Executive Committee. To ensure that the Quality of Life Office is optimally useful and productive, PoCoG is seeking advice from the national clinical trials groups and PoCoG membership regarding their HRQOL-related information needs and ideas for collaboration. An advisory group has been formed and is meeting twice yearly to monitor progress and advise on strategic directions.