

## The Quality of Life Office Team



### Professor Madeleine King, Cancer Australia Chair in Quality of Life

Professor King has been the Cancer Australia Chair in Quality of Life since its establishment in 2008. She is a clinical research methodologist with experience across biostatistics, epidemiology, psychometrics, and health economics – all key aspects of QOL research, which is a multi-disciplinary endeavour. Much of her research has been in cancer.

Over 25 years, she has specialised in patient-reported outcomes (PROs), including health-related quality of life (HRQOL), functioning, symptoms, patient preference and utility. Her expertise spans the research process: study design, measurement, analysis, interpretation and reporting of PROs. The breadth and depth of her expertise is unique in Australia and esteemed internationally. In 2018 she was awarded the John Ware and Alvin Tarlov Career Achievement Award in PRO Measures (jointly sponsored by the Health Assessment Lab and Medical Outcomes Trust). This award recognised the scope and impact of her contributions to setting standards for the adoption of PRO measures in clinical research, promoting the use of PRO measures among health care professionals, and educating clinicians and trialists in PRO principles and methods.

A major focus of her efforts in recent years has been improving standards of PRO/HRQoL research in clinical trials, from protocol development through to peer-review reporting. She co-led an international initiative to set best practice standards for protocol content of PROs and HRQoL in clinical trials (SPIRIT-PRO), and regularly conducts educational workshops on the topic nationally and internationally. She is increasingly involved in local, state and national initiatives to integrate PROs into routine clinical care and health service monitoring and quality improvement.

## Doctor Claudia Rutherford

Dr Rutherford is Deputy Director of the QOL Office and a Senior Research Fellow, University of Sydney. She holds an Honorary position at the Institute of Clinical Trials Research, University of Leeds, UK, is Chair of the Sydney Cancer Research Network Patient-Reported Outcome Special Interest Group, and Co-Editor-in-Chief of the Quality of Life Research Journal.

Claudia has been providing patient-reported outcomes (PRO) advice to CTG members for the past five years, particularly regarding the design and conduct on PRO sub-studies, including the selection of appropriate PRO endpoints, measures and assessment time-points. She is a member of the Primary Care Collaborative Cancer Clinical Trials Group (PC4) and the Psycho-oncology Co-operative research Group (PoCoG) scientific advisory committees.

With under-graduate qualifications in psychology, she completed her PhD in 2011 in Health Outcome Measurement, and since then, has continued to specialise in PROs, including health-related quality of life (QOL) and symptom burden. She has experience undertaking mixed method systematic reviews, qualitative research, developing conceptual frameworks, and PRO measure development, evaluation, and implementation. Claudia's research interests are within the field of Health Psychology, with a focus on methodological research to improve the quality of PRO assessment in clinical research. Specifically, her interests include improving the QOL of people affected by chronic health conditions, and developing valid PRO measures for use in research and clinical practice. More recently, her interests have extended to implementing the routine collection of PROs in oncology health settings for individual patient decision-making and service evaluation.



## Dr Rachel Campbell

Dr Campbell is a psychologist with expertise in both Clinical and Health Psychology. Her PhD research focused on examining the role of psychological factors in predicting sleep outcomes among healthy individuals as well as individuals with a range of chronic health conditions. She received her PhD in 2017 from the University of Ghent in Belgium.

Within her PhD research she used a variety of different research methodologies including cross-sectional, longitudinal, diary and experimental research designs. She has considerable experience in conducting quantitative analyses and is skilled at performing sophisticated statistical analyses on complex multilevel datasets. She has published her research in several high impact journals and has presented her work at a number of international conferences.

In her role as QOL Office Postdoctoral Research Associate, and QOL Technical Services Project Officer, Dr Campbell is committed to supporting the QOL Technical Services by providing advice, education and training with a view to improving the quality of PRO assessment in clinical research.





Mr Dion Candelaria

Mr Candelaria is a QOL Office Research Associate, and QOL Technical Services Project Officer. He previously held an Associate Lecturer position -Clinical Education Specialist position at The University of Sydney Susan Wakil School of Nursing and Midwifery. He is currently completing his PhD at the University of Sydney on health-related quality of life outcomes in patients attending cardiac rehabilitation. His research project aims to identify vulnerable population groups and develop patient-centred interventions. His research interests include improving the quality of health services through the integration of patient-reported outcome measurement in clinical practice and ensuring that interventions are responsive to individual patient needs. Dion looks forward to working with the Sydney QOL Office team providing the QOL-Technical Service.



Ms Margaret-Ann Tait

Ms Tait is the Senior Research and Administration Officer, and has been with the QOL Office since 2015. She has degrees in Psychology, B.A.S. (Hons) and MSc (Coaching Psychology), from the University of Sydney, and is certified in small business management and bookkeeping. In 2021 she will commence her PhD candidature in health-related quality of life.

Margaret has more than 20 years' experience in SME administrative and managerial positions before her career transition into psychology and research. She actively contributes towards research projects, particularly in electronic PRO research data capture, and is responsible for the delivery of daily administration, budgeting, and reporting activities of the QOL Office. Ms Tait has demonstrated ability and experience to provide research administrative services and operational assistance to the QOL Office staff across multiple projects.



## QOL Office Honorary Associates

### Doctor Rebecca Mercieca-Bebber

Dr Mercieca-Bebber was the QOL Research Officer 2011-2017. During that period, she provided PRO advice to CTG members on all aspects of QOL study design, conduct and reporting.

In 2014 she worked part-time while embarking on her PhD, *Patient-Reported Outcomes in Cancer Clinical Trials: What are the Problems and how can we improve the quality and reporting of evidence?*, which focussed on the design, implementation and reporting of PRO sub-studies, and addressed important issues such as missing data and best practice standards for protocol development and reporting.

She completed her PhD in mid-2017 and has since obtained a prestigious NHMRC post-doc fellowship, and is now the QOL Fellow at the NHMRC Clinical Trials Centre.

She led several initiatives through the International Society for QOL Research (ISOQOL), including a review of trials with PROs registered on the Australia New Zealand Clinical Trials Registry (ANZCTR), and a review on the uptake and impact of the CONSORT-PRO Extension for standardised reporting of QOL and PRO endpoints from clinical trials. She is an executive member of the SPIRIT-PRO (Standard Protocol Items for Intervention Trials) Operations team, executive member of the ISOQOL Best Practice for PROs Taskforce and co-chairs the ISOQOL Proxy Taskforce. She is also the Chair Elect of the ISOQOL Australia New Zealand Special Interest Group (ANZSIG) and current secretary for this group. She is the QOL/PRO representative on four international clinical trials with PRO endpoints.

Dr Mercieca-Bebber remains involved in the QOL Office as an honorary associate, and is committed to continuing to contribute to the educational activities of the QOL Technical Services 2018-2021, as well as providing specialist advice, as needed.

### Doctor Dan Costa

Dr Daniel Costa has been affiliated with the QOL Office as either employee or collaborator since mid-2009. He provided psychometric and statistical expertise to the Cancer Australia QOL Technical Services on a part-time basis 2013-2015, assisting with direct advice to CTGs, educational activities, and the development of online resources.

Dr Costa has published articles discussing theoretical and methodological issues related to PROs. He has analysed data for a variety of projects involving PROs since 2009, conducting a range of sophisticated psychometric and statistical analyses with a focus on quality of life, fear of cancer recurrence, perceived cognitive function, unmet needs, and pain. He has also taught statistics and psychometrics to under-graduate students and PRO assessment theory and methods to post-graduates and consumers.

In 2015, Dr Costa obtained a secure position with Royal North Shore Hospital, but remains involved in the QOL Office as an honorary associate, and is committed to continuing to contribute to the educational activities of the QOL Technical Services 2018-2021, as well as providing specialist advice as needed.

#### Doctor Fabiola Müller

Dr Müller is a Health Psychologist specialised in research on psychosocial outcomes in cancer patients and their partners. Her PhD research was dedicated to examine predictors and outcomes of post-treatment cancer-related fatigue, aiming to identify strategies to support couples to adjust to fatigue and reduce its interfering effects on daily life. She received her PhD from the University of Groningen, The Netherlands, in 2018.

Dr Müller is skilled to critically evaluate the psychometric properties of PRO measures to assess cancer patients' symptoms and functioning and in assessing the quality of life and support provision of partners of cancer patients. She has experience working with a diverse set of datasets, analytical methods, and statistical software. She received a travel grant from the Dutch René Vogels Stichting, allowing her to visit the University of British Columbia, Canada, to deepen her skills in applying multilevel modelling to analyse complex, nested datasets (i.e. dyadic diary data). During her academic training, she taught statistics and research methodology, published in high impact journals and presented her research at several (inter-)national conferences. Her research interest is directed towards understanding the impact of cancer and its treatment on patients' and caregivers' HRQOL, facilitating strong methodological cancer research and contributing to improved patient care.

Dr Müller was the QOL Office Postdoctoral Research Fellow 2018-2019. She remains involved in the QOL Office as an honorary associate, and is committed to continue applying her expertise both through advising/training as well as through conducting research to foster the inclusion and clinically meaningful interpretation of PRO measures in clinical cancer trials.

#### Dr Angela Ju

Dr Ju was the QOL Office Postdoctoral Research Associate 2019-2020, and continues to provide expert advice to CCTGs on incorporating PROs throughout clinical trial protocol development. She completed her PhD at the University of Sydney on establishing and developing patient-reported outcome measures for fatigue and life participation, for use in clinical trials that involve patients with end-stage kidney disease. Her research interests are in developing patient-centred interventions and ensuring the proper selection and use of patient-reported outcomes and appropriate measures.

She has extensive experience in patient-centred research, where patients are involved from early stages of research including study design. She has used various consensus-based research methods such as consensus workshops and Delphi method, to involve all relevant stakeholders such as health professionals, patients and caregivers. Her expertise in qualitative methods such as interviews, focus groups and patient forums allows her to utilise mixed-methods in her research, as she believes qualitative work complements information gathered from quantitative analyses.

Angela is currently furthering her education to pursue a career as a medical doctor.