
Handbook of Quality of Life in Cancer

Angelos P. Kassianos
Editor

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 Springer

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Angelos P. Kassianos
Department of Applied Health Research
University College London
London, UK

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This work is dedicated to Panayiotis Kassianos (1945–2006).

Preface

Is quality of life more important or is it quantity of life? Or is it up to the patient to decide? The evidence on the importance of quality of life (QoL) for patients, their lives and their treatment has been widely documented in the literature. There is considerable research on the role of QoL on general well-being, responsiveness to treatment and even longevity. Therefore, it is possible that QoL can even impact quantity of life. At the same time, there are a number of methodological considerations when measuring and assessing QoL with cancer patients. This handbook aims to fill a gap in the literature, collate evidence and bring world experts together to respond to a number of questions, among others, including:

1. What is QoL, why it is important and how is it assessed?
2. What are the theoretical and methodological considerations in assessing QoL with cancer patients?
3. How can QoL be utilised in routine clinical care?
4. How is QoL impacting different cancer populations in terms of site, age, gender and context?

The Handbook of Quality of Life in Cancer summarises current evidence and can be useful for a diverse readership. First, researchers who wish to use QoL assessment tools in clinical trials or other types of research studies. Second, healthcare practitioners including clinicians, nursing professionals, social workers, physiotherapists and psychologists, among others, who want to develop their understanding of how they can utilise QoL in their practice and its importance for the patients they care for. Third, commissioners who can understand why QoL may impact population health and the implications for costs of healthcare systems. Fourth, teachers and academics who can use the handbook to inform their teaching and prepare materials, exam questions or essay topics and facilitate debates in their teaching. Finally, students in diverse fields of study including medicine, nursing, psychology, social work, medical sociology, population health, epidemiology, medical statistics and others who can use the handbook for their studies and for their continuing professional development.

You can use this handbook in different ways that fit your learning purpose. We tried to summarise evidence in each chapter and provide elements that can help you to check your understanding of each topic and facilitate discussions with others either in a classroom or in practice. These elements include:

1. *Questions that can be used in teaching and to test learning.* These are questions that the authors of each chapter have considered carefully in order to help you to test and summarise your knowledge on each topic.
2. *A topic that can be used for discussion in teaching.* These topics are considered key for each chapter and can help facilitate debates and classroom interactive discussions as well as help you to consider issues that can be controversial or that can help develop your critical thinking on the topic.
3. *A 'further reading' list.* These lists are different than the reference lists for each chapter. The purpose here is to highlight what are the important publications for each topic so that you can easily expand your knowledge and identify further resources.
4. *A 'research in context' box* where authors have identified a key topic, publication or tool and have expanded on this with more details so that you can get further in-depth knowledge of a topic.

The first part of the handbook, *Concepts and Definitions*, is introductory and here you can read about important concepts and definitions. Concepts like QoL, health-related quality of life (HRQoL) and wellbeing are defined in Chap. 1, while Chap. 2 deals with what it means for patients to have QoL in relation to quantity of life.

The second part of the handbook, *Quality of Life Assessment*, deals with different aspects of assessing QoL of cancer patients. Generic tools like the WHOQOL group of tools are discussed in Chap. 3, while cancer-specific tools developed by the European Organisation for Research and Treatment of Cancer (EORTC) and the Functional Assessment of Chronic Illness Therapy (FACIT) measurement systems are discussed in detail in Chaps. 5 and 6, respectively. Chapter 4 outlines all aspects that should be considered when developing a cancer QoL assessment tool, and Chap. 7 outlines what should be considered when validating the tools. Modern technologies in assessing QoL are becoming more prevalent and will continue to be in the years to come. These are discussed in terms of using new technologies for QoL assessment in Chap. 8 and in terms of modern psychometric measurement and computerised adaptive testing in Chap. 9.

The third part of the handbook, *Best-Practice Elements When Assessing Quality of Life*, deals with best-practice elements of using QoL data. How the data can be analysed in clinical trials and beyond is discussed in Chap. 10, and how data can be presented visually to communicate these to patients and clinicians is discussed in Chap. 11. Subsequently, Chap. 12 outlines cross-cultural considerations of QoL assessment such as cultural validity and considerations when translating measures or using them with diverse populations and contexts. A number of subsequent chapters outline which topics QoL data can be used for and inform such as mortality aspects (Chap. 13), health-care cost-effectiveness (Chap. 14), patient satisfaction with care in the context of patient-reported experience measures (Chap. 15), decision-making in health care (Chap. 20) and drug development (Chap. 21). Chapter 16 focuses on a specific symptom (fatigue) that warrants greater focus from researchers and clinicians, and Chaps. 17 and 18, respectively, outline the use of QoL data for specific populations (adolescents and young adults) and as a proxy

measure for patients. Chapter 19 outlines the evidence on studies with psychosocial interventions with QoL as an outcome and how mental health can be related to QoL.

The fourth part of the handbook, *Case Studies of Using Quality of Life Tools for Specific Cancer Types*, presents some case studies on QoL aspects of specific cancer populations: breast cancer (Chap. 22), brain cancer (Chap. 23), colorectal cancer (Chap. 24), endometrial cancer (Chap. 25) and melanoma (Chap. 26). These chapters offer more in-depth information on patients with different tumour sites and how their QoL can be affected, as well as the specific tools that can be used for these populations.

The Handbook of Quality of Life in Cancer makes a unique contribution to knowledge by collating contemporary evidence and perspectives with practical guidance. It is also designed to be useful for a diverse readership and offers food for thought for new directions for research and clinical practice towards improving QoL for cancer patients.

London, UK

Angelos P. Kassianos

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About the Contributors

Mustafa H. Abd El Wahab, MBBCH is a medical intern at El-Demerdash Hospital, Ain-Shams University in Cairo, Egypt, with a special interest in surgical oncology.

Olalekan Lee Aiyegbusi, MBChB, MPH, PhD is a PRO research fellow and a deputy director at the Centre for Patient-Reported Outcome Research (CPROR), University of Birmingham, UK. His research currently focuses on the clinical management of chronic diseases, the use of patient-reported outcomes in routine clinical practice and clinical trials, and patient and public involvement and engagement in research.

Amélie Anota, PhD is a senior statistician at the Cancer Care Center Léon Bérard in France. She is expert in the longitudinal analysis of quality of life data in oncology. After obtaining a PhD in biostatistics in 2014 at the University of Franche-Comté, France, she realised a one-year research fellowship in the Health Outcomes Research Unit of the GIMEMA Fondazione in Rome, Italy. She previously worked at the University Hospital of Besançon and is also statistician for the French National Platform of Quality of Life and Cancer.

Iris Bartula, DCP is a clinical and research psychologist. She is a senior lecturer at the University of Sydney and leads supportive care and survivorship research at Melanoma Institute Australia. Both her clinical work and research efforts focus on improving quality of life and emotional wellbeing of melanoma patients. She has particular interest in the development, validation and implementation of psychometric measurements and psychosocial interventions. She is a strong advocate for consideration and integration of psychosocial support into a routine medical practice.

Melanie Bell, PhD, MS is professor in the Department of Epidemiology and Biostatistics at the Mel and Enid Zuckerman College of Public Health at the University of Arizona. Her research focus is statistical methods for handling missing data in randomised trials, and the design and analysis of studies using patient-reported outcomes. She has published extensively both in methodological issues in the design and analysis of patient-reported outcomes, as well as collaboratively for trials that use patient-reported outcomes.

Anne Brédart, PhD is a clinical psychologist and researcher in psychoncology at Institut Curie in Paris, France. She is an active member of the European Organisation for Research and Treatment of Cancer Quality of Life Study Group (EORTC QLG), where she implemented the development and validation of cancer patient satisfaction with care measures. She pursues clinical studies in the field of supportive care needs and quality of life assessment. She also coordinates a research program on psychological and communication issues in breast cancer genetics and advanced cancer care.

Jason Bredle, MFA is the director of licensing operations for FACIT.org and coordinates the translation and linguistic validation of the FACIT measurement system with FACITtrans in the United States. His contributions to linguistics and health outcomes have appeared in *Quality of Life Research*, *International Journal of Infectious Diseases*, *Journal of Palliative Medicine*, *Value in Health Regional Issues*, and *Pulmonary Therapy*, and have been presented at international forums in the United States, Canada, France and the Netherlands, among other places.

Michael D. Brundage, MSc, FRCPC, MD is a professor of oncology and of community health and epidemiology and a senior clinician-scientist at Queen's University, Canada, where he serves as director of Cancer Care and Epidemiology at the Queen's Cancer Research Institute. He is a practicing radiation oncologist and co-chair of the Quality of Life Endpoint Committee of the Canadian Cancer Trials Group, and is co-PI of the PROTEUS Consortium. His research and teaching interests link epidemiological methods in clinical trials with knowledge uptake in clinical practice, access to care and other measures of quality of care in cancer control systems.

Melanie J. Calvert, PhD is a professor of outcomes methodology, director of the Centre for Patient-Reported Outcomes Research and NIHR senior investigator at the University of Birmingham, UK. She has led international efforts to improve the design, analysis and reporting of patient-reported outcomes in clinical trials and routine clinical practice.

Julie Campbell, BEc (Hons), PhD is a research fellow at the Menzies Institute for Medical Research, University of Tasmania, Australia, where she specialises in health economics. She has expertise in patient-reported outcomes, multiple sclerosis and qualitative research.

David Cella, PhD is The Ralph Seal Paffenbarger Professor and chair of the Department of Medical Social Sciences at Northwestern University Feinberg School of Medicine in the United States, and an elected member of the National Academy of Medicine. Dr. Cella's research portfolio extends from health outcomes measurement and applications to clinical trials, comparative effectiveness and learning health system implementation. As an expert in applied health status measurement, he has led the development and validation of the FACIT Measurement System, PROMIS, Neuro-QoL and the emotional

health domain of the NIH Toolbox. These measurement systems are used around the world by thousands in clinical practice and research.

Emilie Charton, PhD is a statistician at the Cancer Care Center Léon Bérard in France. Her work focuses on longitudinal analysis of health-related quality of life data in oncology and social inequalities in health. She defended a PhD in Biostatistics in 2020 at the University of Bourgogne Franche-Comté in France.

Ingrid Cox, MD, MSc, Grad Cert Economics, PMP is a PhD candidate at the Menzies Institute for Medical Research, University of Tasmania, Australia. Dr. Cox has extensive experience as a medical doctor working across many countries in a range of challenging settings. Her PhD focuses on the epidemiology and health economics aspects of idiopathic pulmonary fibrosis. She is the current founding president of the ISPOR Victoria and Tasmania student chapter.

Anne-Sophie Darlington, PhD is a professor of child and family psychological health at the University of Southampton, UK, specialising in health/paediatric psychology. Her programme of work focuses on measuring and improving quality of life of children and young people with a chronic illness through developing and testing interventions. She is an expert on quality of life for adolescents and young adults with cancer.

Barbara de Graaff, PhD is a senior research fellow at the Menzies Institute for Medical Research, University of Tasmania, Australia. She is a health economist with expertise across primary liver cancer and viral hepatitis, along with equitable health resourcing. She is a board member of the Australian Health Economics Society.

Brenda L. den Oudsten, PhD is an associate professor at Tilburg University in the Netherlands, specialising in medical psychology. She is an expert on quality of life and collaborated internationally to develop an add-on for the WHOQOL-BREF in the World Health Organization's WHOQOL-DIS project. She is also interested in topics like intimacy and sexuality, which can affect patients' lives when confronted with a diagnosis or treatment. den Oudsten studies different patient populations, such as cancer (e.g. breast cancer, colorectal cancer, lung cancer), physical trauma and arthrosis.

Mbathio Dieng, PhD is a recognised expert in health economics, epidemiology and cancer quality of life research. She is currently a postdoctoral research fellow at the NHMRC Clinical Trials Centre, a specialised centre of the University of Sydney that has more than 25 years of expertise conducting randomised trials including landmark studies in cancer. Dr. Dieng has strong experience in within-trial and modelled economic evaluation applied to cancer, and her current research interests cover the areas of diagnostic tests, quality of life, benefits and harms of patient follow-up and monitoring, randomised control trials incorporating patient preferences, and the specific economic methods underpinning these.

Linda Dirven, PhD is an epidemiologist at the Leiden University Medical Center and Haaglanden Medical Center in the Netherlands. She became the chair of the EORTC Brain Tumour Group Quality of Life Committee in 2018. She is currently associate editor of *Neuro-Oncology*. The main focus of her research is clinical outcome measures in neuro-oncology, such as health-related quality of life, functioning in daily life, neurocognition, epilepsy and end-of-life care.

Deborah Fitzsimmons, PhD, BN (Hons), RN holds a personal chair and is director of Swansea Centre for Health Economics, Swansea University, Wales, UK. Deb began her research career working on the development of the EORTC pancreatic cancer module as a PhD nurse researcher in 1995 and has worked on many quality of life module development projects since then. She was inaugural chair of the Project and Module Development Committee for the EORTC Quality of Life Group between 2012 and 2018. She has developed a portfolio of work in health economic evaluation in cancer and other long-term conditions alongside her continued work in quality of life assessment.

Lysbeth Floden, PhD, MPH is a senior director on the Quantitative Science Team at Clinical Outcomes Solutions in Chicago, Illinois, USA. She specialises in statistical analysis of patient-reported data in oncology settings and has extensive experience in psychometrics and mixed-methods research. Her research interests include methods to reduce bias and increase precision and interpretability of patient-reported outcomes in clinical trials and real-world studies.

Johannes M. Giesinger, PhD is a senior researcher at the Medical University of Innsbruck in Austria, specialising in patient-reported outcome research. He is a clinical psychologist with a degree in biostatistics who has conducted methodological and clinical research studies, primarily in the oncological field. He has led and contributed to several projects that focus on facilitating the interpretation of patient-reported outcome measures. Since 2008 he is a member of the EORTC Quality of Life Group.

Conrad J. Harrison, BSc, MBBS, MRCS is a plastic surgery registrar by background, reading for a doctorate in psychometrics at the University of Oxford, UK. He has led the development of a range of condition-specific computerised adaptive testing assessments for use in plastic surgery and successfully deployed these in clinical practice.

Lynn Howie, MD is a medical oncologist in the United States specialising in haematology, medical oncology, drug development and patient-reported outcomes (PROs). She has had experience providing clinical care for patients as a general oncologist and haematologist in the community setting. Additionally she has worked as a medical officer at the US Food and Drug Administration. In addition to her clinical and research interests, she is very interested in the role of physical activity in helping to improve the lives of people living with cancer and serves as a volunteer for several organisations

that work to support this. Lynn has an MD from the University of North Carolina at Chapel Hill, completed her internal medicine residency training at the Johns Hopkins Hospital in Baltimore, Maryland, and completed her haematology and medical oncology fellowship at Duke University in Durham, North Carolina.

Sarah E. Hughes, BSc, MHSc, PhD, MRCSLT is a research fellow at the Centre for Patient Reported Outcome Research (CPROR), University of Birmingham, UK. She is a health services researcher with experience in both qualitative and quantitative research methods. Her research interests include hearing loss, patient-reported outcomes (PROs), person-centred care and implementation of PRO interventions.

Olga Husson, PhD is an epidemiologist and research group leader at the Netherlands Cancer Institute in Amsterdam. She specialises in patient-reported outcome assessment in diverse groups of cancer patients, more specifically adolescents and young adults, and sarcoma and other rare cancer patient groups. She leads large (inter)national studies in this field and is supervisor of several PhD students. She is a member of the Executive Committee of the European Organisation for Research and Treatment of Cancer Quality of Life Group (EORTC QLQ).

Ahmed H. Ibrahim is a medical intern at Ain Shams University in Cairo, Egypt, with a special interest in medical oncology.

Lee Jones, MBA is a long-term metastatic colon cancer survivor and active cancer patient and research advocate in the United States. Lee's advocacy activities include serving on the Georgetown University and NCI Central Institutional Review Boards and the Boards of the Cancer Action Coalition of Virginia and the Ruesch Center (Georgetown); reviewing research proposals for the DOD, PCORI and Conquer Cancer; speaking at numerous conferences; co-authoring published papers related to defining tolerability, reporting adverse events and tightening exclusion criteria; and serving as an advocate member of a Cancer Grand Challenge team studying the relationship between the microbiome and colorectal cancer (OPTIMISTIC).

Maria Karekla, PhD is a licensed clinical psychologist, peer-reviewed acceptance and commitment therapy trainer and associate professor at the University of Cyprus in Nicosia. She heads the 'ACTHealthy: Clinical Psychology and Behavioral Medicine' laboratory. Her research focuses on areas of health promotion and the investigation of individual difference factors (especially psychological flexibility parameters) as they relate to the development and maintenance of various behavioural difficulties (especially anxiety, eating and health-related problems). Additionally, she examines the treatment of these difficulties utilising acceptance and commitment-based principles and innovative delivery methods (e.g. digital interventions, virtual reality).

Sadori Khawaja, MD is a teaching associate at the Aga Khan University, Pakistan. She will be starting her paediatric residency training at Saint Louis University School of Medicine, in Missouri. She is interested in health inequities, health policy and digital health. Her publications include various mHealth projects focused on improving vaccination uptake rates in underserved communities in Pakistan through technology. Sadori is also a member of the Aga Khan Health Board for Garden, a community-based organisation promoting wellness through health education focused on prevention. She envisions a career in public health and clinical medicine revolving around health issues in children.

Bellinda L. King-Kallimanis, PhD is the director of Patient-Focused Research at LUNgevity Foundation in the United States. She is an expert in patient-focused drug development, specialising in the use of patient-reported outcomes in cancer clinical trials. Before joining LUNgevity, she worked at the US Food and Drug Administration Oncology Center of Excellence. There, she worked on Project Patient Voice, a resource for patients and caregivers along with their healthcare providers to look at patient-reported symptom data. Bellinda received her Bachelor of Applied Science and her Master of Science from Swinburne University of Technology, Australia, and her PhD in psychometrics from the University of Amsterdam, the Netherlands.

Johan A. F. Koekkoek, MD, PhD is neuro-oncologist at the Leiden University Medical Center and Haaglanden Medical Center, the Netherlands. He is the head of the outpatient clinic at Leiden University Medical Center. In 2015 he obtained his PhD entitled: 'Epilepsy in glioma patients: Optimizing treatment until the end of life'. He is currently associate editor of *Neuro-Oncology Practice*. Johan is an expert on epilepsy, MR imaging and the end-of-life phase in primary brain tumour patients.

Stephanie Kyriacou, MSc, BSc is a certified clinical psychologist who works for one of the main cancer patient associations in Nicosia, Cyprus, PASYKAF. Her work with cancer patients ranges from early diagnosis to end-of-life palliative care. Stephanie applies the principle of 'total care' within an oncological setting, which undoubtedly also includes supporting and advising the family or caregivers of the patient, both during the illness and through the grieving process. Stephanie has worked within an oncological setting for 6 years now and is an advocate of quality of life for patients as well as a smooth rehabilitation post-cancer.

Laila Akbar Ladak, PhD, MScN, BScN, RN is an assistant professor at School of Nursing and Midwifery and has a joint appointment in the Department of Paediatrics and Child Health at Aga Khan University, Pakistan. She is an honorary faculty at the University of Sydney, Australia. Her overall research focuses on patient-reported outcomes, experiences and health-related quality of life in patients with chronic diseases, particularly in low- and middle-income countries. She provides thesis supervision and research mentorship to master's and PhD students, residents and faculty members. She has various scholarly work and publications in her profile.

Julia Lai-Kwon, MBBS, BMedSci, MPH is a medical oncologist and medical oncology fellow at the Melanoma Institute Australia. Her clinical interests include the management of cutaneous malignancies, particularly melanoma. Her research focuses on the use of patient-reported outcomes in research and routine care, and the survivorship experience of patients with metastatic malignancies who are long-term responders to immunotherapy and targeted therapy. She has presented at local and international meetings and published in peer-reviewed journals.

Jens Lehmann, PhD is a research assistant at the Medical University of Innsbruck in Austria, specialising in patient-reported outcome (PRO) research and electronic data capture. He is a psychologist and, since 2019, a member of the EORTC Quality of Life Group where he has worked on several projects. His research focuses on different aspects of PRO research, such as development of PRO measures and their implementation in clinical practice and patient web portals.

Lauren F. Lent, DHA, MS serves as the executive director of FACIT.org and the president of FACITrans in the United States. FACIT.org licenses the FACIT measurement system, and FACITrans provides translation and linguistic validation services to the health outcomes research and clinical trial communities.

Emma Lidington, MSc is a public health researcher with a special interest in patient-reported outcomes in cancer trials and young adult psycho-oncology. She is currently a trial manager at the Royal Marsden NHS Foundation Trust and a PhD candidate at Erasmus University Medical Centre. Her main research focus is identifying supportive care needs in young adult cancer patients. She is also involved in a team that supports the digital collection and use of patient-reported outcomes in clinical trials.

Yiola Marcou, MRCP, FRCR is a consultant medical oncologist at the Bank of Cyprus Oncology Centre in Nicosia. She completed her medical studies at the National and Kapodistrian University of Athens, Greece, and started her internal medicine and oncology training in the UK. During her training in oncology she worked in many academic institutions in London and she was actively involved in postgraduate teaching at the Imperial College. She was accredited as a consultant clinical oncologist at the Charing Cross Hospital in 2003. At the completion of her training she worked as a locum consultant at Charing Cross Hospital. In 2003 she was appointed as a consultant medical oncologist at the Bank of Cyprus Oncology Centre, with main interest in breast cancer. She is the head of the Breast Multidisciplinary Team. She has a special interest in treating younger women with breast cancer. She participates in local and international meetings, and she has been principal investigator in clinical studies. She is an assistant professor at the St. George's Medical School at the University of Nicosia, Cyprus. She is a member of the National Breast Cancer Committee, and she was past president of the Cyprus Oncological Society. She is currently a member of the

National Oncology Committee. Throughout her practice she has joined the cancer NGOs in the education and awareness of the public on breast cancer topics and given hundreds of lectures around Cyprus. She received many local prizes for her work in oncology.

Kedar K. V. Mate, BSc (PT), MSc., PhD is the director of Health Outcomes and Research at the Center for Neurological Restoration, Cleveland Clinic, in Ohio. He completed a postdoctoral fellowship from the Department of Family Medicine and a PhD from McGill University in Canada. He is interested in measurement, quality of life, modern psychometrics, and health outcomes research, mainly focusing on the development and testing of patient-reported outcome measures in various health conditions. He is also involved in developing technological innovations targeted to gait and posture impairments in older persons and people with health conditions. He is an emerging entrepreneur, co-founder, and vice president of Research and Development of PhysioBiometrics Inc. and a trained neuro-physiotherapist.

Rachael L. Morton, PhD, MScMed(Clin Epi)(Hons), DipAppSc is director of health economics at the NHMRC Clinical Trials Centre and professor at Sydney Medical School, University of Sydney, Australia. She is a specialist in health economics and has expertise in economic evaluation, decision modelling, patient preference elicitation and health equity research. She is an international leader in the evaluation of healthcare interventions in melanoma diagnosis, treatment and follow-up.

Niyaz Mostafa, MD is an early career researcher working at the Melanoma Institute of Australia. He has a special interest in melanoma and the psychosocial effects related to cancer and skin disease.

J. Devin Peipert, PhD is an assistant professor in the Department of Medical Social Sciences at Northwestern University Feinberg School of Medicine in the United States. As a psychometrician and investigator, he focuses on the application of patient-reported outcomes (PROs) in patient-focused drug development and in clinical monitoring. In this capacity, he works on establishing evidence to qualify PROs as clinical outcome assessments (COAs) to implement in drug trials. He also has a line of research examining new tools and methods to quantify and manage drug intolerability across multiple therapeutic areas including oncology and solid organ transplantation.

Syeda Fatima Raza, MBBS is a graduate of the Aga Khan University (AKU) Medical College in Karachi, Pakistan. She has served as a research associate in the Department of Paediatrics at AKU and has completed a clinical internship at Dow University of Health Sciences in Karachi, Pakistan. She plans to pursue a career in paediatrics. Her research interests include maternal and child health, paediatric oncology and paediatric cardiology.

Jessica Roydhouse, PhD is a Select Foundation Senior Research Fellow in Health Services Research at the Menzies Institute for Medical Research, University of Tasmania, Australia, where she specialises in cancer and health

services research. She has expertise in patient-reported outcomes, oncology, trials and proxy reporting.

Robyn P. M. Saw, FRACS, MS is a melanoma and surgical oncologist working at Royal Prince Alfred Hospital, Sydney (Head of Department), and affiliated with Melanoma Institute Australia. As well as her clinical responsibilities, she is actively involved in melanoma research and leads major research projects on vitamin D, quality of life and survivorship. Translation of research into clinical benefit for patients is the focus of her research activity. She also has a strong focus on consumer engagement, coordinating the development of early-stage and stage III melanoma booklets. She is passionate about improvement of clinical care through education of students, trainees and clinicians.

Emad Shash, MBCh, MSc, MD is currently the medical director and general manager of the Breast Comprehensive Cancer Hospital at the National Cancer Institute, Cairo University, Egypt. Dr. Shash is a visiting medical oncology consultant and breast cancer program director at Shefaa El Orman Oncology Hospital, Luxor, Egypt, since 2016. Dr. Shash is a consultant and lecturer faculty member of medical oncology at the National Cancer Institute, Cairo University. He earned his medical degree from Faculty of Medicine, Cairo University, in 2004, and completed specialisation in medical oncology from the National Cancer Institute, Cairo University, in 2009.

Christopher J. Sidey-Gibbons, PhD is an associate professor and deputy chair at the MD Anderson Department of Symptom Research in Houston, Texas, USA. He is director of the MD Anderson Center for INSPiRED Cancer Care and health director for the University of Cambridge Concerto Platform. He is an expert psychometrician and data scientist and has developed computerised adaptive tests for patient-reported outcomes.

Suzanne M. Skevington, BSc, PhD, FBPsS is professor emerita at the University of Manchester, UK, where she held a Project Diamond Chair in her health psychology specialty until 2016, founding its International Hub for Quality of Life Research. Suzanne was consultant/advisor to WHO, UN, UNESCO, UNAIDS, OECD and UNEP, and a board member of the International Society for Quality of Life Research. As a Fulbright Scholar (1996), she visited University of Washington, Seattle. Her expertise is on measuring and theorising quality of life and wellbeing in health and health care, also global health and cross-cultural psychology. She takes an international lead in the WHOQOL-Group collaboration.

Claire F. Snyder, PhD is professor of medicine, oncology, and health policy and management at the Johns Hopkins Schools of Medicine and Public Health in Baltimore, Maryland, USA. She is an expert on patient-reported outcomes (PRO), including PRO data visualisation to promote patient and clinician understanding and use. She is an editor of *Outcomes Assessment in Cancer*, led development of users' guides for implementing PROs in clinical practice and integrating PROs in electronic health records and edited a medi-

cal care supplement on interpreting and acting on PRO results in routine care. She is a past president of ISOQOL and currently leads the PROTEUS Consortium (TheProteusConsortium.org).

Samantha Claire Sodergren, PhD is a health psychologist and research fellow at the University of Southampton, UK. She specialises in quality of life assessment of people living with and beyond cancer with a focus on gastrointestinal cancers and young people with cancer. She is an active member of the European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Group and a member of the EORTC Gastrointestinal Group. Samantha leads the development of several EORTC QLG questionnaires.

Martin J. B. Taphoorn, MD, PhD is a professor of neuro-oncology at Leiden University Medical Center and Haaglanden Medical Center, the Netherlands. His research interest is mainly devoted to clinical outcome assessment in brain tumour patients (health-related quality of life, cognition, end of life). He is an active board member of both the EORTC Brain Tumour Group and the EORTC Quality of Life Group and chairman of the international RANO patient-reported-outcomes (PRO) working group. He is currently the editor of *Neuro-Oncology Practice*.

Jake Thompson, BPH(Hons) is a research assistant at Melanoma Institute Australia and the Australian Melanoma Centre of Research Excellence Study Group, located in Sydney, Australia. His current work specialises in psycho-oncology and epidemiology, focusing on the investigation and implementation of strategies to provide effective supportive care to melanoma patients and their caregivers. He currently holds a Bachelor of Public Health (Honours) and is a post-graduate student at the University of New South Wales.

Mathilde Trosdorf, MA is a clinical psychologist trained both in the United States and France, specialised in health psychology. She currently is a PhD candidate at Université de Paris, focusing on patient care in oncology and cardiology.

Stephanie Tsounta, BSc is a student at the University of Cyprus in Nicosia in the field of social and developmental psychology. Besides that, she studied psychology and human resources management.

Daniël J. van der Meer, MSc is a PhD candidate and epidemiological researcher in the field of women's cancers and adolescent and young adult (AYA) oncology at the Netherlands Cancer Institute (NKI) in Amsterdam. His doctoral research focuses on the epidemiological aspects of cancer at AYA age by investigating long-term cancer trends and subsequent cancer risk. With his research, he aims to narrow the existing gaps in knowledge and hopes that his work will positively contribute to improving health outcomes and medical care received by AYA cancer patients.

Pim B. van der Meer, MSc is a neuropsychologist and MD-PhD student at the Leiden University Medical Center in the Netherlands, currently specialising in the antiepileptic drug treatment of primary brain tumours with epilepsy. Cannabinoids and psychedelics as treatment of neuropsychiatric symptoms are a special interest of his.

Vassilios Vassiliou, MD, PhD is a consultant in radiation oncology at the Bank of Cyprus Oncology Centre in Nicosia, leading the Radiation Oncology Unit for gastrointestinal cancer patients. One of his main research interests is the quality of life of cancer patients, leading several EORTC QLQ questionnaire modules and is the chair of the EORTC QLQ for gastrointestinal cancers. He has been an active member of the group for more than a decade.

Kimberly A. Webster, MA is a research assistant professor in the Department of Medical Social Sciences at Northwestern University Feinberg School of Medicine in the United States. She has over 25 years of experience in health outcomes research involving the study and measurement of patient-reported outcomes, disease and treatment-related symptoms, and health status in patients with cancer and other chronic illnesses, as well as in the implementation of these measures in research protocols and clinical care.

Joachim Weis, PhD is full professor for self-help research in oncology, Medical Faculty University Freiburg, Comprehensive Cancer Center in Freiburg, Germany. He trained as a clinical psychologist and psychotherapist with a PhD in psychology and is expert in the fields of rehabilitation, psycho-oncology and quality of life research. Prof. Dr. Weis has been a member of the EORTC Quality of Life Group since 1996. From 2000 to 2001, he was interim head of the Department of Rehabilitation Psychology at Humboldt University of Berlin. From 1998 until 2010 he was head of the Board of the German Society of Psycho-Oncology (German Cancer Society). Since 2005 Prof. Dr. Weis has been the head of the Association for Education and Training in Psycho-Oncology. He is a member of various national and international scientific societies.

Sally Wheelwright, PhD is the co-chair of the Project and Module Development Committee for the EORTC Quality of Life Group. She has been a quality of life researcher and contributed to the development of several EORTC modules since 2010. She is a senior research fellow with the Macmillan Survivorship Research Group (MSRG) at the University of Southampton, UK. MSRG research is focused on living with and beyond cancer, and Dr. Wheelwright's particular research interest is the self-management of nutrition, both in cancer and other long-term conditions.

Julie B. Winstanley, PhD, MSc, BSc, CStat is an honorary associate professor at the University of Sydney and statistical consultant at the Patricia Ritchie Centre in Sydney, Australia. In addition, for over 20 years she is also a co-director of White Winstanley Ltd., a healthcare research consulting company presently based in England. She is a chartered statistician of the Royal

Statistical Society of the United Kingdom, a chartered scientist and active member of the EORTC Quality of Life Group. Her area of expertise is in quality of life outcomes research, quantitative instrument development, psychometric methods, the application of classical test theory and item response theory.

Marianna Zacharia, MSc is a licensed clinical psychologist in Nicosia, Cyprus, working with children, adolescents and adults, specialising in providing psychological support to cancer patients and individuals with intellectual disabilities. She is the clinical psychologist of the 'Breast Center of Cyprus' and the 'Adult Day Care Centre for Intellectual Disabilities'. Currently, she is a PhD clinical psychology student and a special scientist at the University of Cyprus, where in addition to her research she teaches undergraduate students. She received the 'ACBS Research Development Grant' to conduct her PhD thesis on acceptance and commitment therapy for depression and physical pain in female breast cancer patients.

About the Editor

Angelos P. Kassianos, PhD is a senior research fellow at University College London, Department of Applied Health Research, and at University of Cyprus, Departments of Psychology and Computer Science. He is a health psychologist with a public health and behavioural medicine focus. Dr. Kassianos has interests in bio-psycho-social determinants of disease prevention and early diagnosis (mainly cancer), health-related quality of life assessment, vaccination hesitancy and development of digital health interventions.

Abbreviations

ACT	Acceptance and Commitment Therapy
ADL	Activities of Daily Living
AJCC	American Joint Committee on Cancer
ALL	Acute Lymphoblastic Leukaemia
ANOVA	Analysis of Variance
AQOL	Assessment of Quality of Life
AS	Active Surveillance
ATA	American Telemedicine Association
AUC	Area Under the Curve
AYAs	Adolescents and Young Adults
BCT	Breast-Conserving Therapy
BLA	Biological License Application
BP	Brief Psychotherapy
CAHPS	Consumer Assessment of Healthcare Providers and Systems
CAM	Complementary and Alternative Medicine
CASC	Comprehensive Assessment of Satisfaction with Care
CAT	Computerised Adaptive Testing
CAYA-T	Cancer Assessment for Young Adults-Testicular
CBT	Cognitive Behavioural Therapy
CCA	Cross-Cultural Adaptation
CDC	Centers for Disease Control and Prevention
CDF	Cumulative Distribution Function
CFA	Confirmatory Factor Analysis
CFI	Comparative Fit Index
CI	Confidence Intervals
ClinROs	Clinician-Reported Outcomes
CNS	Central Nervous System
COAs	Clinical Outcome Assessments
COC	Consensus on Cancer
COS	Core Outcome Sets
COSMIN	Consensus-based Standards for the selection of health Measurement Instruments
CRC	Colorectal Cancer
CRCI	Cancer-Related Cognitive Impairment
CrF	Cancer-Related Fatigue
CT	Chemotherapy / Cognitive Therapy / Computed Tomography

CUA	Cost-Utility Analysis
DFS	Disease-Free Survival
DIF	Differential Item Functioning
EC	Endometrial Cancer
eCDF	Empirical Cumulative Distribution Function
ECOG	Eastern Cooperative Oncology Group
EFA	Exploratory Factor Analysis
EHR	Electronic Health Records
EMA	European Medicines Agency
EORTC CAT	European Organisation for Research and Treatment of Cancer Computerised Adaptive Testing
EORTC QLQ	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire
EORTC QOL	European Organisation for Research and Treatment of Cancer Quality of Life
EORTC	European Organisation for Research and Treatment of Cancer
EPIC	Expanded Prostate Cancer Index Composite
ePROs	Electronic Patient-Reported Outcomes
ES	Effect Size
ESMO	European Society for Medical Oncology
FACIT	Functional Assessment of Chronic Illness Therapy
FACIT-SP	Functional Assessment of Chronic Illness Therapy-Spiritual Wellbeing
FACT	Functional Assessment of Cancer Therapy
FACT-Cog	Functional Assessment of Cancer Therapy-Cognitive Function
FACT-G	Functional Assessment of Cancer Therapy-General
FACT-GP	Functional Assessment of Cancer Therapy-General Population
FACT-M	Functional Assessment of Cancer Therapy-Melanoma
FACT-PWB	Functional Assessment of Cancer Therapy-Physical Wellbeing
FCR	Fear of Cancer Recurrence
FDA	Food and Drug Administration
FIGO	International Federation of Gynaecology and Obstetrics
FKSI	FACT Kidney Symptom Index
FLIC	Functional Living Index-Cancer
FPQLI	Ferrans & Powers Quality of Life Index
GDI	Good Death Inventory
GDP	Gross Domestic Product
GEE	Generalised Estimating Equation
HADS	Hospital Anxiety and Depression Scale
HBM	Health Belief Model
HCC	Hepatocellular Carcinoma
HCPs	Healthcare Professionals (or Providers)
HL	Hodgkin Lymphoma
HNPCC	Hereditary Nonpolyposis Colorectal Cancer

HPA	Hypothalamic Pituitary Adrenal (axis)
HRQoL	Health-Related Quality of Life
HRSA	Health Resources and Services Administration
HS	Perceived Health Status
HSCT	Hematopoietic Stem Cell Transplantation
HUI	Health Utility Index
IARC	International Agency for Research on Cancer
ICC	Intraclass Correlation Coefficient
ICD-11	International Statistical Classification of Diseases and Related Health Problems
ICER	Incremental Cost Effectiveness Ratio
ICI	Isolated Limb Infusion
ILP	Isolated Limb Perfusion
IOM	Institute of Medicine
IPOS	Integrated Palliative Care Outcome Scale
IPSS	International Prognostic Scoring System
IRT	Item Response Theory
ISOQOL	International Society for Quality of Life Research
ISPOR	International Society for Health Economics and Outcomes Research
IVR	Interactive Voice Response
JLA	James Lind Alliance
KPS	Karnofsky Performance Status
LAF	Lance Armstrong Foundation
LAYA-SRQL	Late Adolescence and Young Adulthood Survivorship-Related Quality of Life measure
LCI	Likely Change Index
LD	Local Dependence
LND	Lymph Node Dissection
LOA	Limits of Agreement
LoL	Longevity of Life
LS	Least Squares
MAR	Missing At Random
MAUCa	Multi-Attribute Utility in Cancer
MAUIs	Multi-Attribute Utility Instruments
MBCT	Mindfulness-Based Cognitive Therapy
MBSR	Mindfulness-Based Stress Reduction
MCAR	Missing Completely at Random
MCS	Mental Component Summary score
MCT	Meaningful Change Thresholds
MDASI	MD Anderson Symptom Inventory
MEK	Mitogen-activated protein kinase
MI	Multiple Imputation
MIDs	Minimal Important Difference
MMRMs	Mixed Models for Repeated Measures
MNAR	Missing Not at Random
MQOL	McGill Quality of Life
MSAS	Memorial Symptom Assessment Scale

MTC	Mastectomy
NATs	Negative Automatic Thoughts
NCCN	National Comprehensive Cancer Network
NCI	National Cancer Institute
NHL	Non-Hodgkin Lymphoma
NHS	National Health Service
NHSS	National Health Services Survey
NICE	National Institute for Health and Care Excellence
NIH	National Institutes of Health
NIS	National Insurance Services
NPC	Nasopharyngeal Carcinoma
ObsROs	Observer-Reported Outcomes
OECD	Organisation for Economic Co-operation and Development
ORR	Overall Response Rate
PASS	Power Analysis and Sample Size
PC	Prostate Cancer
PCM	Partial Credit Model
PCOC	Palliative Care Outcomes Collaboration
PediQUEST	Pediatric Quality of Life and Evaluation of Symptoms Technology
Peds FACT-Br	Pediatric Functional Assessment of Cancer Therapy – Brain
PedsQL	Pediatric Quality of Life Inventory
PerFOS	Performance Outcomes
PET	Positron Emission Tomography
PFS	Progression-Free Survival
PGIC	Patient Global Impression of Change
PhD	Doctorate of Philosophy
PHQ	Patient Health Questionnaire
PMH/PSQ	Princess Margaret Hospital Patient Satisfaction Questionnaire
PREMs	Patient-Reported Experience Measures
PRO-CTCAE	Patient-Reported Outcome – Common Terminology Criteria for Adverse Events
PROMIS	Patient-Reported Outcome Measures Information System
PROMs	Patient-Reported Outcome Measures
PRO-PMs	Patient-Reported Outcomes – Performance Measures
PROs	Patient-Reported Outcomes
PROTEUS	Patient-Reported Outcome Tools: Engaging Users and Stakeholders
QALY	Quality-Adjusted Life Years
QLG	Quality of Life Group
QLIC-ON	Quality of Life in Childhood Oncology
QLU-CIOD	Quality of Life Utility Measure-Core 10 Dimensions
QODD	Quality of Death and Dying
QOF	Quality and Outcomes Framework
QoL	Quality of Life
QOLCC	Quality of Life in Childhood Cancer

QOLIE	Quality of Life in Epilepsy Inventory
RCI	Reliable Change Index
RCT	Randomised Controlled Trial
REML	Restricted Maximum Likelihood
RI	Radiation-Induced Brain Injury
RIME	Relaxation, Mental Images and Spirituality
RMSEA	Root Mean Square Error of Approximation
ROC	Receiver Operating Characteristic Curve
RP	Radical Prostatectomy
RPM	Remote Patient Monitoring
RSM	Rating Scale Model
RT	Radiotherapy
RWD	Real World Data
RWE	Real World Evidence
SDC	Smallest Detectable Change
SEER	Surveillance, Epidemiology and End Results
SEM	Standard Error of Measurement
SES	Standardised Effect Size
SET	Supportive-Expressive Group Therapy
SF-12	Short Form 12
SF-36	Short Form 36
SG	Sun Ginseng
SGO	Society of Gynecologic Oncology
SISAQOL	Setting International Standards in Analyzing Patient-Reported Outcomes and Quality of Life Endpoints
SLNB	Sentinel Lymph Node Biopsy
SML	Social Media Listening
SMR	Social Media Review
SRM	Standardised Response Mean
SRMR	Standardised Root Mean Square (residual)
SRPB	Spirituality, Religion and Personal Beliefs
TAH	Total Abdominal Hysterectomy
TCIs	Threshold for Clinical Importance
TNF	Tumour Necrosis Factor (receptor)
UK	United Kingdom
US	United States
VBT	Vaginal Brachytherapy
WCSQ	Worthing Chemotherapy Satisfaction Questionnaire
WHO	World Health Organization
WHOQOL	World Health Organization Quality of Life

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