

Department of Health Western Australia

Human Research Ethics Committee

Members

CHAIRPERSON

Assistant Professor Judith Allen

Judith Allen is an Assistant Professor in the Law Faculty of the University of Western Australia (UWA). She teaches health law, torts and research ethics to law students and in other faculties. Her research interests include consent, competence and privacy of health information focussing particularly on participation in health research, the regulation of data linkage and the governance of biobanks and databanks. She has served as a board member of the Australasia Institute of Health Law and Ethics as well as the Western Australian (WA) Mental Health Law Centre, as deputy chair of the UWA Human Research Ethics Committee (HREC) and the National Health and Medical Research Council Research Ethics Training Committee. Assistant Professor Allen consults in private practice on policy issues in privacy and confidentiality of health information.

MEMBERS (in alphabetical order)

Dr Anne Atkinson – Lay person

Dr Anne Atkinson has been involved in social justice projects in areas of ethnicity, disability and health for 30 years. After completing a PhD in Chinese Studies and Australian History, she taught at Edith Cowan University before retiring and becoming involved in committee and some consultancy work. She is currently a member of the Community Advisory Council for Royal Perth Hospital and the UWA Population Health Research Community and Consumer Advisory Council. She joined Cancer Australia four years ago as a member of the National Consumer Advisory Group and has participated in several sub-committees. Since then she has also become a member of Cancer Australia Advisory Council and the Cancer Data Working Group. She has previously been a deputy member of the WA Cancer and Palliative Care Network and a member on the steering committee of the WA Cancer Service Directory. Dr Atkinson was previously a member of the Confidentiality of Health information Committee (CHIC).

Ms Kathryn Barker – Lawyer

Kathryn Barker graduated with a Bachelor of Laws and a Bachelor of Arts (French and History) from Murdoch University in 1999. She currently practices as a commercial lawyer, with particular expertise in mining and resources litigation, native title disputes and medical negligence. In 2007, Ms Barker's three year old daughter was diagnosed with Acute Lymphoblastic Leukaemia and for the next three years Ms Barker was engaged caring for her on a full time basis. Because of these experiences, Ms Barker has developed a particular interest in ethical conduct within the medical field generally and in particular with regard to medical research.

Reverend Brian Carey – Pastoral Care

The Reverend Brian Carey is a Minister of the Uniting Church in Australia with many years of involvement in the field of bioethics at a State and National level. He has presented papers on the full range of ethical/medical subjects at conferences, universities etc. He was the Applied Ethicist for the State of Victoria's Bio-technology Committee and a member of the Stem Cell Working Group. He was a member of Monash Medical Centre and Epworth Hospital's HREC for over twenty years.

Dr Gary Dowse – Department of Health Western Australia Representative

Dr Gary Dowse is an Epidemiologist and Public Health Physician, with experience in epidemiological research and public health advocacy associated with emerging non-communicable diseases, including asthma, obesity, diabetes and cardiovascular disease, in developing countries of the Asia-Pacific region. He previously coordinated a number of international cross-sectional and longitudinal population studies and undertook numerous consultancies on prevention and control of non-communicable diseases for the World Health Organisation, AusAID and other agencies. In the Department of Health Western Australia (DoHWA) he has held positions as Director and Public Health Physician of the Midwest Public Health Unit, and since 1997, as the Medical Epidemiologist in the Communicable Disease Control Directorate. In these latter roles he has had responsibility for coordinating communicable disease surveillance and the investigation and management of cases and outbreaks of infectious disease in WA, as well as the broader management of communicable disease prevention and control programs. He has also been the Station Leader at Mawson Station in Antarctica. He has over 120 peer-reviewed publications.

Mr Ross Monger – Lay person

Mr Ross Monger is a retired state public servant following 43 years, primarily in courts administration and dispute resolution. He has been a lay member of the Royal Perth Hospital HREC since 2004 and a Category D lay member of Murdoch University Animal Ethics Committee since 2007. He has been a board member of the Fire and Emergency Services (FESA) since 2008 and the Chairman of the Voluntary Marine Rescue Service Consultative Committee of FESA since 2008. Mr Monger is a qualified accountant and has been a Justice of the Peace since 1988. He is a member of the Royal Association of Justices WA.

Adjunct Professor Peter O'Leary – Researcher

Professor Peter O'Leary is the Director of the Office of Population Health Genomics, within the Public Health Division, DoHWA. After graduating from UWA, he worked as a clinical biochemist at King Edward, Princess Margaret and Royal Perth Hospitals where he developed research interests in reproductive and paediatric endocrinology and population genetic screening. In 2001, he was appointed to establish the Genomics Directorate within DoHWA. In 2001, he formed the Genetics Council of WA as a health network to provide policy advice to the Health Department on genetic testing, familial cancer, genetic ethics, newborn and prenatal screening. He also coordinated the establishment of the Genetic Support

Council of WA, as a peak body for self-help organisations, families and individuals living with genetic conditions.

As the DoHWA representative on several national government committees, Professor O'Leary has actively contributed to reforms of newborn screening for rare diseases, prenatal screening for foetal anomalies and population genetic testing for inherited conditions. Under his leadership, the Office of Population Health Genomics monitors and evaluates the impact on health services resulting from advances in biotechnology and genetics research. The outcomes inform policy advice relating to genetic screening and diagnostic programs that ensure a balance in the consideration of accuracy, clinical validity, clinical utility and ethical, legal, social and economic aspects of clinical genetic services.

Dr Katrina Spilsbury – Researcher

Dr Katrina Spilsbury is a Senior Research Fellow at Curtin University working on the WA Safety and Quality of Surgical Care Project. She is an experienced analyst of linked health data from the WA Data Linkage System and has published numerous articles investigating the epidemiology of both short and long term patient outcomes following surgical procedures. Dr Spilsbury is a qualified biostatistician having completed a Masters of Biostatistics degree through the Biostatistical Collaboration of Australia in June 2008.

Professor Bryant Stokes (Deputy Chairperson) – Professional care, counselling or treatment of people

Professor Bryant Stokes is a Consultant Neurosurgeon, Clinical Professor of Neurosurgery and Professor of Clinical Anatomy at UWA. He is also a past Chief Medical Officer and Commissioner of Health, DoHWA. He is the Clinical Lead and Chairman of the Department of Health's Neurosciences and Senses Clinical Network. He has been the President of the Neurosurgical Society of Australasia and past Senior Examiner in Neurosurgery for the Royal Australasian College of Surgeons.

Professor Stokes has been involved in quality and safety issues for the past twenty years. Following the release of the Quality of Australian Health Care Study in 1995 Professor Stokes served on a number of national committees that were established by the Commonwealth Government to improve the safety and quality of health care in the Australian health care system. These committees included the Taskforce on Safety and Quality of Health Care (1996-1997) and the National Expert Advisory Group on Safety and Quality in Australian Health Care (1997-1999).

Professor Stokes was a member of the Australian Council for Safety and Quality in Health Care between 2000 and 2005 and has held the position of Chairman of the Western Australian Council for Safety and Quality in Health Care since its inception in 2002.

Mr John Wreford – Technological Security of Information

John Wreford is a certified information systems auditor and is currently completing a PhD by research in information systems. Mr Wreford has had extensive experience in the commercial management and privacy of data in health, public housing, banking and finance environments. He has worked as industry partner with Curtin University of Technology on research funded by the Australian Research Council.

DEPUTY MEMBERS (in alphabetical order)

Dr Janine Alan – Department of Health Western Australia Representative

Dr Janine Alan has had a diverse career that includes experiences in the disability and ageing sector, public service and university environment. Her research interests are similarly diverse but most share a common thread – the analysis of linked administrative data. Dr Alan has seventeen peer-reviewed articles that cover topics such as infectious diseases in residential aged care facilities, high cost users of hospital beds, hospital use in the last years of life, and inpatient hospital use in the first year after release from prison. She is currently managing the Subacute Care Data Team, DoHWA. Dr Alan completed her PhD at UWA, School of Population Health in 2004.

Dr David Blackledge – Additional lay person

Dr David Blackledge Bachelor of Arts (Hons.) 1951, Master of Arts 1955, Bachelor of Medicine and Surgery 1959, University of Cambridge, Natural Sciences Prize, Gonville and Caius College, Cambridge, UK, 1951, Member of the Royal College of Obstetricians and Gynaecologists of London 1963, Fellow of the Royal College of Obstetricians and Gynaecologists of London 1988, Fellow of the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (Foundation Fellow) – 1979. Dr Blackledge was previously a lecturer in Obstetrics and Gynaecology at the University of St Andrews, Scotland; in practice as a specialist from 1963 to 2005, a member of the Ethics Committee, WA Branch Australian Medical Association, a member and Chairperson of CHIC.

Ms Samantha Clarke – Professional care, counselling or treatment of people

Ms Samantha Clarke has obtained a Bachelor of Nursing and more recently, in 2009 a Master of Applied Science by research at the Queensland University of Technology. Her clinical experience in nursing spans fourteen years, predominately in the speciality of neurosurgery and is the speciality on which her research interests are founded. Ms Clarke has a keen interest in all aspects of the research process, particularly with regards to informed consent and statistical analysis.

Ms Patricia Fowler RN – Professional care, counselling or treatment of people

Ms Patricia Fowler was firstly a registered nurse in New South Wales from 1979 and then in WA from 1992. She has been the President of the Australian Nursing Federation since 1998. Ms Fowler has served as a member on CHIC from 2000 – 2008.

Dr Alison Garton – Research

Dr Alison Garton is an Adjunct Professor of Psychology at Edith Cowan University where she sat for three years on the Human Ethics Committee. Prior to this she established and chaired a Faculty-based HREC to evaluate low risk projects. She also sat on the Faculty Ethics Committee at the University of Tasmania. Dr Garton has worked in academia, policy and management, has authored one textbook and four monographs along with over sixty refereed articles and chapters. She has supervised countless students at Honours, Masters and PhD levels and has received awards for her supervision. Dr Garton is currently a senior sessional member of the State Administrative Tribunal working in the human rights and vocational regulation streams having been a previous member and chair of the Psychologists Board of WA. She also sat for nine years on the Ethics Committee of the Australian Psychological Society

Reverend Jenifer Goring – Pastoral care

An Anglican priest, Reverend Jenifer Goring is currently working in parish ministry. Previous positions held were at Sir Charles Gairdner Hospital, Princess Margaret Hospital and King Edward Memorial Hospital as an Ecumenical Chaplain. This role involved the multi-faith and multi-disciplinary approach to the provision of healthcare, including issues of reproductive technology and end-of-life decision-making. This role also included lecturing and leading seminars.

Tertiary Qualifications held are Bachelor of Divinity (Murdoch, 1990), Bachelor of Social Work (UWA, 1983) and Bachelor of Arts (UWA, 1981)

Ms Michele Kosky – Lay person - female

Michele Kosky is the Executive Director, Health Consumer Council. She has a background in HIV/AIDS, consumer rights and advocacy, health policy review and patient information. Ms Kosky was the consumer interests representative on the National Health and Medical Research Council from 1995 – 2005.

Mr Gary Langham – Technological Security of Information

Mr Gary Langham has nearly twenty years combined professional experience in the fields of Information Security (IS), Information Technology (IT) Audit and IT Governance. Mr Langham is a member of the Information Systems Audit and Control Association (ISACA), a global IT Governance professional organisation. He has served on two international ISACA Committees relating to the Certified in the Governance of Enterprise IT (CGEIT) and Certified Information Security Manager (CISM) Certifications since 2007. He is also the immediate Past President of the ISACA Perth Chapter which he served from 2004 – 2008. Mr Langham is also an accredited COBIT / IT Governance Trainer and has delivered courses in Australia, USA and Hong Kong.

Ms Meina Lee – Lawyer

Ms Meina Lee holds a Bachelor of Laws and a Bachelor of Science (majoring in genetics) from UWA and a Master of Bioethics from the University of Pennsylvania. Ms Lee is a corporate and commercial lawyer. Prior to practising law, she was a bioethics advisor at a large medical research institute with a particular focus on genetic epidemiological studies. Ms Lee is also currently a member of the UWA HREC.

Associate Professor Rachael Moorin – Researcher

Rachael Moorin is an Associate Professor at Curtin University in the Department of Imaging and Applied Physics and is an adjunct Professor in the School of Population Health at UWA. As Chief Investigator, Associate Professor Moorin has been awarded competitive research grants totalling over \$5 million from State and National funding agencies and has been responsible for the development of novel methods for utilising and analysing linked administrative health data. She has been responsible for many novel research initiatives using these data to describe the epidemiology and cost of health service use in various population groups; measure equity in and access to health care services and study the effect of policy on equity and access to health care services. Associate Professor Moorin is also involved with advocating for community participation in research, working closely with the School of Population Health Consumer and Community Advisory Council to develop best practice methods for community participation.

Dr Tim Threlfall – Department of Health Western Australia Representative

Dr Tim Threlfall is a Public Health Physician and Epidemiologist who has managed the Western Australian Cancer Registry since the early 1990s. He is keenly interested in the ethical use of such whole-population data collections to improve the health of Western Australians.