

PROGRAMME

**Virtual Forum Meeting on
The Protection of Personal Information Act No 4 of 2013:
A Code of Conduct for Research
hosted by the Academy of Science of South Africa (ASSAf)**

The meeting aims to consider the development of a POPIA Code of Conduct for Research to ensure certainty, transparency, and clarity in the use of personal information for research. ASSAf also considers that it is imperative that there will be **one** Code to guide the use of personal information for research in all sectors (including health, social science, genomics, etc.).

Moderator: Prof Himla Soodyall, Executive Officer of ASSAf

10:00 - 10:10 Welcome

Presentations

10:10 – 10:25 Dr Rachel Adams, Senior Research Specialist of the Impact Centre at HSRC

10:25 – 10:35 Prof Michele Ramsay, Professor in the Division of Human Genetics at the National Health Laboratory Service and University of the Witwatersrand

Panelists

10:35 – 10:40 Dr Harriet Etheredge, Ethics and Regulatory at Wits Donald Gordon Medical Centre

10:40 – 10:45 Dr Antonel Olckers, CEO of DNABioTech

10:45 – 10:50 Prof Tobias Schonwetter, Associate Professor and the Director of the Intellectual Property Unit at the University of Cape Town's Law Faculty

10:50 – 10:55 Prof Collet Dandara, Professor of Human Genetics at the University of Cape Town

10:55 – 11:45 Q&A

11:45 – 11:55 Prof Himla Soodyall, Next steps

11:55 – 12:00 Closure



science & innovation

Department:
Science and Innovation
REPUBLIC OF SOUTH AFRICA



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Biographies

Dr Rachel Adams

Rachel Adams is a Senior Research Specialist of the Impact Centre at the Human Sciences Research Council. Dr Adams holds degrees in English Literature and Philosophy (BA, Royal Holloway, University of London), Human Rights Law (MPhil, UCT) and Jurisprudence (PhD, UCT). Dr Adams previously held the position of Senior Researcher Civil and Political Rights at the South African Human Rights Commission and completed post-doctoral studies at the Information Law and Policy Centre, Institute for Advanced Legal Studies, University of London. Her work sits at the intersection of law, ethics, gender and technology. Dr Adams is an Editor for the South African Journal on Human Rights.

Prof Collet Dandara

Collet Dandara is a Professor of Human Genetics, Principal Investigator of the Pharmacogenomics and Drug Metabolism Research Group at the University of Cape Town. From the early days of his career, Professor Dandara's research and publications focused on foundational studies in pharmacogenetics, and later pharmacogenomics, characterising genomes of African populations to identify genomic clues on differential drug responses observed in patients. His work has laid a firm basis on understanding the profile of genetic variants of pharmacogenomics importance in African populations, leading to novel discoveries as well as providing mechanistic understanding of the functional significance of such genetic variants and the networks they are involved in.

Dr Harriet Etheredge

Harriet Etheredge is a medical bioethicist and health communication specialist, with a particular interest in ethical and communicative challenges across highly specialised medical settings. Harriet is a Co-Chair of the Wits Human Research Ethics Committee (Medical) and at national level she is a member of the South African Medical Research Council HREC(M). Harriet advises on research protocol, ethics submission, research compliance and research regulation. Harriet holds an honorary position in the Department of Internal Medicine, School of Clinical Medicine, at Wits University. Before joining WDGMC, Harriet undertook her doctoral studies in the field of medical ethics and organ transplantation. Harriet is a widely published academic author and has presented her work at both local and international fora. Harriet regularly presents CPD and CME ethics talks for health professionals and industry. Harriet was named as one of the Mail and Guardian's 200 Young South Africans in 2016.

Dr Antonel Olckers

Antonel Olckers founded DNAbiotec® in 2001 and has served as its CEO since then. Her expertise in science, innovation and business is integrated in DNAbiotec®. Over the past decade she has transformed DNAbiotec® into a sustainable knowledge-based core biotech company. Dr Olckers obtained her PhD in molecular human genetics from the University of Pretoria (South Africa) with research performed at the Johns Hopkins Medical Institutions in Baltimore MD, USA. During her time at Johns Hopkins she maximised the opportunity to learn from the best in the field of human genetics how science is practised at the global level. After graduation she became the head of the Molecular Biology Group in the Department of Human Genetics (University of Pretoria), and subsequently was head of department, or Director as it was termed, of the Centre for Genome Research (CGR) at the North-West University (NWU).

Prof Michele Ramsay

Michele Ramsay is a Professor in the Division of Human Genetics at the National Health Laboratory Service and University of the Witwatersrand (Wits) in Johannesburg. Her research interests include the genetic basis and molecular epidemiology of single gene disorders in South African populations and the role of genetic and epigenetic variation in the molecular aetiology of fetal alcohol spectrum disorders (FASD) and other diseases exacerbated by adverse lifestyle choices. The FASD research includes the use of a mouse model to investigate alcohol induced epigenetic remodelling as a mechanism of teratogenesis.

Prof Tobias Schonwetter

Tobias Schonwetter is an Associate Professor and the Director of the Intellectual Property Unit at the University of Cape Town's law faculty. He teaches IP and IT law. He currently leads several developments and innovation-oriented research and capacity building projects, including the Open African Innovation Research (Open AIR) project, (www.openair.africa). He regularly advises various government and non-governmental entities on issues relating to IP and, in particular, copyright and open access. In 2018, Tobias became an Associate Member of the Centre of Law, Technology and Society at the University of Ottawa, Canada; and in 2019 he joined the Department of Science and Innovation's Open Science Advisory Board.

