



SANBI in association with NSB is please to invite you to a lecture session (1 hr) focussing on:



“Data sharing and protection in biobank and health research”

Venue: SANBI, Life Science Building, 5th Floor, Core 1, UWC

Date & Time: 21 May at 10h00

1. Dr. Ciara Staunton - Biobanks, data sharing and privacy

Dr Ciara Staunton is a lecturer in law at Middlesex University, London and a Visiting Lecturer at the University of Pecs, Hungary. She is currently a Visiting Fellow at the Department of Genetics, University of Cape Town and is due to be a Visiting Researcher at the Centre for Biomedicine, EURAC in Italy during June and July of this year. Her research interests are in the governance of new and emerging technologies, in particular stem cell research, genomic research and biobanking research, and has published widely on these topics.

Ciara completed her PhD at the School of Law, National University of Ireland, Galway. Her research, funded by the Irish Research Council, explored the regulation of stem cell research in Ireland. During this time she was a Visiting Scholar at the Hasting’s Centre in New York and appointed legal officer of the Irish Stem Cell Foundation. She is currently advising the Stem Cell Regulations Committee on the introduction of stem cell research legislation into the Kingdom of Bahrain.

She completed her postdoctoral research at the Centre for Medical Ethics and Law in Stellenbosch University, Cape Town. There she was co-investigator on the NIH funded Community Engagement for H3Africa Biobanking Research: The Tygerberg Model grant. From 2013 – 2016 she was appointed to the H3Africa Ethics and Regulatory Issues Working Group and the H3Africa Community Engagement Working Group. She was also part of the team that developed the Ethics and Governance Framework for Best Practice in Genomic Research and Biobanking in Africa, published in January 2017.

2. Dr Nora Ni Loideain - The EU General Data Protection Regulation and Researching Health-Related Data

Dr Nora Ni Loideain is Director and Lecturer in Law of the Information Law and Policy Centre at the Institute for Advanced Legal Studies (IALS). She is also an Affiliated Lecturer at the Cambridge Faculty of Law, a Visiting Lecturer for the LL.M. Privacy and Information Law module at King’s College London and a Senior Research Fellow at the University of Johannesburg's Faculty of Humanities. Nora’s research interests focus on governance, human rights, and technology, particularly in the fields of digital privacy, data protection, and state surveillance. Her Ph.D. at the University of Cambridge Faculty of Law examined the impact of the right to respect for private life on the EU Data Retention Directive which mandated the mass retention of EU citizens’ communications metadata for national security and law enforcement purposes. This doctoral research is the focus on her forthcoming monograph - Data Privacy, Serious Crime, and EU Policy-Making (Oxford University Press).

She is an editor of International Data Privacy Law (Oxford University Press). Prior to her academic career, she was a Legal and Policy Officer for the Office of the Director of Public Prosecutions of Ireland and clerked for the Irish Supreme Court.