

Dr Ciara Staunton

Dr Ciara Staunton is a Senior Researcher at the Institute for Biomedicine, Eurac Research (Italy), a Consultant to the WHO (WHO principles for human genome data access, use, and sharing) and an Honorary Research Fellow at the University of Kwazulu-Natal. Her research focuses on the governance of new and emerging technologies, in particular stem cell research, genomic research and biobanking, and the use of health data in research. She has been in receipt of numerous grants including from the Wellcome Trust, the NIH, and the Irish Research Council.

Ciara is a member of a number of international advisory boards providing ethicolegal oversight on these topics and is a member of the National Irish COVID-19 Biobank – Research Ethics Committee (NICB-REC). She has previously been a consultant to the NICD, Global Fund, FIND, the South African Department of Health, the Access to COVID-19 Accelerator, and other public health bodies.

The sharing of health data, and specifically, the international sharing of health data is critical if we are to develop new diagnostics and therapies. Within Europe and outside of Europe, data sharing has been hindered in part by the implementation of the General Data Protection Regulation (GDPR). In response to these challenges, in May 2022, the draft regulation for the European Health Data Space (EHDS) was published. If passed it will introduce one legal framework to facilitate access to electronic health data access for secondary use for eight specified purposes that "would benefit society such as research, innovation, policy-making, patient safety, personalized medicine, official statistics or regulatory activities". The proposed EHDS should facilitate the sharing of electronic health data within Europe, but it will have implications for data sharing beyond Europe. This paper will discuss the EHDS, the changes it will bring to accessing electronic health data within Europe, and specifically reflect on the new requirements for third countries when sharing data with collaborators outside of Europe.

RSVP: MaryAnn Francis, francism@ukzn.ac.za, by the 30 April 2024 for catering purposes.



Professor Anil Chuturgoon, Dean of Research- College of Health Sciences, invites you to a Public Lecture on

The European Health Data Space and its impact on EU/South

African collaborative research

Ву

Dr Ciara Staunton (Italy)

Tuesday, 7th May @ 10h00 -Susser and Stein Seminar Room, Medical Campus

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