



Bioethics Seminar

Trustworthy Governance of Health and Genomic Data: Lessons from Singapore

In this presentation I will report the preliminary findings from three connected studies on public attitudes to data-sharing and precision medicine in Singapore: seven focus groups with 62 participants, conducted in three languages (English, Mandarin and Malay); a household survey in 2020 with 1,000 Singaporeans to assess public preferences on sharing health-related data for precision medicine; and a four-day citizens' jury to deliberate on sharing data with comical companies. This research is important because much of the existing literature on public attitudes to PM and data sharing comes from Europe and North America. Across our three studies, four ethical values emerged as the central considerations for ethical and trusted health data use in Singapore: public interests, fairness, accountability and transparency. In all three studies, consent was not a determinative factor for public trust or support of data sharing. While participants generally thought the potential benefits of data sharing outweighed the risks, they were cognizant of various risks including data leaks, data misuse, privacy breaches, misdiagnosis and threats to the doctor-patient relationship (due to an increasingly data driven approach), and group harms such as stigmatization, discrimination, loss of access to medical care. In this presentation I will draw on our empirical findings and propose recommendations for trustworthy data governance in Singapore and consider how these lessons compare to the New Zealand context.

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Monday, 19 July 2021

1:00-1:50 pm

Room 119, Bioethics Seminar Room
71 Frederick Street, Dunedin

Video linked:

To secure the booking for this seminar video link in Christchurch and Wellington, please register your name, subject and date of seminar for attendance:

Wellington School of Medicine Room C31 Contact: Videoconferencing University of Otago Wellington
avvcsupport.uow@otago.ac.nz or University of Otago Christchurch Room 7.11 Contact:
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