

Hot Topics in Research Ethics

Trustworthy Governance of Data Sharing for Precision Medicine



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You are invited to join this webinar!

April 29 2021 9:00-10:00 PM Eastern Time (US and Canada)

April 30 2021 9:00-10:00 AM (Malaysia)

Advance registration required:

<https://tinyurl.com/3knbwb6j>

After registering, you will receive a confirmation email
containing information about joining the meeting.

Precision Medicine (PM) promises to improve clinical care by tailoring disease treatment and prevention to individual patient factors, such as genetics, lifestyle, and environment. The success of PM is contingent upon effective and trustworthy governance, which is essential in maintaining the social licence for data sharing, especially in the absence of specific consent from data subjects. Dr Lysaght will report the key findings from empirical bioethics research aimed at identifying the boundaries of the social license needed to share data under broad consent for PM. The combined results suggest that Singaporeans value the potential social benefits of PM and may be willing to participate with broad consent, but are concerned about the misuse and exploitation of data shared, especially with private industry. Key provisions necessary for the trustworthy governance systems for PM will be recommended.

Supported by the Fogarty International Center of the United States, National Institutes of Health (Grant R25TW010891) in collaboration with the Berman Institute of Bioethics, Johns Hopkins University.