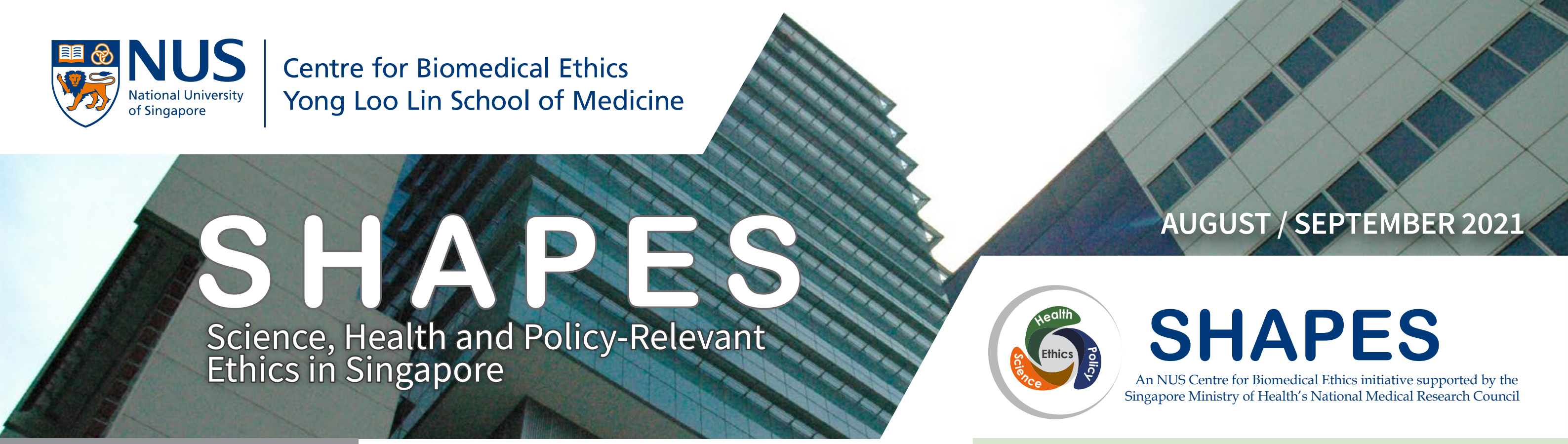


NUS National University of Singapore
Centre for Biomedical Ethics
Yong Loo Lin School of Medicine

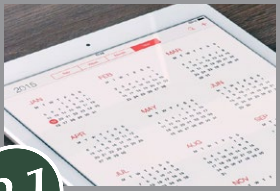
SHAPES

Science, Health and Policy-Relevant Ethics in Singapore

AUGUST / SEPTEMBER 2021

SHAPES
An NUS Centre for Biomedical Ethics initiative supported by the Singapore Ministry of Health's National Medical Research Council

inside... this issue



Dear colleagues,

I take this opportunity to thank you warmly for your interest in the work undertaken by the **SHAPES Initiative** over the years. I also take this opportunity to warmly thank Tim Nicholas Lee for his contribution to SHAPES and wish him the very best with his doctoral studies! Tim will be sorely missed by the team.

It is with a heavy heart that I bid farewell to the SHAPES team and the Centre for Biomedical Ethics, NUS, which has been my home since 2018. Like millions around the world, the global pandemic has played its part in my decision to return to Australia. I feel privileged to have had the opportunity to work with my amazing team, colleagues at CBmE, and our colleagues at the NMRC, MOH.

Best wishes,
Dr Vicki Xafis
SHAPES Programme Director

Events & Webinars:

[Click on the links to register]

20 JULY:
A Match Made in Science: Integrating Bioethics and Biomedical Research
National Institutes of Health (Recording Available)

28 - 30 SEPTEMBER:
GA4GH 9th Plenary Meeting
Global Alliance for Genomics and Health

23 - 25 NOVEMBER:
Singapore Research Ethics Conference
National University of Singapore

2 - 3 DECEMBER:
Singapore Healthcare AI Datathon and Expo 2021
National University of Singapore

News & Comments

[Click on the links to see the full article]

The 'Time Has Come' For A Global Pandemic Treaty, WHO's Tedros Says

NPR

Wanted: rules for pandemic data access that everyone can trust

Nature

S'pore has to ensure biomedical advances benefit its people, are in line with its ethical stance: DPM Heng

The Straits Times

Researchers raise concerns about using genetic risk scores to pick 'healthier' embryos

STAT

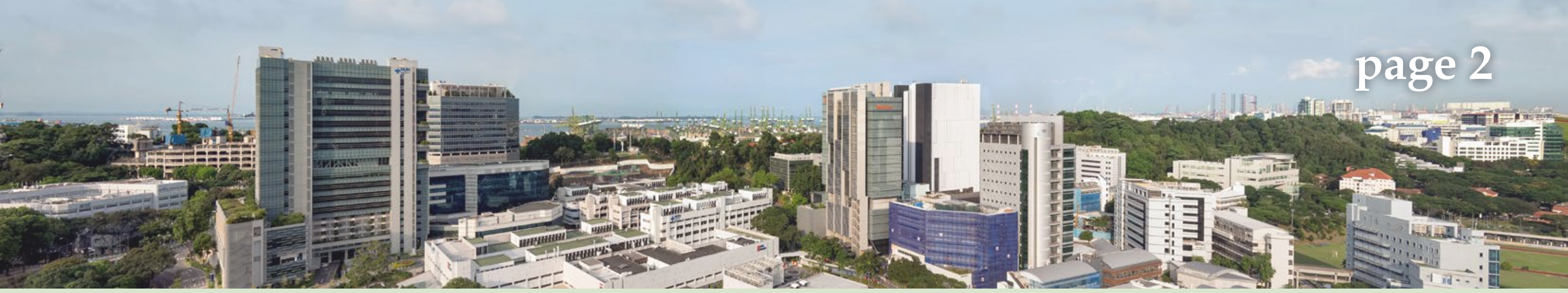
What do AI, bioengineering and nanotechnology have to do with brain cancer research?

SingHealth

Blog Posts

Health data, medical confidentiality, and the right to privacy – is GPDPR the new care.data? by Paquita de Zulueta, Nuffield Council of Bioethics

Preparing For The Next Generation of Ethical Challenges Concerning Heritable Human Genome by Robert Klitzman, Bioethics.net



Reports [Click on the links to see the full article]

Ethics and governance of artificial intelligence for health – WHO Guidance

World Health Organization

This WHO guidance draws on multi-disciplinary deliberations to identify the challenges and risks of the use of AI for health. It recommends six consensus principles to promote the ethical use of AI for health and a set of governance recommendations.

Putting Good into Practice: A public dialogue on making public benefit assessments when using health and care data

GOV.UK

Based on insights from stakeholder interviews and public dialogues in the UK, this report highlights how lay people interpret the concept 'public benefit' and reveals public sentiments and expectations regarding the use of data.

Human genome editing: a framework for governance

World Health Organization

This 6-part publication provides advice and recommendations on appropriate institutional, national, regional and global governance mechanisms for human genome editing.

Human genome editing: recommendations

World Health Organization

Recommendations cover 9 areas: WHO leadership; International collaboration; International registries; International research/medical travel; illegal/unregistered/unethical/ unsafe research or activities; IP; education/engagement/empowerment; ethical values and principles; and the review process.

Academic Articles

[Click on the links to see the full article]

Mobile health and privacy: cross sectional study by Tangari et al., *BMJ*

Serious privacy concerns have been identified across mHealth apps, including the collection of personal user information, and a lack of security and transparency regarding data use. The paper concludes with recommendations for clinicians.

Ethics of genomic passports: should the genetically resistant be exempted from lockdowns and quarantines? by Gyngell and Savulescu, *Journal of Medical Ethics*

The paper explores ethical issues raised by genomic passports and highlights differences and similarities to immunity passports.

Protecting Privacy in India: The Role of Consent and Fairness in Data Protection by Taylor and Paterson, *The Indian Journal of Law and Technology*

The paper examines the unique approach the Indian Personal Data Protection Bill (2019) adopts to balancing the elements of individual consent and fairness-based limitations used in data protection mechanisms in other jurisdictions.

The "Ought-Is" Problem: An Implementation Science Framework for Translating Ethical Norms into Practice
by Sisk et al., *The American Journal of Bioethics*

This paper proposes a framework based on implementation science and argues that ethical norms must eventually lead to ethical actions and that ethicists should consider feasible implementations when formulating norms.

Citizens' views on sharing their health data: the role of competence, reliability and pursuing the common good by Velarde et al., *BMC Medical Ethics*

Presented in this paper are findings from a University of Geneva citizen forum exploring citizens' attitudes toward consent to share health data. Important themes that emerged included: data control, trustworthiness and governance to protect research participants.

Public involvement in the governance of population-level biomedical research: unresolved questions and future directions by Erikainen et al., *Journal of Medical Ethics.*

The study explores key governance challenges and how public involvement can meet these challenges. Themes identified include: the need to move beyond individual consent; benefit and data sharing; the challenge of delineating and understanding publics; and the goal of clarifying justifications for public involvement.