



OCTOBER / NOVEMBER 2021



Dear Colleagues,

Welcome to the newest edition of the bi-monthly SHAPES newsletter, providing you with opinions, reports, and academic articles on ethical issues in genomics, AI and health data research.

This is also the last edition of the stand-alone SHAPES newsletter. From December onwards, we will be joining forces with rest of the Centre for Biomedical Ethics (CBmE) to publish a high-quality newsletter on ethical issues in health research. We will continue to cover the topics of genomics, big data and AI. The new mailer will still reach you via email but through a new communications platform. Your e-mail address will automatically be included but if you wish to unsubscribe, please click here.

Sincerely, The SHAPES Team

# Events & Webinars

{click on the links to register}

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 & Opinion**

UN official calls for moratorium on artificial intelligence tools that breach human rights, *Washington Post* 

Picking Embryos With Best Health Odds Sparks New DNA Debate, *Bloomberg* 

The first polygenic risk score baby, Center for Genetics and Society

Explaining medical AI is easier said than done, STAT

Human genome editing and moral leadership: findings of the WHO Expert Advisory Committee, Nuffield Council on Bioethics

A new approach to the data-deletion conundrum, Standord University HAI

Why should we care about social and behavioural genomics? *bioethics.net* 

## Reports

### Gathering Strength, Gathering Storms: The One Hundred Year Study on Artificial Intelligence (AI100) 2021 Study Panel Report, Stanford University

The second report of the One Hundred Year Study on Artificial Intelligence assesses the progress and risks of artificial intelligence, concluding that AI has made significant leaps in recent years and that there is increased urgency to understand its positive and negative societal impacts.

#### Religious perspectives on precision medicine in Singapore by Toh et al., Asian Bioethics Review

This article presents the outcomes of a knowledge exchange fora with religious authorities in Singapore regarding data sharing for precision medicine. According to religious authorities, sharing precision medicine data with private industry requires a public benefit justification and robust data governance.

#### A call for better, not faster, research ethics committee reviews in the Covid-19 era by Tamariz et al., Ethics & Human Research

Research ethics committees (RECs) are pressured to move through reviews of Covid-19 clinical research studies quickly, yet without relaxing ethical standards. This commentary recommends steps that RECs can take to ensure ethical review of research studies in response to this demand and in future infectious disease outbreaks.

#### Privacy and artificial intelligence: Challenges for protecting health information in a new era by Murdoch, BMC Medical Ethics

As private entities increasingly own and control AI technologies, these entities will play a great role in utilising and protecting patient health information, thus raising significant privacy issues. Regulation should emphasise patient agency and encourage sophisticated methods of data protection.

#### "A cohort of pirate ships": Biomedical citizen scientists' attitudes toward ethical oversight by Trejo et al., *Citizen Science: Theory and Practice*

As bottom-up biomedical citizen science projects beyond the purview of institutional review boards become more prevalent, questions of an 'ethics gap' and ethical oversight emerge. This article reports the preferences of biomedical citizen scientists regarding different mechanisms of ethical oversight.

# **Academic Articles**

Germline genome modification through novel political, ethical, and social lenses by Xafis et al., *PLOS Genetics* 

Applying novel political, ethical and social lenses to aspects of Human Germline Genome Editing (HGGE) can uncover previously under-explored considerations. This article explores four such lenses that enrich the debate about the ethics regulation of HGGE.

#### Germline genome editing: Moratorium, hard law, or an informed adaptive consensus? by Kaan et al., *PLOS Genetics*

This article argues that an international moratorium on HGGE and regulation through traditional legal mechanisms are unlikely to achieve their objectives. Engaging an international community of stakeholders to develop an "informed adaptive consensus" can provide an alternative approach that changes in response to new biomedical knowledge.

#### Digital bioethics: Introducing new methods for the study of bioethical issues by Schneider et al., Journal of Medical Ethics

This article demonstrates how novel methods in digital social science research can be applied in the domain of bioethics. A new domain of *digital bioethics* research can integrate with empirical bioethics and offer ways to tackle complex emerging ethical issues in science and technology.

### Machine learning and algorithmic fairness in public and population health by Mhasawade et al., Nature Machine Intelligence

While much research on machine learning has focused on processes in the clinic, this article considers the ethical implications of using machine learning for population health and highlights opportunities for machine learning, public and population health to jointly promote health equity.