

## Advancing Ethics Oversight of AI-Driven Health Research in Malaysia

[Monday, 22<sup>nd</sup> January 2024 @ 9.30am - 5pm]  
[Tuesday, 23<sup>rd</sup> January 2024 @ 9am - 12pm]  
[Wednesday, 24<sup>th</sup> January 2024 @ 9am - 11am]  
Faculty of Law, Universiti Malaya, Malaysia

### REPORT

#### Day 1: Monday, 22<sup>nd</sup> January 2024

Time	Session
09.30 - 09.40	<p><b>Welcoming Remarks</b></p> <p><i>By Associate Professor Sharon Kaur (Universiti Malaya)</i></p> <p>Sharon Kaur delivered a warm and engaging welcoming address at the beginning of the event. Her remarks set a positive tone for the gathering and effectively welcomed attendees to the occasion.</p>
09.40 - 10.10	<p><b>Current issues/approaches to AI ethics oversight globally and in LMIC contexts</b></p> <p><i>By Professor Effy Vayena (ETH Zurich)</i></p> <p>Professor Effy Vayena discussed AI risks specific to health and provided a comprehensive overview of AI health research oversight, detailing its current landscape and key issues. She discussed various facets of AI health research, from randomised controlled trials to personalised treatment approaches, emphasising the broad spectrum of applications in healthcare. She spoke about the WHO 'Ethics and governance of artificial intelligence for health' and highlighted the fragmented global landscape of ethics and governance of AI health research. Professor Effy Vayena also emphasised the need for robust oversight mechanisms, given the extensive integration of AI into healthcare by both academic institutions and private companies. Ethical oversight mechanisms, particularly Institutional Review Boards (IRBs), were examined for their pivotal role in safeguarding human subjects including their data. Challenges persist in adapting to emerging risks and acquiring specialised expertise to navigate the complex ethical landscape, especially concerning Low and Middle-Income Countries (LMICs). In conclusion, Professor Vayena's presentation emphasised the imperative for ethical, transparent, and inclusive AI-driven healthcare solutions. She underscored the need to update procedural mechanisms and develop new approaches to address unique ethical challenges, particularly in LMIC contexts.</p>
10.10 - 10.40	<p><b>Do we need to broaden our moral gaze of AI health research to include the environment?"</b></p>

*By Dr. Gabrielle Samuel (Kings' College London)*

Dr. Gabrielle Samuel provided a comprehensive analysis of the environmental sustainability of AI health research, urging a broader ethical perspective beyond traditional concerns like privacy and equity. She stressed that there was a moral imperative to consider the environmental impact of AI health research. She emphasised the urgent need to integrate environmental considerations into existing health research ethics frameworks. She recognised that this would involve making decisions in spite of many uncertainties. Issues relating to the measurement to determine harm, the margin of error that is acceptable and who should be held accountable are important matters to consider. She pointed out that the EU Artificial Intelligence Act, which has yet to be finalised, contains provisions dealing with the environmental sustainability of AI health research. Dr. Samuel outlined the significant ecological footprint of AI health research, highlighting its adverse environmental and health impacts. She stressed the necessity for normative changes to address these issues and underscored the exponential growth of health data, which poses privacy risks and environmental challenges. Moreover, Dr. Samuel shed light on the material and labour-intensive nature of digital technology, drawing attention to ethical concerns regarding mining practices and e-waste generation. While UK digital health researchers show a growing awareness of environmental responsibility, they face practical challenges in reconciling these responsibilities. Dr. Samuel discussed the ethical principles rooted in the Ubuntu philosophy, prioritising communal welfare and environmental stewardship. She advocated for the inclusion of environmental considerations in research ethics frameworks and sustainable practices throughout AI health research. In conclusion, Dr. Samuel's discourse highlighted the necessity for a paradigm shift in AI health research towards environmental sustainability. By fostering a collective sense of responsibility and adopting sustainable practices, the field can mitigate its ecological impact while advancing healthcare innovation.

**10.50 - 11.00 Workshop Photography Session**

Participants gathered for a group photo-taking session.

**11.00 - 13.00 Breakout Group**

In the first breakout session, participants were divided into two groups to discuss key questions related to ethics oversight in AI health research. The main question and the points for consideration were as follows:

“Should new approaches to ethics oversight be implemented for AIH research?”

Consider:

- a. The possibility of needing (a) new ethical principles; (b) different practices/processes to implement existing principles; or (c) both/neither.
- b. The influence that different meanings attached to principles/practices can have on research practice in different countries (eg. consent, benefit sharing)
- c. The influence of different cultures and approaches to research ethics (and society) in different countries and how these are/should be

	<p>considered in AIH research ethics guidelines (benefit to individual, community and environment)</p> <p>d. What do your discussions mean for the Malaysian context of AIH research, what similarities and differences Malaysia has compared to other countries in terms of practices and principles, lessons that can be learnt from other countries?"</p> <p>The discussions revolved around the potential implementation of new approaches to ethics oversight for AIH research. Participants explored the need for new ethical principles, different practices for implementing existing principles and the influence of varying cultural interpretations of ethics across different countries. Consideration was given to how these discussions translate to the Malaysian context, identifying similarities, differences and lessons learned from other countries' practices and principles.</p>
<p><b>13.00 - 14.00</b></p>	<p><b>Lunch</b></p>
<p><b>14.00 - 14.30</b></p>	<p><b>AI research and ethics oversight in Malaysia</b></p> <p><i>By Dr. Alex Phang (Universiti Malaya)</i></p> <p>Dr. Alex Phang discussed Malaysia's current landscape regarding AI in healthcare and its ethical governance. Despite global interest in AI, Malaysia faced challenges in fully adopting these technologies due to resource limitations and governance issues. He mentioned that while the government had allocated substantial funds to improve public healthcare and the AI market was projected to grow significantly, the adoption of ethical standards and governance frameworks remained unclear. The bibliometric analysis of his research revealed trends in AI health research emergence, local institutional contributions and specific projects integrating AI into healthcare domains. Dr Phang drew attention to the fact that Malaysia lacked specific legislation governing AI in healthcare, although steps were being taken to develop an "AI Act" under the AI-RMAP 2021-2025 initiative. Dr Phang also pointed out that stakeholder discussions highlighted significant challenges faced by AI innovators and applicators in Malaysia, including a lack of clear oversight, regulatory and ethical bodies' insufficient expertise in AI and bureaucratic management hindering innovation. Ethical considerations surrounding patient autonomy, privacy protection, data security, transparency, bias, accuracy, readiness and liability present complex challenges. Dr Phang highlighted the need to improve AI governance in Malaysia, including establishing clear frameworks, enhancing awareness and education, promoting transparency and encouraging research to address ethical and regulatory gaps. In conclusion, he emphasised the importance of addressing these challenges to ensure the ethical and responsible implementation of AI in healthcare in Malaysia. By embracing AI technologies while upholding robust ethical and governance standards, Malaysia can harness AI's transformative potential to enhance healthcare delivery and patient outcomes.</p>
<p><b>14.30 - 15.00</b></p>	<p><b>The Right Thing, The Realistic Way: Our reflections on implementing the Indian guidelines for the ethical use of AI in health and health research</b></p>

*By Professor Manjulika Vaz, (St John's Research Institute) and Ms. Niyoshi Shah, (Consultant, Quicksand Design Studio)*

In March 2023, the Indian Council of Medical Research (ICMR) released guidelines aimed at fostering ethical practices in AI implementation within the healthcare sector. These guidelines, built on principles such as autonomy, safety, trustworthiness and collaboration, were met with enthusiasm yet raised practical challenges in implementation. To address these challenges, a collaborative effort led by Professor Manjulika Vaz from St John's Research Institute and Ms. Niyoshi Shah, a consultant at Quicksand Design Studio, brought together multidisciplinary stakeholders for workshops and virtual sessions. These engagements sought to translate abstract principles into actionable strategies, emphasising real-world application and stakeholder involvement. Key challenges that were identified included the limitations of manual data collection, inadequacies in data privacy policies and the rush for product development at the expense of ethical considerations. Furthermore, ethical oversight and partnerships in AI development remain complex, highlighting the need for clear guidelines on data ownership, annulment and fair compensation for data contributors. Moving forward, Professor Manjulika stressed the importance of stakeholder engagement, strengthened ethical oversight mechanisms and the integration of altruism and reciprocity into AI development processes. She also noted that customised solutions tailored to India's context and ongoing feedback loops were essential for effective guideline implementation. In conclusion, she emphasised the need for continued collaboration, stakeholder engagement and a commitment to addressing practical challenges in order to realise the ethical use of AI in health and health research in India.

**15.00 - 15.15**

**Break**

**15.15 - 17.00**

**Breakout Group**

In the second breakout session, participants delved into the feasibility and challenges of implementing new approaches to ethics oversight in Low and Middle-Income Country (LMIC) contexts. The main question and the points for consideration were as follows:  
“Should and could new approaches to ethics oversight be implemented in LMIC contexts? What are some challenges?  
Consider:  
a. What might be new or special about ethics in AIH research compared to other forms of health research, both in terms of ethical principles and types of review/oversight system (e.g. Stanford Ethics and Society Review, NHS Algorithmic Impact Assessments)?  
b. What are other countries doing in terms of ethics oversight of AIH research?  
c. What about international collaborative projects? What should happen in terms of data governance and oversight?”  
The participants examined the unique ethical considerations of AIH research compared to other forms of health research and explored existing practices of ethics oversight in other countries. Additionally, discussions focused on data governance and oversight in international collaborative projects,

highlighting the complexities of managing ethics across borders and diverse research environments.

**Day 2: Tuesday, 23<sup>rd</sup> January 2024**

Time	Session
09.00 - 12.00	<p data-bbox="456 464 1372 527"><b>Artificial Accountability: Funders, Philanthropies and the Future of Research Ethics</b></p> <p data-bbox="456 562 964 594"><i>By Dr. Dan O'Connor (Wellcome Trust)</i></p> <p data-bbox="456 632 1372 1866">Dr. Dan O'Connor, representing the Wellcome Trust, engaged the Southeast Asia Bioethics Network in a discussion on "Artificial Accountability." This exploration aimed to elucidate the pivotal roles of funders and philanthropies in shaping research ethics, particularly within the evolving domain of AI and its associated challenges. Dr. O'Connor underscored the emerging complexities in AI science regulation, advocating for clear delineation of roles between public funders and private philanthropies to address these challenges effectively. He emphasised the crucial role of funders in establishing boundaries and promoting responsible research practices, particularly within the realms of AI and its ethical considerations. Furthermore, the discourse delved into the concept of moral accountability within AI research, raising pertinent questions regarding the ethical implications and the shared responsibilities of researchers and funders in navigating these ethical landscapes. A real-world illustration was presented to highlight the inherent lack of accountability in AI systems, underscoring the necessity for a deeper understanding to facilitate proper regulation. The importance of accountability in decision-making processes was emphasised, with Dr. O'Connor stressing that being accountable required offering a reasonable account of one's actions. Moreover, the responsibilities of funders in the rapidly evolving field of AI research were outlined, including the implementation of policies and guidelines to ensure accountability throughout the research process. Public engagement and education emerged as critical components in fostering ethical AI research practices, with an emphasis on transparency and communication to bridge the gap between researchers and the wider public. Challenges in communicating complex AI concepts to diverse audiences were acknowledged, underscoring the need for robust public engagement strategies. Dr. O'Connor concluded the discussion by advocating for continuous dialogue, education and ethical considerations in the dynamic field of AI research. He highlighted the imperative for funders and researchers to uphold transparency and accountability in their actions, underscoring their pivotal role in shaping the future of research ethics. Consolidation Meeting (Angela Ballantyne, Barry Solaiman, Cheah Phaik Yeong, Dan O'Connor, Effy Vayena, Garielle Samuel, Mohd Adli Bin MD Ali, Muhammad Firdaus Bin Abdul Aziz, Serene Ong Sharon</p>

Kaur, Tamra Lysaght and Tay Pek San) to discuss the following questions:

- a. What came out from the workshop that we should give more time for discussion?
- b. Why is or isn't the LMIC context different when thinking about research ethics?
- c. What needs to be thought about in the LMIC context for them to get research ethics right?

The participants engaged in a multifaceted discussion, exploring various aspects including the role of education institutions, challenges in current research processes and the evolving landscape of AI research ethics. They also discussed the potential implications of leapfrogging in LMICs, nuanced differences in regulatory systems and the importance of community engagement in research ethics. The meeting further delved into the intricacies of LMIC contexts, communitarian ethics, and the role of institutions in shaping research agendas. Future conferences and panels on governance of emerging technologies were also deliberated upon, indicating a collective commitment to addressing the complex challenges within the field. Innovation Ethics and oversight were explored in the context of political and cultural diversity, with discussions centering on new guidelines, protocols, and the practicality of adding layers into existing systems. The session underscored the necessity of adapting to the dynamic landscape of AI research ethics while maintaining accountability and transparency.

### Day 3: Wednesday, 24<sup>th</sup> January 2024

Time	Session
09.00 - 12.00	<p><b>Public Forum on Ethics and AI Health Research</b></p> <p>The Public Forum on Ethics and AI Health Research convened on 24th January 2024, at the Tun Mohamed Suffian Auditorium, Faculty of Law, Universiti Malaya, under the moderation of Dr. Dan O'Connor, Head of Research Environment at Wellcome Trust, London. Dr. O'Connor skillfully facilitated discussions among esteemed panellists and participants, fostering a robust exchange of ideas and insights. Accompanying Dr. O'Connor were four distinguished panellists:</p> <ol style="list-style-type: none"> <li>1. Dr. Mohd Adli Bin MD Ali - Assistant Professor, International Islamic University Malaysia, Malaysia.</li> <li>2. Dr. Barry Solaiman - Assistant Dean and Professor, Hamad Bin Khalifa University, Qatar.</li> <li>3. Dr. Muhammad Firdaus Bin Abdul Aziz - Deputy Dean, Faculty of Law, Universiti Malaya, Malaysia.</li> <li>4. Dr. Effy Vayena - Assistant Dean and Professor, ETH Zurich, Switzerland.</li> </ol> <p>Their expertise and diverse perspectives enriched the dialogue, offering valuable insights into the ethical dimensions and implications of AI in health research within the Malaysian and global contexts.</p>

During the forum, attendees also had the privilege of engaging with Mr. Gurmit Sandhu, an AI Practitioner for Digital Health Technologies, who presented on "A Dashboard to Support the Value Assessment of Digital Health Technologies". Mr. Sandhu's presentation provided attendees with practical insights into leveraging AI for the assessment of digital health technologies, further enriching the discourse on AI's role in healthcare evaluation and implementation.

The forum served as a pivotal platform for attendees to delve into the transformative potential of AI in healthcare while navigating the ethical considerations and challenges inherent in its adoption. Discussions highlighted the need for continued collaboration, regulatory frameworks and ethical guidelines to ensure the responsible and equitable integration of AI in healthcare practices and research. The Public Forum on Ethics and AI Health Research catalysed meaningful dialogue and collaboration among attendees, laying the foundation for future endeavours aimed at harnessing the benefits of AI while upholding ethical standards and safeguarding patient welfare.