Exploring The Ethical Landscape for Emerging Technologies In Medicine?

What Are The Issues For Technologists, Medical & Other Stakeholders As They Collaborate For Success?

Workshop Hosted by The Internet Governance Forum (IGF) Recognized,

Dynamic Coalition on Data Driven Health Technologies

March 19, 2021 Virtual Collaboration Session

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Workshop Booklet

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Introduction

This workshop focuses on the emerging frontier for ethics, resulting from the new technologies that are being developed and applied to the medical and biological sciences. These technologies include artificial intelligence, machine learning, blockchain, hologram, sensor, quantum and other technologies.

The workshop outcome is expected to be a report on the top ethical issues for emerging technologies and especially in the medical and biological sciences space, so that more specific discussions can be facilitated.

The workshop is also an opportunity for authors contributing to the Dynamic Coalition's booklet on Ethics in 2021, to collaborate and discuss issues with each other.

The materials and opinions of this workshop, or its report, may not reflect the standards, views and opinions of the United Nations Internet Governance Forum.

Background Reading & Preparation

A Short History of Medical Ethics - Albert R. Jonsen - Google Livres

https://horizon-magazine.eu/article/how-quantum-technology-could-revolutionise-detection-and-treatment-diseases.html

Thought provoking TED talks:

Printing a human kidney (Anthony Atala | TED2011)
https://www.ted.com/talks/anthony_atala_printing_a_human_kidney?utm_source=tedcomshare&utm_medium=email&utm_campaign=tedspread

Ultrasound surgery — healing without cuts (Yoav Medan | TEDMED 2011)
https://www.ted.com/talks/yoav_medan_ultrasound_surgery_healing_without_cuts?utm_source=tedcomshare&utm_medium=email&utm_campaign=tedspread

Miguel Nicolelis: A monkey that controls a robot with its thoughts. No, really. | TED Talk

Internet Society Resources:

Policy Brief: Principles for Responsible Data Handling | Internet Society

Trust & Ethical Data Handling in the Healthcare Context | Internet Society

IEEE Resources:

Webinar: Ethical Considerations for System Design, Part 1 - YouTube

Product Design and the Reasonable Person - Nature versus Nurture?
Publisher: IEEE Michael Steven Morse; Rob Raney

"Abstract:
The reasonable person is one who acts with prudence. To avoid liability, product design must assure that the reasonable person will not be injured. The question addressed herein is how much of the reasonable person is reasonably the result of the design and programming of the human machine itself? Is reasonableness nature or nurture? Avoiding injury is often all about seeing, understanding, and avoiding the danger…."

A few points to consider:

- Informing the public, mitigating harms
- Education and information for risk management
- The ethics of preventative medicine
- Transparency and accountability
- Access and the quality internet
- Timely data and coherent data sets
- Comprehensive data sets for inclusivity
- Carry forward implications for data created
- Bias: unintended, unexpected etc.
- Data cleaning, accuracy, representation and relevance
- Bridging the digital medical divide
- Ethics Common Ground between, Technologists, Medical Profession, The Patient and Business for IT Development:
    - What are the differences in professional practice approaches?
    - What are the risks when there is no common ground?
    - What do some stakeholders take for granted that is particular to them?
    - What can we do to reduce the mis-understandings?
    - What types of issues could take time to resolve between stakeholders?

Privacy principles for a reasonable person

#1 Reference: Canada

"The OPC has determined that the following purposes would generally be considered inappropriate by a reasonable person (i.e., no-go zones):

- *collecting, using or disclosing personal information in ways that are otherwise unlawful;*
- *profiling or categorizing individuals in a way that leads to unfair, unethical or discriminatory treatment contrary to human rights law;*
- *collecting, using or disclosing personal information for purposes that are known or likely to cause significant harm to the individual;*
- *publishing personal information with the intent of charging people for its removal;*
- *requiring passwords to social media accounts for the purpose of employee screening; and*
- *conducting surveillance on an individual using their own device's audio or video functions."*

Source: *PIPEDA fair information principles - Office of the Privacy Commissioner of Canada*

#2 Reference: UK

See MRS utube presentation at: https://www.fairdata.org.uk/principles/

"The new Fair Data Principles are:

Principle 1:
We will ensure that all personal data is processed in line with the reasonable expectations of individuals of our use of their personal data.

Principle 2:
We will only use data for specified purposes and be open with individuals about the use of their data, respecting individuals' wishes about the use of their data.

Principle 3:
We will make sure that individuals have easy access to their personal data that we hold, and that we tell them how we use it and how they can exercise their rights over it.

Principle 4:
We will only collect personal data that we need and will protect it and keep it secure, removing personal data as soon as it is no longer needed.

Principle 5:
We will ensure staff and all persons involved with our organisation understand that personal data is just that – personal – and ensure that it is treated ethically and with respect.

Principle 6:
We will ensure that the vulnerable and under-age are properly protected by the processes we use for data collection, use and management.

Principle 7:
We will manage our data supply chain to the same ethical standards we expect from other suppliers.

Principle 8:
We will ensure that ethical best practice in personal data is integral to our procurement process.

Principle 9:
We will ensure that all staff and persons involved with our organisation who have access to personal data are properly trained in its use.

Principle 10:
We will ensure that privacy vulnerability is risk assessed and controls to protect privacy are embedded in the design and development of all our processes including our software, systems and services for the collection and use of personal data.

Principle 11:
We will ensure that we can adequately resource and demonstrate our responsibility for compliance with data protection requirements.

Principle 12:
We will only use personal data if we are confident that the Fair Data Principles have been applied throughout our organisation.

Source: Principles | Fairdata

#3 Reference: European Union

"Principles of the GDPR | European Commission (europa.eu)

The type and amount of personal data a company/organisation may process depends on the reason for processing it (legal reason used) and the intended use. The company/organisation must respect several key rules, including:

- *personal data must be processed in a **lawful and transparent manner**, ensuring fairness towards the individuals whose personal data is being processed ('lawfulness, fairness and transparency');*
- *there must be **specific purposes** for processing the data and the company/organisation must indicate those purposes to individuals when collecting their personal data. A company/organisation can't simply collect personal data for undefined purposes ('purpose limitation');*
- *the company/organisation must collect and process **only the personal data that is necessary to fulfil that purpose** ('data minimisation');*
- *the company/organisation must ensure the personal data is accurate and up-to-date, having regard to the purposes for which it is processed, and correct it if not ('accuracy');*
- *the company /organisation can't further use the personal data for other purposes that aren't **compatible** with the original purpose;*
- *the company/organisation must ensure that personal data is **stored for no longer than necessary** for the purposes for which it was collected ('storage limitation');*
- *the company/organisation must install appropriate **technical and organisational safeguards** that ensure the security of the personal data, including protection against unauthorised or unlawful processing and against accidental loss, destruction or damage, using appropriate technology ('integrity and confidentiality')."*

Source: *What data can we process and under which conditions? | European Commission (europa.eu)*

#4

ISO / IEC 27001

#5

The AMA Holds Funeral Service for Physical Exam; and Is Technology Changing the Way we Practice Medicine? | Musings of a Doc with an MBA (rorsini.com)

Workshop Activity #1: Ice-breaker

Buddhist breath meditation technique (2 mins)

Focus on the mind and body, controllable interface

Workshop Activity #2: Evaluating The Ethical Landscape For Emerging Medical Technologies

Participants will be requested to put their top three issues / risks / harms and so forth, with regard to emerging technologies in to the chat. Refer to Appendix A for guidance. These concerns are not limited to data, or data driven issues.

1. Priority / Concern / Risk .. #1 (2 mins)
2. Priority / Concern / Risk .. #2 (2 mins)
3. Priority / Concern / Risk .. #3 (2 mins)

This will be followed by a group discussion. Each participant will have 3 mins to outline their identified issues in detail. A question period will follow, once all participants have presented their ideas. Participants may ask each other questions or seek clarifications of each other.

If you are unable to make the Workshop, please email your responses to the DC mailing list by March 26, 2021.

Appendix A

Emerging Issues Identification Matrix For Technology With Medical Ethics

Data Perspective	Harms	Norms	Values /Morals	Traditions	Expectations	Reality	Risks	Digital Health Divide	Spirituality	Preventative	Predictive
Machine Learning											
Artificial Intelligence											
BlockChain											
Robotics											
Sensors											
Cloning .Bio											
NanoTechnology											
Virtual Reality											
Holograms											
Quantum											