

SECOND ASIA-PACIFIC REGIONAL MEETING for NATIONAL ETHICS/BIOETHICS COMMITTEES

Reducing Inequities through Solutions-Orientated Bioethics

22 -23 October 2019 / Wellington, New Zealand

APNECII: Recent Peer-Reviewed Articles on Emerging Technologies with Ethical Implications

Article titles, and brief summaries are provided.

Articles are organised by region (Asia-Pacific-based, or Other Region-based), then organised by Clinical Ethics, Public Health Ethics or Research Ethics. Some articles fit into more than one category, so you will notice a few repeated entries.

Asia Pacific based articles

Clinical Ethics

“Systematic Review of Real-time Remote Health Monitoring System in Triage and Priority-Based Sensor Technology: Taxonomy, Open Challenges, Motivation and Recommendations”

(Albahri et al., 2018)

- Authors based in Malaysia; Iraq
- Reviewed literature on telemedicine
- Common themes and challenges were identified for different technologies:
 - Sensor based
 - Reliability
 - Link quality & packet delay
 - Congestion control
 - Electromagnetic interference
 - Energy efficiency
 - Quality of service
 - Security
 - Evaluation-and-assessment-based sensor
 - mHealth & gateway-based
 - Treatment support and disease surveillance
 - Disaster Management
 - Integration and aggregation
 - Network management
 - Ambient-assisted living

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- Decision support system
- Server Based
 - Analysis process
 - Environmental management
 - Evaluation and assessment-based server
 - Security and privacy-based server
 - Collaboration fields
 - Cooperative environment
 - Tele-expertise between professionals
 - Remote monitoring
 - Patient prioritisation
 - Patient triage
 - Provide services to patient
- Benefits of these technologies are presented (Fig. 7)
- Challenges described (Fig. 8) include:
 - Network optimisation
 - Disease monitoring concerns
 - Concerns on general healthcare services
 - Healthcare data management
 - Power consumption/energy efficiency
 - Decision support systems
 - Triage
 - Security and privacy
 - Disaster/emergency management
 - Ambient assisted living
- Recommendations for Physicians, researchers, service users and developers are described in Fig. 9.

“A Qualitative Study of Thai HIV-Positive Young Men Who Have Had Sex With Men And Transgender Women Demonstrates the Need for eHealth Interventions to Optimize the HIV Care Continuum”

(Anand et al., 2017)

- Research based in Thailand
- Investigates the need to eHealth interventions to optimise HIV care continuum
- Qualitative study interviewed infected individual
 - Identified how eHealth could address needs

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- Preferences for eHealth interventions
- Social stigma negatively impacted retention in care
- Inadequate in-person support led to heavy reliance on online resources, even if these resources were viewed as inconsistent or untrustworthy
- eHealth interventions universally endorsed by participants (examples at end of abstract)

“A Systematic Review of Wearable Patient Monitoring Systems - Current Challenges and Opportunities for Clinical Adoption”

(Baig, Gholamhosseini, Moqem, Mirza, & Lindén, 2017)

NZ & Sweden

- Review to investigate barriers and challenged of wearable patient monitoring solutions
- WPM systems potential solution o challenges arising from ageing population, chronic disease, cost of hospitalisation, and medical errors
- Reviewed studied 2015-2017
- Current studies are looking at advanced sensors, wireless data collection, comms platform and clinical usability
- “Silo” solutions common – tech solutions to solve specific problems, often not scalable/generalizable
- Wearable tech, AI and machine learning at forefront
- Treatments aiming at efficient and affordable

“Algorithms designed for compressed-gene-data transformation among gene banks with different references”

(Luo, Guo, Zhang, Cai, & Liu, 2018)

- Identify issues around storing, transmitting and analysing gene data
- Based in China
- Data from separate gene banks is difficult to merge,
- Aim to use transformational algorithms to more efficiently store genome data
- Tested a number of algorithms
- Overall alludes to need for centralised (globalised?) system for storing gene data

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“Advancing mobile learning in Australian healthcare environments: nursing profession organisation perspectives and leadership challenges”
(Mather, Cummings, & Gale, 2018)

- Mobile devices for learning at point of care lacks governance
- Accessing knowledge to improve services is regarded as positive in Australia, however using a mobile device while working is not (?)
- Study aimed to understand factors influencing mobile learning policy development, from nurse perspective
- Key themes of risk management, perceived use of mobile tech, connectivity to information and real-time access emerged, Nurses were generally reluctant to challenge status quo around mobile devices
- Mobile learning cannot occur at point of care until the themes above are addressed; better communication of risks and benefits to this would be a method of doing this

“Perceptions of trust in bionano sensors: Is it against our better judgement? An investigation of generalised expectancies and the emerging technology trust paradox”

(Mazey & Wingreen, 2017)

- Lead author based in Christchurch, New Zealand
- Examines literature around bionano sensors, potential applications and risks
- Existing research leans towards holding positive beliefs about this emerging technology and its use
- The sampled population believed them to be relatively low risk and nonchalant about perceived risks; perceived bionano sensors to be trustworthy relative to self-driving cars

“Change, Connectivity and Challenge: Exploring the Role of Health Technology in Shaping Health Care for Aging Populations in Asia Pacific”

(Penno & Gauld, 2017)

- Lead author based in Dunedin, New Zealand
- Article aims to explore how aging and healthcare could be shaped by health technologies in the Asia Pacific region
- Broad article with a wide range of information

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- Case studies of a voice based service to provide real-time feedback in the control of type 2 diabetes, and the use of health care robots in elderly people's homes in a rural setting
- Also looks at distribution and diffusion of health technologies around the region, in addition to policy, funding, infrastructure
- Challenges raised included:
 - Requirement of policy makers to collaborate with older people, their families, service providers, funders and society
 - Involve older users with technology development to ensure technical and cultural appropriateness
 - Tangible benefits should be more explicitly communicated
 - Balance potential intergenerational tensions created by the provision of new care models
 - Reconciling differences in beliefs around best possible care between older people and their families, as preferences may differ between parties

“Investigating the adoption of big data analytics in healthcare: the moderating role of resistance to change”

(Shahbaz, Gao, Zhai, Shahzad, & Hu, 2019)

- Lead author based in Harbin, China, but sample is healthcare organisations based in Pakistan
- Investigated adoption of big data analytics in healthcare
- Specifically, looked at the moderating factor of resistance to change between behavioural intention to use big data analytics and actually using big data analytics
- Theoretical and practical applications of findings are discussed

“The role of pathogen genomics in assessing disease transmission”

(Sintchenko & Holmes, 2015)

- Authors based in Australia
- Discusses insights into the spread and transmission of disease using whole genome sequencing (WGS) and genomic scale phylogenetic analyses
- WGS to resolve patient transmission of disease

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- Using WGS data to target cases linked to community or hospital contacts and prevention of disease spread
- Investigate genetically related cases with no clear epidemiological link
- Combination of WGS and epidemiological evidence
- Genomic surveillance can identify determinants of disease transmission, monitor pathogen evolution and adaptation, ensure accurate and timely diagnoses and refine control strategies

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Public Health Ethics

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- Qualitative study interviewed infected individual
 - Identified how eHealth could address needs
 - Preferences for eHealth interventions
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“Biobanking and Privacy in India”

(Chaturvedi, Ravi Srinivas, & Muthuswamy, 2016)

- Large article about biobanking and privacy in India
- IDs as key aspects of privacy in biobanks:
 - Governance and oversight
 - De-identification policies
 - Security policies
 - Database open/controlled access policies
 - Role of informed consent in privacy frameworks
 - Any other restrictions to data sharing for the protection of the privacy of research participants
- Recommends adjustments to privacy codes as following:
 - Privacy should not focus on specific tech, should be generic for flexibility
 - Should cover physical privacy, DNA, audio, video etc
 - Legislation should cover private and public sector
 - Data controller should guarantee privacy, be accountable
 - Industry specific, self-regulation organisations and the privacy commission as primary authority for enforcement of the act

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“Prediction of Causative Genes in Inherited Retinal Disorders from Spectral-Domain Optical Coherence Tomography Utilising Deep Learning Techniques

(Fujinami-Yokokawa et al., 2019)

- Aim to use data driven deep learning approach to predicting the gene responsible for the inherited retinal disorder IRD.
- From Japan, UK, China
- Less about the study aims, more about the “deep learning” approach and use of data

“A bibliometric approach to tracking big data research trends”

(Kalantari et al., 2017)

- Aims to determine worldwide research trends in big data area
- Key authors based in Malaysia; Vietnam
- Massive spike in publications around big data from 2014 onwards
- Mostly publications coming from USA, second most common is China
- Keyword trends in articles: key words related to “big data” articles increasing in frequency over time

“Systematic Predictive Analysis of Personalised Life Expectancy Using Smart Devices”

(Kang & Adibi, 2018)

- Authors based in Australia
- Smartphone apps, wearable devices provide health and fitness data
- This data could be used to provide a personal life expectancy, to encourage positive wellbeing and lifestyle changes
- Predictions up to five years could be extended to lifetime predictions if generic health data was also accessible
- Study concludes that using a combination of big data, AI, machine learning, and wearable monitoring devices, it is feasible to predict a personalised life expectancy
- The study notes that health insurance companies are a potential stakeholder in developing this technology, e.g. could provide incentives for improving customers’ health outcomes

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- Consent for companies to use this data is noted as an issue, however little else is discussed in terms of potential challenges

“Developing a synthetic national population to investigate the impact of different cardiovascular disease risk management strategies: A derivation and validation study”

(Knight, Wells, Marshall, Exeter, & Jackson, 2017)

- Lead authors based in Australia and New Zealand
- Aimed to create a synthetic population representing joint cardiovascular disease (CVD) risk distributions of NZ adult population (based on 2013 census data)
- The synthetic population demonstrated realistic multi-variable CVD risk characteristics
- The first step in developing simulation models to predict the impact of CVD risk management strategies

“Sharing public health data and information across borders: lessons from Southeast Asia”

(Liverani, Teng, Le, & Coker, 2018)

- Lead authors from the UK and Thailand
- Researchers aimed to investigate factors that may affect the transfer, exchange and use of public health data and expertise across borders, especially in developing contexts
- Interviews stakeholders in Cambodia and Vietnam
- Categories included:
 - The nature of shared data and information
 - The nature of communication channels
 - How information flow may be affected by the local, regional, and global system of rules and arrangements.
- Challenges included:
 - Differing standards and practices
 - Language barriers
 - Different national structures of governance
 - Imbalances in capacity/power
 - Sustainability of financial arrangements

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- Best practices require significant involvement of third party brokering organisation/office
 - This office would redress imbalances between country partners, create communication channels and make the most of shared information and data sets

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“Healthcare Databases in Thailand and Japan: Potential Sources for Health Technology Assessment Research”

(Saokaew, Sugimoto, Kamae, Pratoomsot, & Chaiyakunapruk, 2015)

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- Authors based in Thailand, Japan, Malaysia, Australia, USA
- Health databases were reviewed to assess their potential for Health Technology Assessment (HTA) in Thailand and Japan
- Databases included national censuses, surveys, registries, administrative data, and claimed databases, in addition to data on mortality, morbidity, disability, adverse events, quality of life, and other factors
- Concluded that the existing databases were valuable for HTA research, but more unified systems and dialogue across the Asia-Pacific region is needed

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“Report of the International Stem Cell Banking Initiative Workshop Activity: Current Hurdles and Progress in Seed-Stock Banking of Human Pluripotent Stem Cells”

(Kim et al., 2017)

- Lead author bases in South Korea
- Summarizes two workshops of the International Stem Cell Banking Initiative (ISCBI)
- Priority considerations included ensuring safety and efficacy of cell therapy product and quality assured source materials (stem and primary donor cells)
- Other topics and challenges raised in this report include:
 - Data protection, minimum information guidelines for data
 - Stem cell banking activities around the world
 - Quality control focused on genetic stability testing
 - Stem cell characterisation

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- Regulations and informed consent

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“Human Mind Control of Rat Cyborg’s Continuous Locomotion with Wireless Brain-to-Brain Interface”

(Zhang et al., 2019)

- Recent research from China
- Brain-machine interfaces were combined to create a brain-brain interface between a rat and human
- Results showed that a rat with microelectrode implants could be navigated by a human mind to complete a navigation task in a complex maze

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Articles sourced from other regions

Clinical Ethics

“Wearable Health Devices – Vital Sign Monitoring, Systems and Technologies”

(Dias & Paulo Silva Cunha, 2018)

- Portugal
- Vital signs that are currently acquired by wearable health devices are described, including what the requirements are for devices to collect this data
- Commercial devices for cardiovascular monitoring are focussed on, including a t-shirt that collects medical information

“How 5G wireless (and Concomitant Technologies) Will Revolutionize Healthcare?”

(Latif, Qadir, Farooq, & Imran, 2017)

- Joint research between Pakistan and the UK
- Makes the case for the introduction of 5G connectivity facilitating reliable technological growth in the healthcare system
- Notes Internet of Things, big data, artificial intelligence and machine learning as technologies that will rely heavily on 5G connectivity to operate in a reliable way

“The effectiveness of e- & mHealth interventions to promote physical activity and healthy diets in developing countries: A systematic review

(Müller, Alley, Schoeppe, & Vandelanotte, 2016)

- Text messages and the internet were most commonly used to administer interventions
- Overall these interventions were found to be effective in promoting healthy diet and physical activity

“CRISPR-Cas encoding of a digital movie into the genomes of a population of living bacteria”

(Shipman, Nivala, Macklis, & Church, 2017)

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- Introduces the concept of using the CRISPR-Cas method of gene editing
- Also introduces the concept of using DNA as a biological storage device
- Demonstrates the technology to write information into the genome for later extraction and decoding (a video)

“Genomic annotation for clinical genomic diagnostics: strengths and weaknesses”

(Steward et al., 2017)

- Discusses the approaches for the annotation and classification of important elements of the human genome
- Emerging technologies in this area may result in an improved rate of diagnosis

Public Health Ethics

“Responsible Data Governance of Neuroscience Big Data”

(Fothergill, Knight, Stahl, & Ulnicane, 2019)

- Identifies that neuroscience will rely heavily on informatics and large scale data collection as it progresses and innovates
- Data sharing, ongoing informed consent, data protection and privacy are all ethical considerations
- These considerations must also adhere to local cultural norms, in addition to fitting into existing diverse laws

“Making Policies about Emerging Technologies”

(Kaebnick & Gusmano, 2018)

- Cost Benefits Analyses appear to be way forward for policy decisions
- Evidence based Policy analysis is imperative

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- Balancing evidence based and values based policy making, and whether evidence is free of values and biases

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“eRegistries: governance for electronic maternal and child health registries”

(Myhre et al., 2016)

- Investigated ethical and legal issues related to maternal and child health registries in a survey
- Inadequate data safeguards and weak privacy support were common themes
- Overall a paucity of established governance practices for managing maternal and child health data suggests a need for greater attention to this area, and that governing bodies are not keeping up with technological advances

“Framework for Addressing Ethical Dimensions of Emerging and Innovative Biomedical Technologies”

(National Academies of Sciences & Medicine, 2019)

- Outlines the importance of a framework for addressing ethical issues
- Proposed Framework includes these considerations:
 - Promoting societal value
 - Minimise negative societal impact
 - Protect the interests of research participants
 - Advance the interests of patients
 - Maximise scientific rigor and data quality
 - Engage relevant communities

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- Ensure oversight and accountability
- Recognise appropriate governmental and policy roles
- These allow emerging technologies to be systematically evaluated, although competing considerations
- The authors acknowledge that innovation may rapidly overtake ethical thinking in this area, therefore any ethical framework should be considered an evolving entity.

Research Ethics

“A review of Recent Advances in Translational Bioinformatics: Bridges from Biology to Medicine”

(Birney, 2017)

- Genomic data is being translated into health data with broad implications
- Secondary use of patient data has aided this process
- Diversity in the patient data used will make data more accurate and help addresses health inequity; however development of how data is stored and shared is required for this to be done effectively

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“Impact of regulations on innovation in the field of medical devices”

(Guerra-Bretaña & Flórez-Rendón, 2018)

- Paper reviews issues arising from recent developments in biomaterials and medical devices

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- Concludes that regulatory bodies cannot currently keep up with the advancement of health technologies, and must collaborate with stakeholders to overcome problems as they become apparent

“BrainNet: A Multi-Person Brain-to-Brain Interface for Direct Collaboration Between Brains

(Jiang et al., 2019)

- Introduces a non-invasive direct brain-to-brain interface for use between up to three people
- Two senders and one Receiver
 - Senders transmit basic decisions, e.g. how to place a block in a Tetris-like game over the Internet to the Receiver
 - Receiver will integrate the information and the final decision is transmitted to the game.
- Testing was manipulated by artificially injecting noise into a Sender’s signal and observing how this noise was managed by the Receiver
- Future applications include cooperative problem solving from a “social network” of connected brains

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