THERE ISN'T AN APP FOR THIS! REGULATING THE MIGRATION OF HEALTH DATA IN SUB-SAHARAN AFRICA

SUMMER SCHOOL AGENDA

DATES: 4-8th September 2023

VENUE: University of Warwick, Coventry, UK

DAY ONE: Monday 4th September 2023

WORKSHOP ON DIGITAL HEALTH: REGULATORY AND POLICY PERSPECTIVES

TIME	DESCRIPTION	ROOM
9:00-9:15am	**REGISTRATION AND MEET AND GREET OVER COFFEE / TEA**	S2.09
9:15-9:30am	**Opening remarks** (Prof Bitange Ndemo, University of Nairobi, Kenya)	S2.12
9:30-10:15am	**Discussion of broader project context to Workshop on Digital Health and Special Issue** (Prof Sharifah Sekalala, University of Warwick, UK)	S2.12
10:15-11:15am	<u>**EXPLORING REGULATORY PROBLEMS**</u> (Chair: Hadijah Namyalo-Ganafa, University of Warwick, UK) **Legal and Regulatory Preparedness Surrounding Digital Health Applications in Responding to Public Health Threats** (Dr Hui Yun Chan, Centre for Biomedical Ethics, National University of Singapore, Singapore) (20 min) **Opportunities and Challenges of Collecting and Handling Personal Health Data: A Review of Digital Health Innovation in Africa** (Dr Ben Mkalama, University of Nairobi, Kenya) (20 min) **Questions** (20 min)	S2.12

11:15-11:30am	**MORNING COFFEE / TEA BREAK**	S2.09
11:30-12:50pm	<u>**REGIONAL PERSPECTIVES**</u> (Chair: Tatenda Chatikobo, University of Warwick, UK) **Governance of Digital Health Data in India: A Case Study of e-Pharmacies** (Dr Nanditta Batra, National Law School of India University, Bangalore, India) (20 min) **Digital Health and Public Health in Latin America** (Prof Ulf Thoene, Universidad de La Sabana, Bogotá, Colombia, and Prof Roberto García, Universidad de Salamanca, Salamanca, Spain) (20 min) **The EU's Hand in Global Health Inequity in the Age of AI: Digital Ethics Dumping and AI Colonialism in Africa** (Hannah van Kolfschooten and Dr Katrina Perehudoff, Law Centre for Health and Life, University of Amsterdam, The Netherlands) (20 min) **Questions** (20 min)	S2.12
12:50-14:00pm	**LUNCH**	S2.09
14:00-15:20pm	<u>**EXPLORING REGULATORY SOLUTIONS**</u> (Chair: Dr Johannes Machinya, University of Witwatersrand, South Africa) **Defying the Digital Health Tide: Asha Collective's Resistance to Healthcare Digitalization** (Dr Sreerupa, and Sneha Makkad, Institute of Social Studies Trust, New Delhi, India) (20 min) **From Endorsement to Implementation of Human Rights: The Role of Organisations in Transforming the Health Data Governance Landscape** (Belinda Rawson, University of Warwick, UK) (20 min) **Artificial Intelligence, Data Capitalism, and Bioethics in Sub-Sahara Africa** (Golden Lwando Mwinsa, Prof Frances Griffiths and Prof Benjamin Ferguson, University of Warwick, UK) (20 min) **Questions** (20 min)	S2.12
15:20-16:00pm	**Future Planning of the Special Issue** (Chair: Prof Sekalala)	S2.12
17:30-19:30pm	**GROUP DINNER at Benugo Bar & Kitchen**	Warwick Arts Centre

WORKSHOP ABSTRACTS

EXPLORING REGULATORY PROBLEMS

Legal and Regulatory Preparedness Surrounding Digital Health Applications in Responding to Public Health Threats

Dr Hui Yun Chan, Centre for Biomedical Ethics, National University of Singapore, Singapore

Major public health threats such as the Covid-19 pandemic have amplified the use of digital health applications ranging from wearable technologies to mobile health apps. Data collection, a central feature of these applications has enabled public health specialists, regulators and infectious diseases policymakers to make public health decisions and deliver appropriate interventions to populations. These digital health applications are valuable resources for dissemination of public messaging about the status of public health threats, contact tracing purposes, notifications for vaccinations and for users in navigating their health status and daily functioning during public health emergencies. The collected data may also be shared or exchanged with other agencies and pharmaceutical companies for developing vaccines, identifying infection clusters, mapping levels of disease severity amongst populations or establishing comparison with neighbouring countries for infection detections and virus development predictions.

The proliferation of digital health applications, while beneficial to regulators and policymakers comes with its own sets of concerns. These concerns range from undue risks of surveillance and privacy issues to equitable access to the benefits of digital health apps and the extent of legal preparedness in enabling data sharing for pandemic management. Meanwhile, regulatory frameworks surrounding digital health applications often trail innovations in digital health. This paper is motivated by the question: how prepared are laws and regulations relating to digital health applications in responding to broader public health surveillance for pandemic management while balancing user safety and privacy? It argues for responsive legal preparedness in digital health applications in preparation for future pandemics and public health threats. The paper will explore concerns and tensions arising from the use of digital health apps in public health surveillance and the corresponding regulatory readiness in pandemic management. It will draw from relevant examples from the southeast Asia region such as Singapore to illustrate current regulatory developments governing digital health applications. The paper will then attempt to offer appropriate regulatory strategies to address concerns that emerge. Although the paper is situated within the southeast Asia context, the discussions are relevant to nations seeking to address similar concerns in implementing digital health applications. Mitigating the risks from digital health applications is important towards developing a responsible and sustainable socio-legal environment for data collection, use and sharing in countering public health threats.

Opportunities and Challenges of Collecting and Handling Personal Health Data: A Review of Digital Health Innovation in Africa

Dr Ben Mkalama, University of Nairobi, Kenya

The value of data is often commensurate with how personal the data is. Even though healthcare has been slow in embracing digital disruption and transformation, it is now emerging that healthcare is one area where digital solutions are actively sought in the developing world. Nevertheless, technological tools are imported mainly from the developed world. To complement these technological tools, personal health data must be generated globally. Digital health data collected in such a manner provides measurable and continuous insights that are useful not only in individual patient care, clinical research, and basic science but also in the general public health domain. However, once personal data is

obtained, it takes more effort to privatise and steer its control back to its original owner. Focussing on health digital innovation in Africa, we outline the opportunities and challenges of digitalising health data and review the research around specific digitalisation concepts, including passive health data collection and migration. We seek to identify the opportunities and challenges associated with collecting and handling personal data within health apps. In an exploratory research design that uses qualitative interviews in Kenya, we derive thematic and other theoretical perspectives to generate appropriate insights. Our empirical work indicates concerns around the collection, handling, use and, ultimately, ownership of health data. An emerging view is that rather than try to regulate innovation; it is more apt to design co-regulating frameworks within the innovation space.

<u>REGIONAL PERSPECTIVES</u>

Governance of Digital Health Data in India: A Case Study of e-Pharmacies

Dr Nanditta Batra, National Law School of India University, Bangalore, India

The push for digitalization of health services in India got a shot in the arm with the launch of National Digital Health Mission, now Ayushman Bharat Digital Mission ['ABDM"]. However, the launch of the digital health mission, which contemplates creation of health identification numbers and sharing of health data across stakeholders by the construction of digital highways, was done without first etching the foundational principles of data protection in a dedicated legislation. While a dedicated sectoral law to ensure privacy and security of digital health data was initially conceptualized to accompany ABDM, the bill on draft Digital Information Security in Healthcare Act was abandoned to be subsumed in the proposed general data protection legislation. Consequently, the regulatory system for the governance of digital health data currently consists of a patchwork of norms. The lack of general or sectoral regulation on data privacy and security stymied the government's push for use of digital health technologies during Covid-19 pandemic.

The use of particular digital health technologies has also been challenged for the infringement of privacy before multiple Courts in India. How have the Courts responded to those challenges? Have the courts navigated the complex issues of data collection, retention and processing relying only on the principles enunciated by the Supreme Court of India in the K.S. Puttaswamy v. Union of India (the right to privacy case)? Have the courts also nudged the government to bring in legislation?

Through this paper, I seek to analyze firstly, the foundational principles in practice for governance of digital health data in India. Secondly, I aim to test the adoption of those principles by market players. In this case, I will evaluate the privacy policies of the prominent e-pharmacies in India that bundle various health services with the delivery of medicines like e-diagnosis and teleconsultation. Whether these e-pharmacies share health data with third parties? How long do they retain health data? Do they use health data for targeted advertisements? What is the impact of the data policies of these e-pharmacies on public health? The objective of this study is to assess the compliance trajectory of privacy policies of the e-pharmacies currently operating in India with the foundational principles of data protection and applicable regulations.

Digital Health and Public Health in Latin America

Prof Ulf Thoene, Universidad de La Sabana, Bogotá, Colombia, and Prof Roberto García, Universidad de Salamanca, Salamanca, Spain

Digital health has displayed immense potential in revolutionising healthcare provision and access in low- and middle-income countries, such as Latin America, among the world's least equal regions. While digital health is already a worldwide trend, it is growing in significance in Latin America due to its demographic and socio-economic uniqueness and its distinct healthcare systems. It is essential to highlight pertinent issues of privacy and transparency in the use of patient data and records, as well as the technological and regulatory difficulties Latin American countries encounter in implementing digital health services and technologies.

The proliferation and adoption of digital health technologies across the Global South hold remarkable potential for broadening access to and availability of vital health services. These technologies may also offer customised health data for disadvantaged and vulnerable populations and improve accountability and efficiency in the healthcare system. These opportunities contribute directly towards achieving the United Nations Sustainable Development Goals (SDGs) and the commitment to leave no one behind. If these prospective advantages are realised, they could promise improved health and increased productivity for marginalised sectors of society.

This paper will explore areas of research that promise to elucidate debates on digital health in Latin America involving different stakeholders such as governments, NGOs, and the private sector such as those on regulatory frameworks, AI and Big Data, mobile health (mhealth) apps, health information systems, telemedicine, training health workers, public-private partnerships, and social media and health promotion.

The EU's Hand in Global Health Inequity in the Age of AI: Digital Ethics Dumping and AI Colonialism in Africa

Hannah van Kolfschooten and Dr Katrina Perehudoff, Law Centre for Health and Life, University of Amsterdam, The Netherlands

The use of Artificial Intelligence (AI) in healthcare is said to hold great potential for improving human health worldwide. AI systems are deployed to recognize patterns in enormous datasets, predict a certain outcome, and take action accordingly. The use of medical AI could improve the quality, effectiveness, efficiency, and accessibility of healthcare. There are many promising examples of AI uses in resource-poor healthcare settings, such as mobile apps for rural areas using automated audio analysis on coughing sounds to determine whether the person has tuberculosis, clinical decision support tools for hyper-specialized diagnostics and treatment planning in low-resource hospitals, and AI-powered chatbots providing personalized health advice, for example for maternal health at the same time, because of the lack of a global level playing field for AI development, design, and use, AI may deepen existing global health disparities in three ways.

First, the way AI systems are developed and used may cause a "digital divide" between High-Income Countries (HICs) and Low- and Middle-Income Countries (LMICs). LMICs often face technological barriers to accessing high-quality healthcare. Simultaneously, medical AI systems often contain ethnical, racial, and gender biases, and were not designed for deployment in low-resource settings. Second, stricter regulations on data collection in high-income areas such as the EU make big tech companies turn to "ethics dumping": the exporting of practices that would be ethically unacceptable in

Europe to LMICs, for use in the HICs. Third, big tech companies are increasingly guilty of "data colonialism" – they exploit their powers to extort personal data from individuals, imposing burdens on the local community without sharing the benefits. At the same time, "global" AI ethics instruments do not consider the African context, potentially imposing external values on the African continent.

Data colonialism and ethics dumping are however not new phenomena: there are many examples of medical researchers escaping restrictive regulatory regimes in some parts of the world by exporting otherwise prohibited research practices to LMICs. We argue that the rapid emergence of research and development of "data-hungry" AI – governed by strict EU rules – may give rise to a new reality of "AI ethics dumping". Research already suggests that the adoption of strict rules for data protection in the EU seems to affect the exporting of clinical trials to LMICs. The new regulation for AI products proposed by the European Commission in April 2021 may amplify this effect.

In this paper, we explore the parallels between the experience of outsourcing drug development, specifically clinical trials, to LMICs, and the development of medical AI. The aim of this paper is to outline the lessons this experience offers for the future of AI regulation in the EU. Our core message is that as the EU moves forward with regulating its own AI ecosystem, those regulations will have ripple effects in LMICs. Now is the time to consider the global health implications of the EU's internal market AI regulation.

EXPLORING REGULATORY SOLUTIONS

Defying the Digital Health Tide: Asha Collective's Resistance to Healthcare Digitalization

Dr Sreerupa, and Sneha Makkad, Institute of Social Studies Trust, New Delhi, India

The digitization of India's healthcare landscape has been driven by the government's vision of providing accessible and affordable healthcare through the use of technology. Since 2017, the country has actively pursued the digitization of its health ecosystem, driven by policies like the National Health Policy, which emphasizes leveraging digital platforms and tools for better healthcare outcomes. In 2020, the National Digital Health Mission (NDHM) was launched to establish a secure and comprehensive national digital health ecosystem, with subsequent policies and strategies implemented to execute the digital health architecture. In September 2021, the NDHM was renamed as the Ayushman Bharat Digital Mission, with an overarching vision to establish a national digital health ecosystem ensuring efficient, accessible, inclusive, affordable, timely, and secure healthcare for all (Sharma et al., 2023, NHA, n.d). The mission seeks to facilitate evidence-based decision-making for effective public health interventions and support data-driven decision-making and policy analysis. This approach aligns with the growing trend of leveraging data to inform and optimize healthcare strategies, thereby striving to improve the overall health and well-being of the population.

The increasing prevalence of data-driven governance has led to the digitalization of tasks and workflows for one of the key stakeholders in India's public healthcare system – the Accredited Social Health Activists (ASHAs). ASHAs are frontline health workers who have been drawn into extensive on-the-ground digital data collection and pushed to utilize digital technologies to manage their workflow. This paper aims to explore how ASHAs and their collective, represented by the trade union, perceive and respond to this growing digitalization of their work. The research is based on multi-method qualitative fieldwork conducted in Haryana, India, including in-depth interviews with ASHAs, trade union leaders, and key informants in the public healthcare system. Observation and focus group discussions with ASHAs were also conducted, along with a desk analysis of relevant literature and policies.

The narratives presented by the ASHAs and trade union leaders provide a compelling critique of the top-down approach to digitalization in healthcare, as well as the regulations and policies surrounding digital health. The paper delves into the motivations behind the collective's decision to address the

issue of digitalization of ASHAs' work, the strategies employed to tackle the challenges, and the successes they have achieved. The digitalization of healthcare brought about significant challenges for ASHAs, including increased workload, the burden of managing both digital and paper-based tasks and the exploitation of unpaid labour. Additionally, disparities in technology access and digital skills among ASHAs, and violations of their right to privacy were key concerns that demanded collective action. Of particular contention was the integration of the MDM 360 shield app, which was seen as a form of worker surveillance. Through well-organized protests and advocacy efforts, the ASHA collective successfully resisted the mandatory installation of the app, asserting their right to digital privacy and voicing apprehensions about potential surveillance. The paper emphasizes how the collective's resistance not only put an end to intrusive surveillance practices but also demonstrated the resilience and resourcefulness of ASHAs in challenging harmful digital data practices.

From Endorsement to Implementation of Human Rights: The Role of Organisations in Transforming the Health Data Governance Landscape

Belinda Rawson, University of Warwick, UK

The rapid scale-up of digital health products and services in recent years requires a transformation of health data governance frameworks to safeguard against data exploitation and misuse. The Health Data Governance Principles (HDG Principles) developed by over 130 civil society organisations under the stewardship of Transform Health are the first set of equity and human rights-based principles that specifically relate to the collection of health data and could be normatively significant. The HDG Principles recognise the additional inherent risks associated with health data collection in particular, and aim to be a tool for stakeholders to advocate for greater health data protection while encouraging fairer and more transparent health data collection practices to protect citizens and communities around the world.

Through the articulation of eight key principles, each containing a number of 'core elements', the HDG Principles define best practice relating to collection, access, use, ownership, sharing and storage of health data to thwart the abuse of unprotected health data. It is hoped that they can prevent individuals, groups and communities from experiencing various kinds of data-driven harm, while supporting innovation and the use of digital health technologies for the public good. This paper draws on empirical data collected from over 100 stakeholder organisations globally who have endorsed the HDG Principles (and thus, made an explicit commitment to implement them), as well as understandings of how rights are vernacularised to explore some ways in which stakeholder organisations act as rights intermediaries to embed the right to health data protection in law and policy using the HDG Principles. This paper pre-empts a more thorough analysis of the potential of the HDG Principles to underpin a global framework for human rights and equity-based health data governance.

Artificial Intelligence, Data Capitalism, and Bioethics in Sub-Sahara Africa

Golden Lwando Mwinsa, Prof Frances Griffiths and Prof Benjamin Ferguson,
University of Warwick, UK

Artificial Intelligence (AI) has taken the health sector by storm globally. AI is being used to diagnose and predict the incidence of complex diseases such as cancers, Alzheimer's, and sight disorders, and it is also being used to improve treatment of various chronic conditions such as HIV. However, for this technology to operate efficiently and effectively, it requires huge volumes of data (commonly referred to as 'big data'). Consequently, this has inspired the digitisation of patient's health records which in turn generate 'digital data' for processing using AI algorithms.

Digital Health Data (DHD), aggregated from patient's personal data, has therefore become an asset which is mined both for the advancement of healthcare and for commercial purposes by various entities including governments, bilateral, multilateral, non-governmental organisations, private/business, academic, and many more. In Sub Sahara Africa, data mining in health is a growing field of practice which is generating various ethical concerns because of the vulnerabilities inherent in the Bantu communities and societies where this data is extracted. While personal data is now a highly valued and protected commodity globally, it is not given the same value in traditional Bantu communities of Sub Sahara Africa, and little attention is often given to the collection, collation, usage, ownership, and control of this crucial asset.

In this paper we explore the bioethical implications of the use of imported AI in healthcare in Sub Sahara Africa. We specifically discuss how individual data privacy, and the public health good are positioned in traditional communities of Sub Sahara Africa, and we do this by drawing upon two different ethical systems of western ethics and Ubuntu. Ubuntu is a communitarian ethical system practiced by the Bantu speaking people across Sub-Sahara Africa. Its core belief is that; a person is a person through other persons; implying individual identity is granted by the community, and therefore the community claims ownership of that individual.

We juxtapose the rights-based western, and the Ubuntu Sub Sahara African approaches to explore how personal data is shared in western countries and in Bantu community settings. We specifically explore the Ubuntu conception of individual privacy and data sharing, and the ethical challenges that AI and data mining present concerning these two bioethical principles. We also demonstrate that data privacy is conceived and practiced differently in these two ethical systems, and the public health good is positioned differently in relation to data privacy. We argue that in the Ubuntu communities, people tend to value the public health good more than data privacy, and the decision about sharing of personal data is generally a community decision led by a community leader who is expected to consider the good of the community first. Whereas in the western informed constitutional governance, many decisions about data sharing are individual decisions and although an individual may consider the potential for public good by sharing their personal data, this is not an obvious expectation as it is for the traditional community leader under Ubuntu.

Furthermore, we also consider data governance in Sub Sahara Africa and its implications on individual privacy and data sharing, and we demonstrate how the combination of the coloniality of data mining and the vulnerabilities inherent in the Ubuntu ethics and the data governance system, can easily lead to data capitalism and the exploitation of data subjects in Sub Sahara Africa. We argue that while imported AI in healthcare has brought about numerous benefits, the inherent commercial motive in its development and application especially in regions like Sub Sahara Africa raises crucial ethical concerns which must be delt with by robust data protection laws.

DAY TWO: Tuesday 5th September 2023

TIME	DESCRIPTION	ROOM
9:00-9:05am	**Day introduction** (Prof Sharifah Sekalala)	S2.12
9:05-9:45am	**Keynote: Regulation and Policy in Africa** (Prof Bitange Ndemo, University of Nairobi, Kenya)	S2.12
9:45-10:30am	**Perspectives: Exploring different regulatory sites** **Law, regulation, and health** (Prof Sekalala, University of Warwick) (15 min) **Regulatory Sites in the South African Health System: The Scope, Practices, and Challenges** (Dr Johannes Machinya, University of Witwatersrand, South Africa) (15 Min) **Policy and regulatory work on digital health within the Ugandan Ministry of Health** (Mr Solomon Muhumuza, Ministry of Health Uganda) (15 min)	S2.12
10:30-10:45am	**MORNING COFFEE / TEA BREAK**	S2.09
10:45-12:30pm	**Innovative Regulatory Sandboxes in the African Context** (Dr Ben Mkalama, University of Nairobi, and Lyla Latif, University of Warwick)	S2.12
12:30-13:30pm	**LUNCH**	S2.09
13:00-15:30pm	**Workshop: Law and policy aspects for consumers in their use of health apps in select African countries** (Dr Joy Malala, University of Warwick)	S2.12
15:30-15:45pm	**AFTERNOON TEA / COFFEE BREAK**	S2.09
15:45-16:30pm	**Towards harmonized ethical-legal regulation of health data migration in Sub-Saharan Africa** (Prof Pamela Andanda, University of Witwatersrand)	S2.12
17:00-18:00	**Follow on conversation with Sharifah and Pamela** (OI Designers only)	S2.12

DAY THREE: Wednesday 6th September 2023

TIME	DESCRIPTION		ROOM		
9:00-9:05am	**Day introduction** (Prof Sharifah Sekalala)		S2.12		
STREAMS:	**OI DESIGN TEAM**		**ECRS, ACTIVISTS & OTHERS**		
TIME	**DESCRIPTION**	**ROOM**	**DESCRIPTION**		**ROOM**
9:05-10:30am	**Design philosophies, principles and best practices** (Dr Ian Saunders, University of Warwick)	S0.04	**Panel Discussion: Activism in the Digital Health and Human Rights Space** (Ibrahim Nsereko, CEHURD and Afya na Haki, Edrine Wanyama, and Ashnah Kalemera, CIPESA - Chair: Prof Sekalala)		S2.12
10:30-10:45am	**MORNING COFFEE / TEA BREAK**		S2.09		
10:45-11:45am	**Development of a Minimum Viable Product** (Dr Ian Saunders)	S0.04	**Structuring an Article - Interactive writing session** (Isabel Andrews)		S2.12
11:45-12:30pm	**Implementation using preferred language** (Independent work on designs)				
12:30-13:30pm	**LUNCH**		S2.09		
13:30-15:00pm	**Implementation using preferred language (Cont'd)** (Independent work on designs)	S0.04	**Abstract Writing - Interactive writing session** (Isabel Andrews)		S2.12
15:00-15:15pm	**AFTERNOON TEA / COFFEE BREAK**		S2.09		
15:15-16:45pm	**Implementation using preferred language (Cont'd)** (Independent work on designs)	S0.04	**Workshop: Writing Skills and Practice** (Isabel Andrews)		S2.12

DAY FOUR: Thursday 7th September 2023

TIME	DESCRIPTION	ROOM
9:00-9:05am	**Day introduction** (Prof Sharifah Sekalala)	S2.12

STREAMS:	OI DESIGN TEAM		ECRS, ACTIVISTS & OTHERS	
TIME	**DESCRIPTION**	**ROOM**	**DESCRIPTION**	**ROOM**
9:05-11:15am	**Introduction to core computer science concepts** (Dr Ian Saunders)	S0.04	**Using socio-legal methods to synthesise theoretical and empirical findings** (Prof Pamela Andanda, and Dr Johannes Machinya, University of Witwatersrand)	S2.12
11:15-11:30am	**MORNING COFFEE / TEA BREAK**			S2.09
11:30-11:50am	**Introduction to core computer science concepts (cont'd)** (Dr Ian Saunders	S0.04	**Field work, authorship and ethics** (Prof Sharifah Sekalala, Tatenda Chatikobo and Yureshya Perera, University of Warwick)	S2.12
11:50-13:00pm	**Intellectual Property Rights for Software Innovations** (Brendan Spillane, University of Warwick)	S0.04		
13:00-14:00pm	**LUNCH**			S2.09
14:00-15:30pm	**Interactive Activism and Media workshop – Mobile filming and techniques for creative storytelling – Part 1** (Samvaran Rai) **Important:** All participants should bring a fully charged phone to the workshop.			S2.12
15:30-15:45pm	**AFTERNOON TEA / COFFEE BREAK**			S2.09
15:45-16:45pm	**Interactive Activism and Media workshop – Mobile filming and techniques for creative storytelling – Part 2** (Samvaran Rai) **Important:** All participants should bring a fully charged phone to the workshop.			S2.12

DAY FIVE: Friday 8th September 2023

TIME	DESCRIPTION	ROOM
9:00-9:10am	**Day introduction and overview** (Prof Sharifah Sekalala)	S2.12
9:10-11:30am	**OI Designers to present prototypes and group discussion of regulatory and policy environment** (Chair: Prof Sekalala)	S2.12
11:30-11:45am	**MORNING COFFEE / TEA BREAK**	S2.09
11:45-13:00pm	**Keynote: A Comparative Overview of the Regulatory frameworks for health data migration in Kenya, Uganda and South Africa** (Prof Pamela Andanda, University of Witwatersrand)	S2.12
13:00-14:00pm	**LUNCH**	S2.09

STREAMS:	OI DESIGN TEAM		ECRS, ACTIVISTS & OTHERS	
TIME	DESCRIPTION	ROOM	DESCRIPTION	ROOM
14:00-16:00pm	**Data Cleaning and Q&A** (Dr Godwin Yeboah, University of Warwick)	S0.04	**Forward thinking Discussion: Work being undertaken by teams in next quarter** (Chair: Prof Sekalala)	S2.12
16:00-16:15pm	**Closing remarks** (Prof Sekalala and Prof Andanda)			S2.12
16:15-18:00pm	**NETWORKING DRINKS AND REFRESHMENTS**			S2.09

DAY SIX: Saturday 9th September 2023

Free Day to Explore and/or Optional Cultural Activity: Walking tour of Kenilworth and Castle (Led by Belinda Rawson, University of Warwick)

DAY SEVEN: Sunday 10th September 2023

Majority of attendees fly home from Birmingham Airport

Keynote: Regulation and Policy in Africa (Prof Bitange Ndemo, University of Nairobi, Kenya)

In this keynote, Prof Bitange Ndemo will draw on his expertise in regulation and policy to discuss the opportunities, challenges and solutions related to implementing AI in healthcare in Africa.

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Law, regulation, and health (Prof Sharifah Sekalala, University of Warwick)

This session, facilitated by Prof Sharifah Sekalala, will map the legal issues around digital health. Moving from law making at the international level, she will sketch how we can link global objectives on digital health strategies to regional and national ones. Additionally, the presentation will also pose broader questions around the role of legal expertise in a highly technical field, regulating amidst multiple stakeholders, temporality in a field that moves very quickly, cross border regulation and lastly the impact of regulating after the development of technology and the forms of regulation we should aspire to.

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Regulatory Sites in the South African Health System: The Scope, Practices, and Challenges (Dr Johannes Machinya, University of Witwatersrand, South Africa)

The South African healthcare system has different sites of control that stand guard to promote ethical standards within the health system and ensure the safety, quality, and effectiveness of medical products, services, and research endeavours. These oversight structures oversee various aspects of the health system such as the development, production, and distribution of biomedical products like pharmaceuticals and medical devices, clinical trials and research ethics, and also the usage of other healthcare services. In this paper, I delve into the oversight structures for medical products, medical devices, and other healthcare services in South Africa's healthcare system. In particular, I examine the regulatory processes pertaining to these oversight structures, looking at the regulatory scope, practices, challenges, and lessons that can be drawn in relation to Work package 3 that focuses on the regulation of health applications.

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Policy and regulatory work on digital health within the Ugandan Ministry of Health
(Mr Solomon Muhumuza, Ministry of Health Uganda)

In this session, Solomon Muhumuza will share his expertise on the regulatory work on digital health within the Ministry of Health in Uganda, offering unique public sector insights.

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Workshop: Law and policy aspects for consumers in their use of health apps in select African countries (Dr Joy Malala, University of Warwick)

Digitalisation in the spheres of finance and health have reconfigured everyday life in Africa in profound, complex and highly unequal ways. In this workshop, we will explore rights issues that emerge beyond data privacy and transparent data use. Among them, enforcement of fair

advertising and pricing practices, preventing deceptive claims, ensuring affordability, and creating mechanisms for user feedback, dispute resolution and remedies. We will consider how collaborative efforts among regulatory bodies, technology developers, and health professionals are crucial in striking a balance between innovation and consumer rights, ultimately fostering a safer and more trustworthy digital health landscape across regions.

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Innovative Regulatory Sandboxes in the African Context (Dr Ben Mkalama, University of Nairobi, and Lyla Latif, University of Warwick)

This session will include a discussion led by Ben on innovative regulation through sandboxing, covering a brief history of sandboxes, an introduction of what we are trying to achieve with the sandbox we have, and then how the project work is designed to meet these objectives. Lyla will then lead a discussion on how innovation in the financial sector (fintech) has played out within the African context.

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Towards harmonized ethical-legal regulation of health data migration in Sub-Saharan Africa (Prof Pamela Andanda, University of Witwatersrand)

In this session, Prof Pamela Andanda will highlight how some of the regulatory themes discussed will inform our work as we attempt to find common ground in proposing a more harmonised Pan African guidelines for health data regulation.

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Design philosophies, principles and best practices and Development of a Minimum Viable Product (Dr Ian Saunders, University of Warwick)

Dr Ian Saunders leads on modules in the Department of Computer Science at the University of Warwick. In his work, he draws on his experiences as a software developer, entrepreneur and computer scientist, and aims to provide an authentic learning experience through practical team-based activities.

In this session for the design team, Dr Ian Saunders will cover some design philosophies and best practices. He will also introduce the development of a Minimum Viable Product so that the designers can continue their implementation in their own time using their preferred language.

Session prerequisites are:

1. Create a Figma account

2. Complete the "Figma basics" activity from their Figma library to understand Frames, Constraints, Components, Styles.

3. Watch the "prototyping" and "advanced prototyping" sections of this video https://youtu.be/DlfNp1wScwk?t=1498

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Introduction to core computer science concepts (Dr Ian Saunders, University of Warwick)

This session, also facilitated by Dr Ian Saunders, will provide a high-level introduction to core computer science concepts such as programming languages, machine learning, databases etc.

Session prerequisites are:

1. Laptop running Python and Jupyter Notebook (or, alternatively, this can be done from the browser)

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Panel Discussion: Activism in the Digital Health and Human Rights Space (Ibrahim Nsereko, CEHURD and Afya na Haki, Edrine Wanyama, and Ashnah Kalemera, CIPESA)

In this session we hear from three civil society activists about their experiences with human rights activism in the digital health space at the national and regional levels in Africa.

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Interactive writing sessions (Isabel Andrews)

These sessions will be run by Isabel Andrews, a writing and editing professional with twenty years of experience working freelance for various organisations and universities.

Part 1 - Structuring an article: This session is focussed on improving academic article structure (key components, style, voice etc.)

Part 2 - Abstract writing: This session focuses on writing an abstract for an article. Ideally, participants should come with an article in mind.

Part 3 - Workshop: Writing Skills and Practice: This is a focused practical writing session where participants will be able to work on their abstract/article.

Using socio-legal methods to synthesise theoretical and empirical findings (Prof Pamela Andanda, and Dr Johannes Machinya, University of Witwatersrand)

This session contextualises the methodology for our project, taking into account our multidisciplinary project group. It draws on the methodological experiences of Prof Pamela Andanda, and Dr Johannes Machinya including relevant insights from sociology, anthropology, science and technology studies, as well as law and ethics.

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Intellectual Property Rights for Software Innovations (Brendan Spillane, University of Warwick)

This session will provide an introduction to the design team on intellectual property rights considerations for software innovations. It will be led by Brendan who is a software expert at the University of Warwick.

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Field work, authorship and ethics (Prof Sharifah Sekalala, Tatenda Chatikobo and Yureshya Perera, University of Warwick)

In this important session, we will hear from Tatenda Chatikobo, and Yureshya Perera on topics such as fieldwork, authorship, academic integrity and ethics. Prof Sharifah Sekalala and Tatenda will then facilitate a discussion so that we can collectively shape fair and equitable policies pertaining to joint research on the project.

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Interactive Activism and Media workshop – Mobile filming and techniques for creative storytelling (Samvaran Rai)

Part 1: This part includes an introduction of noteworthy films shot on a mobile phone to outline some important visual aesthetics. It will also cover introductory ways of capturing visuals and other components like lighting, framing and composition.

Part 2: This part introduces camera movement techniques while filming and briefly outline different ways to capture a scene for visual storytelling. It will also include a discussion of the basics of editing, the use of montage in social media platforms, and the use of sound and music as a tool to shape narratives.

This session is facilitated by Samvaran Rai, who is a filmmaker and an audiovisual artist and whose practice lies in composition and dramaturgy.

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Keynote: A Comparative Overview of the Regulatory frameworks for health data migration in Kenya, Uganda and South Africa (Prof Pamela Andanda, University of Witwatersrand)

In this keynote, Prof Pamela Andanda will present an advanced version of her paper on the comparative overview of the regulatory frameworks for health data migration in the three case study countries – Kenya, Uganda, and South Africa.

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OI Designers to present prototypes and group discussion of regulatory and policy environment (Chair: Prof Sekalala)

This session is for the designers to present to the project group the most recent version of their digital health app prototypes based on the work carried out during the summer school. There will be a wider group discussion of the regulatory and policy environments for the innovations.

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Data Cleaning and Q&A (Dr Godwin Yeboah, University of Warwick)

This session on data cleaning is run by Dr Godwin Yeboah, a Senior Research Software Engineer and part of the Research Computing team within the department of Research and Technology Platforms in the University of Warwick. His background includes work in research software engineering and the application of geospatial technologies in research or teaching, computer science, geoinformatics and photogrammetry, geodetic/geomatic engineering, and industrial experiences in software/geomatic engineering.