FROM ETHICAL PRINCIPLES TO BINDING LEGAL OBLIGATIONS: THE IMPLICATIONS OF THE DATA PROTECTION AND PRIVACY ACT, 2019 FOR RESEARCH INTEGRITY IN UGANDA

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Coverage

- Background to the Data Protection and Privacy Act, 2019 (DPPA)
- The importance of privacy and confidentiality to research integrity
- The existing legal and policy regime before the DPPA
- The changes introduced by the DPPA
- The implications of the DPPA for research integrity
- How UNCST and other regulators can take advantage of the DPPA
- Conclusion

Background

- According to the Long title of The Data Protection and Privacy Act, 2019, it is '[a]n Act to protect the privacy of the individual and of personal data by regulating the collection and processing of personal information …'

- It is came into force on 3rd May 2019

- It is not primarily a research oriented law, but rather a data privacy law. It applies to all persons, who collect, process, hold or use personal data relating to Ugandan citizens

- Personal data is defined as any information about a person from which the person can be identified

The importance of privacy and confidentiality to research integrity

- Protection of privacy and confidentiality of study participants' personal data is an integral aspect of research ethics -Articles 9 and 24 of the Helsinki Declaration

- Privacy refers to a bundle of rights that the research participant has 'to keep his or her matters and relationships secret.'- Section 4 of The Access to Information Act, 2015

- Confidentiality on the other hand is the protection of an individual's privacy by persons to whom personal information is disclosed in a relationship of trust

- Protection of the privacy of study participants is based on the beneficence principle – and the non maleficence principle – do no harm and maximise benefits

Protection of privacy as a legal duty

- Privacy is a fundamental human right. It is provided for in Article 12 of the Universal Declaration of Human Rights (UDHR), and Article 17 of the International Covenant on Civil and Political Rights (ICCPR).

- In Uganda, it is protected under Article 27 of the Constitution

- The existence of privacy as a human right imposes an obligation on state and non-state actors to ensure confidentiality of personal data of research participants.

- Failure to do this is a violation of the right to privacy and it attracts sanctions.

The existing legal and policy regime before the DPPA

- Article 27 of the Constitution protects the right to privacy while Article 41 protects the right to access to information except private information

- State researchers are more bound to protect confidentiality through laws such as the UBOS Act, and the NIRA Act

- Private researchers have been less regulated with the only binding obligations imposed by the the National Drug Policy and Authority (Conduct of Clinical Trials) Regulations, 2014 regarding clinical trials

- The UNCST's National Guidelines for Research involving Humans as Research Participants, 2014 are non binding as they are more of policy documents than law

- The Ministry of Health passed the National Health Research Policy Uganda 2012 - 2020 guiding health research under the Uganda National Health Research Organisation (UNHRO)

The changes introduced by the DPPA

- The DPPA clearly defines what personal data is
- It gives legal protection to the principles related to data privacy - including informed consent, lawfulness, minimalist principle, use limitation, data quality, openness, individual participation and security safeguards
- It provides for the rights of research participants which include: The right to access personal information held about that person, the right to stop processing of erroneous personal data and the right to be complain to NITA about inaccurate data
- Generally, the DPPA makes the right to privacy and the duty to ensure confidentiality binding

Criminal offences under the DPPA

- The Act creates three offences: unlawful obtaining or disclosing of personal data; Unlawful destruction, deletion, concealment or alteration of personal data; and selling or offering for sale personal data of any person.

- Committing of these offences attracts upon conviction imprisonment of up to ten years or a fine of up to four million and eight hundred thousand shillings or both punishments.

- If it is an institution that commits the offence, then every officer directly connected to the offence commits the offence as well as the institution. The institution can be fined up to 2% of its annual gross turnover

Enforcement measures under the Act

- Establishment of a designated unit within NITA to enforce the Act
- Requirement to have Data Protection officers at institutions – section 6
- Complaints mechanisms – research participants can complain to NITA in case of violations – sections 31 and 32
- Civil action for compensation – research participants have a direct cause of action to sue researchers – section 33
- Criminal liability – any one can complain

Limitations of the DPPA

- Since the DPPA is more oriented towards data protection and privacy generally rather that within the context of research, it has a number of challenges

- Some of its standards are lower than those already existing – for example the need for consent for data on children under section 8

- It also has so many clawback clauses which water down the rights and duties including informed consent

- It thus has the potential to undermine the efforts of the UNCST, NDA and UNHRO in setting standards in research

What UNCST and other regulators can do regarding the DPPA

- Although the DPPA does not make reference to the UNCST, NDA and the UNHRO, these bodies can still adapt the DPPA for their work as follows:

- Adapt the DPPA to research

- Popularise the DPPA among researchers

- Take on part of the roles of the national data protection office as regards research

- Revise the standards and Guidelines in light of the DPPA

Conclusion: All is not well

- Whereas the DPPA is a great piece of legislation and a great arsenal in the hands of regulators as it imposes binding obligations, researchers have to be wary of it

- The express power of research participants to sue researchers is revolutionary and researchers need to be well insured as the case of *Mukoda alias Naigaga v International Aids Vaccine Initiative & 11 Ors,* (2020) reminds us

- The Act requires a lot of vigilance as regards data protection and imposes a lot of obligations which researchers may not have been used to

- It is time for researchers to wake up and take data privacy and confidentiality more seriously!