
Data Privacy and Access Control in Health and Social Science Research among Vulnerable and Protected Persons: Reflections from Research at a Correctional Facility in South Africa

Johannes John-Langba*¹ and Kwanele Shishane²

¹School of Applied Human Sciences, University of KwaZulu-Natal – South Africa

²University of Bedfordshire – United Kingdom

Abstract

The need to protect the privacy of research participants in public health and social science research studies cannot be over-emphasized, particularly data collected from vulnerable populations and/or with protected sociodemographic characteristics. We investigated the associations between mental health, substance use, appetitive aggression, and recidivism among youth offenders at a correctional facility in South Africa. The research ethics committee of the South African Department of Correctional Services provides guidance on participant vulnerability and the importance of ethics and regulatory compliance including additional safeguards to protect offender and researcher rights and safety. This case study presents reflections on fieldwork and data management in a protected environment including ethical considerations related to data access, protection, and privacy. Our study validates the notion that health and social science research with incarcerated persons poses critical questions and challenges regarding privacy and data protection, especially in the context of open science. Limitations related to the implementation of data privacy and access control with implications for data documentation, discovery and interoperation of data and meta-data are illustrated.

Our study reflects and validates the notion that health and social science research with incarcerated persons poses critical questions and challenges regarding **DDI** controlled vocabularies, privacy and data protection, especially in the context of open science.

*Speaker