Data management instruments to protect the personal information of children and adolescents in sub-Saharan Africa

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Abstract

Recent data protection regulatory frameworks, such as the Protection of Personal Information Act (POPI Act) in South Africa and the General Data Protection Regulation (GDPR) in the European Union, impose governance requirements for research involving high-risk and vulnerable groups such as children and adolescents. Our paper's objective is to unpack what constitutes adequate safeguards to protect the personal information of vulnerable populations such as children and adolescents. We suggest strategies to adhere meaningfully to the principal aims of data protection regulations. Navigating this within established research projects raises questions about how to interpret regulatory frameworks to build on existing mechanisms already used by researchers. Therefore, we will explore a series of best practices in safeguarding the personal information of children, adolescents, and young people (0-24 years old), who represent more than half of sub-Saharan Africa's population. We discuss the actions the research group took to ensure regulations such as GDPR and POPIA effectively build on existing data protection mechanisms for research projects at all stages, focusing on promoting regulatory alignment throughout the data lifecycle. Our goal is to stimulate a broader conversation on improving the protection of sensitive personal information of children, adolescents, and young people in sub-Saharan Africa. We join this discussion as a research group generating evidence influencing social and health policy and programming for young people in sub-Saharan Africa. Our contribution draws on our work adhering to multiple transnational governance frameworks imposed by national legislation, such as data protection regulations, funders, and academic institutions.

Keywords

data management, children and adolescents, sub-Saharan Africa, personal information protection, health research

Introduction

Researchers curating data collected from children, adolescents, and their caregivers, often face a dilemma. On the one hand, they support the view that special protection and different mechanisms should be in place to mitigate risks associated with the research, even if it slows data collection. On the other hand, they are willing to accelerate the pace of scientific research with this population group because of the enormous benefits of science and technology (Caldwell et al., 2004). This dilemma is exemplified in research on infectious diseases which predominantly affect children, such as infantile paralysis, measles, and pneumococci. Without collecting data from children, we could not have achieved the development of vaccines which has led to a dramatic reduction in child mortality and improvements in the quality of life, at the same time they relied on clinical trials that are more challenging than those with adult participants (Joseph, Craig & Caldwell, 2015).

Although this discussion re-gained traction through the contentious debates about the rollout of COVID-19 vaccines for children and adolescents (Ledford, 2021), it is not new strife. Ever since the world experienced the horrors of World War II and the Tuskegee Study in the United States, various declarations and codes were constructed to orient ethical research with human participants, from the Declaration of Helsinki in 1964 to the International Ethical Guidelines for Health-related Research Involving Humans and their continuous revisions (Williams, 2008; Shrestha & Dunn, 2020).

With the increased digitalisation of society and the increased risks of making behaviour amenable to datafication (Mbembe, 2019), especially in quantitative research, researchers must consider the implications for research with human participants. In collecting data, where we inevitably transform responses into numbers, what are the most efficient and simple mechanisms to safeguard participants' rights? In the context of research involving children and adolescents, how do we accommodate their rights to privacy with other rights, such as the public interest, to build a corpus of knowledge that could benefit this same population?

Several data protection regulatory frameworks are being elaborated and implemented in this context, and we have seen a drastic increase in these mechanisms across the African continent (Daigle, 2021). Recent legal frameworks such as the South African Protection of Personal Information Act (POPI Act) (2013) recognise the risks of processing the personal information of minors but also allow exceptions for research-specific purposes[14].

Nevertheless, the scientific community, specifically health researchers, is uncertain about which mechanisms to implement to comply with new regulatory frameworks. It is still unclear how to achieve compliance within their research projects and what concrete changes are needed to research governance structures and processes.

Stimulated by these recent discussions and the necessary adjustments for conducting research with children and adolescents in sub-Saharan Africa, this paper outlines data management instruments and practices iteratively developed, tested and refined in a research consortium jointly located in South Africa and the United Kingdom, with research partnerships in Zambia, Malawi, Nigeria, Lesotho, Tanzania, and Kenya. This paper's objective is to: a) discuss data management instruments aimed at safeguarding the protection of children and adolescents' personal information; b) outline practical mechanisms employed by our team to comply with regulatory frameworks; and c) stimulate a discussion on how to improve the protection of sensitive personal information within research contexts in sub-Saharan Africa. The vision is not limited to, but primarily focuses on, data collected in South Africa. It aims to generate scientifically rigorous evidence to influence policy and programmes to support children and adolescents to reach their full potential.

The instruments and practices outlined here were constructed to safeguard the personal information of children and adolescents in longitudinal social science studies and randomised trials, including a large cohort of adolescents living with HIV (Toska et al., 2016), a cohort of adolescent mothers and their children, and several studies of parenting programs in Low- and Middle-income Countries (LMICs) (Lachman et al., 2016; Cluver et al., 2018).

Structuring teams and building capacity

Sustainable data management starts by designing appropriate team structures that vary according to the research project's goals and resources. In the context of transdisciplinary research across different countries, we found that the minimum staff required is one Information Officer per institution, working in collaboration with research staff and the project's principal investigator. Information Officers will be able to respond to daily tasks, such as curating collections, securely storing data, digitising paper-based documents, managing staff access credentials and flagging potential data transfer risks, especially during data collection periods. Data transfer points generally represent the weakest link in any data security chain. Research staff and the Principal Investigators oversee these tasks and engage teams in capacity-building opportunities to enhance collective comprehension of strategies that safeguard personal information collected from research participants.

In reflecting on our field research practices, we identified an opportunity emerging from new data protection regulations such as POPI Act. They trigger the need for 'capacity-sharing spaces' for researchers and potential research participants. These spaces stimulate researchers to develop better data protection and data management skills through interlinked strategies (*Figure 1*). When possible, for research participants, capacity-sharing spaces about their rights enable them to engage in the making of research and empower them as individuals for future interactions with researchers and research projects that may invite them as participants. It can also be seen as essential to any genuinely informed consent process.

Figure 1. Interlinked research governance strategies and data management instruments to safeguard the personal information of children and adolescents in research projects.

Implementing regulatory frameworks such as GDPR and POPI Act invites research teams to engage researchers to simultaneously build understanding and move towards alignment and compliance across ongoing research projects. This also creates an opportunity to streamline processes and delivers efficiencies. The first step is establishing internal forums with experts promoting capacity-building opportunities, which establishes and maintains agreed working practices and data management instruments. This applies to all levels of research staff but is especially useful for Early Career Researchers and new team members. These sessions should cover various topics, such as special data categories, specific research provisions, and data-sharing platforms. There is also a need to put in place processes that create documents demonstrating data protection compliance for research ethics committees and information regulators. These training sessions have proven to be instrumental in creating an understanding amongst our research team about the implications of new legislation. This, in turn, triggered useful internal audits of existing research governance documents and protocols.

Secondly, these forums help strengthen collaborations and essential staff selection to establish a Data Management Team within the research projects. In building an understanding of how to unpack regulatory frameworks and adapt existing research governance practices, teams are invited to revise their structure and assess potential adaptations to ensure alignment and compliance with new legislation. These forums are also an opportunity for study leads (or Principal Investigators) to complete risk assessments to identify the type and format of personal information collected within each study and classify them into different levels (Adams et al., 2021).

Finally, the data management team may identify the training needs of data operators (i.e., a person who processes personal information for a responsible party in terms of a contract or mandate without coming under the direct authority of that party) and field workers. Forums with experts allow teams to implement data security enhancement processes. For example, in our research context, these forums triggered a change to direct data uploading onto protected servers using end-to-end encryption instead of storing data on password-protected laptops for later transfer, as practised previously. In addition, COVID-19 safety requirements and possible remote data collection were a further incentive for researchers to reflect and adapt, particularly in resource-limited settings. Insights from the forums underlined that there must be a clear understanding of how to a) safely provide participants with a copy of the informed consent forms (ICF); b) maintain and track the process of consent (verbally, text messages, and voice recordings) for each phase of data collection; and c) ensure participants have contact details for the research team, ethics committees and responsible parties. The forums also provided a space for ongoing discussion of how to ensure the confidentiality of sharing ICFs, given the high rates of mobile devices being shared in resource-limited settings (He et al., 2020).

Based on our experience, we would argue that compliance and alignment with data protection regulatory frameworks rely on a sustainable data culture with an adequate team structure that can continuously engage in capacity-building activities. In addition, compliance can only be pursued if the additional administrative tasks engage fieldworkers meaningfully with continuous support in transition moments, such as hiring new staff or conducting data collection, especially with new regulations and national data protection legislation in sub-Saharan Africa.

Enhancing data information in ethical applications

Ethical clearance processes from existing Research Ethics Committees (RECs) increasingly request detailed information from researchers about their handling of personal information in the context of the increased digitalisation of society. In some cases, RECs will make favourable ethical approvals contingent on the opinion of an information regulator, such as an institution's information officer, who may or may not be involved in RECs directly. Acquiring clearance for processing personal information from such recognised authorities should be equally important (in terms of timelines, resourcing, and compliance) as receiving ethical approval from existing RECs. Each must be held in continuous review and monitored simultaneously.

In research that includes sensitive data from children and adolescents living under extreme adversities, many in vulnerable contexts, ethical responsibility in research projects is a foremost concern. Given the emergence of previously mentioned personal information data protection regulations across sub-Saharan Africa, this crucial stage in every research project has a new layer of complexity.

Ethical parameters may be set out in research ethics applications enabling researchers to ensure personal information provided by data subjects is protected following principles of ethical research and protection of personal information. In South Africa, for example, Section 34 of the POPI Act prohibits processing minors' personal information unless provisions of Section 35 are applicable. To

meet these special provisions, ethical approvals from RECs are crucial to confirm whether the research and processing of personal information are appropriate and for the public interest.

Relying on more than thirteen years of fieldwork experience in multiple South African provinces (Cluver et al., 2015) and experience from other studies with vulnerable populations in similar contexts (Bostock, 2002; Hensen et al., 2021), it is possible to outline nine considerations which improve ethical parameters in applications in a digital era:

1. Submission of Ethical Applications to suitable RECs, including a clear data flow with all the proposed steps of the data lifecycle.
2. Negotiation of consent from each individual involved at each stage of data collection.
    a. Consent must be provided by a competent person and, where the data subject is a minor, followed by participant assent;
    b. Consent forms must clearly identify institutions and lead investigators responsible for data management.
3. Adhere to the data subject's confidentiality principles, in line with the ICF.
4. Where possible, de-identify (anonymise) datasets at the earliest opportunity and minimise the risk of re-identification.
5. Limit access to personally identifiable information within the research team on a 'need-to-know' basis.
6. Put in place appropriate retention of personal information records for historical, statistical, and research purposes, with sufficient safeguards against the records being used for purposes not approved by RECs.
7. Stress that Responsible Parties should ensure that personal information is always secure throughout data collection, processing, migration, storage, sharing, archiving, and dissemination.
8. Adopt a mechanism for personal information to be withdrawn at request by the data subject and competent person.
9. Ensure trained interviewers interview data subjects in private locations to maximise confidentiality.

Negotiating disclosure through informed consent

Obtaining informed and voluntary consent from research participants is central to conducting ethical research (Strode & Slack, 2012), and negotiation for disclosure during interviews must be explored during capacity-building activities for researchers. This negotiation implies, in basic terms, transparently informing data subjects about how their data will be handled and the risks of participating in the research before requesting voluntary consent for participation. The complete understanding of participation will be consolidated through voluntary consent, a mutual agreement where researchers engage with data subjects.

In the context of research with minors, consent is also a dialogue process with caregivers regarding their child's rights. This renders informed consent a fundamental instrument for informing data subjects about the risks and benefits of providing personal information. With the rollout of data protection regulations, researchers should also use this process to inform children and their caregivers about their personal information and privacy rights (Strode & Slack, 2013).

In sub-Saharan Africa, where children, adolescents, and caregivers may have low literacy rates (UNESCO, 2013), fieldworkers and researchers must be cognisant of the unbalanced power relations in place, adopting strategies to mitigate them. The use of accessible languages in information sheets and consent forms is crucial, and reading documents aloud to the data subjects in their chosen language should be the standard practice. This critical moment in data collection is an entry point for fieldworkers to give participants ample opportunities to ask questions and decide about participation. It benefits all parties to consider the impact this will have on the management and analysis of research data as part of the project. If a participant withdraws consent or requests for their data to be removed, for example, this is an agreed right.

According to data protection regulatory frameworks such as POPIA and GDPR, researchers should ensure that data subjects are informed about: a) which data protection regulations govern the handling of personal information in the research, b) the nature of data that will be collected, c) how it will be processed, d) where it will be stored, e) what security measures will be in place to protect the data, e) who will have access to personal information, f) how long their data will be retained, and g) how they may request for their data to be updated or removed. Particularly in longitudinal studies, researchers should ensure explicit permission from data subjects is obtained to re-contact them in the future.

In one of our projects, HEY BABY (Helping Empower Youth Brought up in Adversity with their Babies and Young Children), a longitudinal cohort study of adolescent mothers and their children in the Eastern Cape, South Africa, all data collected were entered into a password protected Research Electronic Data Capture (REDCap) forms using tablets with log-in passwords. For each form, participant serial numbers, date of birth, and date of administering the questionnaire were used as unique identifiers to ensure that the participants completed the questionnaire anonymously. The study team was trained in how to use REDCap, including all the security features.

Data Management Plan: building a roadmap for sustainable research

The Data Management Plan (DMP) is a core research governance instrument to safeguard data, particularly participants' personal data. It assists researchers in making and enacting decisions about data curation throughout the data lifecycle (i.e., collection, processing, analysing, preserving, sharing, and archiving). Carefully planning and agreeing on how data will be managed at the outset, and keeping this in review, minimises data quality and security risks. Ensuring data is of good quality and is available appropriately throughout the research process enhances the public benefit of research. In addition, DMPs can be used as instruments for articulating the linkages between other data management instruments that may become opaque during large or long-term research projects. It may contain diagrams explaining, for instance, how the data-sharing agreement is linked to Personal Information Impact Assessments or plans for capacity-sharing activities to improve researchers' knowledge in certain areas.

Like other data management instruments, the DMP should be treated as a living document with continuous improvements throughout the research (Whyte et al., 2022). Significant events in the data lifecycle are opportunities to trigger modifications: a) when substantive changes in data needs arise,

b) at scheduled time points, and c) at key study stages (e.g., new waves of data collection, data migration, alignment to new national personal information regulatory frameworks).

There are four key elements to consider when elaborating a DMP: a) project description, b) data storage, c) data security, and e) data sharing and reuse. Each one of these elements triggers different questions that need to be addressed:

1. Will you produce original (primary) data and/or use existing (secondary) data?
2. Where and how will you acquire your data?
3. What types and data formats will you collect, and how will you describe them?
4. Where will you store your data?
5. How will you organise and name your data files?
6. How large are your data?
7. What are the provisions for the secure storage and transfer of sensitive data?
8. Is the data safely stored in repositories for long-term preservation?
9. How and where will you share your data during and after the study?
10. What are your plans for long-term data-sharing and preservation?
11. Who will be able to access the data, under what conditions and for how long?

DMPs' requirements will vary from one institution to another. Research institutions and funders may require DMPs to be a comprehensive piece that brings together relevant information from all instruments used to protect data subjects' personal information. There are challenges in tailoring a DMP for different contexts to this extent. Having it as a research governance roadmap may enhance its acceptability across various settings (e.g., institutional regulatory bodies for research, ethics committees, and legal departments) and thereby give it even further perceived value.

All anonymised electronic data within the HEY BABY study were stored on a secure server housed at the University of Cape Town, South Africa, which is located in a secure room with restricted access on a "need-to-access" basis. Paper-based data, on the other hand, were stored in secure offices at the Centre for Social Science Research at the University of Cape Town.

Assessing personal information risks

Personal Information Impact Assessments (PIIA) and Data Protection Impact Assessments (DPIA) are crucial for alignment with regulatory frameworks such as POPIA and GDPR when processing special category data, such as data from minors with high-risk levels. These assessments support the researcher in considering the necessity and proportionality of processing personal information, including a risk assessment detailing the potential risks to data subjects. Maintaining and updating a personal information data workflow, which depicts the flow of all personal information throughout the lifecycle of a project, can be a valuable and practical process for understanding where significant risks to the rights of data subjects may occur.

These instruments support researchers in evaluating the level of risk involved in data processing. In research involving children and adolescents and vulnerable populations containing highly-sensitive data such as HIV status or other health information that could lead to stigma, such as hereditary conditions, and behaviour deemed deviant and non-normative, all personal data collected is classified

as high-risk. In practice, we have therefore found that the PIIA and DPIA should address specific questions:

1. Is there a risk of individual identification of data subjects that may lead to loss of privacy and unconsented identification?
2. Could personal data being processed lead to stigmatisation, discrimination, bias, trauma, and legal prosecution?
3. Is the personal information being processed in a different place than data collection? If that is the case, are the regulatory frameworks equivalent in the third country/place?
4. Does the data contain unique identifiers, geographic information, or activity identifiers that may threaten data subjects' confidentiality?
5. What are the mechanisms in place for data de-identification?

The fieldwork team within the HEY BABY study is facing increasing pressure to respond to the rising psychosocial referral needs of the study cohort. However, as a research project, we do not provide psychosocial services directly. Still, we refer study participants to access services, including the South African Depression and Anxiety Group, Lifeline, etc. The team worked with a local NGO named Masithete, which provides psychosocial support in the study community, to revise their existing referral protocol. For example, for an emergency referral such as suicide, the team will refer the participant directly to the HEY BABY Masithethe line, where a counsellor will initiate the first counselling session with the participant. For a non-emergency referral such as emotional abuse, the team will refer the participant to Masithethe or Lifeline social workers.

Sharing data and collaborating

Collaboration & Data Sharing Agreements (CDSA) between collaborating research partners across different institutions clarify terms of (co-)ownership and (joint) responsibility for research data. Their success is built on mutual respect, cooperation, trust, and communication. It facilitates transparency and fairness in the treatment of data, ensuring compliance with legal and ethical obligations and that parties take appropriate technical and organisational measures to protect the security and confidentiality of data. In the context of unbalanced power relations between institutions and funders in the global South and North, particularly looking at the sub-Saharan African context, the CDSA is a powerful instrument to stimulate change in decolonising scientific endeavours in light of discussions of restitution of archives to their place of origin (Sarr & Savoy, 2018).

This agreement also clarifies roles and responsibilities for processing personal information. In South Africa, for example, POPIA stipulates that South African research institutions may only transfer personal information if the third party is subject to a "law, binding corporate rules or binding agreement" (Section 71 (1)(a)), which provide an adequate level of protection for the handling of the personal information.

In the context of research projects with children and adolescents in sub-Saharan Africa, this form of agreement gives a basis for how data can be shared between the collaborating institutions and which legislations govern this. This is something beneficial given the transnational nature of our research. It demonstrates that research data may be transferred to a third party governed by other regulations as

long as they provide an appropriate level of protection for the personal information of data subjects and comply with the respective laws that govern their research.

It is essential to highlight a few crucial elements of this instrument. First, it is a contractual document among all relevant parties. Therefore, institutional representatives need to be involved. Secondly, it is vital that the agreement clarifies the names of entities and differentiates between research collaboration and individual studies. For example, the contract may include a Memorandum of Understanding (MoU) template that individual studies may use to enter a partnership with NGOs for research. Additional addendums about processes unique to individuals' studies may be included and governed by the agreement. Finally, a Data Use Undertaking (DUU) template may be included to ensure that both parties use consistent terms for sharing data with external data users.

Data lifecycle awareness

Data protection regulations highlight the importance of implementing security measures to protect personal information throughout the data lifecycle (*Figure 2*). Their interpretation and implementation through a series of innovations in research practice greatly impacted our work. This must be adequately resourced and budgeted, and additional support may be required from services within research institutions and technical experts.

Figure 2. Data workflow from collection to open access repository[15].
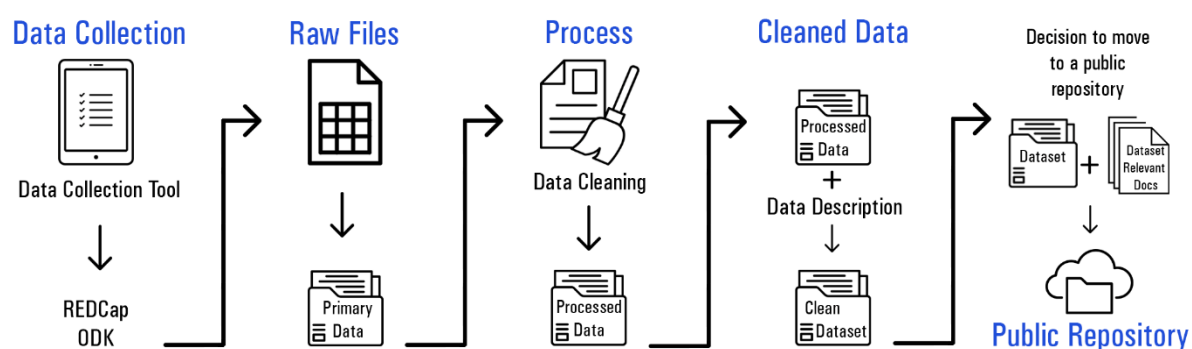
During restrictions imposed by the COVID-19 pandemic, these innovations in practice continued, and researchers have transitioned from face-to-face to remote data collection, enhancing the digitalisation of data collection processes. This demands proportionate changes in security measures, such as using reliable open-sourced data collection platforms such as REDCap and Open Data Kit (ODK). Both have sufficient technical capabilities and functionalities for data collection processes with end-to-end encryption technologies.

Research institutions may have preferred software and hardware options and processes for evaluating the level of security of third-party services, devices, and tools, reducing the demand for research teams to resource this expertise internally. Both security and information protection compliance should be assessed before use. Low-tech techniques (e.g., concealing sensitive information by using unique identifiers or pseudonyms) may also be used to ensure the security of personal data. Electronic

data captured should be submitted to servers daily and encrypted between the data collection device and the data servers. Finally, specific protocols may be developed to support compliant data collection, processing, and storage governance, defining procedures and parameters for: a) data retention, b) de-identifying data, and c) managing access credentials to enable responsible parties to establish common and compliant standards. This data management work needs to be well-resourced, as it incorporates additional layers of research governance required by data protection regulations beyond sub-Saharan Africa.

Conclusion

In this paper, we explored a series of best practices for safeguarding the personal information of children, adolescents, and young people (0-24 years old) (Sawyer et al., 2018). This key age group represented nearly half of South Africa's population in 2021, and adolescents are the fastest-growing global populational group in the world (UNICEF, 2019). The focus was to stimulate a broader conversation on how to improve the protection of children's and adolescents' sensitive personal information in sub-Saharan Africa and inform considerations that need to be addressed by Research Codes of Conduct currently under development (Adams et al., 2021). The aim was to discuss possible actions to ensure that new regulatory frameworks effectively build on existing data protection mechanisms for research projects at all research cycle stages.

As a research group generating evidence that influences social and health policy and programming for young people in sub-Saharan Africa, our contribution draws on our work adhering to multiple transnational governance frameworks imposed by national legislation, such as data protection regulations, funders and academic institutions. This has involved the use of the data management instruments outlined. Continuous reformulation and adaptations of these strategies are needed, such as including recurrent training in the curricula of our institutions to achieve the constant process of building a sustainable and ethical data culture in our research projects.

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[14] POPIA's Section 35 alongside regulations on prior consent of a competent person for data collection, with specific provisions in Section 11.

[15] Data sharing may also occur, for non-profit use, before data is moved to public repositories, in the case of other researchers approaching our team requesting to access datasets.