ETHICAL CONSIDERATIONS FOR DATA COLLECTION AND MANAGEMENT: Research in South African Deaf Communities

Report of the project, Advancing SASL for 4IR Technological Development using Place Names
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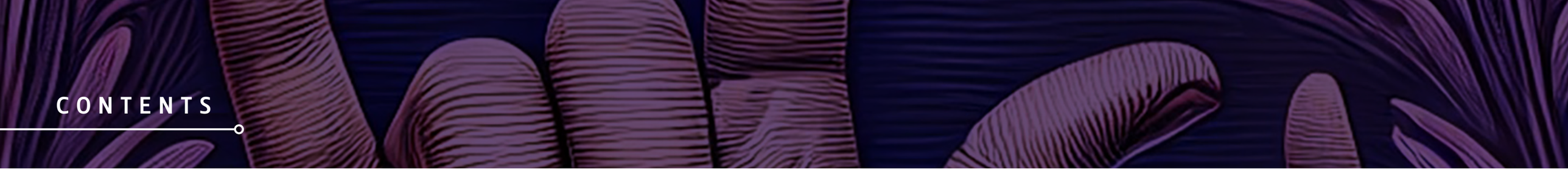

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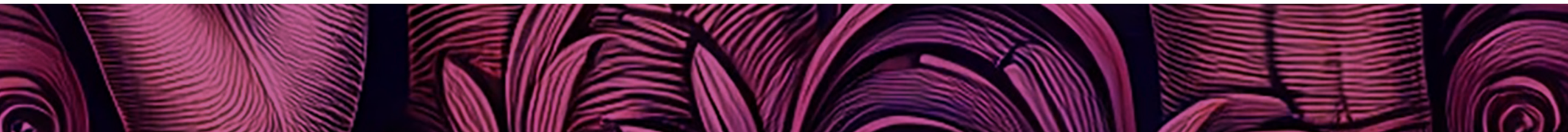

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FOREWORD

The general purpose of legal ethical frameworks in research is to protect the rights of participants. In South Africa there are several legal frameworks that are used to guide research with human participants, but there are no such frameworks that are used specifically with deaf participants. It appears that there are no specific legal frameworks for conducting research in Deaf communities hence the need for a specialised guide. The National Health Research Ethics Council (NHREC) (2011) posits that there are limited research-specific laws to support national ethical standards in South Africa. This has compelled researchers to seek guidance from non-research law.

This report aligns the provisions of these legal frameworks with ethical considerations for research in Deaf communities. The guide will be used as the basis for designing future protocols for studying Deaf communities in South Africa. Research in Deaf communities is fascinating owing to the unique but rich and dynamic knowledge and heritage these communities possess. However, it is not that easy for hearing researchers to access these communities especially if they have limited or no experience with Deaf communities. The same goes if the researchers have insufficient knowledge of Deaf culture and Sign Language and are unaware of the relevant ethical considerations.

Our ultimate goal is to develop such a framework. Since our major interest relates to research in Deaf communities, we want to come up with an ethical framework that will ensure that researchers respect the culture and language of Deaf communities and abide by ethical standards for best research practices. Safeguarding the security and integrity of data from Deaf communities is a unique practice in need of constant conscious reflection and improvement. The aim of this guide is therefore to equip researchers and other interested stakeholders with foundational knowledge and skills for accessing Deaf communities.

DR PATRICK SIBANDA

1. BACKGROUND

1.1. Introduction

Deaf people all over the world have their own language and culture, yet they are a dynamic population. They use signed languages, which are not universal. They also belong to a Deaf culture that is unique and rich with complex aspects. So, when conducting research in Deaf communities, researchers should consider ethical guidelines that are consistent with Deaf cultural and linguistic practices. Guidelines for research in Deaf communities are not necessarily different from those for researching other human communities (whether dominant, minority or vulnerable) but should be adapted to the needs, norms and values as well as traditions of Deaf communities. Some scholars regard Deaf communities as vulnerable and fragile. However, Deaf communities themselves want to be recognised as cultural and linguistic minorities not as a disability or a vulnerable group. Instead, they may be exposed to vulnerability and fragility by the hearing researchers who ignore ethical considerations that respect their rights and dignity as a cultural and linguistic community. Research ethics were originally introduced following historical abuses and violations of especially minority communities which were assumed to be vulnerable, such as Deaf communities. When conducting research with Deaf communities, high ethical standards that are tailor-made to the specific needs of the communities are required. This section defines ethics and explores basic concepts relating to Deaf culture, views about deafness and some important information about the nature of Deaf communities and about research in Deaf communities. The general aim of the unit is to lay a foundation for understanding and applying ethical guidelines for research in Deaf communities.

1.2. What is Research Ethics?

The term 'ethics' is defined variously but, in this manual, we define it in the context of research in Deaf communities. In its basic form, the term entails the principle of separating what is right from what is wrong. In our context it encompasses the 'dos' and 'don'ts' of research in Deaf communities. ***Now let us consider the following definitions of research ethics by various scholars:***

- Research ethics are a set of principles and guidelines that shape and guide the way any research involving sentient beings (i.e., people and animals) is designed, conducted, managed, used and disseminated (Oxfam International 2020).
- Research ethics refer to the specific principles, rules, guidelines, and norms of research related to behaviour that a research community has decided are proper, fair and appropriate (Davies & Lachlan 2017).
- Research ethics are the application of moral rules and professional codes of conduct to the collection, analysis, reporting, and publication of information about research subjects, in particular active acceptance of subjects' right to privacy, confidentiality, and informed consent"(Arafat 2024).

With regards to research in Deaf communities, research ethics therefore entail those principles and guidelines that respect the human dignity, language and culture of the deaf people during collection, presentation, analysis and dissemination of data. The major

purpose of research ethics here is to **protect the rights and human dignity of research participants who are deaf.** This includes respect for Sign Language and Deaf culture.

1.3. Research, Deaf Culture, and Sign Language

Culture is a way of life of a people. Central to each culture is language. Thus, each community of a people has its own culture and language which researchers are expected to be cognisant of and to respect. Deaf communities have their own Deaf cultures and Sign Languages. Sign Language is a complete language with its own grammar and lexicon, yet it is not universal. For instance, South African Deaf communities use South African Sign Language (SASL) which has several dialectical variations. This information is important to researchers of Deaf communities in South Africa as they are expected to use SASL when conducting research in Deaf communities. Researchers are also expected to respect the traditions of the Deaf communities. Where researchers are not fluent in SASL, they should engage Sign Language interpreters and/or collaborate with deaf researchers and recruit deaf assistants especially those that are popular or wield significant respect in the community. To appreciate the need for using Sign Language and for respecting Deaf culture, researchers must first understand the major worldviews or perspectives about deafness. These are the medical (pathological) and cultural (sociocultural/anthropological) perspectives. In the next section we distinguish between these two perspectives of deafness.

1.4. Medical Versus Cultural Perspectives of Deafness

The medical or pathological view is mainly advanced by hearing communities and presupposes that deaf people are disabled or sick and that they therefore need curing or 'fixing' as it were. The medical perspective presents a deficit model of deafness (Golos, et al. 2021) and presents a picture suggesting that deaf people need speech to communicate more effectively. The medical perspective is seeming the more dominant perspective and has informed most previous research and educational practice. However, most deaf people themselves subscribe to the cultural or sociocultural view which posits that deafness is not a disability but a form of human difference or cultural identity. This cultural perspective resonates well with the tenets of Deaf culture which many deaf people subscribe to. We use the small letter 'd' to denote the medical perspective and capital letter 'D' to denote the cultural perspective. However, in this guide, we also use small letter 'd' to frame deaf as a generic term.

Differences between the Medical and Cultural Perspectives of Deafness

MEDICAL/PATHOLOGICAL PERSPECTIVE	CULTURAL/SOCIOCULTURAL PERSPECTIVE
Advanced by the hearing community	Advanced by the Deaf community including professionals who work with Deaf communities
Emphasises the negative aspects of deafness	Emphasises the positive aspects of deafness
Views deafness as a sickness or medical deficit	Views deafness as a natural variation of human experience
Regards deafness as a disability needing 'fixing' using e.g., medication, surgery and amplification (hearing aids, hearing aids etc.)	Regards deafness as a cultural identity unified by use of Sign Language
Focuses on the physical aspect of deafness i.e., hearing impairment	Focuses on the cultural, community and identity aspects of deafness

Researchers who approach Deaf communities from a pathological perspective are likely to be met with hostility. Some hearing researchers lack cultural and linguistic competence to accurately study Deaf communities. More often than not such researchers will fail to elicit authentic, complete and valid data from deaf participants. Additionally, for some researchers the medical perspective dictates that communication should be in spoken language using solely speech or oral methods. In contracts, from a cultural perspective, human communication can take place through signed language.

Even when deafness is not considered a disability, researchers and participants still find themselves inevitably connected to the concept of disability (Park et al. 2015: 6). Regulations, ethical codes, and legally or policy-mandated accommodations are all based on a disability framework. Some deaf individuals do feel comfortable with the disability- or even charity-based view held by the hearing community. This is because in legal and social contexts, government and private sector resources often align with this perspective, helping them access the necessary support. **Therefore, it falls on the researcher to navigate this system, balancing institutional guidelines and available resources with the specific needs and practices of the community being studied.**

1.5. Research in Vulnerable and Fragile Communities

While Deaf communities are in themselves not necessarily vulnerable as we argued in the introduction, the medical views that characterise many hearing researchers and professionals present them as such. The power dynamics that exist between hearing and Deaf people exacerbate the situation. One example of such power dynamics is when hearing researchers harbour feelings of superiority over deaf participants and the deaf participants submit to feelings of inferior due to some visible socioeconomic differences. We notice that most of the guidelines for researching vulnerable communities are applicable to research in Deaf communities. ***The obvious reasons being that the authors of these guidelines are mainly hearing people who believe that deaf people are indeed vulnerable. Some of these overlapping guidelines are:***

- Seek ethical approval with consideration for the specific community from a registered ethics review board.
- Identify the needs, concerns, way of life and expectations of the community prior to undertaking the fieldwork.
- Demonstrate interest in and respect for their culture and language.
- Utilise community leadership, partnerships and/or respected members of the community to gain trust and access. Deaf participants would only engage with researchers for whom they have gained their trust.
- Obtain informed consent (or assent in case of minors). This should be done with utmost care and high standards of professionalism.
- Be wary of power dynamics. Do not act as the master but as someone who is determined to learn from the participants. In addition, do not be sucked into the 'community wars.'
- Guarantee the safety and privacy of the participants.
- Never make promises that will never be fulfilled.

1.6. The Minority Status of Deaf Communities

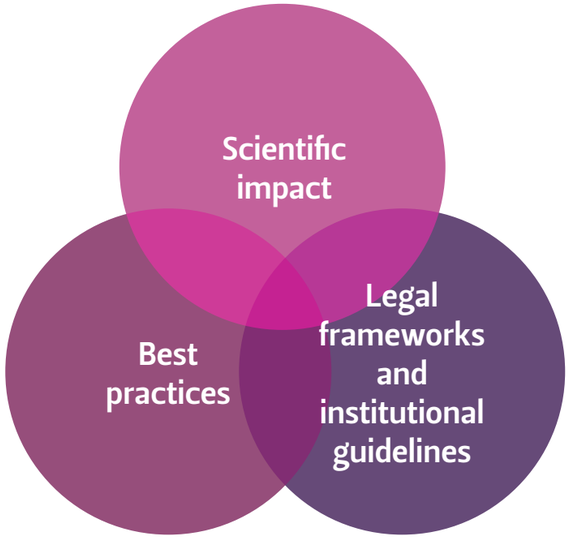
Historically, deaf people were discriminated against and looked down upon. Hearing people acted on their behalf, something which disempowered deaf people. However, deaf people are now progressively expressing and valuing their own self-constructed identity. Like we have expressed elsewhere, deaf people today are identifying themselves as a cultural and linguistic minority with unique needs and expectations. This is opposed to them being viewed as a disabled and vulnerable group. Today's Deaf communities are demanding the rights

that are accorded to other minority groups. Hearing researchers who subscribe to the ideologies that frame deaf participants as vulnerable are likely to be faced with many ethical concerns and dilemmas. Thus, instead of framing Deaf communities as vulnerable communities, researchers would rather recognise them as a minority special interest group with its own cultural, linguistic and legal rights. In avoiding describing deaf people as disabled or vulnerable, Singleton, Jones and Hanumantha (2014) prefer to identify them as a special linguistic demographic.

We argued that while Deaf communities are not necessarily vulnerable, considerations for researching vulnerable communities apply to them. We prefer "inherently vulnerable" rather than just "vulnerable." Deaf individuals often face challenges such as limited literacy, education, and employment opportunities, which contribute to their vulnerability. However, our perspective is that **these issues are a result of the marginalisation by the hearing community, not something inherent to deafness.** On these bases, we opposed the notion of deaf people as a disabled or vulnerable group. In these regards, we urge researchers to take utmost care in their encounters with Deaf communities and to avoid opinions that define deaf people through the medical perspective.

2. ETHICAL PRINCIPLES AND THE REVIEW PROCESS

Ethical research requires careful considerations of and adherence to the current best practices in the discipline, the applicable legal framework, and national guidelines; balanced against the requirement of useful research to have scientific impact.



2.1. General Best Practices

Researchers who are interested in studying Deaf communities should be conscious of their responsibilities that in turn facilitate the process of gaining access to these communities. Executing appropriate researcher responsibilities is also essential for gaining trust of Deaf communities. Gaining the trust of deaf participants is the first step toward gaining trust of and access to Deaf communities. Further, gaining trust of the Deaf community is the foundation for collection of authentic and complete data. Once the researcher loses deaf participants at the point of entry into the community, they may never be able to gain their trust again. Hence, they are bound to fail in conducting credible research. ***These are some of the researcher responsibilities that are crucial for gaining access to Deaf communities:***

- Protect the scientific integrity of the research versus the rights of the participants i.e., balance own research interests against the needs of the deaf participant.
- Demonstrate concern about culture, language and the betterment of Deaf communities.
- Be respectful of Deafhood practices, that is, be compassionate, be Deaf culturally sensitive, show patience and appreciation. One way to do this is to communicate in Sign Language. If researchers are not fluent, they should at least try for basic communication and always ensure professional interpreters are available when needed.
- Observe the cultural and linguistic rights of the deaf participants.
- Maintain conducive conditions for the collection of data that are consistent with the needs of deaf participants e.g., arrange a recording room with adequate lighting and away from visual distractions.
- Arrange for Sign Language interpretation in case the researchers cannot sign.

- Be aware of political as well and power dynamics and differentials that characterise the Deaf community under study. For example, strategically address interference or influence of Deaf organisations or powerful individuals that has the potential to disrupt, or enhance, the research process.
- Avoid the intensification of existing conflicts through, for example, tokenism. Tokenism is the practice of including a small number of deaf participants to make the research appear inclusive at the expense of considering the real needs of deaf participants.
- Involve the Deaf in decision making e.g., ensure they take ownership of the results by conducting member-checking sessions.
- Give back to the Deaf community. Take a stance of responsibility, not advocacy, and share the results of the study.
- Manage the consent process, interview dynamics and special considerations for the use of video data. This includes providing enough information to help deaf participants make an informed decision about whether or not to participate in the study.

2.2. The Legal Framework

In South Africa, researchers are expected to abide by legal frameworks that protect the rights of participants to human dignity and to privacy. Such measures have been put in place to counter historical unethical research practices and abuse of particularly minority groups. Legal ethical frameworks in South Africa are leveraged on the Constitution of the Republic of South Africa (1996) Chapter 2 which covers the Bill of Rights. It appears that there are no specific legal frameworks for research in Deaf communities hence the need for this publication.

Primarily, there should be no unlawful access to personal information or data that has been collected for research or other official purposes. Legal frameworks in South Africa are strict on securing the integrity and confidentiality of personal information. These frameworks tend to be even stricter when relating to 'vulnerable' participants. Several legal frameworks including the Constitution, the Protection of Personal Information Act (POPIA) (2013), and the Ethical Legal Protection for Vulnerable Research Participants in South Africa, are used to regulate access to especially personal data that have been collected for legitimate purposes such as research. Access to data collected for research purposes must be restricted only to legitimate persons who have signed confidentiality agreements.

The Constitution of South Africa Chapter 2

Section 7 of Chapter 2 of the Constitution of the Republic of South Africa (RSA 1996) declares that the State has the responsibility to respect, protect and fulfil the rights contained in the Bill of Rights. This suggests that researchers who violate legal ethical considerations are breaking a supreme law. Section 10 further provides that every person (including deaf persons) has inherent dignity and the right to have their dignity respected and protected. This provision is important in that it reminds researchers to respect every person, including deaf individuals. Similarly, Section 12 (2) prescribes that every person has a right not to be subjected to scientific experimentation (research) without their consent. For minor participants, assent should be sought from their parents or guardians. This provision underscores the need for researchers of Deaf communities to seek the participants' informed consent prior to data collection without fail. In addition, the researchers need to respect the decisions of deaf persons not to participate in the research or to withdraw at any stage without reprimand. More importantly, Section 14 talks about privacy which is also consistent with the need for protecting the identity of the deaf participants. This is also aligned with the need for confidentiality of deaf participants' responses during and after the research process.

Protection of Personal Information Act (2013)

POPIA derives from Chapter 2 Section 14 of the Constitution of the Republic of South Africa (RSA 1996). The Act's sole purpose is to protect the privacy of individuals and organisations in settings such as research. It was enacted to safeguard the integrity and confidentiality of every personal information despite the social standing of an individual. Part of the purpose of POPIA is to promote the protection of personal information processed by public and private bodies. It also aims to introduce conditions for minimum requirements for processing personal information. This includes conditions for seeking consent and protocols for data collection, processing, analysing, storage and information dissemination.

Draft on Ethical Legal Protection for Vulnerable Research Participants in South Africa (2011)

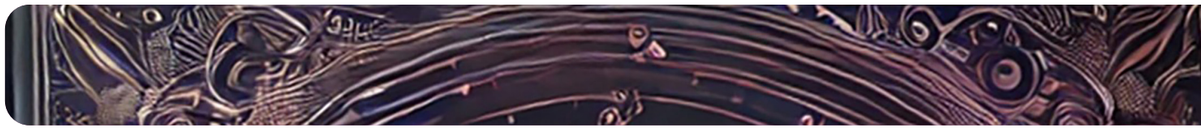
The Draft on Ethical Legal Protection for Vulnerable Research Participants in South Africa (2011) is a comprehensive framework that takes audit of laws and ethical guidelines that are used to regulate research on human beings in South Africa***. The following are some of its highlights that are relevant to studying Deaf communities:***

- Seek voluntary informed consent. The process used should be explained in detail when applying for ethics clearance.
- Justify the research itself, research on minors, proxy consent by parent/guardian etc.
- Explain the inclusion and exclusion criteria to safeguard participants against stigma and discrimination.
- Conduct a risk-benefit assessment, thus conducting research only when it is necessary.
- Maintain privacy, confidentiality and anonymity.
- Ensure protection against exploitation, abuse and degrading treatment.

Other Instruments and Laws Used to Regulate Research in South Africa

In the absence of a framework that specifically regulates research in Deaf communities, here is a list of instruments and laws that are currently used to safeguard vulnerable participants, hence deaf participants:

- National Health Act (2003)
- Mental Health Act (2002)
- Children's Act (2005)
- Electronic Communications and Transactions Act (ECTA) (2002)
- Consumer Protection Act (2008)
- Promotion of Access to Information Act (PAIA) (2000)
- Department of Health (2004, 2006) guidelines
- Medical Research Council (2001, 2003) guidelines
- Health Professions Council of South Africa (HPCSA) (2008) General Ethical Guidelines for Health Researchers
- Human Sciences Research Council (1997)



2.3. National Ethical Guidelines

Every discipline or research paradigm has its own set of ethical principles and guidelines for best practices. However, researchers must apply for ethical clearance at a registered, designated committee, who ensures that the national standards for ethical research are met. This section explores the national guidelines against the backdrop of research conducted amongst the Deaf; whether it is on issues specific to the Deaf or to ensure a more inclusive approach in other research.

In South Africa, the National Health Research Ethics Council (NHREC) is the national governing body for ethical research involving human participants or animals. Under mandate of section 72 of the National Health Act 61 of 2003 (RSA 2003), the NHREC established the national guidelines, ***South African Ethics in Health Research Guidelines: Principles, Processes and Structures*** (NHREC 2024) ***(Guidelines,*** henceforth), that provides the standards for ethical research. Research Ethics Committees (RECs) oversee the implementation of these guidelines by researchers. RECs must register with the NHREC, which in turn acts as the auditing and disciplinary authority over RECs.

Download the ***Guidelines*** on the website of the National Department of Health:
https://www.health.gov.za/nhrec-guidelines/

2.4. Ethical Review Application

Before commencing the study, researchers must obtain ethical clearance from the relevant REC. ***There are some grounds for exemption:***

Research involving observation of people in public spaces (including virtual public spaces), and natural environments usually need not undergo formal ethics review, provided that

- the researcher does not interact directly with individuals or groups
- the researcher does not stage any intervention
- the individuals or groups do not have a reasonable expectation of privacy
- dissemination of research findings does not identify individuals or groups (NHREC 2024: 1-2).

However, student researchers are usually required to submit an application for ethics review regardless, to ensure that the above conditions are met.

The application should provide a detailed explanation of the purpose and research design of the intended study. Applicants have to justify all decisions on matters that might have ethical implications. RECs usually provide templates to ensure all possible issues are addressed. Novice or student researchers may benefit from consulting handbooks or introductory texts on research ethics. This could allow them to develop a deeper understanding of ethical considerations, which will enable them to make informed, thought-through decisions when they have to adapt their protocol. At some institutions, a scientific review to evaluate the scholarly merit of the proposed study might be required. The outcome of this review should accompany the ethical clearance application.

Researchers are advised to contact the relevant REC well ahead of time to i) clarify the administrative procedures, including deadlines, ii) obtain the instructions as to the content of the application as well as supplementary documentation, iii) and find guidance on any aspects of the research protocol that might be posing ethical dilemmas. Researchers should be mindful of the fact that their proposals might not be accepted with first submission. They might be required to provide clarifications, modify certain aspects of their protocol, or even to resubmit a proposal or have it entirely rejected.

Contact your relevant REC well ahead of time. The list of registered RECs can be found at: https://www.health.gov.za/nhrec-registration/ (NHREC 2024).

It is important that developing the research protocol and preparing the ethical review application not simply be seen as a process to "follow the rules". Despite its lack of sufficient nuance (see Knight 2019), the guidelines highlight crucial issues**. It is the responsibility of the researcher to develop an in-depth understanding of the ethical considerations within their own field, and to thoughtfully consider and consult on how these will play out during research.** Especially social and community-based research is dynamic and emerging. The researcher should be adaptable to context, circumstance, and feedback from the community. It is recommended to inquire with the relevant REC if they facilitate phased applications.

2.5. Ethical Review

The review process is guided by the ethical principles provided in the NHREC guidelines. The following overview serves as an introduction of the issues that should be considered carefully when designing a suitable ethical research protocol aligned with national guidelines. For a more in-depth discussion, or for planned research

that involves clinical, health or health-related research; or minors as research subjects, refer to the *Guidelines* (NHREC 2024) as well as the relevant REC. ***In summary, the purpose of the ethical review process is to enforce the application of ethical standards to:***

- Protect participants from harm.
- Hold researchers accountable.
- Promote social and ethical values (NHREC 2024: 4).

2.6. Benefits and Risk of Harm

"The principle of beneficence includes beneficence (do good), non-maleficence (do no harm), autonomy (the freedom to choose freely, where they are able), justice (ensuring fairness)" (NHREC 2024: 8).

Benefits of the study can take the form of direct advantage to the individual participant or the group they represent, a contribution to a future betterment for either, or more generally to humankind. The beneficence of the study should be to **"improve or at least understand what it means to be human, even if only as a medium to long term goal"** (NHREC 2024: 8). Do not exaggerate the potential benefits of the study or of participation.

Harm can take different forms, including emotional, social or financial; not just to the participant but the researcher as well. Risks of harm, as well as the measures to mitigate it, should be discussed fully. Overall, the research protocol should be designed to result in more benefits than harm or the risk thereof. This benefit-risk analysis should be discussed clearly in the informed consent process and forms.

Applying this general standard requires a deep understanding of the Deaf lived experience. If researchers do not have a high level of cultural competence, it is essential to ensure sufficient representation from the Deaf community on the research team to develop a protocol that is respectful and beneficial to the Deaf community.

2.7. Fair Selection of Participants

The underlying consideration here is the principle of distributive justice. This principle dictates that the benefit and burden of participating in research should be fairly divided amongst the suitable candidates. What this means in practice, is that no one should be reasonably deprived of the opportunity to participate in research. If there are barriers to participation, the onus is on the research team to address those. **Therefore, even if the study does not focus on issues pertaining directly to the Deaf, this group should not be automatically disregarded as participants.** As with any other societal group, there is a high level of internal diversification within the Deaf community. Deaf people have qualities and identity markers other than deafness, such as ethnicity, health concerns and gender identity, that qualifies them for participation in research on related issues.

Decisions about inclusion and exclusion criteria should be guided by this principle. If the related group can benefit from a participant's involvement, barring reasonable exceptions, they should be considered for inclusion. Exclusion criteria should be well motivated, beyond simple convenience. Keep in mind the constitutional prohibition against discrimination on the following grounds: race, age, sex, sexual orientation, disability, education, religious belief, pregnancy, marital status, ethnic or social origin, conscience, belief or language (section 8 of the Constitution) (RSA 1996).

2.8. Respect for Persons

The considerations that fall under this principle serve to protect the autonomy and dignity of participants. ***Throughout the study, researchers should:***

- Continue to respect the autonomy of the participants.
- Ensure that they are voluntarily willing to continue participating and understand their right to withdraw.
- Monitor their welfare.
- Inform them of the results when appropriate.
- Rigorously exercise the ethical duty of confidentiality.

Autonomy

Autonomy is the ability to make independent decisions and act accordingly. Put measures in place to protect participants who lack capacity or have diminished capacity to make responsible decisions. Being deaf is not equitable to having diminished capacity. However, it is associated with frames of reference and lived experiences that might differ from that of the researcher, including access to knowledge. It is the responsibility of researchers to ensure that the decision to participate or not is fully informed, and that the participant understands the implications of their decision.

Recruitment and Voluntary Participation

The recruitment strategy should focus on enabling **voluntary** participation. This means that participants should not be deceived, pressured or coerced into involvement. Potential participants should be allowed sufficient time to consider potential implications, consult with relevant parties in their lives, or even with the local Deaf community as a whole. Individuals are still representatives of the Deaf community, and might want to find consensus or support before agreeing to act as such. A layered or phased recruitment process can assist to ensure that candidates are fully informed and feel supported.

Avoid deception

Deception means deliberately misinforming participants so they make decisions based on false or wrong information. Researchers have to be as transparent as possible. Deaf participants are often suspicious of strange hearing researchers and therefore deceiving them will only escalate to participants withholding data that could have been crucial for the study. Transparency is key, and participants should be fully informed about the purpose, procedures and potential risks of the study. This could be done through a no-bounds information session prior to data collection. It is important to address research misconception, whereby participants misunderstand the purpose, procedures or outcomes of the research, or the role of the researcher. The latter is especially pertinent when there is a pre-existing relationship between the researcher and the participant.

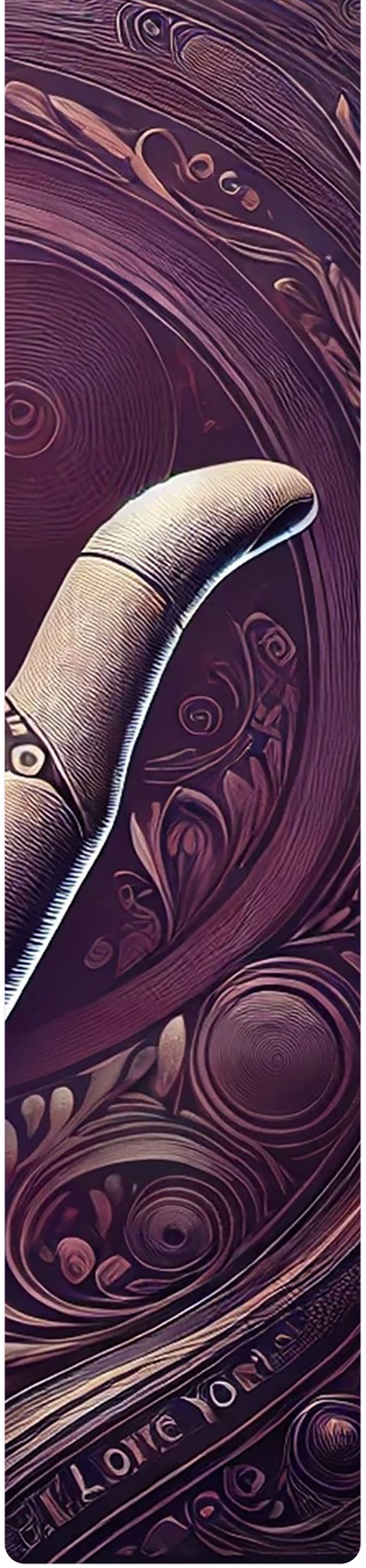
Community access

It is not always easy for Deaf communities to welcome hearing researchers, especially those who are strangers and are incompetent in Sign Language. Singleton et al. (2014) rightfully observe, **'... coming from a history of "being studied" and misinterpreted, it is reasonable that many Deaf people are skeptical of hearing researchers and shun the vulnerable identity.'** One important way to gain the trust of Deaf participants and hence access to Deaf communities is to use gatekeepers from the host community. Thus, to overcome barriers to accessing Deaf communities, researchers need to diligently develop strong relationships with Deaf community organisations and influential Deaf individuals. In rural setups, researchers should also work closely with the local leadership. In essence, researchers of Deaf communities should present themselves as visitors or learners to these communities, with the Deaf community members acting as hosts or gatekeepers (Harris, Holmes & Mertens 2009). Researchers should admit that Deaf communities, not themselves, possess rich repositories of knowledge. From the perspective of Deaf communities, using community members who are deaf as gatekeepers serves to protect deaf citizens from unethical research practices.

Potential gatekeepers that researchers could work with are:

- Associations for the Deaf.
- Deaf clubs.
- Schools for the Deaf.
- Deaf individuals who are well-known and respected in the local community.

In working with organisations for the Deaf such as associations and clubs, researchers should be wary of the political and power dynamics that may interfere with the progress of the research, but also potentially enhance it.



Information sessions

An information session or even a series of them has to be arranged as a preface to the consent process. The key issues to be addressed in the information session(s) should guide the participants towards making voluntary informed decisions as to whether they will participate in the study or not.

There are different ways to disseminate such information. One way is for researchers who are fluent in Sign Language to share the information face-to-face. The other way is to use a competent interpreter while the other one is sharing a pre-recorded introductory video. The introductory video could be distributed prior via social media communication groups. It is advisable to use someone who is competent in the Sign Language of the target community. Preferably, the person should be deaf or a child of deaf adults (CODA). The employment of a local fieldworker can also facilitate the process. If this person understands the relevant information, they can assist in conveying it in a way that is relatable to the specific local community.

The information session should address pertinent issues such as:

- The purpose of the study.
- What the study entails or involves.
- Types of data sought and how they will be collected, used, stored and disseminated.
- Potential harm.
- Potential benefits. This should be done in a non-coercive manner e.g., researchers should avoid overstating the benefits.
- Risk-benefit analysis
- Autonomy to voluntarily withdraw at any stage of the research.
- Assuring anonymity, privacy and confidentiality.
- Procedures and purpose of the consent process.

Reimbursements and inducements

Reimbursements and inducements could influence a candidate's decision, and the Guidelines provides clear instructions on these two considerations.

Participants should not incur costs to partake in the study, and if they do, they should be reimbursed. The rate for this is calculated with the Time, Inconvenience and Expenses (TIE) method, using the current hourly rate for unskilled labour, whether or not the participant is employed. The protocol as well as the informed consent form should include payment schedules and amounts.

If the researcher expect recruitment to be difficult, inducement may be offered in the form of cash, store vouchers, airtime, etc. However, using inducements should be clearly justified and proper recruitment strategies should still be worked out. Additionally, the way in which inducements are offered should not unfairly influence the participant's decision. The Deaf community often struggle with access to services, knowledge, and employment in ways that affect their socio-economic status. Reimbursements and incentives should not be offered in a way that is coercive. Other ways of expressing appreciation can be considered, such as catering meals during sessions or arranging transportation.

PROPOSED RECRUITMENT PROCESS

Preplanning: Research team (inclusive of Deaf researchers) and stakeholders

Approach gatekeepers

Contact local leadership

Identify a local Deaf fieldworker or community go-between

Invitation video to information session

Information session(s)

Time to reflect and consult

Privacy and Confidentiality

The right to privacy is protected in Section 14 of the Constitution (RSA 1996), as well as in the Protection of Personal Information Act 4 of 2013. Privacy is an aspect of autonomy (the ability to exercise self-determination), in that **people have the right to control access to their personal information.** This means that others can only access a person's personal information with the permission of that person, unless its legally required.

Ethical duty of confidentiality

Confidentiality is the measure whereby privacy is protected. **The researcher is responsible for taking all reasonable steps to prevent the disclosure and accidental disclosure of information, whether personal or otherwise, that might result in the identification of the participant.**

Protection of Personal Information Act 4 of 2013 (POPIA)

Also see the section, The Legal Framework

POPIA regulates the protection and processing of personal information. This includes the exceptions made for research purposes: **"The Act seeks to balance the individual's right to privacy against the public interest in benefiting from locally conducted cutting edge research" (NHREC 2024).** To further regulate the application of the exceptions in research, various research bodies have developed or are developing their own codes of conduct, for example the Academy of Science of South Africa and the Human Sciences Research Council. Researchers are advised to also consult the codes of conduct issued by the institutions relevant to their discipline.

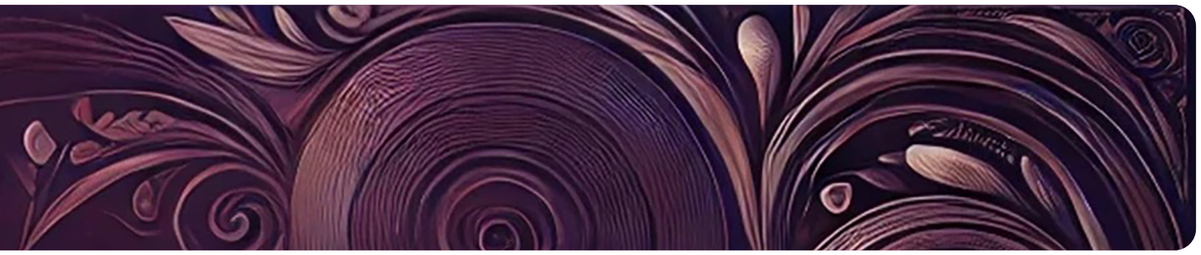
Personal information can take various forms, including biographic information, socio-economic and biomedical backgrounds, and personal views (refer to 'Personal information' in the Glossary).

In addition to consenting to take part in research, participants are also required to consent to have their personal information processed. POPIA (Chapter 1 Section 1) defines consent as:

"consent" means any voluntary, specific and informed expression of will in terms of which permission is given for the processing of personal information.

The research protocol should fully consider all types of personal information, how it will be processed, and how the resulting data will be handled. In short:

> "In general terms, a participant should know what personal information is being collected, why it is being collected, what will happen to it, how long it will be retained, whether it will identify the participant, whether it will be shared with others and why, whether it will be shared with third parties inside South Africa and why, whether it will be sent outside South Africa and why. The participant should agree to these terms" (NHREC 2024).



Anonymity

Even when data have been stripped of personal information, i.e., made anonymous, other information might still allow a third party to at least partially infer the identity of a participant. As with personal information, the collection of identifying information should be restricted.

Maintaining confidentiality and the anonymity of participants is challenging when conducting research with the Deaf. Deaf communities are usually close-knit. This means that members know each other well enough to infer identities from even non-personal information. In cases where researchers do not have sufficient linguistic or technical skills, auxiliary workers like interpreters and camera operators might also be involved. During data processing, translations, linguistic annotations and re-recordings might necessitate contracting in additional people from outside of the immediate research team. **The most challenging aspect to confidentiality is the very nature of signed languages as visual-gestural modes, in which facial expressions play a determinative role.** In some cases, replications (re-recordings and re-enactments with consenting signers) can suffice, for example as demonstrations in conference and other research papers. However, in other types of data-based investigations, such as linguistic research and even machine learning, the raw, original data is required for accurate results.

The research protocol must:

- Provide scientifically-based justifications for collecting and processing personal and identifying information – the participant's consent alone is not enough.
- Stipulate the measures to manage and protect data.
- Include an assessment of how data might be inadvertently disclosed, which is a risk of harm. C
- Explain how data records will be stored, the length of time they will be kept, and who will be responsible for the storage as well as the final disposal.
- Specifically indicate and justify intentions to use raw research data for any purpose other than research, such as for training material (also see the section on AI and Machine Learning Data Ethics). The participant must also consent specifically to this use of their data.

Safeguarding the security and integrity of data

Data collected from Deaf communities are often in form of video recordings.

Some of the strategies for safeguarding the security and integrity of such data include:

- Collect the minimal personal data necessary for the study.
- Personal data should be collected for a well-defined purpose and should be used only for the purpose of the current study.
- Store all data on password protected computers or digital storage spaces, or other secure methods.
- Do not retain data longer than is necessary. Although this is not cast on stone, often the maximum acceptable maximum period is 5 years.
- Destroy data records to prevent the recovery or reconstruction of the data.
- Secure the integrity and confidentiality of the data through making all those with privilege of access to sign confidentiality agreements.

De-Identifying data

De-identification of data entails removal of both direct and indirect identifiers that could potentially be combined and used to trace the identity of the participant from data records. Such identifiers include names and demographic characteristics. The recommended standard practice in research is de-identifying the data to a level where it cannot be re-identified with the participants. ***Some strategies for de-identifying data are as follows:***

- **DATA AGGREGATION:** Combine all data categories and summarise them using a unified format devoid of obvious identifiers.
- **CODING:** Assign labels to categories of data in place of original identifiers.
- **PSEUDONYMISATION:** Replace names or other descriptors with imaginary other names or values that prevent identification.
- **HASHING:** Transform data into an unreadable format which is impossible to reverse and attach a private key to access the original meaning using a computer programme.
- **REDACTION:** Remove sensitive data from the core research findings to protect the privacy of informants or participants.
- **BLUR FACES** on video data.
- **RE-RECORDING:** Reproduce video data using another competent person who has consented to their identity being made public to protect the identity of the participants.
- **USE SYNTHETIC DATA:** Generate synthetic data using a computer to mimic the original data.
- **DATA AUGMENTATION:** Create modified copies of existing data using a computer.

Informed Consent

"The principle of respect (which includes autonomy) underpins the ethical requirement that a person should choose voluntarily whether to participate in research, based on information that allows an informed choice to be made" (NHREC 2024).

The consent process is one of the most crucial legal ethical procedures in research, particularly when dealing with special interest groups such as Deaf communities. It is during this process that researchers should uphold their most important responsibilities and accountabilities to the research ethical practices. While many researchers believe that gaining access to and conducting research in Deaf communities is difficult, our experience is different. We submit that, given the right attitude, respect and recognition, deaf people are readily willing to participate in research that is relevant to their needs.

Researchers are required to obtain formal consent from all participants before the study begins. However, **the onus is on the researcher to continuously monitor that the participant is aware of the implications of their choices throughout, especially considering the occurrence of emerging methodologies and contexts prevalent in social research.** Participants should be fully informed of all aspects of the research process during recruitment as well as during the research study. The right to withdraw at any time necessitates sufficient information to keep on making the choice to participate. Therefore, consent is not a once-off event before participation, but rather a continuous process.

"A characteristic of social science research is that informed consent is in most cases not a once-off event or action, but rather a trust-based process and relationship between the researcher and the research participants, groups and communities that extends over time; consent must be negotiated and renegotiated as the research continues and develops" (NHREC 2024).

Obtaining consent

Obtaining consent is the final step in the recruitment process. The researcher or recruiting agent should engage with the potential participant and provide all necessary information before they decide. This includes providing the information in a way that is accessible to the participant.

The ***Guidelines*** make provision for additional considerations for consent from vulnerable communities and those with limited capacity. In light of the historical treatment of Deaf communities, it is worth highlighting this point: Even though these ***Guidelines*** approaches deafness from a biomedical, disability paradigm, they make it clear that deafness does not equate incapacity:

> "When recruiting participants, the crucial elements are whether the person retains the capacity to decide whether to participate and whether they can communicate that decision. The first point to note, therefore, is the difference between the capacity to decide and the ability to communicate the decision. The capacity to decide necessarily includes the capacity to understand the information that is communicated to them. The ability to communicate includes the ability to hear and to speak or otherwise signal or express their wishes. For example, deafness should never be mistaken for incapacity to decide. Similarly, the inability to speak should not be mistaken for a lack of capacity to decide whether to participate" (NHREC 2024).

While we do not see the Deaf as a vulnerable community per se, some of the aspects of their lived experience correlate with how vulnerability is defined in the ***Guidelines.*** This includes potentially limited access to services, education, and social support. If factors such of these are present in the participant group, researchers have to take additional measures to protect their rights and welfare interests.

Even if a potential participant is capable of making independent choices (i.e., competent and over the age of 18), they might still wish to consult with others or need time to think it over. Regardless, participants should not be pressured to make immediate decisions. There should be time for consultation between recruitment and the decision.

The ***Guidelines*** contains a detailed exposition of factors to consider during the recruitment process. Researchers are advised to consult this document to ensure they follow the guidelines specific to the context of their study (see Factors to ***Consider during Recruitment and To Obtain Informed Consent). In summary, all steps should be taken to ensure that:***

- The potential participant can make the choice freely and fully informed.
- All the necessary information is provided in an accessible manner.
- Contact details of the REC and researcher are supplied.
- The purpose of the research is explained.
- The role of both the researcher as well as the participant is clear.
- The research protocol is set out clearly.
- The measures to protect personal information and maintain the confidentiality of data is shared.

When the study entails an emerging research design and it is not possible to provide all the details in the beginning of the project, the ongoing nature of informed consent is especially important. In the case of group research, confidentiality depends on the group members not disclosing any information outside of the research setting. Therefore, participants should be duly warned against disclosing any personally sensitive information.

There are ***dos*** and ***don't*** to ensure a legitimate consent process

THE **DOS** OF THE CONSENT PROCESS

- **Explain every step of the process in detail.**
- **Create a Deaf-friendly space. Ensure the language of the event is Sign Language. Use Sign Language if you are competent otherwise engage a Sign Language interpreter or even train a local fieldworker or representative.**
- **Use visual aids for clarification.**
- **Show respect for Deaf culture and Sign Language.**
- **Be honest.**
- **Avoid deception.**
- **Avoid tokenism.**
- **Be patient – answer all questions and address all concerns.**
- **Assure anonymity, privacy and confidentiality.**
- **Provide clear information on the purpose of the research.**
- **Discuss the risk-benefit ratio i.e. potential risks and benefits.**
- **Explain the right to discontinue participation at any point of the research.**
- **Give the participants time to reflect and make decisions e.g. overnight.**
- **Provide a consent form with comprehensive information written in simple and straightforward language.**
- **Provide a full Sign Language translation of the consent form, and discuss any aspects.**
- **Give a copy of the signed consent form to participants as well.**

THE **DON'TS** OF THE CONSENT PROCESS

- **Do not be coercive.**
- **Do not withhold information that would have led the participant to a different decision.**
- **Do not make false promises.**
- **Do not act master.**
- **Do not overstate the potential benefits.**

2.9. Stakeholder Engagement

Stakeholders can be co-researchers and non-academics like community representatives and governmental departments. Engagement with stakeholders early and throughout the research fosters transparency.

Their input can:

- Shape the research protocol to be useful, relevant and safe to the Deaf community.
- Lead to the employment of effective and collaborative methodologies.
- Build deeper trust and understanding on both sides.

This contributes to scientific imperative of building knowledge of what it means to be human, and for scholarly efforts to be directed appropriately. An important consideration is the inclusion of Deaf researchers as key role-players of the research team.

Collaborating with Deaf researchers

It is desirable to collaborate with deaf researchers in studies involving Deaf communities. However, deaf researchers have complained in previous studies that they are often treated as tokens causing untold frustration. They say that they are often relegated to low status positions in the research teams. Even in the case of collaborative research between hearing and Deaf researchers, deaf scientists are often relegated to lower status positions (McGuire 2020, Boness 2016). A competing concern is that the number of deaf researchers or deaf scholars is low. This scenario is attributable to the historical disparities in education which persist today. The net result of this has been a general lack of Deaf–centric perspectives in scientific research involving Deaf communities. All the same, deaf researchers themselves are implored to guard against potential bias as deaf researchers are bound to impose their personal experiences or biases that are devoid of scientific evidence. This is not a surprising trend, as it is often characteristic of researchers from other minority communities.

Advantages of Collaboration with Deaf Researchers:

- Enables multicultural perspectives to research in Deaf communities.
- Eases communication with Deaf communities.
- Facilitates trust between the research team and the Deaf community.
- Enriches the research team's potential to access the Deaf community, collect more credible data and derive valid conclusions.
- Enables mentorship of deaf researchers who could in turn train more other deaf peers.

Engaging Deaf Research Assistants

Closely related to collaboration with deaf researchers is engagement of deaf research assistants. These should be recruited from the host Deaf communities and trained for example in interviewing skills. The advantages of engaging deaf research assistants are like those of collaborating with deaf researchers. In addition, engaging and training deaf research assistants is a way of skills development and giving back to the Deaf community.

2.10. Scientific Integrity

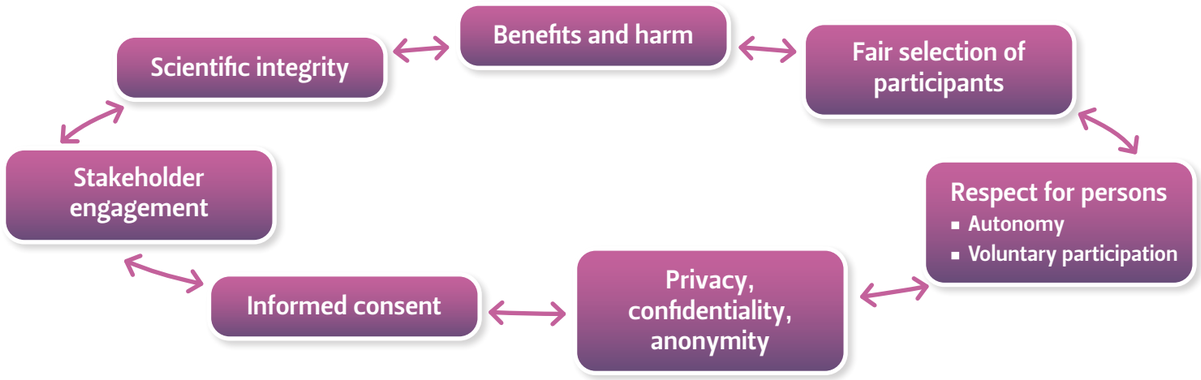
Ethical research should also maintain scientific integrity. ***The overall contribution of any research study should have relevance and value in the following categories:***

- Relevance and responsiveness to the needs of the South African people.
- Contribute to knowledge generation.
- Preferably have translatability into products, interventions, processes or services that address the needs of the South African people.
- Enhance the discipline's body of knowledge.
- Result in reliable and valid data and outcomes that address the research objectives.
- Carry no unnecessary risk and produce sufficient benefit in the form of useful knowledge gained.

The research design should meet the following specifications:

- Align with relevant discipline-specific standards.
- Be feasible for the circumstances with due consideration of available resources.
- The scientific question should have an appropriate level of importance and novelty.
- The aims and objectives should be achievable and likely result in valid outcomes.
- Include a thorough and appropriate evaluation of relevant literature.
- The theoretical paradigm and methodology must be suitable in light of stated aims and objectives.
- The ethical implications of the selected design, methodology and research plan must be analysed.
- The research procedures should be described clearly so the rationale and details are clear.
- The team should include suitably qualified researchers. This includes having researchers that are fluent in the relevant Sign Language, and a high level of cultural competence.
- Have an appropriate research data management plan.
- Include a plan to disseminate results. This includes providing feedback to the Deaf community in accessible formats, such as summaries of the research outputs in Sign Language.
- Address potential or existing conflicts of interest.

In summary, the figure below illustrates the ethical principles researchers should take into consideration when designing their research protocols. These issues should be clearly addressed in the application for ethical review. Even more so, having clarity on these issues will guide researchers when the research context changes, and they have to adapt. See the next section for decision-making frameworks.



3. ETHICAL DECISION-MAKING FRAMEWORKS

Ethical decision-making can be complex and could present challenges for many researchers, yet it is central to upholding high research standards. In effect, many ethical decisions are uncomfortable to contemplate especially when they involve sensitive issues. The purpose of this section is generally to provide guidelines for making good ethical decisions in research involving Deaf communities. This is done by referring to existing ethical decision-making frameworks whose main goal is to facilitate appropriate ethical decision making which would culminate in better ethical practice of research in Deaf communities. The overview is premised on the understanding that, bad ethical decision-making impacts negatively on the feasibility and credibility of research particularly of minority communities. In so doing, this unit covers the ethical decision-making process, principles and models of ethical power, and strategies for handling ethical dilemmas in research involving deaf participants. A preliminary ethical decision-making framework aligned to research of Deaf communities is proposed in the unit.

3.1. Definition of Ethical Decision-Making Framework

An ethical decision-making framework is a structured process for evaluating and choosing a course of action in a situation with moral implications (Farayola 2024). Thus, an ethical decision-making framework is the logical process of evaluating and choosing among alternative decisions to come up with that which is consistent with ethical principles. It helps to perceive and eliminate unethical options and select the best ethical alternative. Ethical decision-making frameworks in research emphasise the importance of respecting individual participants' choices. Such frameworks also emphasise the need for ensuring fairness and equitable treatment of participants. They encourage researchers to actively seek to do good while avoiding harm and maintaining trust through honesty and reliability.

3.2. The Ethical Decision-Making Process

The ethical decision-making process constitutes a series of logical steps that combine to enable making a decision that maximises benefits and minimises harm. ***The standard step-by-step process is sequenced as follows:***

- Obtain unbiased facts about the ethical issue at hand. Do this by locating the specifical aspects of the ethical issue.
- Identify distortions, misses and gaps in the information.
- Study and understand the situational or contextual factors.
- Consider all the parties involved. Assess who could be affected by your decision i.e., who is likely to be harmed and who is likely to benefit.
- Identify the values of the Deaf community under study and note competing values such as attitudes towards use of natural Sign Language versus effects of oral contact.
- Seek additional assistance where required.
- Formulate different decision options.
- Abide by the alternative decision that produces maximal benefits and minimal risks.
- Evaluate the effects of the decision made.

3.3. Weigh Alternative Decision Options

To arrive at the best ethical decision option (as part of the decision-making process) certain fundamental questions should be asked. The purpose of the questions is to ensure that the best possible and most ethical decision is arrived at. ***Regarding ethical decisions made in research involving Deaf communities, the questions could be packaged this way:***

- Which action is likely to provide most good and least harm?
- Which action respects the rights of the Deaf community?
- Which action treats all the involved parties partially or equally?
- Which action serves the needs of the whole Deaf community?
- Which action makes the researcher become the person s/he should be?

3.4. Models/Types/Lenses of Ethical Decision-Making Frameworks in Research of Deaf Communities

A close analysis of these questions show that they form the foundation of models, types or lenses of ethical decision-making frameworks that are adaptable to research of Deaf communities. These models inform what researchers would use to define what entails an ethically correct or ethically valid decision. ***We outline these below:***

- **RIGHTS MODEL:** Respects the rights of the Deaf community.
- **JUSTICE MODEL:** Aims at making decisions that treat everyone equally.
- **UTILITARIAN MODEL:** Concerned about how decisions are likely to impact on the other concerned individuals. This is done by balancing good over harm.
- **COMMON GOOD MODEL:** Focuses on how the decision taken impacts on the common good i.e., how the decision impacts on the whole Deaf community.
- **VIRTUE MODEL:** Biased towards actions consistent with certain virtues of the researcher.
- **CARE ETHICS MODEL:** Rooted in the maintenance of relationships rather than in rigid application of rules. It relies on empathy to arrive at what are believed to be ethical decisions.

3.5. 5Ps of Ethical Decision Framework

The 5Ps of ethical decision frameworks are considered to be key principles for ethical power in decision-making. Ethical power constitutes consistency in upholding ethical principles. ***These 5Ps comprise purpose, pride, patience, persistence and perspective.***

- **PURPOSE:** Entails the conscience of what the researcher wants to achieve by making the intended ethical decision. Researchers of Deaf communities need conscience for the need to collect valid and complete data that would result in credible research. In this context, purpose also entails the researcher's attitude towards the ethics guiding research of Deaf communities and the morality surrounding them.
- **PRIDE:** Ability to stick to what the researcher knows and believes is right despite external forces that have potential to sway the decision. Pride is tied to the researcher's self-esteem. A sense of inferiority, self-doubt or inadequacy is likely to negatively affect ethical decision-making. Similarly, false pride, which is a distorted image of one's importance, for example that their research is the most important or that they have better knowledge than the deaf participants will blur the purpose of ethical decision-making.
- **PATIENCE:** Ability to rigorously reflect on alternatives before making a final decision. It also entails being thoughtful and taking time to arrive at a decision without rushing. It involves exercising self-control to ensure good ethical decision-making. Relative to Deaf communities, patience would also entail taking time to understand the Sign Language variations and the values popularly held by the parties involved.
- **PERSISTENCE:** Persistent researchers are those who maintain their moral commitment to ethical decisions, adherence to ethical principles and accountability to the values and needs of deaf participants.
- **PERSPECTIVE:** Ability to reflect on a decision, to seek guidance for improvement from others and to settle for an alternative decision that is most appropriate to the ethical issue at hand.

According to Obodo and Chukwuma (2021), it is not always possible to accurately predict the exact outcome of an ethical decision based solely on the five principles of ethical power because good intentions are not always enough. The authors write, 'Sometimes well-intentioned decisions backfire because they are bad ideas, or because they are poorly implemented.' The 5Ps can therefore be complimented with what to Watts, Medeiros, McIntosh and Mulhearn (2021) refer to as 3Cs which act as pre-conditions for ethical decision-making.

3.6. The 3Cs of Ethical Decision-Making

In the context of the 3Cs of ethical decision-making, a decision is considered ethical if it satisfies three basic principles of compliance, consensus and consequence. ***These principles would apply when reflecting on alternative ethical decisions to choose the one aligned to the ethical expectations of the Deaf community.***

- **COMPLIANCE:** Entails that an ethical decision must comply with explicit rules i.e. policies, regulatory frameworks and the broad principles of autonomy, justice, beneficence, maleficence and fidelity.
- **CONSENSUS:** Implies that for decisions made in research regarding Deaf communities to be ethically correct, they must abide by the implicit rules that guide the collective consciousness of the Deaf communities. Thus, a decision is ethically correct if the majority of the members of the Deaf community view it as right or ethical.
- **CONSEQUENCE:** Means that a decision is ethically correct if it maximises the benefits and minimises harm to the generality of the members of the Deaf community.

Even ethical decisions based on both 5Ps and 3Cs are not an absolute guarantee for effective implementation and best ethical outcomes. As such, psychological factors of ethical knowledge, ethical skill and upholding an ethical personality should be used collectively with the 5Ps and 3Cs to strengthen the resultant ethical-decision framework.

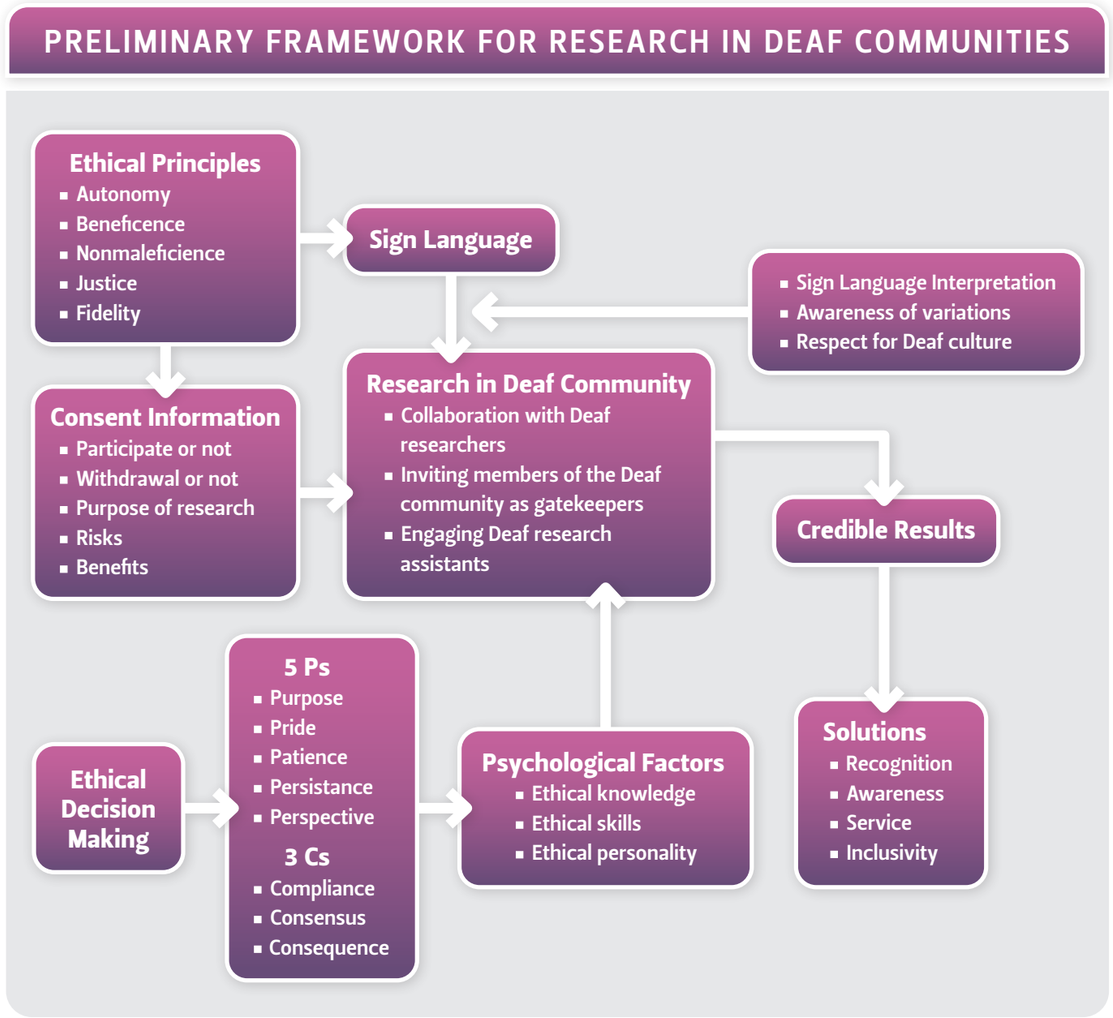
3.7. Psychological Factors in Ethical Decision-Making

- **ETHICAL KNOWLEDGE:** Relates to the researcher's understanding of regulations, policies, guidelines, procedures and norms that are consistent with good ethical decision-making in research involving Deaf communities. Since ethical knowledge equips researchers of Deaf communities with ability to make defensible ethical decisions, it also minimises or prevents violation of ethical standards.
- **ETHICAL SKILLS:** These are capabilities that promote the process of ethical decision-making such as reflecting on personal values and biases, managing one's emotions and analysing consequences of decisions on different members of the Deaf community under study.
- **ETHICAL PERSONALITY:** Personality perse entails stable patterns that work together to characterise the behaviour of an individual and therefore shape ethical decision-making. Conscientiousness for

example is a personality attribute which can enable a researcher to make ethical decisions that comply with the norms of the Deaf community. (Watts et al. 2021). Conscientiousness enables awareness and self-control and therefore coordinates well with ethicality.

3.8. Preliminary Model of a Framework for Decision-Making in Research of Deaf Communities

Ethical decision-making frameworks serve as systematic guidelines for good ethical decision-making. For our purpose they promote appropriate ethical decision-making in research involving deaf participants. This unit puts together aspects of the ethical decision-making process, the models and principles of a generic ethical decision-making framework to develop a preliminary model of an ethical decision-making framework specific to research conducted in Deaf communities.



4. AI AND MACHINE LEARNING DATA ETHICS: CONSIDERATIONS FOR SASL

4.1. Supervised and Unsupervised Learning

Machine learning (ML) techniques are broadly categorised into supervised and unsupervised learning. These approaches are fundamental to the development of artificial intelligence (AI) applications, including those tailored for South African Sign Language (SASL) recognition and translation.

4.1.1. Supervised Learning

Supervised learning relies on labelled datasets, where each data point is associated with a known output. The model learns by mapping input features to the correct labels through an iterative training process. ***This method is commonly used in SASL-related AI applications, such as:***

- **GESTURE RECOGNITION –** Training models to identify specific hand movements and associate them with their corresponding signs.
- **TRANSLATION MODELS –** Mapping visual inputs of sign language gestures to textual or spoken outputs.
- **FACIAL EXPRESSION AND CONTEXTUAL ANALYSIS –** Recognising expressions and context to refine SASL interpretations.

4.1.2. Unsupervised Learning

Unsupervised learning, in contrast, does not rely on labelled data. Instead, it seeks patterns, structures, or relationships in datasets without predefined outputs. ***This approach can be beneficial in:***

- **SIGN CLUSTERING –** Grouping signs with similar visual structures for linguistic analysis.
- **FEATURE EXTRACTION –** Identifying key motion patterns in sign language videos without requiring labelled datasets.
- **ANOMALY DETECTION –** Detecting uncommon variations in sign articulation that may suggest regional or individual signing differences.

Both supervised and unsupervised learning contribute to advancing SASL-related AI applications, but they differ significantly in data requirements and ethical considerations.

4.1.3. Data Requirements for Supervised Learning

The success of supervised learning models hinges on the availability of high-quality, diverse, and representative datasets. SASL, like many other sign languages, is not monolithic. It consists of various dialects influenced by geographical location, historical factors, and community preferences. Different regions within South Africa may use unique signs for the same concept, resulting in potential misunderstandings if an AI model is not trained on a sufficiently broad dataset. To address this, training data should include samples from signers representing different provinces, urban and rural areas, and educational backgrounds. Additionally, factors such as language borrowing from indigenous spoken languages or influences from international sign languages should be considered when curating datasets. Failure to study these variations can lead to inaccurate model outputs and exclude certain communities from effective research and data collection of SASL as a low HLT resource language.

For AI systems to function equitably, they must reflect the diverse demographic spectrum of SASL users. This includes children, young adults, and older signers may use signs differently. Some variations arise due to generational shifts in language use, while others are influenced by learning experiences. Male, female, and non-binary individuals may exhibit subtle differences in signing styles due to cultural and physiological factors, such as hand size or movement fluidity. Signers from different ethnic groups may incorporate culturally specific gestures or stylistic nuances into their signing, which should be represented in datasets. People with disabilities or motor impairments may sign differently, and ensuring the inclusion of such variations promotes accessibility and inclusivity in AI applications. Without broad demographic representation, AI models risk perpetuating biases that lead to poor recognition accuracy for underrepresented groups, reducing the practical usability of SASL-related AI tools.

Sign language is highly dependent on context. The meaning of a sign can shift based on the surrounding conversation, the emotional state of the signer, or even the speed at which a sign is performed. AI models should be trained on datasets that reflect such contextual variations, including fast, conversational signing differs from slow, instructional signing. Training data should incorporate both to ensure robust recognition across different interaction styles. Facial expressions are an integral part of SASL, often modifying the meaning of a sign. For example, the same hand movement might convey a question or a statement depending on accompanying facial cues. AI models must be trained to interpret these expressions accurately. Signs may be influenced by what has been previously communicated in a conversation. AI models should be trained to recognise patterns in discourse and adjust their interpretations accordingly.

4.2. Data Quality

The quality of labelled data directly influences model accuracy and reliability. Ensuring consistency and accuracy in annotations is crucial for the development of reliable SASL HLT models. Variability in annotation practices can introduce inconsistencies, leading to errors in AI predictions. Ethical governance mandates that Annotations should be performed by trained linguists or native SASL signers who understand the nuances of the language. Multiple reviewers should validate annotations to reduce subjective bias and enhance reliability. Standardised annotation protocols should be established, ensuring uniformity in dataset labelling across different projects. Contextual accuracy should be prioritised, recognising that the same sign may have different meanings depending on the conversational setting.

The quality of input data significantly affects the ability of AI models to accurately represent SASL. Low-resolution or poorly recorded videos may hinder sign AI HLT tasks, particularly in intricate hand movements and facial expressions, which are integral to sign language. Ethical guidelines recommend that high-definition (HD) video recordings should be prioritised to capture precise hand shapes, movements, and facial expressions. Consistent camera angles and lighting conditions should be maintained to prevent variations in model training outcomes. Frame rates should be sufficient to capture sign transitions smoothly, ensuring that models can distinguish between sequential movements. Data augmentation techniques should be used cautiously, ensuring that artificially enhanced images do not distort the original signing patterns.

Bias in dataset composition can lead to disproportionate model performance, where certain groups of signers or specific signs are overrepresented. ***To mitigate this issue, AI governance must ensure that:***

- Dataset distribution reflects demographic diversity, including signers of different age groups, genders, ethnicities, and abilities.
- Linguistic variations are accounted for, including regional dialects and community-specific signs.
- Underrepresented groups receive targeted data collection efforts to prevent AI models from reinforcing social inequities.
- Dataset bias assessment should be an ongoing process, with regular audits to detect and rectify imbalances in representation.

4.3. Ethical Data Collection

To align with ethical standards, supervised learning datasets for SASL should be collected and managed with a strong commitment to ethical principles that safeguard participant rights, privacy, and data integrity. Firstly, obtaining informed consent from participants providing data is essential. Next, contributors must have a clear understanding of how their data will be used, the potential benefits and risks, and their right to withdraw at any time without consequences. After that, informed consent should be facilitated through accessible formats, including signed and visual explanations, to ensure inclusivity for all SASL users.

Then, privacy and data protection laws must be rigorously followed to maintain the confidentiality and security of participant data. Personally identifiable information (PII) should be anonymised or removed to prevent the risk of re-identification, aligning with legal frameworks such as the South African Protection of Personal Information Act (POPIA) and the General Data Protection Regulation (GDPR). Secure storage, encrypted transmission, and transparent data retention policies should be implemented to prevent unauthorised access or misuse.

Finally, ensuring data ownership and accessibility is crucial in preventing the exploitation of SASL signers and their communities. Sign language users should have control over their linguistic data, retaining rights to its use and distribution. Ethical governance frameworks should include oversight by independent review boards to monitor data collection and application. Additionally, AI developments leveraging SASL data should benefit the broader signing community, with research findings and technological advancements being made accessible in formats that support inclusivity. By adhering to these ethical principles, AI-driven SASL models can be developed responsibly, fostering trust and fairness within the community.

4.4. Bias in Supervised Learning

Bias in supervised learning arises when models learn patterns that reflect pre-existing imbalances in training data. These biases can lead to unfair or inaccurate outcomes, particularly in applications involving sign language recognition. In the context of SASL, bias can negatively impact model performance, leading to misinterpretations of signs and disadvantaging certain groups of signers. Understanding and mitigating bias is therefore essential in developing AI systems that are fair, accurate, and inclusive.

One major source of bias in SASL-related supervised learning is dataset imbalance. When certain signers, signing styles, or regional variations are overrepresented in training data, the resulting models may struggle to generalise to the full diversity of SASL users. This can lead to disproportionately poor recognition rates for underrepresented communities, reinforcing existing disparities. Annotation bias is another concern, as subjective interpretations of signs by annotators may introduce inconsistencies. Differences in linguistic expertise, cultural perspectives, and annotation guidelines can lead to errors in labelling, reducing the reliability of AI predictions. Technological bias further exacerbates the issue, as variations in camera angles, lighting, and recording quality can impact model accuracy for different groups. If training data is predominantly collected in controlled environments with optimal conditions, AI systems may fail to perform well when faced with real-world variations in sign language usage.

To mitigate these biases, AI governance must prioritise representative and inclusive training data. Datasets should be carefully curated to reflect the full diversity of SASL users, including individuals from different age groups, genders, ethnic backgrounds, and linguistic communities. This ensures that AI models are trained on a wide range of signing styles and contextual variations, improving their ability to generalise effectively. Additionally, fair and transparent model evaluation practices should be employed. Bias detection techniques, such as performance audits across different demographic groups, should be implemented to assess and correct any imbalances in model predictions. Finally, continuous ethical review is essential to maintaining fairness in AI-driven SASL applications. Regular audits of model performance should be conducted, and feedback from the SASL community should be incorporated to identify and rectify unintended biases. By embedding these mitigation strategies into AI development processes, it is possible to create sign language recognition models that are both accurate and equitable, supporting the diverse needs of the SASL community. Bias in AI-driven SASL recognition can lead to unfair disadvantages for certain groups of signers, potentially marginalising specific communities. Ethical AI governance must therefore prioritise fairness, inclusivity, and accountability to ensure that SASL models serve all users equitably.

FACTORS TO CONSIDER DURING RECRUITMENT TO OBTAIN INFORMED CONSENT

The process to obtain informed consent should include the considerations below.
Extract from NHREC (2024: 21-24):

- **THE SETTING WILL**
  - minimise the possibility of undue influence
  - be sufficiently private and appropriate
- **THE PERSON WHO WILL CONDUCT THE PROCESS**
  - will be appropriately trained, independent, and bias-free
- **THE TEXT**
  - is in plain language and appropriate to the participants' level of understanding*
  - is translated into the language(s) best suited for the population and context of the study
  - has content, language(s) and procedures that are simplified and modified to accommodate any written or verbal language differences or impairments with which the participant may present
  - is free of jargon and unexplained acronyms
  - is clear and explains technical terminology e.g., randomisation
  - states that participants may contact the REC at the contact details provided if they have queries or complaints about their rights and welfare as research participants
  - states that participants may contact the researcher at the contact details provided if they have queries about the research project
  - conforms to the protocol

NOTE: *If appropriate, the consent documents can be translated. Merely translating documents is insufficient to ensure that consent is informed, however: illiteracy is prevalent in some contexts, language dialects vary substantially across regions, some words and terminology are not easily translated, translated written materials may not be helpful to some participants, and professional translators are not content experts so mistranslation may occur. Consider whether it may be more useful to train a research assistant/interpreter who can explain information about the study verbally to potential participants in their language of choice and answer any questions they may have about the study.*

* The Flesch-Kincaid readability tool should be used to assess the complexity of text. This tool is built into MS Word's spelling & grammar check tool as 'readability statistics'. No more than Grade 8 equivalency should be the target complexity level.]

- **THE INFORMATION EXPLAINS**
  - that the person is being asked to participate in research
  - that the choice whether to participate is voluntary
  - that refusal to participate will not be penalised
  - that choosing to participate can be reversed, i.e., the person may decide to withdraw from participation at any time without explanation or prejudice
  - the purpose and nature of the research procedures and components

- the research-related activities and procedures that the participant is being asked to consent to
- the expected duration of participation
- the nature of the participant's responsibilities
- the nature of the researcher's responsibilities
- the anticipated risks of harm or discomfort
- the measures to minimise risk of harm
- instances where a legal obligation to disclose information may arise
- whether reimbursement for expenses is available
- that sponsors of the research and regulatory authorities may inspect research records
- who the researchers are and the nature of their expertise
- how the personal information of participants, including confidentiality of data collected during the research, will be protected
- who will have access to participants' information, biological samples and associated data, including whether samples will be shared with other researchers
- that participants may request that corrections to their information be made or that their information or samples be deleted or destroyed. In cases where withdrawal of samples and information is not possible, the potential limitations and consequences of not withdrawing samples and data from research should be explained
- whether feedback about the study will be provided and, if so, how it will be provided
- whether biological samples will be used for commercial benefit
- where relevant, whether incidental findings will be shared with participants
- the potential benefits, if any, for participants both during and after the research
- that the research may be terminated early in particular circumstances
- that the research has been approved by a registered REC (include identifying details)
- where relevant, information or resources relating to compensation for research related injury of harm

NOTE: *Social science research projects may use research designs that emerge during the research process rather than being fixed at the planning stage. This means 'the researcher cannot provide full information about the research design and process at the start of the project. It also means that social science researchers must be aware that informed consent is not merely a signature-on-a-piece-of-paper action, but a deep appreciation of the participants' contextual circumstances, including the use of culturally appropriate consent procedures. In some cases, oral consent may be more appropriate and/or acceptable than written consent'. [See Visagie R, Beyers S and Wessels JS (2019) Informed Consent in Africa – Integrating Individual and Collective Autonomy …for an in-depth discussion of informed consent and individual/collective autonomy for social science research in Africa. (In Nortjé N, Visagie R & Wessels JS (eds.), 2019. Social Science Research Ethics in Africa. Springer Verlag. pp. 165-179. DOI: 10.1007/978-3-030-15402-8_6.).]*

NOTE: *Consent alone is insufficient to justify processing of some types of personal information. Necessity must be evident too, e.g., information about a person's race or ethnic origin must be necessary for the research activity (section 29(a)) or for affirmative action purposes (section 29(b)); information about a person's health or sex life must be necessary for the research activity (section 27(1)(d)); information about a person's inherited characteristics (genetic makeup) must be necessary for the research activity (section 32(5)(b)); biometric20 information about a person must be necessary for the research activity (section 27(1)(d)).*

- a measure to probe understanding and comprehension of the information is planned (e.g., a teach-back method), and how it proposes to do so especially for very vulnerable potential participants.

GLOSSARY

The South African Ethics in Health Research Guidelines: Principles, Processes and Structures (HREC 2024) is the nationally binding document on ethical research with human participants.
Below are some key terms from its glossary (pp. 102-109).

Anonymous – *see Identifiable*

Autonomy – *the capacity to understand information; to act on it voluntarily; to use own judgement to make decisions about own actions, including whether to participate in research*

Capacity – *the ability to understand relevant information; to appreciate the consequences of decisions based on the information*

Coded data or materials – *identifiers are substituted by a number, symbol or other method to provide a code; a key to the code exists so that the specimen can be linked to its original source*

Community engagement – *a collaborative process whereby researchers involve community stakeholders in an early and sustained manner across the study lifecycle to enhance the scientific and ethical quality of a study; the degree of collaboration may vary depending on the circumstances*

Confidentiality – *management of information that an individual has disclosed in a relationship of trust and with the expectation that it will not be disclosed to others without permission in ways that are inconsistent with the understanding of the original disclosure. Management of information includes whether and how research data might be disclosed carelessly or inadvertently by researchers, thus revealing the individual's identity or category, making them potentially vulnerable to harm*

Consent – *indication of agreement to participate in research, based on adequate knowledge and understanding of relevant information, freely given and revocable; documented in writing, signed by the participant and dated; see also POPIA for consent to process personal information*

Data – *information usually comprised of facts and numbers used to analyse something and to decide, or reach a conclusion or infer further information*

Data curation – *means the process of creating, organisation and integration and maintaining of data sets so that the value of the data is maintained over time, and the data remain available for reuse and preservation. It involves collecting, annotating, structuring, indexing, cataloguing, publication presentation of the data for users.*

De-identify – *see POPIA*

Ethics review – *review of research protocols (all the documents to be used for the proposed research) by RECs prior to commencement of the research, as well as of amended documentation as necessary*

Harm – *anything that has a negative effect on participants' welfare, broadly construed; its nature may be physical, emotional, psychological, social or legal*

Identifiable information – *reasonably expected to identify an individual alone or in combination with other information*

Identifier – *information such as a name, initials, address, folder number, or biometric identifier (e.g., fingerprint) that can identify a particular donor*

Incentive – *anything offered to encourage participation in research*

Inconvenience – *a minor negative effect experienced in research less serious than discomfort*

POPIA –

Biometrics – *a technique of personal identification that is based on physical, physiological or behavioural characterisation including blood typing, fingerprinting, DNA analysis, retinal scanning recognition (section*

1 of POPIA) and voice

Consent – *any voluntary, specific and informed expression of will in terms of which permission is given for the processing of personal information*

De-identify – *in relation to personal information of a data subject, means to delete any information that— a) identifies the data subject; b) can be used or manipulated by a reasonably foreseeable method to identify the data subject; or c) can be linked by a reasonably foreseeable method to other information that identifies the data subject, and ''de-identified'' has a corresponding meaning*

Personal information – *information relating to an identifiable, living, natural person, and where it is applicable, an identifiable, existing juristic person, including, but not limited to—*

a) information relating to the race, gender, sex, pregnancy, marital status, national, ethnic or social origin, colour, sexual orientation, age, physical or mental health, well-being, disability, religion, conscience, belief, culture, language and birth of the person

b) information relating to the education or the medical, financial, criminal or employment history of the person

c) any identifying number, symbol, e-mail address, physical address, telephone number, location information, online identifier or other particular assignment to the person

d) the biometric information of the person

e) the personal opinions, views or preferences of the person

f) correspondence sent by the person that is implicitly or explicitly of a private or confidential nature or further correspondence that would reveal the contents of the original correspondence

g) the views or opinions of another individual about the person, and

h) the name of the person if it appears with other personal information relating to the person or if the disclosure of the name itself would reveal information about the person

Privacy risks – *potential harms to participants from collection, use and disclosure of personal information for research purposes*

Proposal – *initiates research by describing what is to be researched, why it is important, and how it is to be researched, sometimes in great detail (used interchangeably with protocol in some disciplines)*

Protocol – *documents that explain in detail the background, rationale and objectives of planned research; describe its scientific and social importance, its design, methodology, organisation and conditions under which it is to be conducted and managed, including all documents to be provided to potential participants; see also Proposal*

Research – *a systematic investigation or study designed to produce generalisable knowledge based on conventional scientific and ethical standards appropriate for the context. It includes a range of activities conducted by many different disciplines that may use different methodologies and explanatory frameworks to extend knowledge through disciplined inquiry or systematic investigation*

Research data – *Research data is any information that has been collected, observed, generated or created to validate original research findings. Research data may be arranged or formatted in such a way as to make it suitable for communication, interpretation and processing.*

Risk – *a function of the magnitude of harm and the probability that it will occur*

Risk mitigation – *strategy to diminish or avoid circumstances that threaten risk of harm*

Stakeholder engagement – *a process of involving and collaborating with the people who have an interest or stake in the research at an early and in a sustained manner, for the duration of the study, to enhance the scientific and ethical quality of a study. It involves implementing actions to meet the needs and expectation* of the different role players and stakeholder groups and aims to achieve accepted outcomes for all the parties with the level of collaboration dependent on the circumstances.

Undue influence – may occur where an offered good is regarded as sufficient to impair decision-making, or to undermine the comprehending of risks by potential participants; an inherently subjective inference; should be considered mindfully with awareness of the dignity of participants

Vulnerability – diminished ability to fully safeguard one's own interests in the context of a specific research project; may be caused by limited capacity or limited access to social goods like rights, opportunities, and power

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Ethical Considerations for Data Collection and Management: Research South African Deaf Communities reports on knowledge developed during the execution of the research project, Advancing SASL for 4IR Technological Development using Place Names (funded by the Department of Sport, Arts and Culture, April 2022 – June 2025). The sociolinguistic component of this project involved the collection and documentation of signed place names and associated information directly from the Deaf community in South Africa.

It is a comprehensive overview of general ethical considerations, legislation and national guidelines for ethical research, and current best practices in Deaf studies, infused with the lessons we had learned during our research in the South African context. Novice researchers, scholars new to research with Deaf communities, and other stakeholders will find this report to be a solid basis from which to develop ethical protocols for research in the South African Deaf community.

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