

A directory of the legal rights of child & adolescent research participants in South Africa

HIV AIDS VACCINES ETHICS GROUP

SECTION 2: PRIVACY RIGHTS OF RESEARCH PARTICIPANTS WHO ARE MINORS



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SECTION 2: PRIVACY RIGHTS OF RESEARCH PARTICIPANTS WHO ARE MINORS

In this section we look at the **privacy rights** of child research participants

This is a complicated issue because the research relationship may involve not only the child participants, but also their parents or legal guardians. This is particularly an issue when the protocol involves older children or adolescents as research subjects, as they may have expectations of privacy regarding information that they will disclose to researchers or that researchers may obtain during the research process. In addition, they may be used to consenting to and receiving confidentiality for medical treatment.

It is also complicated because **the law does not deal directly with children's privacy rights in research** so general principles must be applied.

In this section we refer to both the right to privacy and confidentiality. The difference between these terms is:

- **Privacy** includes the right to seclude oneself from the public or publicity, the extent to which is determined by the individual themselves; and
- **Confidentiality** is generally the manifestation of the right to privacy within a particular relationship between for example, a doctor and their patient. It requires that professionals do not disclose information obtained from the relationship without consent.

A (i) BRIEF OVERVIEW OF LEGAL PRINCIPLES

1. Everyone has a constitutional, and common law right to privacy. This right is not absolute, however, and only extends to those aspects of a person's life that the person him or herself, as well as society, recognizes should be kept private. This right protects both adults and children.
2. In many instances our laws spell out instances when a person is entitled to the right to privacy. These are:
 - Draft regulations issued by the Minister of Health in terms of the National Health Act (2003), entitled Research with Human Subjects, state in Regulation 2(f) that research involving human subjects must ensure that "participants' rights toprivacy are respected, protected, promoted and fulfilled" The draft regulations do not give any further explanation of how this right will apply to research or of the nature of the duty that it

imposes on researchers. This means the draft regulations simply confirm the existing constitutional, statutory and common law rights to privacy do apply to the relationship between researchers and research participants;

- In terms of s14 of the National Health Act (2003) every user (patient) has the right to confidentiality regarding all health information “including information relating to his or her **health status**”. Section 1 of the National Health Act defines a user as a person receiving treatment in a health establishment or using a health service. If the user is under the age at which they can consent to medical treatment (currently 14), then the user includes the parent, guardian or other person authorised by law to act on their behalf. In terms of s16 of the National Health Act, a user’s health records may be used for research purposes without consent if their identifying details are removed;

In terms of s13 of the Children’s Act (2005), a child has the right to privacy regarding their “**health status**”. Health status is not defined but it is assumed that this refers to a child’s medical condition or diagnosis. No person may disclose the fact that a child is **HIV positive** without consent in terms of s133 of the Children’s Act; and children over the age of 12 have the right to access **contraceptives** and to confidentiality regarding the obtaining of condoms, contraceptives or contraceptive advice in terms of s134 of the Children’s Act.

It should be noted that the National Health Act and the Children’s Act have different approaches to a child’s right to privacy. The National Health Act links privacy to consent through the definition of a “user” in section 1. In terms of this definition if a user is under the age at which they can consent to medical treatment (currently 14), then the term user includes their parent, guardian or other person authorised by law to act on their behalf. This means that children below the age of 14 do not have a right to privacy regarding their medical treatment. However the Children’s Act does not link the right to privacy regarding a child’s “health status” to age of the capacity to consent to treatment. This means that children of any age would have a right to privacy even if their parents or guardians have consented to their medical treatment. However the privacy right in the Children’s Act is limited by the doctrine of the best interests of the child and where it is not in the child’s best interests information on their health status may be disclosed. It appears that the only way of reconciling the differences between the National Health Act and the Children’s Act is to argue that a child has a right to privacy regarding their health status from the age at which they can consent to medical treatment. It is not in the best interests of children who do not have the capacity to consent to medical treatment to enjoy the right to privacy.

3. Where the law is silent on whether a right to privacy exists in the circumstances, our courts use the legitimate expectation test to determine whether something is capable of being protected by the right to privacy, where the right to privacy is shaped by the limits of legitimate expectation and the community’s values regarding what information ought to be kept private. In terms of this test:
 - A person must have the capacity to form an expectation that the information will be kept private; and
 - The expectation itself must be regarded as reasonable by the community.
4. The right to privacy is not absolute and may be limited in certain circumstances. Relevant limitations on the right to privacy include:
 - The “grounds of justification”: These grounds can be used to justify an invasion of privacy. If a ground of justification exists, then it would not be wrongful to disclose private information. In other words, there are some situations where even though information is private, it can be disclosed

to others in specific circumstances. Grounds of justification include: where consent has been given for disclosure; 'necessity' (where the law considers a disclosure to be necessary for various reasons); or where a law provides for a limit to privacy (see below);

- Health related laws which limit the right to privacy:
 - s14 of the National Health Act (2003) limits the rights of users to confidentiality by providing that disclosures may be made if the user consents, if law requires it, or non-disclosure presents a serious public health threat. Furthermore, s15 provides that a health care worker may disclose a user's personal information if it is within the ordinary scope of their duties; necessary for a legitimate purpose and is in the interests of the user;
 - s13 of the Children's Act (2005) states that a child's right to privacy regarding their health status may be limited where maintaining confidentiality it is not in the best interests of the child; and
 - s133 of the Children's Act (2005) provides that a child's HIV status may be disclosed in certain defined circumstances, such as in terms of a court order. Consent to the disclosure may be provided by the child if they are over 12, or by the child if they are under 12 but understand the benefits, risks and social implications of the disclosure. If the child is under 12 and doesn't have understanding, consent may be given by the child's parent or care-giver, a hospital superintendent, the children's court and a designated child protection organisation; and
 - The Child Care Act (1983), the Family Violence Act (1993) and a variety of other laws, place mandatory reporting obligations on certain individuals. These laws limit a child's right to privacy as they oblige designated persons to disclose private information. See Chapter 3 for more information on these laws.
5. Even where a person has a right to privacy, this privacy right may be waived. A waiver is an agreement to not use a right in the future.
6. There are currently no proposed law reforms relating to a child's right to privacy except for the changes to the mandatory reporting laws which are dealt with in Chapter 3.

A (ii) APPLICATION TO RESEARCH

The law does not give any detail on the right to privacy or confidentiality in research. All the Draft regulations on Research with Human Subjects say in 2(f) is that research involving human subjects must ensure that "participants' rights toprivacy are respected, protected, promoted and fulfilled." These terms have a specific meaning in our law:

Respect – the right must be protected. In other words, researchers must make sure that they do not violate (infringe) the right to privacy.

Protect – steps must be taken to ensure that violations of the right do not occur. In other words researchers must describe the privacy rights of children in the informed consent document and ensure that research practices do not violate these rights.

Fulfil – steps must be taken to make sure that the right has meaning. In other words researchers must take positive steps to ensure that the right to privacy will be meaningful to participants by ensuring that steps are taken to promote the right within a research context.

In summary respecting, protecting and fulfilling the right to privacy means that researchers must ensure that this right is recognised and protected within a research context. Although these terms are very broad and they do not tell us how the right applies to specific research contexts, it is possible based on the health laws and general principles described above to make the following conclusions on the rights of research participants to privacy:

1. **Every person has the right to privacy regarding research participation.** This means that researchers cannot (without consent) disclose information such as:
 - The list of persons who have participated in the study; and
 - Link persons to personal findings within the study.

2. **Children or legal minors in research also have the right to privacy, even if they require parental assistance with consent to participate.** This means that:
 - Where research involves medical interventions that may establish a child's "health status" (such as STI tests) this must be kept confidential, provided the child is over 14;
 - Where research involves HIV testing, the results of such tests must be kept confidential, provided the child is 12 or older;
 - Where research involves provision of contraceptives or contraceptive advice, this must be kept confidential, provided that the child is 12 or older; and
 - Where research involves provision of advice on terminations of pregnancy (TOP), this information must not be disclosed without consent; however, girl children must be advised to "consult with her parents, guardian, family members or friends" before the termination, regardless of the child's age.

3. **Where the law is silent on minor's rights to privacy in research, the general test for privacy must be applied.**
 - This requires that the minor must be mature enough to form an expectation of privacy, despite the fact that a parent or guardian may provide consent for the research as a whole. This assessment doesn't need to be done individually with every adolescent. It can be assumed that most older adolescents would have expectations of privacy regarding their personal interaction with researchers during the research process if they (amongst others) had the right to consent to the procedure independently outside of a research context or had an existing legal right to privacy;

- This expectation must be reasonable. It is argued that the expectation would be reasonable if adolescents had the capacity to consent to an intervention within a trial. Children have the capacity to consent to: terminations of pregnancy at any age, contraceptives from the age of 12, HIV testing from the age of 12, medical treatment from the age of 14, and a medical operation at 18; and
 - If a child does not have an expectation of privacy, or where they have an expectation that is not reasonable, they will not have a right to privacy. In this case, the parent or guardian must be informed. For example, it is argued that children between the ages of 12 – 14 would not have a reasonable expectation of privacy to medical treatment as they cannot consent to such treatment independently.
4. **A child’s right to privacy regarding their health status within research may be limited**, for example, where this is in their best interests. For example, maintaining confidentiality regarding a child’s HIV status may not be in their best interests as HIV is a chronic, long-term condition that requires specialist treatment and emotional support; therefore in such instances child participants may be asked to involve a trusted adult. Privacy rights may also be limited by mandatory reporting requirements – see Chapter 3. Finally, in some cases the law gives children the right to privacy but advises them to draw on the support of others. This is not a direct limitation on their right but it obviously involves a consensual disclosure or limitation of private information, e.g., health providers are required to advise girl children to “consult with their parents, guardian, family members or friends” before a TOP.
 5. **Parents/ guardians or children may waive their right to privacy regarding certain information**. In this situation, parents or children may agree not to exercise their rights to privacy in the future and accordingly another party may be provided with confidential information. For example, a child may agree to waive their right to keep sexual risk information private. This should be clearly stipulated in the informed consent document.
 6. **Every effort should be made to explain to children and their parents what aspects of the research will remain confidential and what aspects will not**. It is possible that the parent/ guardian may refuse enrolment when they understand these matters, or the child may refuse to take part.

B FREQUENTLY ASKED QUESTIONS ABOUT CHILDREN'S PRIVACY IN RESEARCH

This section sets out some of the practical questions that researchers would face when considering how privacy rights for child research participants should be implemented. We try to anticipate some of the issues that are raised in chapter 3 on mandatory reporting to authorities, as this poses a major limit on confidentiality rights for child participants.

1 Where a parent consents for a minor's research participation, do minors still have privacy rights?

Yes. Even though a parent or guardian may consent to research participation as a whole, a minor may nevertheless have a right to privacy regarding certain **health-related information within the research**. Minors have a right to privacy if they can form an expectation of privacy that is regarded as reasonable by society. Generally speaking this would probably mean that older children would be entitled to have information they considered to be private, respected. Generally, the expectation would be reasonable if the child has the capacity to consent to an intervention independently, accorded to them by statutes.

Currently, children have the capacity to consent independently to:

- Terminations of Pregnancy at any age (s 5, Choice of Termination of Pregnancy Act, No. 92 of 1996);
- Contraceptives from the age of 12 (s 134, Children's Act of 2005);
- HIV testing from the age of 12 (s 130, Children's Act, No. 38 of 2005);
- Medical diagnosis and treatment from the age of 14 (s 39, Child Care Act, No. 74 of 1983); such as STI screening and treatment, vaccinations with proven vaccines, PEP, circumcision assessments;
- Medical operations at 18 (s 39, Child Care Act, No. 74 of 1983).

This means that girl child participants should have privacy for pregnancy tests and TOPs; child participants from 12 onwards should have privacy for HIV testing and contraceptives/ contraceptive advice; and child participants of 14 onwards should have privacy for any aspect of research that amounts to medical diagnosis or treatment (e.g. STI screening and treatment, vaccination with proven vaccines, PEP and circumcision assessments).

Child participants who are 12 and 13 years old cannot consent independently to medical diagnosis/ treatment; therefore it is argued that they would not have a reasonable expectation of privacy for elements of research that amount to medical interventions.

Parents and children should be made aware, in the consent form and process, of those procedures, tests, services and interventions for which child participants will enjoy privacy.

2 Do minors have a right to privacy regarding their sexual behaviour in research?

This is a complex question because the results of a sexual risk assessment do not easily fall into the category of a child's "health status" covered by statutory privacy rights. Therefore, one must apply the general test for privacy described above.

We would suggest *that older adolescents (16-18)* would have an expectation of privacy for their sexual risk data and that society would regard this as reasonable once they can consent to sex at 16. For *younger adolescents (12-16)* we argue they may have an expectation of privacy but there may be some debate as to whether this would be regarded as reasonable by society. On balance, the latter may not hold given that sexual behaviour among under-16s is illegal and their judgment is still evolving.

We recommend that the results of sexual risk assessment be given to older adolescents (16-18) and not their parents. For younger adolescents (12 – 16) parents should be asked not be informed, even while they may legally receive this information. Safeguards like counselling and access to services should be built in to the trial.

The circumstances in which adolescent information will be kept private should be spelled out in the consent form and process to enable parents and children to have a good understanding of the privacy norm, that is, what results parents will or will not have access to. Based on this understanding, children or their parents may or may not agree to enrolment.

3 When is it in a child's 'best interests' to disclose confidential information?

Our courts have held that the best interests of child standard requires a wide range of factors to be considered during decision-making in order to promote a child's physical, moral, emotional and spiritual welfare. This means decision-makers must weigh and balance a range of competing factors including the child's own views when deciding what would be in their best interests. The views or standards of the individual parent, child or other interested party are not the only factors to be taken into account. Decision-makers must also consider what is best for the child within the broader context of current social values.

If we apply this to research, it is argued that it would be in the best interests of children if their rights to privacy were limited in the following situations:

- Where they do not have the capacity to consent to medical treatment, i.e. 12 – 14 year olds undergoing medical diagnosis or treatment like syphilis testing, STI treatment, HPV vaccinations, PEP treatment, emergency contraceptives and circumcision assessments;
- Where they do not have the capacity to consent independently to an operation, i.e., male participants who wish to undergo a circumcision will need parental assistance with this procedure until they are 18. They will therefore not enjoy privacy over this procedure; and
- Where the condition is long-term and has serious emotional and physical consequences, for example, HIV-positive test results.

4 Should disclosures triggering mandatory-reporting obligations be kept confidential?

No. There are a number of limitations on a child's right to privacy through mandatory reporting obligations. These are described in more detail in Chapter 3. However the privacy implications are described below.

a) Should disclosures about inadequate care be kept confidential?

Research staff are not under a legal obligation to report children without adequate care (e.g. they have been abandoned by parents or are living on the streets) unless such research staff also fall into certain designated categories, such as social workers. However, research staff may, depending on the circumstances, elect to make a statement under oath to a commissioner of child welfare in order to facilitate an investigation into the child's circumstances.

This issue may arise where researchers are studying particularly vulnerable groups such as street children or child-headed houses. Given that there is no direct legal obligation to report but that staff may elect to report to a commissioner of child welfare, this issue may pose a **limit to confidentiality** which should be explained in the consent process.

b) Should disclosures about abuse and ill-treatment remain confidential?

No. Currently, research staff have a legal obligation to report abuse and ill-treatment of children. This would include an obligation to report physical abuse against children, the exploitation of children, and the neglect of children (such as failure to provide adequate care for the child's needs). This means that when adolescents disclose various forms of failure by adults to provide adequate care, or physical or sexual abuse; then this information will have to be reported to a social worker, police officer or commissioner of child welfare. In addition, researchers will want to assist children by, for example, referring them to various forms of support. This reporting requirement is a limit to confidentiality and should be explained in the consent process. It should also be explained to parents that the researchers are not required by law, and therefore may not necessarily inform the parent, even while they may have to report to authorities. Adolescents and parents may refuse to consent when they understand this issue.

c) Should disclosures about child labour or inappropriate work remain confidential?

Currently, a researcher is not under a legal obligation to report child labour or inappropriate work. They may however be under an ethical obligation to act in the best interests of the child by reporting such information to a labour inspector at the Department of Labour. This ethical obligation may be a limit to confidentiality and should be explained in the consent process. It should also be explained to parents that the researchers are not required by law, and therefore may not necessarily inform the parent, even while they may choose to report to authorities. Adolescents and parents may refuse to consent on these grounds.

d) Should disclosures about sexual offences remain confidential?

Generally speaking, no. Currently, when a minor reports a sexual offence this must be reported to the South African Police Service (SAPS). Sexual offences are: a) rape or indecent assault, b) sex work, c) underage sex or d) underage statutory sexual assault. However, we argue that consensual, non-exploitative sex or activity should not be reported to the police. See also question 2 above.

e) Should disclosures about not attending school remain confidential?

Generally speaking, yes. Researchers are not under a legal obligation to report truancy or other reasons for children not attending school. However given that parents are required to ensure that children under 15 attend school and they may be unaware that their child is not attending, there may be an ethical obligation on researchers to tell parents of under 15 year-olds, so that parents can act to fulfil their duty. This ethical obligation may be a limit to confidentiality and should be explained in the consent process.

f) Should disclosures about crimes be kept confidential?

Generally speaking, yes. Currently, a researcher is under no general legal obligation to report information regarding a child who has committed, or is committing, criminal offences. However, where a child, involved in a criminal offence, is being exploited (e.g. being required to engage in sex work by an adult), this should be reported to the police or other relevant authorities as this would amount to ill-treatment. When a child is committing crimes, a researcher should feel ethically obligated to intervene because this would be in the best interests of the child. Therefore, children should receive assistance, support and appropriate referrals. It should also be explained to parents that trial site staff may not necessarily divulge to them when their child is engaged in an offence but that steps will be taken to see that children get appropriate assistance.

Also, if a researcher becomes aware of a **third party** who has been the “victim” of a crime or has “committed” a crime they are not under a legal duty to take any further action. However they may be under an ethical duty if another child is in clear and imminent danger, for example from a violent boyfriend. In such a case they should assist the child research participant to report this information to the local police or social workers for further investigation.

C THE IMPLICATIONS OF LAWS FOR RESEARCH

LEGAL PRINCIPLE	SOURCES OF LAW: CURRENT	SOURCES OF LAW: FUTURE	RESEARCH IMPLICATIONS
Every person (including a minor) has the right to privacy.	<p>Section 14 of the Constitution of the Republic of South Africa Act No. 108 of 1996 gives every person the right to privacy</p> <p>The common law gives everyone the right to <i>dignitas</i> which includes the concept of the right to privacy.</p>	There is no new law or proposed law reform.	Every research participant, including those below the age of 18 years, have the right to privacy
There are laws spelling out rights to privacy for health-related information.	<p>Section 14 of the National Health Act No. 61 of 2003 says that any information relating to a person's health status, treatment or stay in a health establishment is confidential.</p> <p>Section 13, of the Children's Act No. 38 of 2005 says that every child has the right to confidentiality regarding their health status.</p> <p>Section 133 of the Children's Act (2005) says that every child has the right to confidentiality regarding their HIV status.</p> <p>Section 12 of the Children's Act (2005) states that children over the age of 12 have the right to confidentiality regarding the accessing of contraceptives and contraceptive advice.</p> <p>The Choice of Termination of Pregnancy Act says that health care workers may not disclose information on a termination of pregnancy to a child's family without consent; however they must advise a child to "consult with her parents, guardian, family members or friends" before the termination.</p>	The draft Regulations on Research with Human Subjects, 23 February 2007, state in Regulation 2 that researchers must ensure the protection of the privacy and confidentiality of participants in health research.	<p>Every research participant (including a minor) has the right to have their medical information kept confidential while taking part in a research project. This includes confidentiality regarding:</p> <ul style="list-style-type: none"> • HIV testing • Contraceptives • Advice on terminations of pregnancy <p>Researchers should ensure the privacy of minor research participants is protected with regard to the storing of information, access to this information and any special measures in respect of minor research participants.</p>
In the absence of specific laws interpreting the right to privacy in various contexts, the general principles apply.	The general test of privacy has been developed by our courts in various cases, such as <i>Burnstein and Others v Bester and Others NNO</i> (1996) (2) SA 751 (CC) and <i>Directorate for Serious Economic</i>	There is no new law or proposed law reform.	Where a minor research participant is capable of forming what society considers to be a reasonable expectation of confidentiality with regard to information

LEGAL PRINCIPLE	SOURCES OF LAW: CURRENT	SOURCES OF LAW: FUTURE	RESEARCH IMPLICATIONS
<p>The general legal principles regarding privacy state that a person has the right to privacy in respect of:</p> <ul style="list-style-type: none"> Information that an individual reasonably expects to be kept private Where the expectation is also regarded by society as reasonable. 	<p><i>Offences v Hyundai.</i> (2001). (1) SA 545 (CC).</p>		<p>revealed during the research process, he or she should have that right. This is a complex legal analysis.</p>
<p>There are some express limitations on a child's right to privacy.</p>	<p>Section 16 of the National Health Act No 61 of 2003 says that a user's health records may be used for research purposes if the user's personal particulars are removed.</p> <p>Section 13 of the Children's Act No 38 of 2005 says that every child is entitled to confidentiality regarding their health status except where this is not in their best interests.</p> <p>Section 133 of the Children's Act also says that no person may disclose a child's HIV status without consent, unless to do so is within the person's powers or duties, it is necessary to do so, or it is required in court proceedings or by way of a court order.</p> <p>Our law also contains special protections for children who are ill-treated. These protections frequently result in breaches of the right to confidentiality. See Section 3.</p>		<p>Research involving minors may lawfully limit the right to confidentiality in the specified circumstances. For example, privacy may be limited by mandatory reporting requirements.</p> <p>Furthermore, where maintaining a minor's right to confidentiality is not 'in the best interests of the child', a disclosure may be lawful. For example, if a child is HIV positive and is considered to need care and support to comply with ARV treatment, then it may be considered to be in their best interests to ensure that this information is disclosed to a trusted adult so they can secure support.</p>
<p>Even where there is no limitation on a right to privacy, it can be waived (not used).</p>			<p>Any person may waive (not exercise a right). A parent in an informed consent document may waive their right to information regarding their child's trial participation. For example, even where parents may have rights to information</p>

LEGAL PRINCIPLE	SOURCES OF LAW: CURRENT	SOURCES OF LAW: FUTURE	RESEARCH IMPLICATIONS
			<p>about the sexual behaviour of very young adolescents, they may agree not be informed given that children will be provided with counselling, services and other support.</p> <p>Researchers and RECs should develop SOPs to be followed where a minor research participant's right to confidentiality will be limited using the "best interests" standard.</p>
<p>Child participants and the parent/guardian should understand which aspects of the research will remain confidential and which aspects will not.</p>			<p>Informed consent documents should specify potential limits to a minor's right to confidentiality.</p>