



## FORUM

# Child privacy rights: A 'Cinderella' issue in HIV-prevention research

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Legal debates regarding child participation in HIV research have tended to focus on issues of informed consent. However, much less attention has been given to privacy; accordingly, we classify this as a 'Cinderella issue' that has been excluded from 'the ball' (academic debate). Here we argue that privacy issues are as important as consent issues in HIV-prevention research. We describe a child's right to privacy regarding certain health interventions in South African law, and identify four key norms that flow from the law and that could be applied to HIV-prevention research: (i) children cannot have an expectation of privacy regarding research participation if they have not given independent consent to the study; (ii) children may have an expectation of privacy regarding certain components of the study, such as HIV testing, if they consent independently to such services; (iii) children's rights to privacy in health research are limited by mandatory reporting obligations; (iv) children's rights to privacy in HIV-prevention research may be justifiably limited by the concept of the best interests of the child. We conclude with guidelines for researchers on how to implement these principles in HIV-related research studies.

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Health research among children (age <18 years), including HIV-prevention and -treatment research, is legally complex, because they have limited legal capacity and laws require them to be protected against their lack of experience and knowledge.<sup>[1]</sup> To date, legal debates have tended to focus on informed consent for child research. As a result, much of the literature has dealt with questions such as which parties should give consent to child research,<sup>[2-5]</sup> and what forms of research risk can be consented to on behalf of, or by children.<sup>[6-10]</sup> This article uses the analogy of Cinderella to describe the 'exclusion' of child privacy rights from academic debates on health research. It suggests that like Cinderella, who was left to clean the house rather than being invited to the ball, privacy has been overlooked or viewed as less important than the 'two ugly stepsisters' of *who* can consent and to *what* can be consented in child research.

It is argued here that the privacy rights of children participating in HIV-related research are as important as the consent rights for several reasons. Firstly, every child has the right to privacy.<sup>[11]</sup> It is argued that this right extends to ensuring that children have confidentiality regarding certain aspects of research participation. Secondly, South African courts have recognised that the failure to protect private medical information can have a direct public health impact, because without confidentiality, individuals are discouraged from seeking medical treatment or divulging personal information to healthcare providers.<sup>[12]</sup> It is argued, likewise, that undermining the confidential nature of the research relationship may erode public trust in research and researchers.

In previous articles, we argued that the privacy rights of adolescents (age 12 - 17 years) will have to be delineated carefully in HIV-prevention trials.<sup>[1,7]</sup> This article attempts to

build on earlier work, by comprehensively setting out the nature and sources of a child's right to privacy regarding health interventions, and by developing four key norms which can be applied to a range of HIV-prevention studies. Adolescents are at risk of HIV infection, and in order to make new HIV-prevention products available to them, they will need to be enrolled in HIV-prevention trials – provided that rigorous ethical criteria are met.<sup>[13]</sup> For example, it is possible that, within the next 24 months, adolescent females will be enrolled in a clinical trial of a microbicide gel (FACTS 002), once sufficient safety and efficacy data have been obtained from adult participants.<sup>[14]</sup> There are also many other behavioural studies exploring aspects of HIV prevention in adolescents, e.g. explorations of knowledge, attitudes and practices among teenagers.

There are many complexities raised by a child's right to privacy within the context of trials of HIV-prevention products, as well as in related social-behavioural studies. Parents or guardians, who are aware of their child's involvement in such research through the consent process, may have expectations that personal health information reported to, or identified by researchers will be disclosed to parents. However, adolescents aged ≥12 years who have the capacity to consent independently to certain health interventions (such as testing for sexually transmitted infections) may have expectations of privacy regarding such interventions.<sup>[1,3,7]</sup>

## The right to privacy in health-related matters

According to section 14 of the Constitution of the Republic of South Africa, everyone has a right to privacy.<sup>[11]</sup> This right enables individuals to be left alone or not to be observed by others.<sup>[15]</sup> It only extends to those aspects of a person's life that they and

society believe should be kept private.<sup>[16]</sup> Thus, an individual's right to privacy will exist if they have an expectation that the information would be kept private, and if such an expectation is regarded as reasonable by society.<sup>[16]</sup> Whether information can reasonably be regarded as private is established through an assessment of the impact of the violation on the individual's autonomous identity.<sup>[17]</sup> The right to privacy is also shaped by the grounds of justification. If a ground of justification exists (such as consent to the disclosure, necessity or where the law limits the right), the invasion of privacy will not be unlawful.<sup>[18]</sup>

## A child's right to privacy in health-related matters

Constitutional and other rights apply in most instances to adults and children equally.<sup>[16]</sup> By implication, children are entitled to the right to privacy. However, a child's expectation of privacy may be limited, and in some instances, society would not recognise their expectation as reasonable.<sup>[1,7]</sup>

### National Health Act (2003)

Currently, there is no legal guidance on how the right to privacy applies to child research participants, because the National Health Act (NHA)<sup>[19]</sup> is silent on this issue. However, section 14(1) of the NHA provides that a user (patient) has the right to confidentiality regarding health information, 'including information relating to his or her health status'.<sup>[19]</sup> However, such information may be disclosed in certain defined circumstances where the Act regards the disclosure as justifiable (section 14(2)(a)-(c) and 15(1), NHA).<sup>[19]</sup> It appears that the NHA does *not* create an independent right to privacy for children who do *not* have the capacity to consent to medical treatment, because if a parent or guardian consents on behalf of a child, then the parent/guardian is granted all the rights of the user, including the right to confidentiality (section 1, NHA).<sup>[19]</sup> This means that children, who cannot consent independently to a medical intervention would not have a right to keep information about such an intervention from the adult providing proxy consent.

### Children's Act (2005)

The Children's Act, in contrast, provides that all children have a self-standing right to privacy regarding their 'health status' (section 13(1)(d), Children's Act).<sup>[20]</sup> 'Health status' is not defined, but it is assumed that this refers to a child's medical condition or diagnosis. The Act also provides that 'children are entitled to privacy from the age of 12 years regarding access to condoms, contraceptives and contraceptive advice' (sections 13(1)(d) and 134(3), Children's Act).<sup>[20]</sup> Furthermore, no person may disclose that a child is HIV-positive without the consent of the child (if they are aged  $\geq 12$  years), or another responsible adult if they are aged  $< 12$  years (section 133(1), Children's Act).<sup>[20]</sup>

The Children's Act provides that a child's rights to privacy regarding their health status may be limited where this is in their best interests (section 13(d), Children's Act).<sup>[20]</sup> Such rights may also be indirectly limited through mandatory reporting obligations. These require certain individuals such as medical practitioners, to report children who are abused, neglected or in need of care/protection (section 110, Children's Act).<sup>[1,7,20]</sup> The definitions of abuse, neglect and children in need of care and protection are very broad. Resultantly, reporting is required if, among others, children: (i) are performing child labour (i.e. working while aged  $< 15$  years); (ii) are dependent on drugs and they are 'without any support to obtain treatment for such dependency'; (iii) are being exploited, e.g. used by adults to commit

crimes; or (iv) have been physically or sexually abused (section 150(2), Children's Act).<sup>[7,20]</sup>

## The Choice of Termination of Pregnancy Act (1996)

The Choice of Termination of Pregnancy Act (CTPA) also deals expressly with the right to privacy, by providing that the 'identity of a woman who has requested or obtained a termination of pregnancy shall remain confidential at all times unless she herself chooses to disclose that information' (section 7(5), CTPA).<sup>[21]</sup> Woman in this context means a 'female person of any age' (section 1(xi), CTPA).<sup>[21]</sup> This provision is tempered by section 5(3), which provides that minors must be advised to 'consult with their parents, guardian, family members or friends' before the termination (section 5(3), CTPA).<sup>[3,21]</sup>

## The Criminal Law (Sexual Offences and Related Matters) Amendment Act (2007)

The Sexual Offences Act (2007) limits a child's right to privacy by requiring the mandatory reporting of all sexual offences committed against children, including consensual crimes (section 54(1), Sexual Offences Act).<sup>[22]</sup>

## Applying privacy laws to adolescent HIV-prevention studies

We argue that by applying the law on privacy to HIV-prevention studies, the following norms emerge:

**A child does not have a right to privacy regarding participation in an HIV-prevention study unless they have consented independently to research participation.** It is submitted that older adolescents may have expectations of privacy regarding participation in an HIV-prevention trial as they may have been recruited while independently accessing health services. However, this would not be regarded as reasonable given that ethical guidelines require parental consent for clinical trials,<sup>[23]</sup> and for more than minimal risk research.<sup>[24]</sup> Recently, section 71 of the NHA was operationalised, requiring parental or guardian consent for all forms of health research with minors.<sup>[19]</sup> While the section 71 requirements are overly broad, we argue that in the case of clinical trials, children do not have the right to keep their involvement private, because a parent or legal guardian should provide proxy consent.

In low-risk studies related to HIV prevention in adolescents, it is possible that research ethics committees (RECs) may grant approval for independent consent by adolescents despite the implementation of section 71 of the NHA, and in such cases, adolescents would also have an expectation of privacy for their enrolment in such studies. It is submitted that in this instance, such an expectation would be regarded as reasonable given that the REC has recognised their capacity to act without parental assistance.

**An older child has the right to privacy regarding certain therapeutic health interventions that form part of the HIV-prevention study.** We argue that where HIV-prevention studies involve a range of health services, older children may be entitled to privacy regarding these, for a number of reasons.<sup>[25]</sup> Firstly, in some circumstances *the law specifies that children are entitled to privacy* (see section above). As a result, children have the right to confidentiality regarding condoms, contraceptives and contraceptive advice, and their HIV status, from age 12 years.<sup>[3,20,25]</sup> Girl children are entitled to privacy regarding a termination of pregnancy at any age.<sup>[21]</sup> Secondly, in other situations, although the law does not

expressly set out that a child is entitled to confidentiality for that health intervention, e.g. medical treatment, it nevertheless provides that all children have the right to privacy regarding their health status.<sup>[20]</sup> This considered, it is argued that *when the law specifies that children have the capacity to consent independently to a particular intervention, they should have a corresponding right to privacy regarding their health status.* We argue that in such a situation the child would have an expectation of privacy, given their right to confidentiality regarding their health status, and that society would regard this as reasonable, as they are able to access the service without assistance.<sup>[1,25]</sup> Thirdly, in all other situations (where the law is silent on a child's right to privacy or it does not specify that they have the capacity to consent independently), the *general principles regarding the right to privacy would have to be applied.* This issue is discussed elsewhere.<sup>[1,25]</sup>

**A child's right to privacy in the HIV-prevention study (where it exists) is limited by mandatory reporting obligations for abuse, neglect and sexual offences, and in some instances, ethical obligations to protect children.** The Children's Act provides indirect limitations on a child's right to privacy by requiring the mandatory reporting of children who are abused, neglected, or those who are in need of care and protection.<sup>[1,7,20]</sup> This includes children performing child labour (i.e. working when aged <15 years) or those who are dependent on drugs and are not receiving any support for their addiction.<sup>[20]</sup> The Children's Act does not extend this obligation to report children in need of care and protection to third parties, i.e. other children whom child participants themselves may identify as being in a crisis situation. For example, if an adolescent research participant reports that a third party has been the 'victim' of a crime, or has 'committed' a crime, site staff will not have to report this information.<sup>[25]</sup> However, they may have ethical obligations to intervene if a child is in clear and imminent danger, e.g. from a violent and abusive parent. In such a case, they should assist the child participant to report this information to the appropriate authorities (local police or social workers) for further investigation.<sup>[25]</sup>

The Sexual Offences Act<sup>[22]</sup> also requires the mandatory reporting of sexual offences against children and this may affect a child's privacy rights within an HIV-prevention study.<sup>[25]</sup> This is discussed in detail elsewhere.<sup>[26]</sup>

**A child's right to privacy regarding health status in HIV-prevention research may be limited by the concept of the best interests of the child.** The right to privacy regarding a child's health status may be limited where maintaining confidentiality is not in the best interests of the child.<sup>[20]</sup> The Children's Act does not envisage an absolute concept of privacy, but rather a flexible approach in which a range of individual factors would need to be considered in establishing whether privacy is appropriate in the circumstances. For example, maintaining confidentiality – and not informing the child's parents – regarding a child's truancy from school may not be in the best interests of the child, because parents are under a legal duty to ensure that their children attend school until the end of the year in which they turn 15 years.<sup>[25]</sup>

## Conclusion

It is argued that a child's right to privacy in research is a Cinderella issue that has received little direct attention in the literature, unlike the two consent stepsisters. This article has attempted to act as privacy's fairy Godmother and present this as a significant issue that requires urgent attention, to ensure that the privacy rights of adolescent participants are maintained without undermining their best interests.

We recommend that HIV-prevention researchers consider the following guidelines: (i) children should be advised during the recruitment

stage of HIV-prevention trials or studies that they will have a limited right to privacy regarding their overall participation in the research if parental consent for enrolment is required; (ii) if parental consent is required, parents should be informed during the informed-consent process that, despite their consent, they will not receive direct feedback from researchers regarding many key components, because their children have legal rights to privacy for such components; (iii) standard operating procedures should be developed on the circumstances in which a child's right to privacy will be limited by mandatory reporting obligations.<sup>[1,25]</sup>

It is likely that some parents will not agree to enrolment because this approach may not be consistent with their values or preferences.<sup>[27]</sup> However, it is also likely that many will be willing to enrol their children in such studies when they receive assurances that children will be linked to appropriate counselling, support and health interventions to assist them.

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