Talking to children about their HIV diagnosis: a discussion rooted in different global perspectives

Katie Warburton, Lars Navér, Juliet Houghton and Kamila Fatikhova

ABSTRACT

An online meeting was arranged with four professionals representing four countries to debate current practices and future steps in naming HIV to children (disclosing HIV status). This article considers the evidence and reports on the commentary and debate from the meeting. Naming HIV to children remains a challenge. Although studies identify some of the facilitators and barriers to informing children of their HIV diagnosis, further review of practice is required. This article presents a global perspective of naming practices from different settings. The article comprises commentary and a report of the online debate, along with supporting evidence. The four participating authors concluded that health professionals must work in collaboration with families to support early naming of HIV to children or having an open discussion about HIV in clinics. Naming when a child is younger reduces self-stigma and empowers children and young people to adhere to their medication, make informed decisions and share their own diagnosis appropriately. The authors concluded that health professionals play a key role in educating colleagues and the public to reduce stigma and discrimination. Professionals working with children and families living with HIV require support and resources to instil confidence in naming and facilitate naming of HIV status to a child.

Key words: HIV ■ Children ■ Disclosure ■ Naming ■ Children's rights

Zanele is 11 years old and in her final year of primary school. She was diagnosed with HIV at the age of 7 years and had engaged in care since diagnosis. Following a clinic review, it was noted that she was not taking her medication and blood results indicated a high viral load and drug resistance. When adherence was explored, Zanele explained that she was no longer taking her medication because she felt fine and didn't seem to need it. Reflection on this case highlights that drug resistance may have been avoided if Zanele had understood the reasons behind her need to take the medication.

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Background

Global data indicate that 1.8 million children (aged 0–14 years) were living with HIV in 2019 (UNAIDS, 2021). According to UNAIDS (2021), in 2019 150 000 children were newly infected and 95 000 children living with HIV died. Most children living with HIV acquire the virus perinatally through mother to infant transmission (Kourtis et al, 2006). Routine testing in pregnancy and advances in treatment and care have resulted in the risk of mother to infant transmission reducing from as high as 40% to less than 0.5% in developed countries (Townsend et al, 2014). Access to effective treatment allows HIV to be managed as a chronic health condition, which should result in a normal life expectancy (Hayes, 2021). Despite the decline in new infections and advances in treatment, medical and supportive care of children and young people living with HIV must stay high on our agenda.

Talking to children about their HIV status has changed along the timeline of effective treatment developments; in the pre-treatment era, children were rarely told about their HIV status (Weiner et al, 2007). As treatment availability improved, children were told before adulthood and later during adolescence in recognition of young people becoming sexually active (Weiner et al, 2007). Stigma and discrimination play an unacceptable role in not talking about HIV. Sharing, or not sharing a HIV diagnosis, can lead to social isolation and discrimination at a life-changing level. When a child is HIV positive, this often affects at least one other person within the family unit, which presents a more complex scenario when telling a child their HIV diagnosis.

This article reports on the viewpoints of four professionals from four countries, following an online discussion meeting arranged to debate current practices and future steps in naming HIV to children. The article explores the evidence and presents a commentary based on current 'naming' practice—the process of informing a child who is HIV positive of their diagnosis—across the globe. The discussion took place between two paediatric nurses, a consultant paediatrician and a social worker, all of whom have been actively involved in naming HIV to children across the past two decades, in different international settings. These health professionals (the authors) came from the UK, Sweden, South Africa and Uzbekistan.

International healthcare settings

A comparative discussion identified significant differences in these four countries. However, according to Gregory (2016), most countries face similar challenges—that is, how to manage the bridge between primary and secondary care, prevent avoidable illness and integrate physical and mental health needs.

Additionally, the UK must adapt to the needs of an ageing population, technological advances and an under-resourced workforce (Health Systems and Policy Monitor, 2021a). The authors agree that these are recognised challenges across the four countries under discussion. Knowledge of their healthcare systems is crucial to enable understanding of how paediatric HIV care is impacted within each country.

South Africa, which has the highest number of children living with HIV, is identified as a developing country (United Nations, 2014). Despite the end of apartheid three decades ago, Maphumulo and Bhengu (2019) reported that its impact continues to play a role in inequality across the healthcare system. A large percentage of the population is dependent on the public health system, which is predominantly nurse driven and the fair distribution of health professionals remains a challenge (Maphumulo and Bhengu, 2019). Treatment is free at the point of delivery.

Similarly, healthcare delivery presents challenges in Uzbekistan, which became an independent country following the dissolution of the Soviet Union in 1991. Data from the World Health Organization (WHO) indicate that there was a dramatic increase in HIV cases in Uzbekistan from the year 2000 (when estimates put the number of children at 100) up to the time of the report when the figure stood at 2800 (Ahmedov et al, 2014; World Bank, 2021). This trend has continued, with more recent data showing a rise from 2900 in 2015 to 4100 in 2020 (World Bank, 2021). Uzbekistan is part of the WHO-driven Universal Health Coverage Partnership scheme, which aims to drive the development of primary health care and the delivery of equitable healthcare within the country (Ahmedov et al, 2014).

The NHS in England is funded predominantly through taxes and its overall budget is decided by government. Treatment is free at the point of delivery, and much of the population depends on the NHS for health care (NHS England, 2021). It must be noted that funding for health care in the UK is lower compared with some European countries (Health Systems and Policy Monitor, 2021a). Although, like the UK, Sweden has a public health care system that is government funded, it is organised differently: there are 21 county councils that are individually responsible for health care in their areas, so within Sweden approaches may differ and may depend on a county council's political persuasion (Health Systems and Policy Monitor, 2021b). Despite potentially differing policies, this does not affect the national regulation of treatment, which is free at the point of delivery.

While there are similarities, there are also significant differences across the healthcare systems. When debating any aspect of care provided for children and young people, it is imperative that service provision in the local context is considered. This is especially vital when considering the needs of the specific population of children and young people living with HIV and the numbers of those on treatment in each country.

Table 1. Demographics of paediatric HIV cohorts

Country	Number of children living with HIV	Children on treatment
Sweden	122 (aged <18 years)	100%
UK	489 (aged <18 years, mainly in paediatric care)	98%
Uzbekistan	4100 (0–14 years)	85–90%
South Africa	310 000 (aged 0–14 years)	63%

Source: Collaborative HIV Paediatric Study, 2021; UNAIDS, 2021

Demographics

Table 1 presents some of the demographical differences between the paediatric HIV cohorts in the four countries. The cohorts in Sweden, Uzbekistan and the UK are significantly smaller than the cohort of children accessing care in South Africa. Although the differences between the Swedish and UK cohorts and those in Uzbekistan and South Africa are significant (Collaborative HIV Paediatric Study (CHIPS), 2021; UNAIDS, 2021), the need for specialist care remains pertinent. Furthermore, despite the differences in cohort sizes, the importance of sharing best practice and learning from international cohorts is imperative (Bamford and Lyall, 2015).

Advances in care pose new focuses. The need to name HIV to children growing up with HIV is not new; however, it remains a reported challenge in clinical practice.

Why does naming HIV to children matter?

Children need to be empowered to manage their health and live well with HIV. The needs of children and young people should drive care delivery. All children have the right to information and resources that promote their physical, social, spiritual and mental health (United Nations, 1989), and this must include empowering them to manage their HIV.

Many studies report that naming HIV to children can improve their adherence to medication (Weiner and Battles, 2006; Arun et al, 2009, Vreeman et al, 2010, Kallem et al, 2011; Abebe and Teferra, 2012; Vreeman et al, 2013; Pinzón-Iregui et al, 2013; Jemmott et al, 2014; Punpanich et al, 2014), which is essential for long-term health and survival. There is no doubt that if a child does not know why they are taking medication it is difficult to expect ongoing adherence. All authors identified this as a practice challenge. It must also be noted that the child may feel physically healthy without medication and therefore unlikely to identify a need to take medication.

Vreeman et al (2010) and Boon-yasidhi et al (2013) have argued that when children are aware of their HIV status their self-esteem is improved. Other research has found that parents experience less depression once a child is aware of their HIV status (Doat et al, 2019). Further, according to Rydström et al (2016), the quality of life of children living with HIV was normal or better than normal for children who knew their diagnosis. A quantitative cohort study in the UK comparing young people aged 13-21 years who were HIV positive and HIV negative (who had a sibling or parent living with HIV) reported similar levels of anxiety and depression, with scores in both groups comparable with UK normative data. However, although self-esteem scores were also found to be similar in both groups, these were lower than UK normative data (Le Prevost et al, 2018).

In their discussion, the authors of this article highlighted that not telling children until adolescence often resulted in negative psychological consequences. Fear of affecting a young person's anxiety, depression or self-esteem should not be a reason to prevent naming.

Why should we tell children?

The evidence already cited supports the need to talk to children about HIV and to stop withholding their health information. Collectively, the authors agree that there is a need to act to counter stigma and normalise HIV. In debating the subject, the authors highlighted that the advantages of talking openly about HIV could ultimately result in improved community support for people living with HIV—and there was a consensus that this would be beneficial to all.

The best interests and the rights of the child are paramount and this should be the driver for informing children of their HIV diagnosis.

Why are children not told their diagnosis?

In the context of Uzbekistan, the author based in the country (KF) highlighted the fact that parents' fears pose the biggest obstacle. She stated that it was not unusual for parents to request that informing their child should wait until adulthood, perhaps even after marriage. In the UK, professionals report parental resistance as the most significant barrier to naming HIV to children (Rowson, 2017). The author representing practice in South Africa (JH) concurred that health professionals in the country encounter the same barriers, which can be complicated by the reluctance of health professionals to tell children about their HIV diagnosis.

There is supporting evidence that many parents want to delay the naming of HIV to children until they are older (Weiner et al, 2007; Kallem et al, 2011; Vreeman et al, 2013). However, in Sweden, since a drive more than a decade ago to talk openly about HIV in paediatric clinic settings with children about their diagnosis, the author based in the country (LN) reported that anecdotal evidence from clinical experience indicates that there has been little parental resistance or negative feedback. There is also an ethical obligation to enable children to learn more about their health in an honest, age-adjusted way.

All authors were in agreement—and their view is supported by the evidence—that parents experience feelings of guilt in relation to transmission of the virus (John-Stewart et al, 2013). Parents fear that they will be blamed and that onward disclosure by the child may lead to stigma and discrimination for both the child and the family (Vreeman et al, 2013). Empathy from health professionals is essential. However, one of the authors (JH) noted that, particularly in the context of South Africa, the scenario is more complex: where a health professional is HIV positive and is therefore managing their own emotions, their delivery of care invariably draws on their personal experiences.

It is also important to consider a number of other complications that may impact on parental willingness to inform their child of their HIV status. For example, experiencing an HIV-related death within families or communities is likely to have a significant impact (Instone, 2000; Vreeman et al, 2010; Cantrell et al, 2013). Evangeli and Kagee (2016) reported that the personal experience of caregivers of the way in which they found out about their HIV status may affect their readiness and willingness to tell their child.

The willingness of professionals to persuade parents that naming HIV is the appropriate step to take must be considered. The authors argued that professionals must be confident in naming HIV to children to ensure that it is clear to caregivers that it is the right thing to do. There was a consensus between the authors that confidence is paramount. They agreed that professionals may have concerns about how this might negatively impact their therapeutic relationships with the family. However, the Swedish experience, the authors agreed, has shown that this risk is overestimated.

The debate between the authors also highlighted that some health professionals worry about the reaction of the child, which can delay or prevent naming HIV. History also plays a role, with many health professionals supporting children and families living with HIV across a number of decades. The era of no treatment, inadequate treatment and extreme stigma is not very far back in the past and at times can still feel significant. This vestige of the past can be particularly challenging in some cultures and communities. We learn from practice, our experience influences our future practice and past experiences can exacerbate fears.

Cultural challenges were highlighted in the author debate and cannot be underestimated. When caring for children with HIV, it is therefore vital to consider the impact of different healthcare systems, different community priorities, different normative levels of stigma and different family beliefs.

Stigma

There was no doubt in the discussions between the authors that stigma and the fear of stigmatisation is the dominant factor that prevents naming HIV to children.

Public ignorance and misunderstanding of HIV leads to prejudice against people living with HIV and negative attitudes, with the result that people with HIV continue to experience stigma and discrimination (UNAIDS, 2021). The perceived social stigma in all cultures and the need to maintain secrecy of the diagnosis is therefore often part of growing up for children living with HIV (Bamford and Lyall, 2015).

Stigma has been overwhelmingly highlighted as the reason parents do not want their child to know that they are HIV positive (Merzel et al, 2008; Arun et al, 2009; Kallem et al, 2011; Vreeman et al, 2013, Cantrell et al, 2013; Kyaddondo et al, 2013; Jemmott et al, 2014; Punpanich et al, 2014; Evangeli and Kagee, 2016; Doat et al, 2019).

The authors suggested that there are generational differences in the perspectives of parents and that of young people wanting to share their HIV status. A cross-sectional study in Kenya (Vreeman et al, 2014) concluded that parents are more likely than the child to report their child had experienced HIV-related stigma. This highlights an exacerbation of fear in the caregiver and a resulting reluctance to name HIV to children, along with a fear of children sharing their diagnosis.

What's happening globally?

UK guidelines suggest that naming HIV to children should occur in most cases before the age of 9 years (Children's HIV Association (CHIVA), 2017). The clinical practice of naming HIV to children in the UK was audited in 2017 (Rowson, 2017), with the findings showing that a significant number of children aged over 9 years were unaware of their HIV status. Anecdotal evidence suggests that this has remained unchanged since 2017.

Similarly, in South Africa (National Department of Health South Africa, 2016) and Uzbekistan, national guidelines state that children should be fully aware of their HIV status by the age of 10 years. This is recognised as full disclosure.

In Uzbekistan, the practice is to start talking about HIV to children from the age of 7 years. The authors of this article highlighted that legal, ethical, and developmental considerations play a role. There was agreement that it is important to consider individual circumstances. However, after much debate, the authors concluded that there is never a right time and, due to the challenges highlighted, a reason to delay is almost expected in all settings.

In Sweden, the recommendation is to talk openly about HIV from the first consultation and to continue to have a dialogue with the parents about why naming HIV is good for the child; this has been a standard of practice for 12 years (Eriksen et al, 2020). A reflective discussion between the authors in the meeting suggested that, within the context of Sweden, a number of children who had initially said that they had not known about their HIV at disclosure later revealed that they had been aware of their status long before HIV was named. The effect of a hidden secret can result in self-stigma and may play a role in whether or not young people share their diagnosis in future.

A cross-sectional study conducted in Sweden (Rydström et al, 2016) found that children and young people have some concerns around onward disclosure of their HIV status, so providing children with support is essential. Weiner and Battles (2006) discovered that children who learnt about their HIV status at a younger age reported higher onward sharing of their diagnosis in interpersonal relationships. The authors of this article called attention to the risk of creating self-stigma through not naming HIV to a child. Normalising HIV is key to reducing the impact of stigma on children and young people. Sessions at CHIVA camps organised for young people with HIV have explored the impact and experiences of secrecy and stigma using the medium of art (*Figure 1* and *Figure 2*).

Children's HIV Association

Figure 1. Young people's artwork made at a Children's HIV Association camp

Figure 2. Young people's artwork made at a Children's HIV Association camp

Challenging stigma

The discussion between the authors highlighted that, as health professionals, we have a responsibility to challenge stigma and change people's perspectives. There was a clear consensus in the debate that health professionals play a crucial role in educating both colleagues and the general public. Perpetuating stigma creates a vicious circle—and it is our professional responsibility to break it.

Disclosure versus naming: a debate

It can be argued that disclosure is a term often associated with sharing something negative. When talking about HIV status, the words 'naming' or 'sharing' would be more appropriate terminology. One of the article authors (KW) reported that, in the UK, activists and professionals are trying to stop the use of 'disclosure' as a term in the context of sharing HIV status. Research continues to refer to disclosure, which is a recognised term, and this presents a challenge.

The authors agreed, however, that this term is outdated. With adequate treatment, HIV is now managed as a chronic disease and there needs to be a positive shift in discussions about practice. The author based in South Africa (JH) reported that there have been attempts to change this in that country, but guidelines still refer to disclosure. In Uzbekistan, the locally based author (KF) stated that disclosure is the recognised term used in health and social care settings in the country.

Changing the terminology is a challenge and will take time, and all four authors agreed that health professionals should be mindful of the impact that word choices can have on children and families. It was also agreed that children should be offered age-adapted education to be able to accept and learn to live with a chronic health condition. It is important that young people are knowledgeable about their diagnosis, treatment, transmission and how to live well with HIV.

When can we talk openly?

The authors suggested within the debate that it is time to talk openly about HIV in line with the positively accepted changes in practice that have occurred in Sweden. The debate between the authors determined that professionals need to take courage and confidently promote openness about HIV status. It is time to educate and challenge the public and professionals—there will be challenges, but these will be overcome through talking openly about the subject, not by keeping silent.

KF reported that stigma is a significant challenge in Uzbekistan, which prevents changes in practice. One of the other authors (JH) reported that open public discourse is often triggered following a new serious disease or event.

What next?

The WHO (2011) promotes positive collaboration between health professionals and the family in the process of talking to a child about their diagnosis. Britto et al (2016) conducted a systematic review that highlighted the pivotal role of the health professional in naming HIV. A study by Vreeman et al (2014) highlighted that, although the fear to disclose remained, trust between the health professionals and the family was an important factor for both parents and children in successfully naming HIV to the children.

Dematteo et al (2002) reported that younger children had less of an emotional reaction when HIV was named. Their findings are reflected in the experiences of the authors of this article in naming HIV to children at younger ages.

The authors propose that the best approach would be to support individual clinics to change practice and share best practice with health professionals working in similar community settings. This approach, following the Swedish example, could also be considered in national teams across the UK, South Africa and Uzbekistan. Equipping health professionals with the appropriate education, support and adaptable resources is key to achieving this.

Conclusion

It is essential that practice experiences are shared, and this commentary has created the opportunity for an international debate summarising the current practice approaches of telling a child that they are HIV positive. It is imperative that children's rights remain at the forefront of clinical practice. This debate has also opened the opportunity of collaborating and sharing resources and experiences on an international platform.

Health professionals play a vital role in reducing stigma and normalising HIV, dispelling myths and disseminating information. Approaches to destigmatisation will involve ensuring that healthcare organisations, communities, and the media have access to up-to-date evidence-based information. Each author involved in this debate will take this forward and consider culture-sensitive approaches to overcoming stigma and normalising HIV. The time has come to talk about the subject.

Although we hope to open the discussion in all settings, this will necessitate a complex multidimensional process. We conclude this article with a call for action and draw readers' attention to the role they can play themselves in addressing stigma and normalising HIV. **BJN**

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Abebe W, Teferra S. Disclosure of diagnosis by parents and caregivers to children infected with HIV: prevalence associated factors and perceived barriers in Addis Ababa, Ethiopia. AIDS Care. 2012;24(9):1097–1102. https://doi.org/10.1080/09540121.2012.656565

Ahmedov M, Azimov R, Mutalova Z, Huseynov S, Tsoyi E, Rechel B; for the European Observatory on Health Systems and Policies. Uzbekhistan. Health system review. 2014. https://tinyurl.com/2s3rtz96 (accessed 16 December 2021)

Arun S, Singh AK, Lodha R, Kabra SK. Disclosure of the HIV infection status in children. Indian J Pediatr. 2009;76(8):805–808. https://doi.org/10.1007/s12098-009-0177-z

Bamford A, Lyall H. Paediatric HIV grows up: recent advances in perinatally acquired HIV. Arch Dis Child. 2015;100(2):183–188. https://doi.org/10.1136/archdischild-2014-306079

Boon-yasidhi V, Chokephaibulkit K, McConnell MS et al. Development of a diagnosis disclosure model for perinatally HIV-infected children in Thailand. AIDS Care. 2013;25(6):756–762. https://doi.org/10.1080/09540121.2012.749331

Britto C, Mehta K, Thomas R, Shet A. Prevalence and correlates of HIV disclosure amongst children and adolescents in low- and middle-income countries: A Systematic Review. J Dev Behav Pediatr. 2016;37(6):496–505. https://doi.org/10.1097/DBP.0000000000000303

Cantrell K, Patel N, Mandrell B, Grissom S. Pediatric HIV disclosure: a process-oriented framework. AIDS Educ Prev. 2013;25(4):302–314. https://doi.org/10.1521/aeap.2013.25.4.302

Children's HIV Association. CHIVA standards of care for infants, children, and young people with HIV (including infants born to mothers with HIV. 2017. https://tinyurl.com/yckwmkut (accessed 20 December 2021)

Collaborative HIV Paediatric Study. Summary data. Summary data to the end of March 2021. 2021. https://tinyurl.com/kxbjdxha (accessed 16 December 2021)

Dematteo D, Harrison C, Arneson C et al. Disclosing HIV/AIDS to children: the paths families take to truth-telling. Psychology, Health & Medicine. 2002;7(3):339-356. https://doi.org/10.1080/13548500220139395

Doat AR, Negarandeh R, Hasanpour M. Disclosure of HIV Status to children in Sub-Saharan Africa: a systematic review. Medicina (Kaunas). 2019;55(8):433. https://doi.org/10.3390/medicina55080433

Evangeli M, Kagee A. A model of caregiver paediatric HIV disclosure decision-making. Psychol Health Med. 2016;21(3):338–353. https://doi.org/10.1080/13548506.2015.1058959

Eriksen J, Carlander C, Albert J et al. Antiretroviral treatment for HIV infection: Swedish recommendations 2019. Infect Dis (Lond). 2020;52(5):295-329. https://doi.org/10.1080/23744235.2019.1707867

Gregory S. How do the health care systems in the United Kingdom compare with others internationally? 2016. https://tinyurl.com/uh6zj58f (accessed 16 December 2021)

Hayes R. Life expectancy for people living with HIV. 2021. https://tinyurl.com/yc6cf3be (accessed 16 December 2021)

Health Systems and Policy Monitor. 2021a. United Kingdom. Health Systems in Transition (HiT) profile of United Kingdom. 2021a. https://tinyurl.com/44pta6ds (accessed 21 December 2021)

Health Systems and Policy Monitor. Sweden. Health Systems in Transition (HiT) profile of Sweden. 2021b. https://tinyurl.com/2p9c53ph (accessed 21 December 2021)

Instone SL. Perceptions of children with HIV infection when not told for so long: implications for diagnosis disclosure. J Pediatr Health Care. 2000;14(5):235–243. https://doi.org/10.1067/mph.2000.107338

Jemmott JB 3rd, Heeren GA, Sidloyi L, Marange CS, Tyler JC, Ngwane Z. Caregivers' intentions to disclose HIV diagnosis to children living with HIV in South Africa: a theory-based approach. AIDS Behav.

2014;18(6):1027–1036. https://doi.org/10.1007/s10461-013-0672-0
John-Stewart GC, Wariua G, Beima-Sofie KM et al. Prevalence, perceptions, and correlates of pediatric HIV disclosure in an HIV treatment program in Kenya. AIDS Care. 2013;25(9):1067–1076. https://doi.org/10.1080/09540121.2012.749333
Kallem S, Renner L, Ghebremichael M, Paintsil E. Prevalence and pattern of disclosure of HIV status in HIV-infected children in Ghana. AIDS Behav. 2011;15(6):1121–1127. https://doi.org/10.1007/s10461-010-9741-9
Kourtis AP, Lee FK, Abrams EJ, Jamieson DJ, Bulterys M. Mother-to-child transmission of HIV-1: timing and implications for prevention. Lancet Infect Dis. 2006;6(11):726–732. https://doi.org/10.1016/S1473-3099(06)70629-6
Kyaddondo D, Wanyenze RK, Kinsman J, Hardon A. Disclosure of HIV status between parents and children in Uganda in the context of greater access to treatment. SAHARA J. 2013;10(Suppl 1):S37–S45. https://doi.org/10.1080/02664763.2012.755323
Le Prevost M, Arenas-Pinto A, Melvin D et al; Adolescents and Adults Living with Perinatal HIV (AALPHI) Steering Committee. Anxiety and depression symptoms in young people with perinatally acquired HIV and HIV affected young people in England. AIDS Care. 2018;30(8):1040–1049. https://doi.org/10.1080/09540121.2018.1441972
Maphumulo WT, Bhengu BR. Challenges of quality improvement in the healthcare of South Africa post-apartheid: A critical review. Curationis. 2019;42(1):e1–e9. https://doi.org/10.4102/curationis.v42i1.1901
Merzel C, VanDevanter N, Irvine M. Adherence to antiretroviral therapy among older children and adolescents with HIV: a qualitative study of psychosocial contexts. AIDS Patient Care STDS. 2008;22(12):977–987. https://doi.org/10.1089/apc.2008.0048
National Department of Health South Africa. Disclosure guidelines for children and adolescents in the context of HIV, TB and non-communicable diseases. July 2016. https://tinyurl.com/ptfayrwz (accessed 4 January 2022)
NHS England. An introduction to the NHS. 2021. https://www.england.nhs.uk/get-involved/nhs (accessed 16 December 2021)
Pinzón-Iregui MC, Beck-Sagué CM, Malow RM. Disclosure of their HIV status to infected children: a review of the literature. J Trop Pediatr. 2013;59(2):84–89. https://doi.org/10.1093/tropej/fms052
Punpanich W, Lolekha R, Chokephaibulkit K, Naiwatanakul T, Leowsrisook P, Boon-yasidhi V. Factors associated with caretaker's readiness for disclosure of HIV diagnosis to HIV-infected children in Bangkok, Thailand. Int J STD AIDS. 2014;25(13):929–935. https://doi.org/10.1177/0956462414526576
Rowson K. Naming HIV to children: it's time to talk. HIV Nursing. 2017; 17:138–141. https://tinyurl.com/4895fxsb (accessed 16 December 2021)
Rydström LL, Wiklander M, Navér L, Ygge BM, Eriksson LE. HIV-related stigma and health-related quality of life among children living with HIV in Sweden. AIDS Care. 2016;28(5):665–671. https://doi.org/10.1080/09540121.2015.1120267
Townsend CL, Byrne L, Cortina-Borja M et al. Earlier initiation of ART and further decline in mother-to-child HIV transmission rates, 2000–2011. AIDS. 2014;28(7):1049–1057. https://doi.org/10.1097/QAD.0000000000000212
UNAIDS (Joint United Nations Programme on HIV/AIDS). UNAIDS data 2020. 2021. https://tinyurl.com/2p94ranx (accessed 16 December 2021)
United Nations. The United Nations Convention on the Rights of the Child. 1989. https://tinyurl.com/3xuypfc3 (accessed 16 December 2021)
United Nations Department of Economic and Social Affairs. World Economic Situation and Prospects 2014. 2014. https://tinyurl.com/23nt5k95 (accessed 16 December 2021)
Vreeman RC, Nyandiko WM, Ayaya SO, Walumbe EG, Marrero DG, Inui TS. The perceived impact of disclosure of pediatric HIV status on pediatric antiretroviral therapy adherence, child well-being, and social relationships in a resource-limited setting. AIDS Patient Care STDS. 2010;24(10):639–649. https://doi.org/10.1089/apc.2010.0079
Vreeman RC, Gramelspacher AM, Gisore PO, Scanlon ML, Nyandiko WM. Disclosure of HIV status to children in resource-limited settings: a systematic review. J Int AIDS Soc. 2013;16(1):18466. https://doi.org/10.7448/IAS.16.1.18466
Vreeman RC, Scanlon ML, Mwangi A et al. A cross-sectional study of disclosure of HIV status to children and adolescents in western Kenya. PLoS One. 2014;9(1):e86616. https://doi.org/10.1371/journal.pone.0086616
Wiener LS, Battles HB. Untangling the web: A close look at diagnosis disclosure among HIV-infected adolescents. J Adolesc Health. 2006;38(3):307–309. https://doi.org/10.1016/j.jadohealth.2005.03.024
Wiener L, Mellins CA, Marhefka S, Battles HB. Disclosure of an HIV diagnosis to children: history, current research, and future directions. J Dev Behav Pediatr. 2007;28(2):155–166. https://doi.org/10.1097/01.DBP.0000267570.87564.cd
World Bank. Children (0–14) living with HIV–Uzbekistan. 2021. https://tinyurl.com/3wr59csj (accessed 20 December 2021)
World Health Organization. Guidelines on HIV Disclosure counselling for children up to 12 years of age. 2011. https://apps.who.int/iris/handle/10665/44777 (accessed 16 December 2021)

KEY POINTS

- Access to effective treatment allows HIV to be identified as a chronic health condition and can result in normal life expectancy
- Naming HIV to children (disclosure) remains a challenge internationally
- Stigma and discrimination remain significant for children and families living with HIV
- Health professionals must challenge and re-educate colleagues and the public to overcome stigma and discrimination

CPD reflective questions

- Consider public perceptions about HIV. Do you think the general public has a good understanding of HIV prevention, transmission and treatment outcomes?
- Reflect on whether you have witnessed or been aware of stigma and discrimination related to HIV in clinical settings. How can you play a role in reducing stigma?
- Consider the care needed to support children and families to live well with HIV. How can you support families living with or affected by HIV in the community setting?