

The Children's HIV Association of the UK and Ireland (CHIVA) supports the following statement concerning children's knowledge about their HIV. Practitioners are urged to evaluate their approaches to supporting children's knowledge and understanding of HIV with due regard to this statement.

Health practitioners should consider telling children that they have HIV from the age of 6, taking into account their cognitive capacity and any current social considerations, aiming for most children knowing the name of their diagnosis before the age of 9. Health practitioners should lead this, in collaborative partnership with carers and voluntary sector and social care services.

This statement is based on a range of considerations:

Experience and evidence:

- Published evidence that supports the WHO *Guideline on HIV disclosure counselling for children up to 12 years of age*, which recommends that primary school age children (defined as age 6 and above) should be told their HIV status. http://www.who.int/hiv/pub/hiv_disclosure/en/index.html
- Evidence from practice, which has frequently reported increased social and psychological challenges and stresses within families where knowledge about HIV is actively kept from the younger child, and when naming HIV happens very close to the onset of adolescence.
- Other chronic illnesses of childhood show that most children's ability to cope with their condition is best supported if they are given knowledge about it as they grow up.

Key aims and principles:

- To reduce anxiety and the stigma that has been associated with HIV by providing the child with appropriate knowledge about their own condition. This explanation should be separate from the adult family members' experiences and associations of HIV.
- The child should be supported with approaches that:
 - build their knowledge and understanding of HIV appropriate to their differing needs as they get older
 - provide ongoing opportunities to have open and honest conversations about HIV
 - promote conversations that explore how and when to manage wider sharing of their HIV.
- All parents and carers will need to experience confident conversations from their doctors and other health professionals about the benefits of children knowing about their HIV diagnosis at a younger age.
- To help achieve more confident and open discussions; in addition all new families new to a clinic should experience open discussions about HIV with the child present, whatever the age of the child.

Health professionals should consider their confidence around this issue and, where needed, seek guidance and support from their CHINN network lead centre.

Further detailed exploration of the issue of children's knowledge about their HIV status is covered in two documents available here:

1. *CHIVA practice guidance for health professionals on talking to children about health and HIV: conversations and approaches to enhance understanding and wider disclosure*

This guidance, based on UK and international evidence, promotes approaches to support conversations with children to happen as early as possible through working in a collaborative way with carers and families. It considers factors that influence successful communication with children as well as the process of building more understanding over time, and how obstacles to understanding may be overcome.

https://www.chiva.org.uk/files/7914/7627/7970/Talking_to_children_about_HIV_in_health_settings-1.pdf

2. *CHIVA Quality Standard: open and honest practice when working with children*

This quality standard addresses the practice of those working outside of the clinic setting and considers how conversations about HIV in families are approached. The standard outlines 'Aims' that support practice, ensuring 'open and honest' conversations about HIV with children take place, and the spheres of secrecy around HIV that exist in many support organisations are addressed.

The standard contains tools, which organisations can apply when working towards achieving the aims.

A range of organisations and professionals working outside the clinic setting may find the standard useful, for a rationale for 'open and honest practice' with children who have HIV, and for guidance and tools to address practice. Those working in the clinic setting may also find the standard useful to explore the evidence base in published research, and to support collaborative working across services.

https://chiva.org.uk/files/8015/0642/1695/CHIVA_STANDARDS_2017.pdf