

Grace, GiGi and HIV: Co-Producing National Resources to Support Communication and Naming HIV to Children (Chiva, UK)

Background

Effective and age-appropriate communication of an HIV diagnosis to children remains a challenge for families and healthcare professionals. Global evidence suggests that many children and adolescents are unaware of their HIV diagnosis, with limited professional support and a lack of up-to-date resources identified as key barriers. To address this gap, a series of co-produced resources were developed to support the early naming of HIV to children. This work builds on evidence highlighting the importance of developmentally appropriate HIV communication and the need to address the intergenerational stigma that can delay discussions about HIV, and influence children's understanding of their diagnosis (Warburton et al., 2022; Warburton et al., 2026).

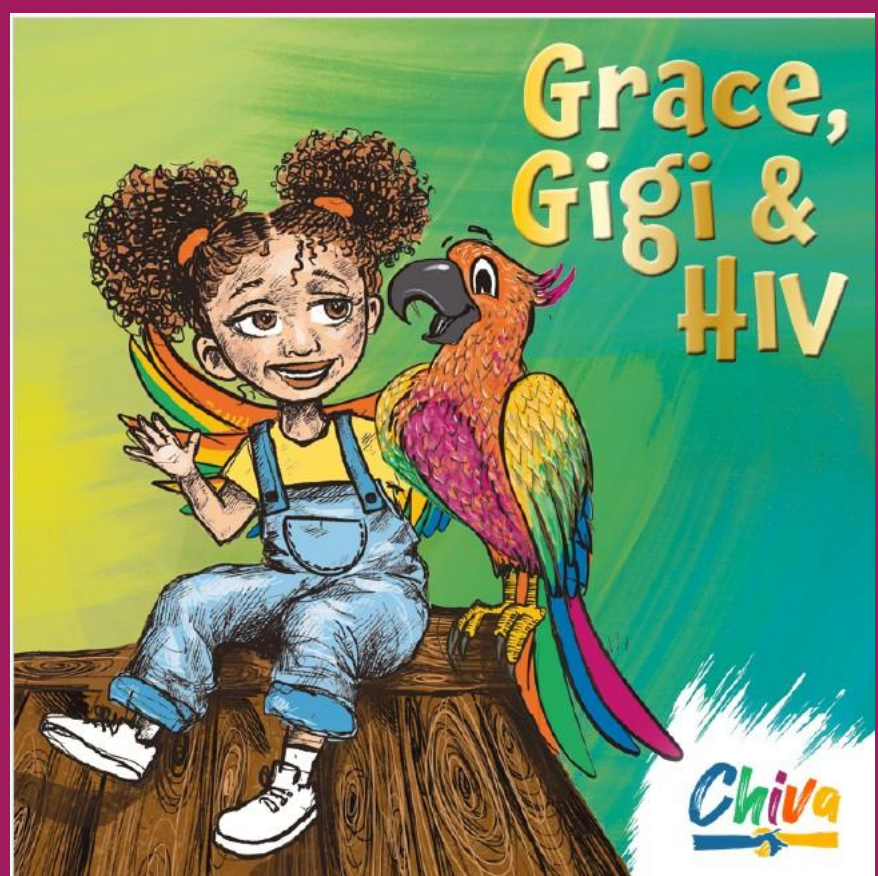
Methods and Approach

Co-production was essential in resource development to ensure that resources were meaningful, culturally sensitive, and responsive to the needs of children and families living with or affected by HIV. A series of participatory focus groups and reviews involved children, adolescents and parents sharing their experiences to inform the development of appropriate, accessible resources. An artist was identified and attended the workshops using live capture methods.

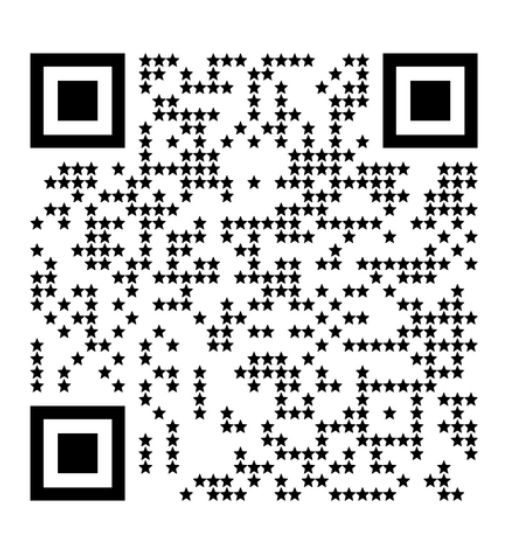
Three focus groups were conducted involving children and young people, parent and families living with or affected by HIV. An artist captured narratives in all groups. A book, card set and video explanation were identified as preferred formats.



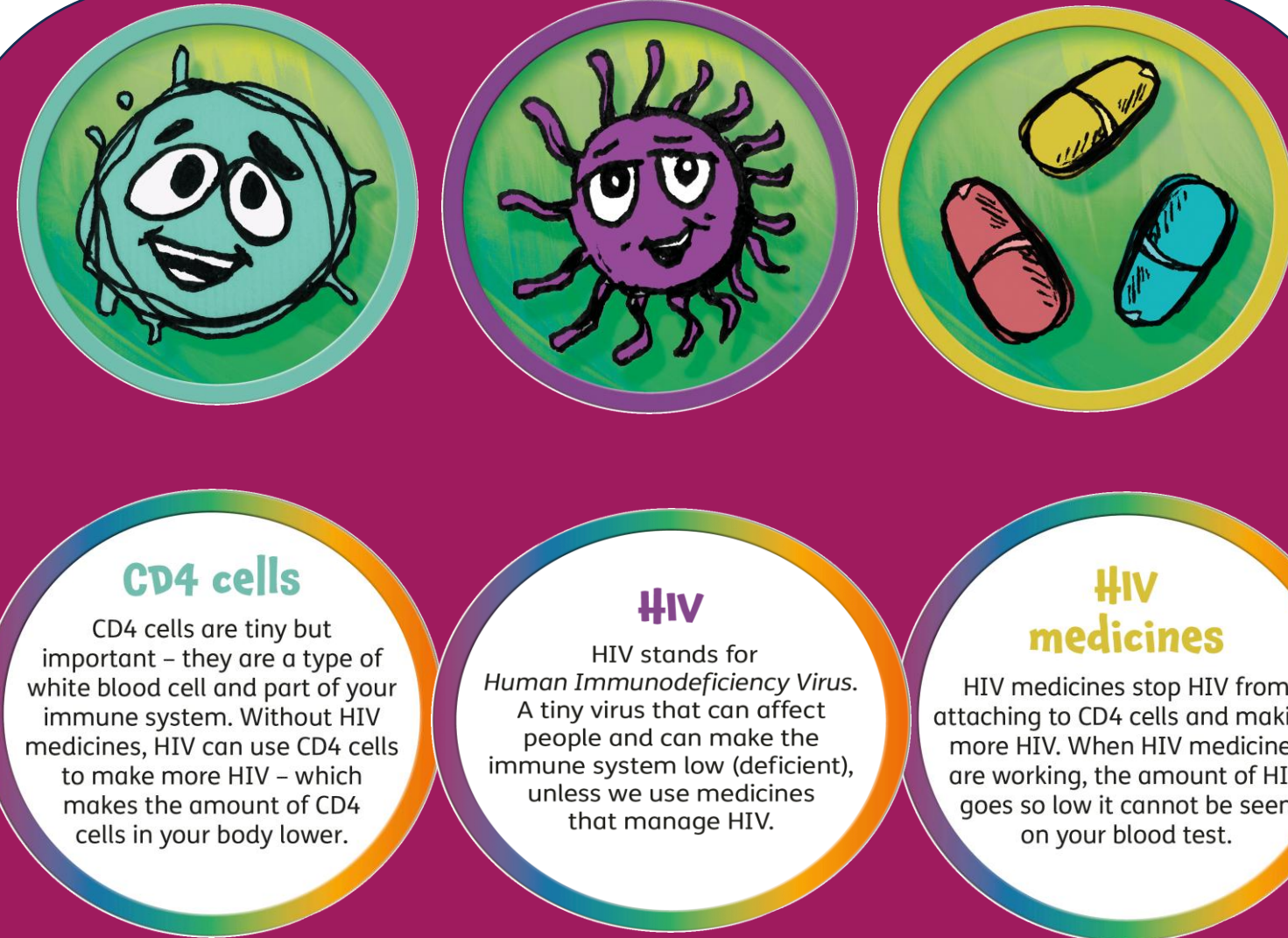
Regular development meetings, combined with input from children, young people, parents, community representatives, and healthcare professionals, supported the iterative refinement and co-production of the resources.



Read online



Children's Book



Explanation Cards



Growing Well with HIV

A video for professionals support naming HIV to children

Training Video

Findings



Children and young people expressed a clear desire to know and understand their HIV diagnosis early through honest, age-appropriate communication.

- Participants highlighted the importance of clear, accurate language, relatable narratives, visual materials, and culturally diverse representation to support understanding and reduce stigma.
- Professional confidence and leadership was found to be very important.

Conclusion and Recommendations

- Co-produced resources can support earlier naming of HIV and promote open conversations.
- Children want truthful information about their diagnosis, and parents feel more empowered when equipped with professional support and appropriate resources.
- Healthcare professionals should adopt a confident, proactive approach to discussing HIV with families, using accurate and consistent language.
- Embedding these resources within routine care may reduce secrecy and stigma while supporting children's knowledge, wellbeing and long-term engagement with HIV care.

