

Chiva Impact Report 2024



Company no. 06337017 Charity no. 1122356

CHARITY MISSION STATEMENT

Chiva is dedicated to enhancing the health and wellbeing of children, young people, and young adults growing up with HIV. Chiva works to ensure that young people living with HIV have the treatment and care, knowledge, understanding, skills and wider support needed to live well and achieve their greatest potential.

Chiva achieves its mission by providing direct support for children, young people and young adults living with HIV and their families, working closely with clinic teams, and by delivering programmes which offer comprehensive and integrated support to empower young people towards healthier and more fulfilling lives.

HOW WE WORK

Chiva delivers its work through a dedicated team of staff, supported by volunteers, Trustees, Steering Group members, and strategic partnerships. Together, we provide vital support and advocacy for children, young people and young adults living with HIV across the UK and Ireland.

Our work is structured around distinct projects that align with our mission, ensuring young people receive tailored support. By operating at a national level, we bring young people together through residentials, allowing them to build peer networks that foster connection, understanding, and support. Regionally, our staff collaborate closely with clinical teams to provide direct, locally based support and practical assistance.

Beyond direct support, Chiva plays a key role in strengthening professional practice. We produce clinical guidelines and resources, facilitate education and professional development opportunities, and offer access to a professional peer network through Chiva membership.

Advocacy and research are central to our work. We engage in research, audits, and studies to ensure the needs of young people with HIV are fully understood. By representing their interests in NHS

service commissioning and influencing wider policy, we help shape the future of care and support for this community.

Public awareness is another key focus. Through developing campaigns and educational resources, we work to improve wider understanding of HIV, particularly as it affects children and young people.

Young people's voices are at the heart of Chiva. Our dedicated participation programme provides meaningful opportunities for young people to influence and shape our work, contribute to policy development, and raise awareness. We also offer paid and volunteer roles, including co-production, peer leadership, and youth facilitation, ensuring young people can progress from programme participants to leaders within the organisation.

Chiva remains committed to empowering young people, strengthening professional networks, and driving systemic change to improve the lives of those growing up with HIV.

STRATEGY AND OBJECTIVES

Chiva's strategy to achieve its mission is framed around three pillars;







Six core objectives are linked with the pillars:

- 1 Develop comprehensive and integrated support that addresses the physical, emotional and social needs of children, young people and young adults living with HIV.
- Enhance public awareness and understanding of HIV in the wider population of children, young people, and young adults.
- 3 Enhance professional understanding of best practices in HIV.

- Assess the impact of Chiva's support programmes and identify areas for improvement or expansion.
- **5** Ensure young people participate fully in the research agenda and evidence generation.
- Influence the research and policy agenda to enable prompt identification of emerging needs among young people and ensure these inform policy.

Our strategic objectives outline our commitment to comprehensive support, public awareness, professional understanding, influencing and engaging with research, youth participation, and impact assessment.

ACHIEVEMENTS IN 2024

The number of young people and young adults who were provided with support from Chiva in the year grew in 2024 resulting from an increase in referrals from healthcare professionals. Engagement data suggests increased awareness of the support and services available at Chiva and is also reflective of the more limited access to support from wider sources.

The number of young people who engaged with particular projects is outlined (right), in addition 256 young people were provided direct support from regional staff members, who work closely with clinic teams year round. Chiva staff based in regions work to provide psychosocial support and practical assistance in cases of hardship. This direct support work is becoming more extensive and often involves staff working with multiple agencies to meet identified needs. As public sector services continue to face capacity and resource challenges, demand for support from charities is only likely to increase. In the past year Chivas' case work has included advocacy and support relating to homelessness and destitution, welfare rights, mental health, managing late diagnosis of HIV and support for those newly arrived in the UK.

CHIVA SUPPORT 2024



Total number of young people supported

388



- Number of young people who attended F2B camp
- Number of young people who attended the Families' Weekend
- Number of young people who engaged as part of the Chiva Youth Committee (CYC)
- Number of young people who had Peer Leadership and Volunteer roles
- Number of young adults who engaged with the Blueprint programme
- Number of young adults who attended Art Is Key
- Number of young people supported by regional staff

Chiva staff are providing a service which supports medical teams in an effort to ensure positive health outcomes for young people which can only be achieved when basic needs and psychosocial wellbeing is attended to.

KEY EVENTS HELD DURING THE YEAR

MARCH 2024

In March, the 18th annual Chiva conference was delivered in Birmingham, engaging health professionals and other stakeholders to address Chiva's objectives to improving care and outcomes for young people living with HIV and enhance professional understanding. This was the first inperson only conference delivered since the Covid-19 Covid-19 pandemic and 138 people attended from across the UK and international delegates came from Ireland, Denmark, Sweden and Albania.

18TH ANNUAL CHIVA CONFERENCE



Number of professionals who attended Conference

138

Attendees spanned **65** different hospitals, universities and organisations

100% of the 80 respondents to the evaluation survey agreed or stongly agreed that the day was interesting and relevant to their professional needs

Fabulous day. Well planned. Great topics, brilliant location. Well done Chiva for all your hard work in putting together such a wonderful conference for us all!

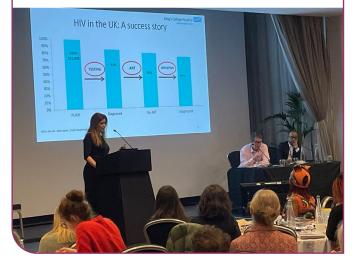
As it was my first time I was very impressed with the content of all the guest speakers.

The programme included sessions focused on how HIV-related stigma can be better understood and effectively addressed; evidence from engagement in care research; and understanding trauma and its effect on health care engagement and outcomes.

The annual Chiva conference remains the UK's key professional learning event on HIV in childhood and young adulthood, providing continued professional development and is accredited by the Royal College of Paediatrics and Child Health (RCPCH).







APRIL 2024

Chiva's Art is Key project was delivered across a week in April in partnership with Turtle Key Arts. This project supports young people aged 17-25 to share their stories through the creative arts, producing powerful pieces of music, drama, spoken word, or podcasts.

20 young people attended the residency and worked with a number of film, music, drama and design leaders to create stories, songs, settings and ultimately a series of animated scenes inspired by their journeys.

Young people reflected the benefits of connections formed with peers and the positive impact on their confidence and feeling at ease that developed through the week.

"My magical moment is when we all shared a laugh together and felt like one big family."

"I'm taking with me a lot of good friend[s] that last a lifetime."

"I learnt to open up to people"

Also recognising their talents and acquiring new skills.

"Being able to tap into my inner music creativity."

"Learned new skills [...] able to put those skills to use and explore however we wanted."



At the end of the project, young people were asked for one word which described how they felt after the week's residency. Responses below.



The animation shorts developed by the young people at Art is Key 2024 can be seen here: www.chiva.org.uk/art-is-key

JUNE 2024

The second Chiva Families' Weekend residential was delivered in June. 60 individuals comprising 20 families attended, including infants through to teenagers. There was strong support for this residential and high numbers of applications received. The evaluation revealed a high need for family focused support and a desire among families to connect and build peer networks.

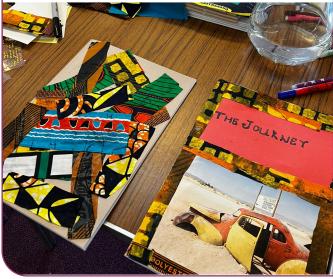
"Being open and honest was a challenge at the start of our journey... we are forming a strong bond as a community." (Parent/carer at the end of the Families' Weekend)

The evaluation demonstrated that the weekend had helped to build a sense of connection and community which was valued by participants. It also served to build knowledge of HIV and provided support with managing other issues in families. The impact of this support strengthens coping strategies among families and reduces isolation.

Art-based activities and use of creativity was well received allowing for exploration of sometimes sensitive and difficult topic areas in a comfortable way. This facilitated creative expression and sharing.







JULY 2024

A second cohort of participants completed the Blueprint programme for 18-25-year-olds between November 2023 and July 2024. The programme supports young people growing up with HIV with the transition into adulthood. It covers themes of confidence and self-esteem, financial literacy, mental health, and HIV. These are addressed through a range of activities including online group sessions - sometimes with expert guests to deliver education workshops, one-to-one coaching, day meet-ups and a residential retreat. In addition, four bespoke workbooks, connected with the programme themes, were designed for the programme to enable participants to extend their learning and engagement.

In the 2023-2024 programme, 27 young people attended a residential retreat at the beginning of the programme. Engagement dropped to 24 following the residential. In total, 99 one-to-one coaching sessions were provided, nine online group educational and support sessions, and an in-person day meet-up on mental health and wellbeing. The programme has had a strong co-production focus from its initial development.





Participants reported high enjoyment in online sessions, with increased confidence and engagement over time. The programme provided a safe space for shared experiences, with mental health, confidence, and self-esteem being the most valued themes. All participants said they would recommend it.

"It was a safe space for me, it's a lot easier to talk to people that have similar shared experiences"

(Blueprint participant)

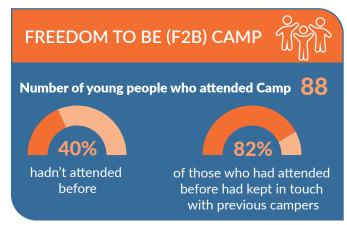
The new 2024 cohort included 24 new recruits, with 20 actively engaging ongoing. The residential retreat held in November 2024 focused on confidence, self-care, and wellbeing, alongside educational and creative sessions. Increased peer roles in the delivery team for young adults with HIV clearly enriched the experience for participants.

"It was great to learn how different people navigate through living with HIV and learn from other experiences"

(Blueprint participant)

AUGUST 2024

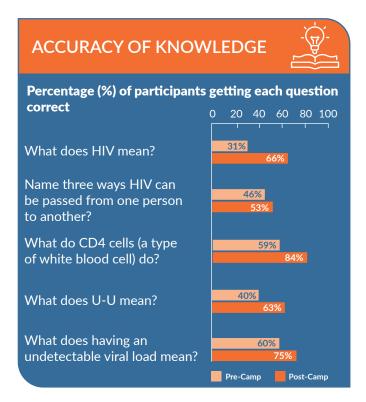
Freedom to Be (F2B), the residential support camp for 11–17 year olds growing up with HIV in the UK and Ireland, was delivered in August, taking place over five days. It was the 15th annual F2B camp and 88 young people attended.



F2B camp provides young people the opportunity to build connections with peers whilst learning more about HIV through an action-packed week of workshops and activities, from adventure sports to creative arts, yoga and wellbeing.

Camp is delivered by staff and long-term associates and relies on the commitment of volunteers and partners to support delivery. Many young people return to camp as volunteers when older. The Camp Leader volunteer programme provides dedicated roles for youth peer mentors who have grown up with HIV.

The evaluation undertaken indicates that the camp was successful in meeting its principal aims to provide a safe and supportive environment for young people living with HIV to connect, learn, and build confidence. Key findings show improvements in HIV knowledge, increased comfort talking about HIV, and a strong sense of belonging reported by participants.



"I've learned that if you take your meds at the right time consistently, eventually you won't be able to spread it as it'll be too undetectable."

(YP reported learning at end of camp)



Participants reported feeling more comfortable discussing their HIV status after camp.

"I learned about how to tell people about your feelings and not to keep your HIV to yourself and try to tell people more about it".

"That I can be open and confident about my HIV."

"HIV doesn't change me."

One of the most significant impacts of attending F2B is a reduction in social isolation and building social connections. It is consistently identified as the key benefit of attending by young people, leading to a greater sense of acceptance of self and HIV and a sense of belonging in a community.





PROGRAMME ACTIVITY THROUGH THE YEAR

EXPANDING SUPPORT TO YOUNG PEOPLE AND FAMILIES LOCALLY

Chiva extends support to young people and their families through the year, via a regional support programme delivered by Chiva specialist support staff working in different regions of the UK. Staff are based in London, Birmingham and Sheffield covering the surrounding regions, with core team members based in Bristol covering Bristol, the South West and Wales.

Staff work closely with the medical teams in these locations to provide support for clinic appointments as well as undertaking work in the community and collaborating with other agencies to deliver support and provide advocacy. Staff engage in home visits and organise peer meet-ups through the year to enable peer support networks to grow locally and deliver HIV education activities aimed at building self-efficacy skills.

CHIVA SUPPORT 2024



Number of young people supported by regional staff

256

EVENTS



Total number of residential or day events held

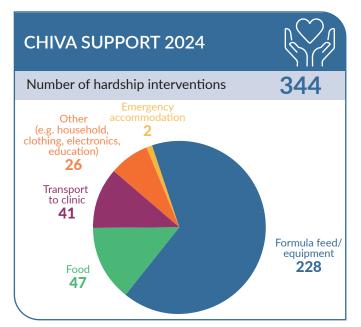
13 Of which were regional meet-ups

Chiva staff regularly follow up with young people who have missed appointments, and address welfare and housing issues and provide mental health support, all of which will impact engagement with clinical care if not effectively addressed. Staff provide an advocacy role supporting young people's engagement with statutory services. Chiva staff are increasingly supporting young people who have had complex childhood experiences and adversities such as parental bereavement, which can result in increased support needs in early adulthood with known risks to health and wellbeing.

Appropriate psychological support has been increasingly difficult to access via NHS services. Where support has proved impossible to access, Chiva have funded psychological and therapeutic support privately for a number of young people, to ensure mental health needs are addressed, whilst continuing to advocate for the need for psychological support to be available via NHS services.

Chiva continues to provide practical assistance through a hardship support fund where there are ongoing needs.

The graphic below illustrates what was provided to young people and their families in 2024. Chiva partners with the Food Chain to distribute food and formula feed to families who are referred to us for this assistance.



PARTICIPATION

Participation opportunities for young people within Chiva include: the Chiva Youth Committee (CYC); Camp Leader programme at the F2B camp; peer leaders at regional meet-up events; youth speakers at conferences and education events held by Chiva and wider organisations; and engaging with the media and other public forums.

The CYC comprises 20 young people living with HIV who are aged under eighteen when joining the committee. They meet regularly throughout the year.

SOME OF THE KEY ACHIEVEMENTS FROM THE CYC IN 2024

- A symposium at the annual Chiva conference;
- Supporting a Chiva Steering Group led project developing a clinic experience survey;
- Participating in a project aiming to eliminate discrimination of people living with HIV in tattoo shops;
- Attending two international conferences, the International AIDS Society conference in Munich in July and the Adolescence and HIV conference in Nairobi in October:
- Providing consultation on the development of the new Government HIV Action plan;
- Contributing to social media campaigns such as the Children's Commissioners first 100 days campaign - sharing young people's priorities for the new Government;
- Participating in a Patient and Public Involvement (PPI) Group at the Medical Research Council Clinical Trials Unit; and
- Generating content for Chiva's new TikTok account targeting youth audiences with HIV awareness raising content.





Evidence collected through exit interviews and ongoing evaluation of engagement illustrates how being a member of the CYC provides valuable participation benefits for the organisation and delivers wider campaigns aligned with Chiva's strategy. It also supports young people in their own growth and development and helps improve their relationship with their HIV, leading to increased confidence and coping skills.

"I felt like all my inputs were considered and might significantly impact the lives of other young people that can relate to me".

Member of the CYC

Attendees at the annual Chiva conference for professionals again commented on the value of young people's participation at this event for their learning and understanding:

"This was my first ever attendance at a Chiva conference and I was touched and thoroughly impressed by the work the youth are doing and their overall engagement and growth."

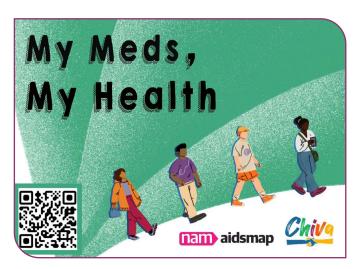
"Fantastic. Excellent. Clear, articulate, engaging and great to hear the voices of young people."

(Comments from delegates in the Chiva conference 2024 evaluation)

Youth participation was also evident at the annual British HIV Association Conference, where two young people accompanied the Chiva CEO to deliver a session on adolescent mental health and wellbeing.

HIV AWARENESS & UNDERSTANDING

"My Medicines My Health" resource development project was initiated in 2023 and the development work was completed in 2024. Ongoing promotional work and dissemination continues.



The resources developed through a co-production approach with young people from the CYC included:

- A comprehensive medicines handbook;
- Information sheets on specialist topics including PrEP, PEP, contraception and developments around finding an HIV cure;
- An animation series which explores different aspects around HIV-related health, medicines, and growing up living with HIV; and
- Video content for sharing on social channels to raise awareness among wider youth audiences.

A screening of the animations took place at the International AIDS society conference in Munich in July 2024.

Chiva made two films in 2024 in celebration of 15 years of delivering Freedom to Be (F2B) support camp. The short film, *Safe With Me*, was co-written by a 17-year-old student and tells the story of two young people who make a connection at Chiva camp, exploring themes of HIV-related stigma, based on real life experiences of young people who have attended Chiva's annual camp.

Freedom to Be: 15 years of Chiva Camp is a documentary exploring the profound impact camp has had on the lives of the young people who attend, hearing from the people who help to deliver the camp and young people who have taken part over the years.

Both films were finalists at the Smiley Charity Film Awards 2025 and Safe With Me won an award.



SOCIAL MEDIA AND COMMUNICATIONS

Chiva has a strong presence on social media and uses different channels to communicate with partners in the HIV sector and wider stakeholder organisations and individuals, as well as raising awareness and challenging myths which can prevail in the public.

Digital platforms serve to communicate our work activities and deliver campaign messaging. Chiva has two Instagram accounts with targeted audiences, one being in the public domain used for awareness raising and general promotion and one private account aiming to reach young people and families who may wish to engage with our programmes and resources.

Chiva launched on TikTok in the summer of 2024 and this platform will be used primarily for youth generated content aimed at awareness raising among the wider youth population.

Videos for this platform have been created by the CYC and also commissioned as part of the My Medicine My Health resource project, providing engaging and educational content on topics such as PrEP and PEP and developments with finding a cure for HIV.



The Chiva website is regularly updated with news and information ongoing, offering a hub of resources for clinical use and to support wider understanding of HIV. It also provides HIV-related information for young people and parents/carers and highlights projects and support offered by Chiva. In 2024, Chiva updated its website, with a full review of content, a refreshed design and simpler navigation to improve presentation and access.

Chiva produces a quarterly newsletter for its professional and affiliate membership. The newsletter provides updates on current Chiva activities, information concerning wider events of potential interest to members, recent research and publications.



DIGITAL MEDIA	#
Number of website views	35,118
Number of social media post views	74,602
Number of social media post engagements	1,861
Number of Youtube video views	5,405

WORKING WITH PROFESSIONALS

Chiva's work with professionals is led by the Chiva Steering Group. The Steering Group meets twice a year and expert groups within the overall group meet additionally, to work on specific areas. Their focus is on providing support to professionals working in HIV and ensuring optimal care and outcomes for young people.

PROFESSIONAL MEMBERSHII



- Average number of professional Education Meeting attendees
- 247 Number of Chiva Professional Members
- Average number of professional newsletter subscribers

CONFERENCES, EDUCATION MEETINGS AND EVENTS

In addition to the annual Chiva conference, Chiva also delivered four education meetings to provide access to specialist topics of interest for Chiva members and wider stakeholders. Expert speakers presented information on topics such as; highlights from an international conference on retroviruses; complex cases of resistance to HIV medication; and supporting young people's sexual health.

CLINICAL GUIDELINES AND TOOLS

In 2024, the Chiva Guidelines Group undertook a review of the resources and guidelines on the Chiva website, ensuring that the guidelines and tools continue to be managed through a robust peer review process and resulting in a re-categorisation of resources for professionals and identification of areas which would benefit from new guidance.

The Chiva Standards of Care were reviewed and comprehensively updated.

Guidelines in final stages of update include Sexual Health, and a revision of the Psychological Standards of Care.

The group have agreed to undertake a larger scale project around guidelines for HIV testing of children and young people, which will be developed throughout 2025.

AUDITS AND COMMISSIONING

The key activity in the year for this group involved taking forward an audit of transition and establishing a partnership with the National HIV Nurses Association (NHIVNA) to deliver the clinic audit.

A qualitative phase of a previous study, quantifying the number of young people attending clinics who were in care or had been adopted, also took place via focus group discussions held by a master's student at the University of Bristol in partnership with Chiva. A report from this study will provide insight into particular experiences and potential needs identified among this group.

Chiva holds a place on the British HIV Association (BHIVA) Audit committee and is involved in the design of their annual national audit.

Chiva CEO and clinicians from the Steering Group attend the Clinical Reference Group (CRG) meetings which manage the commissioning of HIV clinical services in England, to ensure key decisions on service delivery and care quality discussions include consideration of young people's needs. Chiva also chaired a working group for updating the service specification on paediatric HIV clinical services, working with the NHSE (NHS England). This updated service specification is now finalised and aims to ensure the continuation of expert led specialist HIV paediatric clinical care, which has been developed over the past 30 years, to ensure optimal care for children and young people in the future.

HEALTH ORGANISATION LINKS

This group leads on links with other health organisations, coordinating responses to consultations by engaging with Chiva membership to collate their practice-based experiences and evidence and submitting these to influence policy and service development. It also facilitates meetings for professional groups working in the sector.

In 2024, Chiva worked with the National AIDS Trust to provide a response to the Relationships, Sex and Health Education (RSHE) Guidance Consultation, contributed to a NHIVNA consultation on personcentred models of care and provided a response to the AII Party Parliamentary Group on HIV (APPG) HIV/Sexual Health services consultation as well as completing a survey from Feed UK regarding the cost of infant formula.

PROFESSIONAL GROUPS

Chiva facilitates professional engagement and networking by coordinating groups focused on current priority issues in practice and exploring opportunities for new projects identified by Chiva members. These groups include paediatric nurses, psychologists, and a young adult special interest group, along with a research group for pursuing research initiatives.

Supporting these professional groups ensures awareness of key issues in practice, which in turn informs strategic planning.

The research group undertook a Patient Reported Outcome Measures (PROMS) and Patient Reported Experiences Measures (PREMS) project in 2024, to assess the benefits of developing these tools for use with young people and young adults. The group then focused on the development of a PREM in collaboration with the CYC. This is now being rolled out in clinics across the UK. The tool provides clinics a means through which to capture patient feedback on the experience of attending clinic and identify any necessary improvements or issues to address.

PARTNERSHIPS

In 2024, Chiva has continued to strengthen and expand its key partnerships across the HIV sector. working collaboratively and lobbying to improve outcomes for children, young people, and families affected by HIV. Chiva maintains active relationships with national HIV associations, including BHIVA and NHIVNA, and holds representation on the BHIVA audit group. As an expert resource, Chiva provides guidance to national organisations such as the Department of Health and Social Care, NHS England, commissioning bodies, and Royal Colleges. Additionally, Chiva supports ongoing data reporting on HIV in childhood through working with the CHARS team at UCL and has worked with the UK Health Security Agency to ensure accurate data collection is maintained across the whole of the UK.

Chiva continues to engage with the All-Party Parliamentary Group on HIV/AIDS and maintains strong partnerships within the HIV voluntary sector. In 2024, key collaborations included partnering with the National AIDS Trust to contribute to the HIV Outcomes initiative and Government consultations on the new HIV Action Plan. Chiva also worked alongside National AIDS Trust and The Food Chain on a significant campaign advocating for universal access to formula feed for all infants of infants of mothers/birthing parents with HIV who require it.

Chiva is also a member of the Fast Track Cities Initiative in Bristol and continues its involvement in the HIV Outcomes Group Steering Group, both at the European level and within the UK, working to improve the quality of life and long-term health outcomes for people living with HIV.











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Chiva

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