



Family Conference 3rd March 2018 Evaluation Report

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Children's HIV Association

CHIVA aims to ensure that every child and young person living with HIV across the UK has the optimum health care provision, and access to social and peer support. Through working with health care professionals, providing information, resources and clinical guidelines and providing support and information to children, young people and their families.

We work to raise awareness of HIV and tackle the stigma and discrimination experienced by people living with HIV. Our youth committee provides a voice for children and young people with HIV and ensures their wishes and experiences shape the development of CHIVA and are heard in public forums.

CHIVA provides critical support to children with HIV. Our peer support and education programmes aim to reduce the extreme isolation children growing up with HIV frequently face, support them to accept and understand their HIV status and support their health and wellbeing. Our programmes provide emotional and educational support to improve awareness, understanding and acceptance of HIV and provide access to a critical peer support network

CHIVA holds an annual conference in the UK. In 2018, on the 2nd and 3rd March CHIVA ran their 12th Annual Conference 'Going Forward' at the Friends House, Euston London. 'Going Forward' offered professionals the opportunity to develop and enhance their knowledge and understanding of the needs of children growing up with HIV and be informed by the patient experience whilst learning from their peers on critical clinical issues and be informed about developments in HIV research. Conference helps to ensure that clinical care is informed by most current scientific knowledge and research, professional expertise and patient experiences.

1. Family conference overview

CHIVA's family conference was the second day of the national annual CHIVA conference, 'Going Forward'. The event was the first one of its kind, and built on previous work in the HIV sector of whole family 'systemic' work.

The family conference was for young people and parents living with HIV and professionals, to share a space and collaborate. Providing a family-based intervention provided a critical opportunity to support the development of essential skills and knowledge and address the complex health, social and emotional impacts of HIV on families.

The family conference aimed to:

- enable a better understanding of the needs of different family members

- offer an opportunity to address key issues such as ensuring all family members understand recent developments in HIV treatment and care.
- provide an enhanced experience of open communication around HIV in the family, providing valuable insight for family members. Support ongoing family communication which is beneficial to all members, strengthening family relationships and developing resilience to manage the impacts of HIV on all family members.
- enable understanding about specific needs in families and also needs in particular regions and if further work is needed to address family based needs.

The event provided a unique opportunity for families from across the UK to come together to access HIV information and current research relating to treatment and care. Access to the conference was supported by partner HIV charities. Workshop facilitation, travel bursaries and childcare was supported by Metro PPC. An education grant to deliver the conference was provided by Gilead Sciences Ltd.

A minimal professional presence enabled a structured exploration of social and emotional issues, and impacts of HIV on family relationships and behaviours whilst enabling young people and parents to dominate the 'safe' space, supporting the development of confidence and skills to manage these impacts.

This report will capture the feedback and discuss key learning on family-based needs for the wider HIV clinical and voluntary sector. Recommendations are made in relation to research, practice development, policy and guidelines and activism.

1.1 What happened on the day?

The programme was packed and the attendance impressive considering the days of snow, freezing conditions and travel disruptions leading up to the event.

In typical conference style there was a mixture of lecture and workshop, open discussion and panels of experts. A creche was provided - enabling and encouraging parents of younger children to attend - and the inclusion of those with lived experience was central.

In the morning, speakers provided information about preventing mother to child transmission, current treatment for younger children and treatment developments for older children, and transition from paediatric to adult clinical care. These short talks were followed by time for questions.

A workshop programme included three issue based choices - childhood bereavement, HIV in schools and young people caring in the home. These were designed to enable structured discussion with specialists in the topic areas.

Opportunities were provided to encourage people to share experiences if they wanted to.

In the afternoon, there were two parallel workshops on 'Family Communication around HIV at home' which provided a therapeutic space to have open and enhanced discussions.

The programme was top and tailed by the CHIVA executive and youth committee, and punctuated throughout by young people living with HIV sharing their stories using different formats. Towards the end of the conference an extended time was given to a feedback and reflection session.

See Appendix on page 31 for full programme details.

1.2 Evaluation details

The conference was evaluated using questionnaires. One questionnaire specifically for parents and one for young people. They were provided at the beginning of the day to gain appreciation of current experiences of HIV communication at home and feelings and confidence around HIV communication in families. At the end of the day another questionnaire was provided for all participants in order to capture the usefulness of the conference and gain feedback on specific areas.

Approximately 77 people attended the conference and included young people, parents, professionals and volunteers. 24 took the young people's survey (all were living with HIV except 1 who is HIV affected living with a mother and sister with HIV), 12 took the parents survey and 31 participants contributed to the overall programme evaluation.

Observations, quotes and feedback from attendees, workshop notetakers, facilitators and twitter feeds were also collected and provide valuable material for this report. Boxes within the report contain examples of responses and quotes.

1.3 Young person attendee questionnaire

The aim of this questionnaire was to learn from the experience of young people of being told about their HIV diagnosis and the communication of HIV at home.

Results:

Finding out about HIV: How old were you? and who told you?

Age (years)	Total
From Birth	1
4	1
8-9	2
10-11	11
12-13	6
14-15	3
TOTAL	24

Who told you?	Total
Doctor	7
Nurse	4
Doctor/Nurse	2
Doctor/Nurse/psychologist with parent	2
Parent only	6
Social Worker	1
Teacher	1
Family Member	1
TOTAL	24

Box 1: **What went well when you found out about HIV?**

"Nothing"

"Everything"

"I think being told about my mums status beforehand was helpful and acted as a transition to being told about me"

"In a private place (home)"

"Got a detailed explanation"

"There was a follow up with a nurse and psychologist"

"I was contacted by CHIVA to come to a residential where I felt supported and was able to understand HIV more. For my mum to be a part of the process."

Box 2: **What could have been better?**

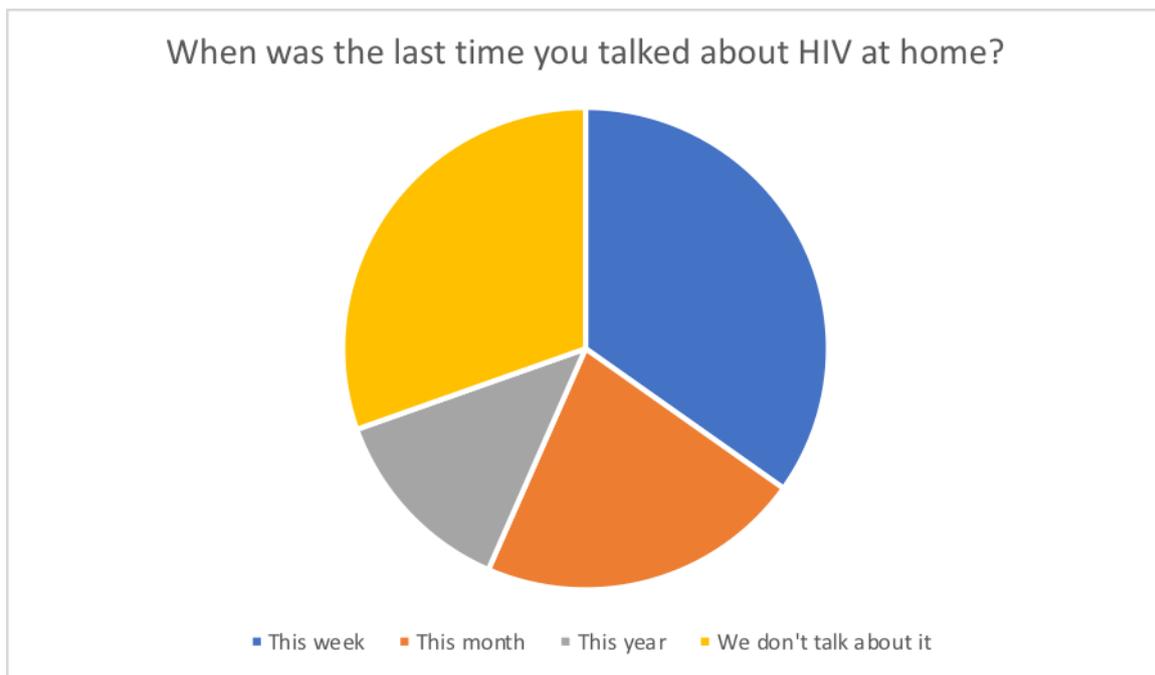
"Nothing"

"I don't know"

"One of the things my Mum said was to not mention it to anyone, but I also interpreted it as not talking about it at home either"

"Could have told it in a better way instead of shouting it out"

"For my Mum to be a part of the process."



1.4 Analysis:

a) Being told about HIV:

Two thirds of the young people were 11 or under (primary school age) when told about their HIV. The rest were told during secondary school (12-16 years old). The CHIVA guidelines 'Talking to children about HIV in health settings' (Melvin and Donaghy 2014)¹ states that '*health services in the UK and Ireland should promote approaches which enable the majority of children with HIV to be told their diagnosis during primary school years, ideally by 9 years.*' 20 out of the 24 children were over 9 years old when they were told about their HIV, suggesting that the ideal age of 9, is the exception rather than the rule. A national 'naming' audit of 282 children in 2016² from 0-18 years old found that 80.7% knew about their diagnosis but only 11% were under 11.

29% were told by their parent or family member (7), and for the rest a professional was involved. However, only 8% (2) said that their parent and professional told them together. The guidelines suggest that '*the familiar clinic nurse or doctor in the paediatric clinic may be in the best position to initiate conversations with the child about health and HIV, in partnership with the parents.*' (Melvin and Donaghy 2014)³ It was helpful to one young person that both parents were

¹ Talking to children about HIV in health settings. Authors: Diane Melvin & Sheila Donaghy Date of Preparation: 21st February 2014 https://www.chiva.org.uk/files/7914/7627/7970/Talking_to_children_about_HIV_in_health_settings-1.pdf Page 3

² Collaborative HIV Paediatric Study. 2016. Summary Data. Available at: www.chipscohort.ac.uk/patients/summary-data/

³ Referenced within Rowson, K (2017) Naming HIV to children: It's Time to Talk HIV Nursing 17 https://www.chiva.org.uk/files/8715/1855/1322/Its_Time_to_Talk_HIV_Nursing.pdf Page 11

present, and another felt it would have been better if their Mum had been part of the process.

Where a professional had been involved in telling the young person about their HIV, 5 different professions were named - Doctor (11), Nurse (8), Psychologist (1), Social Worker (1) and Teacher (1), and appeared to share the role in telling 4 young people.

It would be useful to look further into this - there is a context of discussion and planning between parents and clinicians before the 'naming' takes place, that the young person may not be aware of. Also, the young person may not experience the 'naming' of HIV as a one off event. Where one individual was identified having the 'naming' conversation with the young person, it might have been that the parent or doctor / nurse were also in the room. With 62% naming a clinic-based professional it could be assumed that about two thirds were told in the clinic setting and a third elsewhere. An additional question could be asked, where were you told?

Half of the young people identified what went well about how they were told, and notably one quarter suggested that nothing went well.

BOX 3: Is there anything else you would like to tell us about your family experience of communication around HIV or talking about HIV at home?

"We don't talk about it much "

"HIV should have been mentioned earlier. We didn't start talking about it until I mentioned HIV at 16"

"HIV isn't talked about that much with my Mum but she is slowly being more open to talking and understanding my experiences around HIV"

"Knowledge of HIV is also something that gave me confidence to talk about HIV"

"Me and my mother are comfortable with it"

For those who identified that something 'went well' fell equally into three categories:

-How I was told (4) - identifying the importance of home or the parent's role. One young person found it helpful to learn about her mother's HIV status beforehand.

-The explanation / understanding widened (4) - full detail within the explanation was important.

-The follow up / support opportunities (4) - for example, support groups including camp to increase social network, and a follow up appointment/s with a nurse and psychologist was identified.

Only 10 young people (42%) identified what could have been better (with how they were told about their HIV). 6 gave answers about the delivery: the explanation could have been better, more clarity about who they could tell, and how being told they couldn't mention it to anyone had led to the assumption that this meant HIV could not be spoken about at home either. The way they were spoken to, could have been better, with two young people mentioning 'shouting' and 'overreacting'. In terms of the process, one wanted their mother involved and the other suggested it could have been done earlier.

These lower numbers on the two questions that required the young person to reflect on their experience could relate to the age at which they were told, when the memory might have been more vague or perhaps it is a question that might do better in a verbal discussion that gives more time for a fuller picture to appear.

b) Talking about HIV at home:

We don't know how regularly HIV is discussed in the home but from the young person's questionnaire we can see that it was 'talked about at home' within the last week or month for over half of them (56.5%). However, one third (30.4%) said that they don't talk about it.

7 young people provided additional comments when asked if there was anything else you would like to tell us about your family experience of communication around HIV or talking about HIV at home? For some 'HIV isn't talked about that much' at home but for others the experience is 'comfortable' and they are 'able to speak openly about HIV'. For one young person talking at home about HIV 'has gradually gotten better with support from charities and organisations. Knowledge of HIV is also something that gave me confidence to talk about HIV talking about HIV'.

2. Parent Attendee Questionnaire

This questionnaire aimed to establish from a parent's point of view some of the barriers about communication of HIV at home and a general idea of confidence in doing so, and what support was sought, provided and still needed. The parents surveyed are not necessarily the parents of the young people surveyed and vice versa.

Results:*What age is your child?*

Age	Total
10-11	4
12-13	2
14-15	3
Over 18	4
Total	13

What age were they when they were told about their HIV?

Age	Total	Was this the right age?	
		Yes	No
From birth	1	1	
8-9	5	3	1
10-11	3	3	
12-13	3	2	1
14-15	1	1	
Total	14	12	2

Have you had any support to have conversations with your child about HIV?

Yes (12) No (0) and abstain (1)

If yes, who has given support?

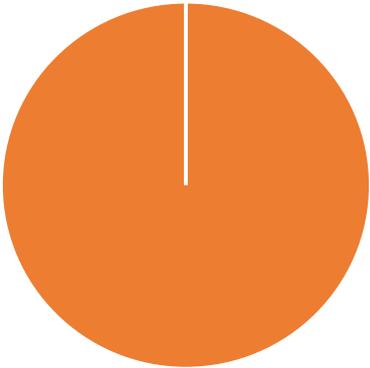
Who has provided support?	Number (12 respondents)
Clinic	8
Family	1
Support Group (5 groups)	19
Total	28

Parents reporting an open conversation with their child about HIV in the past...



■ Week ■ Month ■ Three months ■ Not in the past 6 months

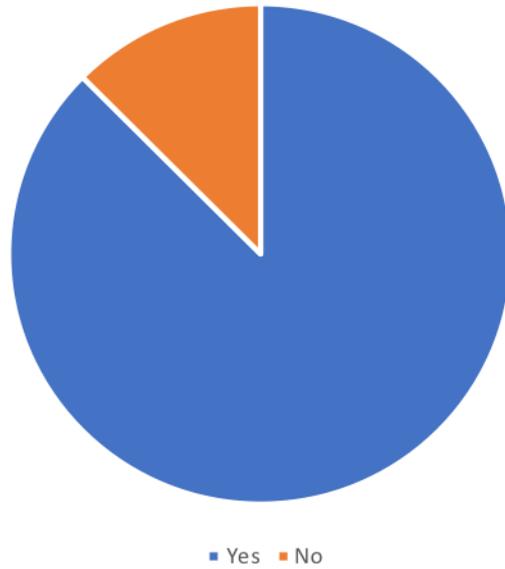
Parents reporting barriers to having open conversations with their child (ren) about their HIV at home.



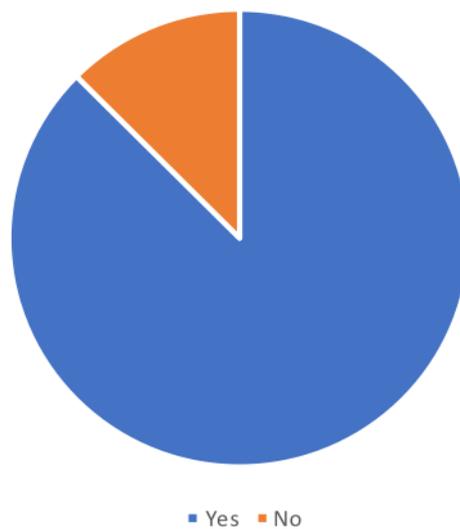
■ Yes ■ No

Parents reporting agreement/or not with statements below in relation to barriers:

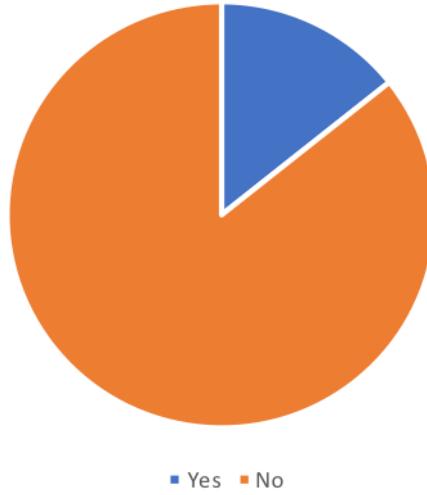
1. I find it difficult/uncomfortable talking about HIV



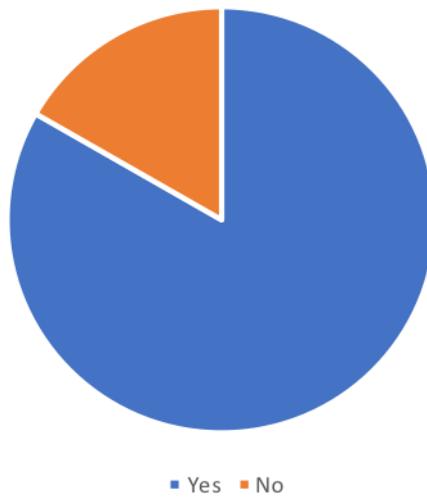
2. Other people in my household do not know about my child's HIV which makes it difficult to talk about



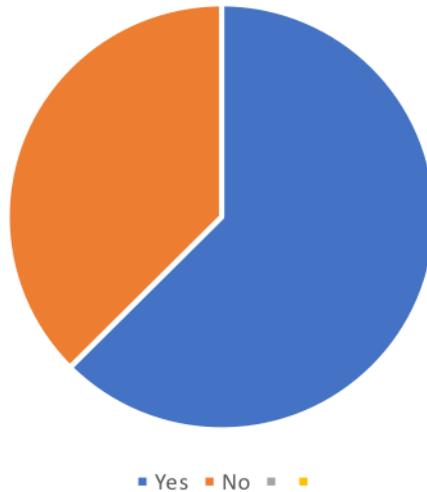
3. I don't think its important to talk to my child about HIV at home



4. I don't understand enough about HIV myself to feel confident talking to my child



5. My child and I don't often have conversations about important things



BOX 4 : Parents were asked if there was anything else that they would like to share about family experiences of communication around HIV at home?

"I don't .. often like to hear or say the word HIV, I would rather like it to be referred to as 'the condition'"

"Not much cause I don't really talk about it much"

"I have an 8 year old and a 14 year old I haven't told them about me and my daughters HIV status"

"My other children who are not living at home do not know about our HIV diagnosis (child living at home) at the moment, it's difficult for me to tell them"

"We are a free family and we are able to discuss about everything"

"We even discuss future plans with my daughter regarding careers, marriage and children"

"Talking to my children about HIV in our family was a huge relief. Their ability to also attend support groups, programmes related to HIV makes them have more knowledge about HIV"

2.1 Analysis:

a) Your child being told about their HIV:

All the parents had one or more children over 10 years old who are living with HIV. 64% (9) had children who were told about their HIV aged 11 or under, similar to what young people reported in their questionnaires. The parents said it was the right age for their child, except for one who thought 12 was too young for their child with learning difficulties.

12 out of 13 had had support for telling their child about their HIV and one person abstained. The 12 were then asked where they got the support from and identified 28 places because more than one source of support was identified.

Support groups at 68% were the most important cited source of support for 'conversations with your child about HIV', with family being the least important (4%) and the clinic in the middle (30%).

b) Talking at home about HIV:

Overall the 13 parents felt confident in talking to their children about HIV with 10 reporting 3 or 4 on the scale :1 (not at all) to 4 (completely).

However when responding to the statement ' I have had an open conversation with my child about their HIV status' just over half had had a conversation with their child about HIV in the last week or month (53.9%). The finding is similar to the young person's survey. The parents weren't given an option for 'we don't talk about it' so the comparison is limited.

When asked if there are any barriers to having open conversations with their child about their HIV at home, none of the participants said yes. So, no barriers were perceived to exist. Yet when they were asked to identify those barriers, if they existed, over half then went to identify at least one barrier (within a pre defined list).

Two parent experiences from their questionnaire responses are reflected here (names have been changed):

BOX 5: Grace

Grace rates herself as 'not at all' confident in talking about HIV and hasn't had an open conversation about HIV in the last 6 months.

Grace tells us that her child is 11 and was told about HIV at 10 which she felt was the right age. She received support from the clinic and two support groups.

Grace agreed with the statements that she found it difficult / uncomfortable talking about HIV, and doesn't think it's important to talk to her child about HIV at home. In her own words Grace feels that her 'child knowing about [their] condition is enough and ... does not need to talk about it all the time'. In addition she doesn't 'often like to hear or say the word HIV, [she] would rather like it to be referred to as 'the condition'

BOX 6: Zaina

Zaina has two children living with HIV who are in their mid to late teens and were told about HIV when they were 10 and 14 years old. She felt this was the right age. She tells us that 'We are a free family and we are able to discuss about everything' Zaina said she had support to have conversations with them about HIV by one support group. She feels completely confident and has had a conversation about HIV in the last week. Although Zaina does not think there are any barriers to open conversation about HIV at home she does agree with the statement 'My child and I don't often have conversations about important things'.

Three quarters of the parents, including Zaina and Grace, agreed that they would benefit from further support to help with having conversation with their child about their HIV, indicating that there is an appetite for further support around aspects of family HIV communication despite feeling confident overall.

3. Conference Evaluation (results and analysis)

All attendees were asked to complete questionnaires that measured the impact of attending the family day in the following areas:

- the development of HIV related knowledge and understanding;
- the impact of attending on their emotional well-being and self-confidence;
- insights into their understanding of family related HIV issues.

31 people (predominantly adults) took the questionnaire though not all the questions were completed.

Everyone felt that the conference had met its aims, with 80% agreeing it had done this 'completely', and that overall the conference was very useful. In the table below there is more detail on how useful each of the conference sections were (they were given a rating scale of 1-5)

Conference Section	No. of responses	% of Excellent scores (5)	% of Poor Scores (1-2)
- Mother to Child transmission / treatment issues	28	67.9	0
- Treatment issues for older children	29	58.6	3.4
- Childhood bereavement	14	50	0
- Young people caring in the home	15	53.3	0
- Young people sharing	13	69.2	0
- Family communication around HIV	27	81.5	3.7

The feedback by section shows a resoundingly positive experience with ratings of excellent (5) being the greatest response in all the sections and 98% of the sessions scoring between 3-5. Notably all those who fed back on 'Young People sharing' was either 4 or 5. However, the response is low for this section - 42% of the survey takers. It could be that 'Young People Sharing' was too vague for people to understand which section this was, as 'young people shared' throughout the conference. If the content 'reading letters to our parents' for example, had been identified within the form, it could be that more would have responded.

What was the most useful part of the conference and why?

Comment Summary	No of Comments
Everything	1
Workshops (comm workshop)	6
School solutions	2
Mother to child transmission	1
Better understanding about HIV	1
Hearing from young people	5
Younger children being supportive	1
Seeing acceptance and courage to speak about HIV	2
Listening and sharing	9
TOTAL	28

BOX 7: What was the most useful part of the conference?

“The presentation by the young people living with HIV and their letters to their parents/friends. It made me really emotional to hear the young people read what they would like to have said to their parents.”

“Family communication around HIV. I personally felt like this was useful to all of us as some parents (family) might find it extremely hard to discuss their status. Communication is very hard but can be made easier if help is provided.”

“All aspects were extremely important but the discussion on family communication was so lovely, informative and enlightening. It gave so much opportunity to all there to give their different experiences and discuss about moving forward without fear and pretence.”

28 comments came from 22 responses. People mostly commented (see table above) on the facilitated sections of the conference, with listening and sharing experiences being the most useful (9): open and honest discussion (2), connection with other parents / people (3) and discussion between parents and young people (4).

Hearing from young people and seeing theirs' and others, acceptance and courage to speak about HIV was also the most useful (7). 6 people specifically found the workshops the most useful, 4 of which was the family communication workshop.

What was least useful part of the conference?

Only 5 responded to this section and included comments on more time, poor facilitation and some talks not appropriate for their age and stage

Was there anything missing?

Only a handful of responses (Box 8) to this question but some useful pointers for future planning.

Suggestions for further support opportunities for families which you would find helpful?

BOX 8: What was missing?

"My Mum"

"More time and games (related to HIV)"

Topics such as:

- **How to support other negative children in the family**
- **Why it's a stigma, New drugs and cure**
- **Living as normal as possible so that your status does not define you.**

21 individuals gave a number of ideas about what kind of support would be useful and is summarised in below and in Box 9.

Overall a day like today would be welcome and could include more workshops, more time built in, and continuation of the conversations. People also wanted time away with other families or regular support or social groups including ways to be in touch. Parent peer opportunities as well as whole families support for young people, parents and negative and younger family members and '*more places and speak freely*'. These ideas backed up from the feedback session on 'What's Next - Parent Response' - see below.

Someone asked for parallel support for parents from CHIVA where they could get information if their child runs into problems.

Education and teaching everyone about HIV was cited as a support opportunity, and comes up time and time again when consulting families affected by HIV⁴ Another 'systemic' aspect highlighted was a request for better links to bereavement charities and mental health services - a reminder that other areas of life can present challenges, and getting timely professional support can depend on good navigation.

Additional comments:

22 freely made comments were overwhelmingly positive and expressed gratitude for the organisation, venue (except for an unheated workshop room), food, for the benefits of open discussion and the opportunity to meet others.

The space, time and tone given over to the communication aspects were highly valued and judging by the feedback the right balance was achieved. 100% of 28 responses said they would like to attend a future event similar to this.

BOX 9: What type of support would be useful?

"Still wish all parents would attend. Please can we have another conference"

"More of these family conferences"

"Let's start earlier and give workshops more time to run"

"Include those children who are affected with HIV"

"More about how you contract HIV"

"Continue with open sharing, more places and speak freely"

"More conversations between young people and parents"

"Away days as families to enable bonding"

"Giving parents more social opportunities as some people, parents felt they didn't and don't have a support group."

"For ways to parents to stay in touch, WhatsApp group?"

"Teach everyone about HIV"

How did you hear about the conference?

Out 26 who responded only 3 heard about the conference from a family member - this perhaps reflects the extent of family communication about HIV, but also that it is the first conference of its type. The rest were informed by Metro (8) and CHIVA (6), support group / organisation (4) and 'email' (2); then a further 2 by the same nurse and 1 through a social worker.

⁴ A whole-school approach to being HIV-friendly is outlined in pp20-3 'HIV in Schools - A good practice guide to supporting children living with and affected by HIV' Magda Conway (2015) NCB & CHIVA https://www.ncb.org.uk/sites/default/files/field/attachment/HIV_in_Schools.pdf

3.1 Additional workshop feedback

Young carers workshop

The Children's Society Include Service and a member of staff from Metro PPC delivered this workshop on young people caring in the home of families affected by HIV. Attendees were asked to complete three exercises in small groups:

1. Discuss tasks undertaken by a young carer, as well as the feelings and impacts experienced by young carer (Box 10)
2. Discuss the barriers to a young carer, the cared for person, and the whole family seeking support (Box 11)

The facilitators summarised that people's fears around the stigma associated with HIV, the concerns over being judged, and the worry that confidentiality may not be respected, are the chief barriers to families seeking support. Also worth noting is that families do not know where to go to get the support that they might need.

BOX 10: **Examples of tasks of young carers:**

"Reminder to take any required medication"

"Encourage the adults to eat, drink, and stay positive"

"Go to Drs appointments"

"Take care of other additional family members"

Examples of impact of caring:

"Grow up a lot quicker"

"Late and missing school"

"Feelings of guilt"

"Look for family elsewhere - sense of belonging"

"Relationships suffer"

BOX 11: **Examples of barriers to seeking support:**

"The fear of being judged; feeling like you're going to be judged; fear -rejection, judgement; scared of judgement"

"Might not like being around people, shut yourself away, isolation"

"Not knowing about support; do not know where to seek support; don't know who to ask"

Schools workshop

The workshop explored school awareness and understanding of HIV, why and how one might want to tell a school about their child's HIV, and what support is available.

The participants appeared to be both empowered and relieved from these discussions. For example one person said that now they would *"..be able to feel comfortable to go into school, without worry"* and another said that they understood that their *"school can help with when [they] feel like [they] need to tell something about [their] HIV"*. One person felt educated that *"there [are] different ways of telling people at school like the head teacher and that children can still go on trips"*.

A young person was able to share the impact of telling the school: "Now my school knows I feel relieved that they can help me when I need someone to talk to".

Family Communication Workshop

There were two parallel workshops on this topic. The conference participants (parents and young people) divided themselves between the two.

These workshops were facilitated to enable parents/carers and their children to experience conversations, with the support of facilitators, which encouraged openness and approaching topics which may present discomfort, and to reflect upon this experience. With the aim being to support an understanding of how it feels to be able to talk about HIV openly in family relationships.

Box 12 gives a good impression of how the workshop was experienced.

Young people spoke about the impact of not talking about HIV in the home and the number of different ways their parents overreacted to things, encouraging their parents to ask questions, and listen. Parents wanted it to be understood by their children how hard their journeys have been, but also that they were grateful to be able to talk and listen openly like this. One parent said:

"I found the communication workshop very informative and important to me hearing what the children thought. I saw it as a way to move forward."

BOX 12: Examples of the responses and reflections from the Family Communication workshop:

Talking about something that interests you:

"You find you have common ground"

"Surprised to find that you can find things in common, whatever age you are"

Talking about something difficult - sex!:

"Sometimes it's difficult to talk to my mum about things as its easier to talk to my friends"

"It is difficult to discuss difficult issues as you don't know (how) they will react and can't predict how they will respond"

"You don't want to change the dynamics of the relationship"

Sharing about HIV:

"Feel enlightened and know how to better my relationships"

"More comfortable about talking to others"

"I will communicate more with my children"

"I feel like a weight is lifted when I can talk about it"

"Don't feel sorry for being who you are as the right people will accept you for who you are"

"The only way you can open your heart and yourself is to accept it"

"I wish all parents could be here to experience this"

"From today my channel of communication with my son will be different"

Facilitators feedback

The facilitators of the Family Communication workshop gave detailed feedback from their sessions reflecting the feedback they had received and their own responses. They were struck by the genuine opening up of the conversation between parents and young people;

"The conversations we had there were extraordinary and I was moved and touched by the willingness to share pain AND solutions."

"Hearing both parents and young people humbling themselves and trying their hardest to put themselves in each other shoes and becoming closer as a result"

One participant told them that she had 'never before been able to discuss HIV with her son and that the event had given her the confidence to do so in more straightforward ways'. For others, the workshop was a pivotal moment in their journey towards 'being at peace with that part of them relating to HIV' and a step towards a future without fear.

One facilitator felt that gender and cultural differences, between young people born in the UK versus parents' experience being brought up elsewhere, was a shared and influencing component to communication and relationships, and that practicing this openness within the workshop was therefore useful.

Both facilitators felt strongly that it would be better to have had men and fathers present at the conference to complete *'the picture of 'family'*, to breakthrough the pattern of clinical engagement with mothers and children and contribute to *'how issues related to sex, relationships and communication about HIV could be best achieved'*. Understanding the reasons why they didn't attend was seen as essential to finding a solution.

4. Key themes and learning

There is a need, appetite and energy across the board for improving the experience of family communication of HIV at home (see Box 13).

Despite the attendees being a self-selected group who were prepared to come to an HIV specific event where family members are present, it was marked how few people in the pre-conference questionnaires talked at home about HIV, easily and generally feeling confident and supported. Hearing from young people and taking part in conversations throughout the day enlightened parents, in particular, to what was missing in their relationships and the potential for improved family communication of HIV at home.

BOX 13: Quotes from Parents captured during the afternoon session

'I thought I had accepted my condition but I realised I hadn't. Talking with my son today has changed that for me'

'I had that burden....it's going to get better'

'I haven't told my other daughter about me and my child who have HIV.....now I want to tell her'

'Acceptance.....it has taken me 17 years to accept who I am.....'

'From today my channel of communication with my son will be different'

'I will communicate more with my children'

'I feel like a weight is lifted when I can talk about it'

'I haven't told my other daughter about me and my child who have HIV.....now I want to tell her'

'I want to tell my best friend as it is difficult to have a close friend who I can't talk about it with'

'I Feel enlightened and want to better my relationships'

'It starts with us in the home'

Social Support e.g. Weekends away together / getting together:

The evidence from the conference demonstrates that people are empowered and motivated in a space where connections are made, relationships cemented and common ground is established. The body of evidence for these families living with HIV is also demonstrated through CHIVA camp ('Friendships made at camp last a lifetime' Amanda Ely, CHIVA manager) and the two Family residentials run by the UK Family Project during its implementation from 2009-2012.⁵

When a child finds out about their HIV diagnosis:

The reporting about when and how young people were told about their diagnosis seem to suggest that age wasn't necessarily the main focus anymore but how it is done. We could understand more about how children are told about their diagnosis and showcase good quality case studies. It would seem parents aren't as involved in the telling of an HIV diagnosis as might be assumed. A young person knowing their own and their parent's HIV diagnosis does not translate into free discussion at home and young people valued having their parents involved.

One young person found that learning about her mother's HIV status beforehand, helped with the transition to being told about their own diagnosis. The CHIVA guidelines (Melvin and Donaghy 2014)⁶ suggest it is helpful for a child to know about the source of their HIV when they are told about their own diagnosis. Whilst recognising that this is not necessarily an easy option for parents who worry about the impact of sharing the source of their own diagnosis, in practice the 'shared' experience has offered opportunities to be closer. Perhaps there is scope to separate this process out further so that the young person learns of their own HIV status after they have been told about their parent's and to ask the question if there is silence about HIV in the home, what is the impact of a child told about theirs and their parent's diagnosis all at once?

The power of witness:

As a society, we are beginning to understand the power of 'representation' and seeing people like you in a positive and powerful light. More and more videos are being made which bring out the visibility and voices of those living with HIV.⁷ The conference was able to show this effect:

For the parent:

"The confidence [of] the infected and affected children at the conference was mind-blowing"

⁵pp8-9 Morris, V (2012) 'Three UK Services work in partnership to develop resources and models of support for HIV positive parents and the professionals that support families living with HIV.' Positive Parenting and Children (unpublished)

⁶ page 13

⁷ Examples: Positive Faith (CAPS) 2017 www.positivefaith.net,
<https://www.theguardian.com/society/video/2015/dec/01/generation-hiv-the-young-britons-born-hiv-positive-video>
<https://www.gmfa.org.uk/theundetected-video>

'2 HIV+ Parents talk to their children' <https://youtu.be/ZX4MeYWkeCI>

"Having people to have the courage to speak out and confidence to be yourself and accept the illness."

"See the young teenagers talking openly and their acceptance."

For the young person:

Several participants referred to the usefulness of practicing 'openness' within a safe workshop with other young people and they expressed how they felt empowered by each other's courage.

"Hearing mums talking about their situation was good as I imagined it being my mum saying those things about HIV"

For the professional:

"It was also touching to be a witness to so many conversations between parents and young people"

"The conversations we had there were extraordinary and I was moved and touched by the willingness to share pain AND solutions."

"Those letters changed everything today. CYC, you are beyond amazing- what a privilege, how much these young people have put into telling their families how they feel and what they need"

5. Impact in relation to conference aims:

- **Understanding of the needs of different family members**

Conference gave voice to different family members, through questionnaires, workshop participation and sharing in spaces throughout the day. Parents / carers and young people created a dialogue that provided its own momentum and shed light on what each other needed. Parents expressed wanting more support in communication about HIV in the home which includes their HIV affected / negative family members. Young people expressed wanting to have these conversations at home and to feel closer to their parents on their shared HIV journeys.

Notably the needs of fathers as parents were not explored in the conference and mothers were the main representatives of 'parents'.

To summarise the conference enabled us to understand that families need:

- more support in the facilitation of communication about HIV at home
- more connection within families and between families
- more support to accept HIV diagnosis
- the opportunity to address key issues such as ensuring understanding of all family members of recent developments in HIV treatment and care.

- **Enable the understanding of all family members of recent developments in HIV treatment and care.**

Bite size lectures were given on recent developments in HIV treatment and care by clinicians who provide care for young people and mothers. A range of topics were presented that included an overview as well as recent developments. Topics chosen were directly relevant to children, young people and parents (mothers in particular) across the age and lifecycle. There was very little feedback garnered through the evaluation of the day on how useful people found the presentations; it seems that people liked the workshop format and so perhaps found the 'lecture' style less accessible. A clear understanding of the impact of the 'bite-sized lectures' was perhaps over shadowed by the response to the work done on the family communication of HIV at home. Although references to needing access to HIV related information and feeling well educated were consistent in feedback.

- **Provide an enhanced experience of open communication around HIV in the family to support ongoing family communication.**

This is probably the most tangible area where impact can be seen. The experience for many, of open communication was like the quenching of a great thirst. Decisions were made then and there that things would be different.

Capturing and understanding better the parent's story and appetite to continue the conversation and communicate better. Parents like Zaina, who have an empowered approach to family communication, alongside other parents who took decisions to do things differently, may be able to lead further change. Fathers and HIV affected wider family members were unrepresented at this event but have an important part to play.

The energy of coming together, being connected, forming friendships and relationships was very evident from the day.

6. Recommendations:

6.1 Further research and understanding

- A follow up questionnaire for the family members to understand further the level to which family relationships were strengthened and resilience developed over time. Appreciating the long-term impact of open HIV communication family style events and CHIVA summer camp.
- Considering further context issues and detail of information provided in work 'naming' HIV to a child.

- Further appreciation of general family communication.
- Understanding the nuances of HIV related stigma and how it can manifest in family relationships and language around HIV.

6.2 Practice development

- For CHIVA to address the need for whole family approaches, appreciating the family life cycle, and developing and changing needs.
- Service providers to address the need for regular spaces for open discussion about HIV within families.
- For HIV specialists (clinical and support professionals) and CHIVA to explore coordinating family communication workshops in all regions.
- Clinics and support organisations to explore talking about HIV in the home with families more proactively.
- Increase the online / social media platforms for supporting families who don't have equality of access to HIV specialist support.
- Consider developing a working party to lead development of a model and resource development⁸ on family communication of HIV and how to come to terms with an HIV diagnosis; harnessing the parents' and young people's energy to continue what was started at the conference.
- Publicise support services for young carers, ensuring that services explicitly accept families affected by HIV and are HIV aware.

6.3 Policy / guideline development

- Update CHIVA guidelines about naming HIV to a child to include direct work on parental readiness and acceptance of their own HIV status, as part of the framework for supporting the impact of 'naming' in the long term, whilst prioritising the child's right to know their own HIV status.
- Protocols across adult clinical services to reach parents who don't come into contact with paediatric services, to ensure they get support for accepting their HIV diagnosis and communication of HIV at home.

6.4 Activism and campaigning

- Increase the representation of young people living with HIV, their families and issues at the centre of family life with HIV; in film, media and relevant positions of influence, including the HIV professions.
- A planned approach to retain HIV paediatric and family expertise and knowledge as the sector shrinks.
- Representation of young people on national initiatives to combat stigma, equality within the U=U breakthrough, living well with HIV campaigns.

⁸For example: Review and update the UK Family Project family communication materials 'It's good2talk'; storytelling and video resources like 'Positive Faith'

- Achieving HIV friendly schools, particularly in areas of high prevalence and inclusion of HIV in compulsory sex education.
- Free formula feed for all infants of HIV positive mothers until they are one year old.

6.5 Considerations for the delivery of a future family conference

- Explore co-production that includes all family members in programme planning and delivery. Moving on from only having youth led sessions.
- More 'experiential' workshops and open forums and less traditional knowledge based sessions.
- A programme of engagement with fathers to increase their representation in future events.

- **APPENDIX: The Family Conference Programme**

Welcome - Dr Amanda Williams (Chair of CHIVA) and CHIVA Youth Committee (CYC) member

Overview of CHIVA: Who we are and what we do - Amanda Ely CHIVA Manager

The work at CHIVA includes providing 'Freedom to be' support camps to help young people living with HIV to understand and talk confidently about HIV, to create peer support networks and socialise together in a safe space. 'Art is Key', for young adults living with HIV, a project using music, drama, performance poetry to explore moving into adulthood. 'CHIVA Youth Committee' which ensures young people have their voices heard and take on campaigning and influencing work, raising awareness and shaping policy and practice.

Poem performed by Bakita.

Preventing mother to child transmission and current treatment issues for young children - Dr Amanda Williams and Dr Jolanta Bernatoniene

Over-time, mother to child transmission of HIV has been reduced to less than 1% because of anti-retroviral viral treatment (HIV medicine) during pregnancy, delivery and for the baby (for the first four weeks);

Recommendations for bottle or breast feeding remain confusing and complicated, and societal and community pressures to breast feed are significant. However, because bottle-feeding is 100% safe this is still the recommendation. Whilst there is still momentum to explore options for breastfeeding, the evidence is that 1-2/1000 breast fed babies of women who are have HIV 'undetectable' levels, will be infected by HIV.

Treatment issues for older children and transitioning to adult clinical care - Dr Alasdair Bamford

Transition into adult services for young people living with HIV is compounded by the complexity of developmental tasks for this age group. Issues around medication regimes, adherence and side-effects were some of the main concerns from the young person's point of view 'It is very important to understand that taking medication can be emotional for many young people - it's not just taking a pill' - It is critical to convey empathy and appreciate the challenges of long term HIV medication adherence.

Young Person Sharing - Mercy Ngulube former chair of the CHIVA Youth Committee

Workshop programme -

1.Childhood bereavement - Grief Encounter

An introduction to understanding bereavement for children. What children who have been bereaved can experience and what can be helpful for them.

2.HIV in school -

An exploration of telling a school about your child's HIV, and school awareness and understanding of HIV, why you might want to tell a school and what support is available.

3.Young people caring in the home - The Children's Society and Metro PPC

An exploration of what caring roles young people in the home sometimes take on and what being a young carer means. What support is available to young carers, and overcoming some of the challenges to accessing support.

LUNCH

Young People Sharing- CHIVA Youth Committee. Reading out letters young people had written to parents sharing what they need from them for support around growing up with HIV.

Family communication around HIV at home

Dr Tomas Campbell and Nina Bengtsson (Metro PPC)

The workshop was delivered in two groups, with the aim to reflect on family relationships and communication around HIV at home. Exploring why communication around HIV in families can be helpful for children. What can be difficult and what can help. Practising having conversations between parents and children which can feel difficult, in a supported space.

BREAK

Closing session:

Feedback session from family communication workshop and Young Peoples Panel - Chair: Mercy Ngulube

Final reflections from conference and what next?

Conference evaluations and conference close - Dr Amanda Williams and CYC members.