



## CAB 64: Children and teenagers with HIV Friday 19 January 2018

### Meeting report

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This report was written by Alex Sparrowhawk and Memory Sachikonye

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**CAB 64: Children and teenagers with HIV**  
**Friday 19 January 2018**

**Programme**

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Chair: Ben Cromarty	
09.20-09.40	Arrival, tea and refreshments
09.40-10.00	Welcome and introductions, UK-CAB updates
10.00-11.30	<b>Introduction to clinical trials</b> – Damian Kelly
11.30-11.45	<b>BREAK</b>
11.45-12.30	<b>Mind the Gap - transition to adult care</b> – Dr Caroline Foster, Imperial College NHS Trust
12.30-14.00	<b>LUNCH</b>
Chair: Garry Brough	
14.00-15.30	<ol style="list-style-type: none"> <li>1. <b>Personal experience</b> – Tania Okito, Peer Youth worker, Positively UK</li> <li>2. <b>Achieving holistic well being for children and young people growing up with HIV’;</b>  <b>An overview of CHIVA’s work</b> – Amanda Ely and CHIVA Youth Committee member</li> </ol>
15.30-15.45	<b>BREAK</b>
15.45-16.55	<p><b>Conferences feedback – EACS, BHIVA</b></p> <p><b>Community reps feedback</b></p> <ul style="list-style-type: none"> <li>• BHIVA standards of care – Ben Cromarty</li> </ul> <p><b>Reflection and feedback of the meeting member updates, residential training feedback</b></p>
16.55	<b>AOB</b>
17.00	Meeting close

## Speaker biographies

**Caroline Foster** is a Consultant in Adolescent HIV and Infectious Diseases at Imperial College Healthcare NHS Trust and is the clinical lead for transitional care in HIV.

Current research studies include, the long-term outcomes for adults born with HIV, the characterisation of the latent reservoir and the development of in vitro therapeutic vaccines in paediatric HIV. Research/education/guideline development and lecturing includes BHIVA, CHIVA, HYPNET, CHIPS, AALPHI, PENTA, EPIICAL, UNICEF and the WHO.

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**Tania Okito** is a passionate youth peer case worker in the HIV sector, working with organisations like POSITVELY UK and CHIVA equipping young people with knowledge, skill and confidence to make informed choices on how to manage their own health.

Outside of the HIV sector, Tania empowers young women through personal development workshops and enjoys travelling.

Tania also has experience in community development having volunteered in countries like Ghana and South Africa, creating opportunities for young people in resource- poor communities to become more confident and skilled in order to inspire hope in their communities.

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**Amanda Ely** is a qualified social worker specialising in HIV. She began work in the field of children and families and HIV in 1997.

Amanda practiced as a social worker in London for a number of years before becoming a lecturer in social work at London Metropolitan University.

She is an associate lecturer in Childhood Studies for the Open University, and having worked for CHIVA, (The Children's HIV Association of the UK and Ireland) since 2008 she is now the CHIVA manager.

# Meeting attendees

	Name	Organisation	Destination
1	Alex Sparrowhawk	UK-CAB SG/THT	London
2	Angelina Namiba	Salamander Trust	London
3	Ben Cromarty	NYAA	Yorkshire
4	Christopher Millican	Personal	Hull
5	Damian Kelly	UK-CAB SG	Manchester
6	David King	UK-CAB SG/Positively UK	London
7	Diana Onyango	Positively UK	London
8	Douglas Jones	Skyline Leeds	Leeds
9	Esther Ndungu	Positive Child UK	London
10	Fabiola Bayavuge	Personal	Manchester
11	Fernando Monteiro	UK-CAB SG	London
12	Florence Obadeyi	BHIVA rep	Hull
13	Garry Brough	UK-CAB SG/Positively UK	London
19	Husseina Hamza	African Advocacy Foundation	London
14	Jake Chambers	HRA	Bristol
17	James Dunworth	HIV i-Base	London
15	Jane Shepherd	UK-CAB SG	Portsmouth
16	Jo Josh	UK-CAB SG	Surrey
18	Memory Sachikonye	UK-CAB	London
20	Nyambe Mukelebai	BHA Leeds	Leeds
21	Roger Pebody	NAM	London
22	Roy Trevelion	HIV i-Base	London
23	Rupert Jones	Skyline Leeds	Leeds
24	Simon Horvat-Marcovic	Positively UK	London
25	Tania Okito	Positively UK	London

## Apologies

Longret Kwardem, OurSpace Peterborough  
 Michael Harking, THT Scotland, Glasgow  
 Silvia Petretti, Positively UK, London

## Session 1: Introduction to clinical trials – Damian Kelly

Clinical trials in HIV help researchers find better ways to prevent, detect or treat the virus, they may include new treatments or known interventions that require further study.

Much of the discussion at the latest UK-CAB meeting was around community engagement with clinical trials. To be meaningful people living with HIV should be involved during all stages, from the prioritisation of research, research design and planning, research conduct and operations right through to research dissemination, communication and post-approval.

There was a general consensus during the meeting that most people living with HIV are not aware of what trials are currently in progress and that the language used by researchers is often off-putting and not understandable within the general population. Clear, simple English should be used to talk about clinical trials if researchers are to meaningfully involve people in them.

A useful resource to find clinical trials around the globe is <https://clinicaltrials.gov/> where you can complete a search by condition and country.

Slides from the meeting are here: <https://tinyurl.com/ya4vguxs>

### Discussion:

The meeting discussed the need for community involvement in clinical trials through:

- Participation – being a participant in a clinical trial.
- Engagement - with pharma when they are invited to UK-CAB meetings. The UK-CAB is already involved a way when researchers ask for our feedback to trials they are designing. The last feedback was to Dr Paolo Cicconi (July 2017 meeting) on REACH UP (RE-evaluation of Annual Cytology using HPV testing to Upgrade Prevention): a feasibility study in Women Living With HIV. The study has not been submitted and awaiting outcome on funding.
- Role of community involvement in R&D – community being asked to feedback into proposed study – study design, literature and informed consent; study logistics; recruitment and retention; dissemination.

More information about community involvement in clinical trials is available from the MRC CTU: [http://www.ctu.mrc.ac.uk/resources/multimedia/ppi\\_films/](http://www.ctu.mrc.ac.uk/resources/multimedia/ppi_films/)

### Members' comments from this session:

1. *"It would have been excellent if more participation particularly around involvement in clinical trials as members wanted to engage in this discussion but there was not enough time to finish this dialogue".*
2. *"We would like to have an internal training session at the beginning of each UK-CAB meeting? This could be around various topics such as today's introduction to clinical trials."*
3. *"It will be good to have a couple more sessions focussing on how CAB members can get involved in clinical trials, advisory boards, etc. We also need a strategy about how to disseminate that information to the community".*

## Session 2: Mind the Gap - Transition to adult care – Dr Caroline Foster

Dr Caroline Foster from Imperial College Healthcare NHS Trust provided an insight young people living with HIV experience in the transition to adult care. As of 2016 almost 80% of UK and Irish people who had acquired HIV in childhood were 15 or older, so much of the clinical care of young people is focused on this age group rather than young children.

Of the obstacles these young people face growing up with a condition that's transmitted sexually before you've had sex can be complicated to process and can make negotiating relationships, contraception and safer sex a bigger issue than for their peers.

Clinicians who see adolescents in their care also have to think about how to design their services with young people living with HIV in mind, for example offering afternoon appointments to avoid no-shows and remembering just like adults young people want a confidential and respectful service.

The issues with transitioning into adult care are often well versed but there are benefits too, with young people enjoying being treated as adults. However, it was upsetting to hear that many young people state that one of the main reasons for avoiding adult care is the perception of stigma from adults living with HIV in clinic waiting rooms. There is need to build bridges between transitions. The 900 clinic outcomes will be presented at BHIVA conference in April 2018.

### **Discussion:**

This was a very interesting presentation and highlighted the differences in care for young people in other places. Given that there are personalised care plans for young children with HIV in the UK, most countries in Africa have no transition clinics. Children are treated with adults. She is working on speaking to doctors and nurses in Africa to change their mind set especially around confidentiality.

## Session 3: Achieving holistic well being for children and young people growing up with HIV; an overview of CHIVA's work

Amanda Ely has been working with children and families affected by HIV since 1997 and explained the history of CHIVA and their experiences of working with young people living with HIV. The concerns of most young people centre around the fear of rejection from their peers and the burden of not only keeping their own HIV status private, but their parent's and/or siblings too. In the long-term these issues can impact on a young person's ability to look after their health and engage in their own care.

One way CHIVA looks to address this is by hosting it's annual summer camp, inviting around 80 young people from the ages of 11-16 to spend five days together sharing their stories and experiences. 86% of attendees remain in contact with other young people they have met at camp via social media and WhatsApp, enabling peer support to continue beyond the week they spend together. A member of the CHIVA Youth Committee spoke about their experience of camp and the meeting also heard from a youth peer case worker from Positively UK.

The CHIVA Youth Committee was set up to review guidance, resources and to talk to professionals about how to talk to young people living with HIV. The group consists of 12 young people and their gender, age and geography around the UK is balanced to reflect the diversity of this group. The group also help manage a password protected website for young people living with HIV as well as sharing their experiences on Twitter via @Freedom2spk.

Amanda Ely's slides are here: <https://tinyurl.com/y7m4vcrg>

## Personal stories from young people

The meeting also heard from the Children's HIV Association (CHIVA) and a member of their Youth Committee. She agreed to have this part of her story shared.

Tania also shared her personal story of growing up with HIV and taking medication.

*It's unfortunate we live in a place so cruel  
But CHIVA provides the opportunity to rise above the cruelty  
To rise above the stigma  
To not be afraid anymore  
To not be fearful  
But to be strong and start finding whom you are  
Going on your journey as a brave soldier  
To defeat and not to fear.  
I can finally confidently say  
I am whole  
I am one again.*

### Tania's story:

Tania started treatment on syrups then switched to tablets. She was told about her HIV status at 11 years old, she parked the thought and just carried on. She had a positive experience growing up at the 900 clinic and used to look forward to going there.

When she was transitioning, her care was transferred to Mortimer Market. During that time she was in college and stopped taking meds and lied to doctors about adherence. When growing up, she wanted to be an HIV Clinical Nurse Specialist. This was due to the care she had received in the paediatric clinic. While in college, she shared her HIV status with a friend. She was discouraged when she got incorrect information. Someone told her she could not work as a nurse at all due to her HIV status. She started missing college and stopped her HIV treatment.

She was then encouraged by a close friend to go to CHIVA as camp leader. She was really inspired by everyone at the CHIVA camp and went back on medication. CHIVA helped empower her and other young people, this helped in diminishing self stigma. She had had no peer support when she was growing up. She is grateful for support from Body and Soul and Positively Women and enjoyed social activities as part of the support.

Tania now works as a youth peer worker at Positively UK where she trains peer mentors and supports young people in clinics. She concluded by highlighting the importance of letting young people understand how treatment works; U=U is an eye opener for a lot of young people in relationships.

### Discussion:

The meeting was very impressed by the personal stories of the two young African women. One other person in the meeting had come through CHIVA and has now finished his university studies. They all reiterated their positive outcomes from support from CHIVA. They all agreed how their support needs changed with age. When asked how they felt about being role models to their peers, they said it was through the support they received to be able to be confident and speak out. One was asked how their mother feels about her living openly with HIV as this automatically discloses her mother's HIV status. She said that is important to have a good mother and daughter relationship. This involves attending family HIV meetings and other events that help build both child and parent's confidence.

## Session 4: Conferences feedback, members' updates

**EACS conference** reports are available from HIV i-Base: <http://i-base.info/htb/32932>

### **BHIVA feedback** - Roy Trelvelion

Roy gave his three highlights from the autumn BHIVA conference, which he introduced by saying: *'A friend's advice for this presentation was – keep it simple. But the restructured NHS is anything but simple – it's difficult for a patient rep to know where to input.'*

He covered the following topics:

- a) BHIVA standards of care 2018 update. The standards have new sections. (see Ben Cromarty's slides in next section)
- b) Richard Harding's Gazzard Lecture on Palliative care and HIV. This focuses on moving the conversation from *why* people die to *how* people die.
- c) How to survive a sexual health tender – the complexities of councils having to cut about 30% budgets to win a tender. Sexual health and HIV have been split making it difficult for patients.

Roy's slides are here: <https://tinyurl.com/y7bfjt8u>

### **BHIVA standards of care update** – Ben Cromarty

The BHIVA standards of care 2013 are being updated. Ben is one of the two community reps on the standards. UK-CAB appointed 17 representatives to work on different sections of the standards. Ben informed the meeting that he would like to also, like discussion on the UK-CAB forum. This will perhaps widen debate and comments. Each community rep to lead discussion on their section(s). The reps will then summarise key points in appropriate format and pass to their writing group. It is to be noted that this would not be a formal UK-CAB response...rather, a selection of reflections. To comment on the standards, you can go here:

<http://i-base.info/htb/33394>

The deadline for feedback is 20 February 2018

Ben's slides are here: <https://tinyurl.com/yabj39v4>

### **Residential training feedback**

Four trainees from the residential training gave a brief feedback:

- Simon: I had lost all knowledge about science, it all came back after the training. I now understand science and attended a BHIVA consultation.
- Hussein: I have since become a community rep on the London Drugs Commissioning group. I am still learning and being supported by Garry. I enjoyed the film [Fire in the blood] about the history and access to treatment.
- David: I have learnt more about treatment which helps in my new role at Positively UK. I applied for and was elected as a member of the UK-CAB Steering Group.
- Diana: I learnt about HIV research and now applying the knowledge in her daily work as a Women's Coordinator.

The programme, presentations, reading material and final report are online: <http://tiny.cc/o89kqy>

## Members' updates:

- Jo is now working as the official BHIVA media advisor.
- Robert and Longret submitting an abstract to BHIVA on Positively Involved. They will interview community reps on their experiences as UK-CAB representatives. This is a follow up to the study from the UK-CAB presented as a poster at BHIVA in 2017. The study showed the importance of including HIV positive people as active partners when planning research and when writing treatment guideline. Read more about this study and download the poster here: <https://tinyurl.com/y9uwl73z>

### Aim of research

As community we have specific skills and experiences that are usually not otherwise included in these research groups. They will ask 8 questions on the details of direct examples of how community involvement has changed direction/impact on research:

- a) How long have you been a community representative, what forums have you been involved with and why did you decide to be involved as a UKCAB rep with those organizations
- b) What direct examples can you give of the difference community involvement has made? Change in direction, decision, perspective, inclusion of something not previously thought, emphasis, etc.
- c) How is community involvement managed within the organization?
- d) What unique skills and experiences do community members specifically bring to the group?
- e) What challenges have you come across? How was that managed?
- f) What available resources or knowledge/information/capacity building might support involvement for community reps and for organizations/committees
- g) What would you say to another person living with HIV who may not have a chance or be reluctant to be a community representative?
- h) What in your opinion is the future for community involvement for the UKCAB?

## Next meeting:

Date: 21 April 2018

Venue: Waverley Care Edinburgh

This meeting will take place in Edinburgh, to take advantage of the BHIVA/BASHH conference. The meeting will focus on Guidelines feedback, in relation to quality of life: community reps for guidelines will provide feedback.

UK-CAB will use a different registration form for this and future meetings. The Steering Group will select members who will attend this meeting. We also hope to engage with members in and around Edinburgh and Scotland and the north of England.