



UK-CAB 80: Long-acting agents, CROI and BHIVA conference feedback

Manchester, Saturday 23 April 2022

Meeting report

Meeting Overview

- Long-acting injectable treatment
- Feedback from CROI 2022
- HIV and migrants, and the impact of the Ukraine crisis
- Breastfeeding and HIV
- Feedback from BHIVA Spring Conference
- Update on UK-CAB Online Training Programme
- UK-CAB Reps: why we need them, what it involves
- Member updates
- Attendee list

Please see accompanying slides and reports which complement the conversational content within this report.

Long-acting injectable treatment (see also slides from Dr Chitra Babu)

The UK-CAB Community Workshop focused on long-acting injectable treatment at the Annual BHIVA Spring Conference, this session reviewed how this therapy works and then continued to answer questions from members, and a discussion on barriers and advantages to injectable treatment.

Members drew on some of the discussion from the conference on the issue of attending clinic much more frequently than most people with HIV do currently. People in rural areas, or who live far away from their clinic may struggle with travelling to appointments. Conversely to this people in smaller communities were thought more likely to be concerned about keeping their status private, and could benefit from not needing to worry about hiding medication etc.

Members questioned what research exists in people with a detectable viral load taking the treatment. And also, the benefits for people who struggle to adhere to medication, and whether long-acting injectable treatment is an incentive to adhere to pill-based medication, in order to become eligible for injectables.

Trials using no oral lead-in were discussed, as was the feasibility of providing the treatment close to home, in community settings such as pharmacies, or via local GPs.

Members were asked to send further questions in order for us to liaise with ViiV when we arrange to talk to them later this year.

Feedback from CROI 2022 (see slides from Simon Collins)

This discussion focused on some of the key research to emerge from CROI this year:

- Islatravir, which had potential as treatment and PrEP as a long-acting agent, has been paused as trials found it was decreasing CD4 in those taking it.
- Lenacapavir, another new long-acting agent which would need to be partnered with other long-acting agents.
- Cabotegravir as PrEP, which is shown to work with very few people diagnosed with HIV. We were advised AfroCAB have challenged ViiV on access to the drug due to current high costs.
- Latest cure research, the biggest media story from CROI was of a woman who is the 4th person in remission following a stem cell transplant.
- bNAbs, the group reviewed the latest information about this new type of treatment technology, created from individual's 'good' immune responses.
- ANCHOR study which looked at the increased risk in anal cancer in people with HIV. Despite the high risk compared to the general population, it is said there is no capacity to routinely screen people for it at present. Women with HIV questioned whether the procedure could be added onto routine cervical screening. It was suggested this would be a good topic for a future BHIVA conference session, which members present were agreeable to.

Members were encouraged to catch-up with video recordings for further information from the conference.

- BHIVA – Best of CROI 2022: <https://www.bhiva.org/BestofCROI2022>
- HIV Prevention England and NAM CROI 2022 Highlights: <https://www.youtube.com/watch?v=jGZ6vRHoeHc>

An update on the latest Cure strategy was shared in December which members will still find useful:

- IAS Strategy for a Cure 2021: <https://i-base.info/ias-towards-an-hiv-cure-2021/>

HIV and migration (see notes from George Westwood)

Following the crisis in Ukraine members briefly spoke about what the HIV sector in the UK had done and what information was available. Members heard from George at NAT who provided some highlights from their HIV and migration report, published last year. Migrants often have a good relationship with their HIV clinic, but face barriers and issues elsewhere in the healthcare system. It was felt the system was built to support providers of healthcare, rather than those they look after.

Members were keen to talk about the discrepancies between migrants and refugees from Ukraine, compared to those fleeing and seeking safety from conflict elsewhere, especially countries such as Syria, Yemen and across parts of Africa. It was noted how the HIV sector had responded swiftly to supporting 'white migrants' but in recent times the same cannot be said for migrants from outside of Europe. It was also recognised that due to high prevalence of HIV (and other conditions such as HCV) in Ukraine that tailored support and translated information was needed, but this did not negate the fact that many other migrants have previously not been offered as much support.

Members agreed it was helpful when new information being produced was able to support all migrants.

NAT report: shorturl.at/inGMW

Breastfeeding and HIV

A UK-CAB member, Becky, provided their lived experience of breastfeeding their infant following their diagnosis. They were given full support from their clinic, which members were happy to learn about. It was recognised that this decision is not easy, but with regular monitoring, and being in possession of the full facts (including the BHIVA guidelines) it is possible to do so safely.

Members were keen to know more about research in infants who are or who are not breastfed, including their development etc. Also, it was recognised that much of the existing research has been undertaken in Africa, rather than European or North American settings.

BHIVA Spring Conference feedback (see slides from Roger Pebody)

Members who attended the conference spoke about their highlights, some of the topics discussed with Roger included:

- The language around frailty, and how people with HIV do/or don't recognise their own frailty
- UKHSA data on people with detectable HIV – especially in the context of COVID-19 and disengaging from HIV care
- Causes of death in people with HIV, again reviewing the stark impact COVID-19 had in 2020 (23% of deaths, the leading cause)
- BHIVA audit on HIV-2
- Changes to the BHIVA treatment guidelines

Update on UK-CAB Online Training Programme (OTP) (see slides from Ben Cromarty)

UK-CAB meetings often include presentations from clinicians, researchers and Pharma companies on specialised topics related to HIV. It's useful for UK-CAB members to have some background information about HIV, and about how research and clinical trials are done, so that they can get the most out of these meetings. For this reason, later this Summer we are introducing a free online training programme (OTP) about HIV and the science behind it. It is aimed at both people new to HIV and anyone wanting to increase their knowledge. Content is at an introductory level, and in non-technical language.

The programme is in three sections, each with around six 1-hour modules. It will be live online, using pre-recorded presentations, but ending with a "live" Q&A session with the presenters. The sessions and live Q&A discussions themselves will afterwards be available online on the UK-CAB website so that members can view them at their own convenience.

Section 1 looks at life before HIV treatment became available and then goes on to focus on how HIV treatment was developed. It looks at HIV treatment today in the UK, with practical information on accessing and getting the best from treatment. There are also modules on HIV testing and prevention, HIV vaccine and cure.

Section 2 looks at evidence-based medicine. A key part of this is randomised clinical trials (RCTs), often run by Pharma companies. We cover how to interpret trial results and how they go on to be used in clinical practice. Government and National Institute of Health and Care Excellence (NICE) approval are needed before new medicines can be used in HIV clinics. We explore the role of the community, especially UK-CAB's involvement with public bodies and with the British HIV Association (BHIVA).

Section 3 looks at more general issues related to living with HIV in the UK. It will cover topics such as sexual and reproductive health; ageing with HIV; health inequalities; children and HIV; and tools for effective advocacy.

Update on UK-CAB rep recruitment (see slides from Ben Cromarty)

One of the most important things that BHIVA does is review evidence about HIV treatment for UK HIV treatment guidelines. There are currently 13 BHIVA treatment guideline writing groups which each include HIV healthcare professionals and are chaired by an expert on the subject concerned. There are two community representatives on each writing group.

Community reps bring their own lived experience, plus a broader community perspective, to the group, rather than scientific or medical knowledge. This is crucial to the development of effective treatment and care guidelines. For example, there is a section called “Support for Patients” and a non-technical summary in plain English. Reps also play an important part in sharing the information about new guidelines when they are published.

There is UK-CAB training material for new reps, as well as mentoring support – we will be covering this in the online training programme. BHIVA writing group members are always very supportive. Look out for news of community rep posts on the UK-CAB online forum as they come up.

Member updates

HIV Vitality – looking for support to share their retreat information.

Attendee list:

Name	Destination	Organisation
Adela Senkubuge	Manchester	Reinventing Success CIC
Alex Sparrowhawk	Manchester	UK-CAB and THT
Andy Hilton	Lytham St. Annes	<u>HIVitality</u>
Angelina Namiba	London	4M Network of Mentor Mothers
Bakita Kasadha	London	Researcher at Oxford Uni and CHIVA Associate
Beatrice Osoro	London	Positively UK
Ben Cromarty	Northallerton	Yorkshire Mesmac; York & S'bro Teaching Hospital
Bryan Dramiga	Bolton	CHIVA
Colin Stewart	Aberdeen	Our Positive Voice (Grampian)
Esther Ndungu	London	4M net
Fabiola Bayavuge	Manchester	Personal
George Westwood	London	National AIDS Trust
Jeff Ukiri	Manchester	George House Trust
Jo Josh	Surrey	UK-CAB Steering Group & BHIVA Communications Officer
Joshua Wharton	Manchester	George House Trust
Julie Willis	London	Positively UK
Lauren Duffy	Manchester	LGBT Foundation
Mel Rattue	Watford	THT 4MNet Fast track Cities London
Memory Sachikonye	London	UK-CAB
Rebecca Mbewe	London	Positively UK/4M Mentor Mothers Network CIC
Rebecca Walker	Newcastle	Blue Sky Trust
Robert James	Brighton	UK-CAB
Roger Pebody	London	NAM aidsmap
Shiellah Mushunje	Cambridge	Diverse and CAPS
Simon Collins	London	HIV i-Base
Simon Horvat-Marcovic	London	Positively UK/UK-CAB/THT
Susan Cole	London	NAM aidsmap
Tremaine Cornish	Lytham St. Annes	HiVitality