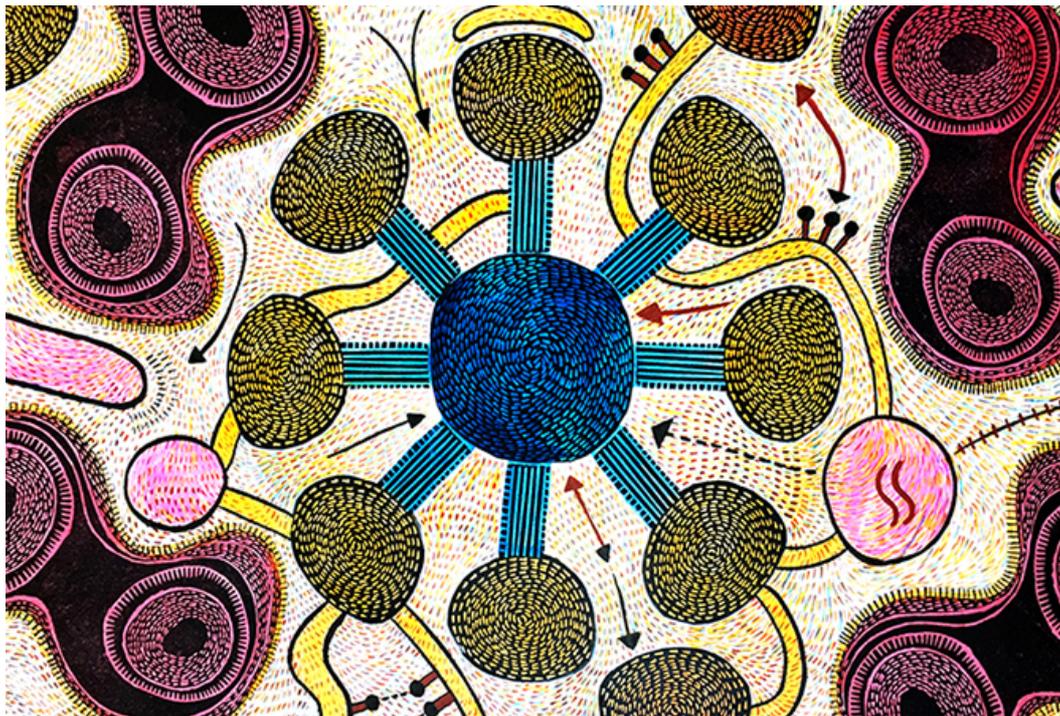


REPORT

Treatment activism training: UK-CAB skills and training course

Lane End Conference Centre, Buckinghamshire
12-14 February 2016



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Background

The 2016 training programme was the third to be run by the UK Community Advisory Board (UK-CAB.) The 21 participants were from diverse backgrounds across the UK, ranging from patient groups to HIV charities and other organisations. The intensive training ran from Friday afternoon to Sunday lunchtime, and included a change of pace with optional yoga sessions before breakfast, a poetry workshop and a film screening.

The overall objective was to expand the UK-CAB's network of skilled treatment advocates in order to meet the challenges presented by the changing landscape of the NHS, and HIV treatment and prevention technologies. Equipped with treatment knowledge and new skills, the trainees will be able to take roles as patient representatives, at a national level and within their own local networks.

Friday 12 February 2016

Introductory session

Following a short introduction, welcome and ice breaker, participants shared what they wanted to achieve from the training. Key objectives were:

- To advance knowledge and increase advocacy skills
- To build confidence
- To do something "out of my comfort zone"
- To find out more about UK-CAB and its activities.

Participants wanted other participants in the programme to:

- Maintain confidentiality
- Show respect to one another
- Be honest/be real/be themselves
- And to have fun.

Trials and research

Introduction to trials and research – Robert James

Robert James provided an entertaining and engaging introduction to trials and research in order to equip potential advocates with the rationale to read and interpret studies for themselves. He explained trial design, methodology, terminology and the necessity for evidence-based research.

His presentation provided: *"Trials and research made simpler and understandable."* Participants rated this presentation highly as follows: excellent – 8, very good – 7 and good – 4.

Robert's presentation is [here](#).

Virology and immunology

Virology and immunology: being a doctor and working in the NHS – how advocates and doctors can work together – Dr Iain Reeves

Dr Iain Reeves gave a clear and engaging explanation of virology and immunology, responding to questions from participants on scientific details and their own personal experiences. To quote feedback from one participant: *“Iain was a very good presenter who made complex theories very easy to understand.”* Iain went on to share his 20+ years experience as an HIV consultant, ending with an energetic question and answer session that could have continued all evening. Respondents rated the presentation on virology and immunology as very good or excellent, and two thirds nominated it as one of the things that stood out on the first day.

Dr Reeves presented Dr Waters’ slides and gave his own perspective as a doctor working in the NHS. The slides are [here](#).

Saturday 13 February 2016

Introduction to statistics

Measuring risk – Dr Colette Smith

Colette Smith used worked examples to help participants understand how to calculate prevalence, incidence and incidence risk. She illustrated this by looking at the relative risk between men and women, with a consistent differential in viral load in favour of men.

Participants were asked to read the START study paper, (*New England Journal of Medicine 27 August 2015*), in advance. The study concludes that initiation of antiretroviral therapy in HIV-positive adults with a CD4 count of more than 500 cells/mm³ provides net benefits over starting such therapy in patients after the CD4 count has declined to 350.

The implications of the NHS delay in applying these results to treatment commissioning until 2017 were discussed, remembering that each patient is an individual, and should have the support needed to make informed choices on when with what drugs to start treatment. The majority of participants (19) said that their confidence in their ability to understand statistics post training was good/very good or excellent, as compared to only 7 before. Colette gave: *“an insight on how stats work and why they are important to understand the trends of HIV and its dynamics.”*

Colette's slides are here: a) [Measuring risk](#), b) [practical exercises](#) and c) the START study paper.

Meetings and public speaking

Elisabeth Crafer, Silvia Petretti and Godwyns Onwuchekwa

The combination of these three speakers increased the confidence of participants, with 19 saying their confidence was good to excellent post training, as opposed to 8 before: *“Silvia and Godwyns’ sessions helped me move out of my comfort zone.”*

Dealing with people in authority and running an effective meeting – Elisabeth Crafer

Elisabeth shared her years of experience in influencing and managing meetings, giving invaluable insights into how to achieve the desired result. Straightforward tips on how to be effective ranged from being informed (advance reading of minutes and papers) to body language, positioning and taking control of a flip chart.

Participants found this useful: *“Dealing with authority was very interesting.”* Ratings ranged from excellent (6) to very good (9) and good (3.)

Elisabeths’ slides are here: a) [Dealing with people in authority](#); b) [Running an effective meeting](#); c:) [Meetings do and don’t](#)

Public speaking techniques – Silvia Petretti

Silvia inspired her audience by sharing the learnings that had enabled her to address an audiences successfully. She emphasised the need for structure (three points,) simplicity and telling a story/using personal experience to help the audience to connect.

She reminded participants that, in addition to PowerPoints and images, the speaker is also a visual aid – and to laugh at themselves. To quote Cicero: *“The skill to do, comes with doing...”* 12 respondents rated the session as excellent, and 5 very good.

Silvia’s slides are [here](#).

Poetry for activism – Godwyns Onwuchekwa

Godwyns showed participants how they could use poetry to express a topic they are passionate about: *“Poetry talks to you in a way that you do not expect.”* He shared examples from his own experience, including how he had reached an audience in East London with a poem that had made them stop and think.

Participants created their own short poems, firstly in small groups and then as individuals. By so doing they discovered how and why poetry can: *“force you to think more deeply, and can even make you calm.”* 11 respondents rated the session as excellent, 5 very good and 2 good.

A compilation of poems by Godwyns is yet to come.

Film: Fire in the blood

This powerful film records the struggle for access to ARVs in sub-Saharan Africa and India. The production of generic versions in India, at a fraction of the cost, was backed by a change of international patent laws. The problem of pricing remains, with pharmaceuticals making drugs available at the highest price the market will bear, instead of relating price to need; this is increasingly becoming an issues also affecting patients in the UK.

Discussion about what advocates and activists could do to change this continued the following day: *“Very empowering film, perfect to set the activist mode.”*

To watch a trailer and more about the film, please go here: <http://fireintheblood.com>

Sunday 14 February 2006

Effective representation

Participant presentations, community representation and the role of a UK-CAB community representative.

Participant presentations

As a practice for public speaking participants each gave a three-minute presentation on a subject of their choice. These were varied in content and style, very honest, and with some personal testimonies. Their tone reflected the shared trust and acceptance established within the group.

Remembering what they had learnt from Silvia, each member of the group wrote down two things that they thought each speaker did well, and one they thought could be improved on. Speakers were told that these responses would be anonymous, but would be fed back to each participant after the course.

Participants helped to build each other's confidence by listening and responding positively, making the presentations a less daunting and more rewarding experience for everyone: *"so enjoyed presentations session and listening to other trainees."*

NHS structures, BHIVA executive committee, clinical trials steering group and being a community representative – Garry Brough

Role of community representatives

Garry looked at community representation in research governance – historically and today. He covered Phase I and Phase II trials, explaining why women were excluded (in case of pregnancy,) whereas Phase III trials could include "special populations" (like women).

He also discussed inferiority or superiority trials (dolutegravir being a recent example of a superiority trial), cohort and observational studies and qualitative studies. He explained the importance of the data safety monitoring board, using the examples of START and PREP. Both trials were stopped because conclusive results meant that it was unethical to exclude control groups from access to medication.

Garry also stressed the value of the contribution of community reps because they can influence the questions and the methodology of research, as well as moderating the language used on patient information sheets.

BHIVA committees

Garry shared his experience of working with BHIVA for many years, with examples of how community members can influence guideline updates.

HIV Clinical Reference Group

He also explained membership and remit of the Clinical Reference Group (CRG.) There are currently three community members who are able to influence outcomes. There is a further opportunity for activists to influence as registered stakeholders at the public consultation stage.

The session ended with a five minute description of the role of a community rep from Fernando Monteiro.

Garry's presentations were highly rated, with respondents scoring in the good to excellent bracket: *"Garry's insider knowledge of organisational structures was truly informative."*

Final comments from participants

- *"I have learnt, enjoyed myself, feel empowered, I feel listened to and appreciated."*
- *"I have learnt so much and it has given me confidence for my role in the CCG."*
- *"And of course all the people that took part made it so educational."*
- *"Public speaking – everyone's presentation added something to my knowledge."*
- *"How to join and get involved to impact change."*
- *"Representing the community is imperative."*

Garry presented slides from Matthew Williams on [Community representation in research governance](#)
Garry's slides on [Community representation](#) – BHIVA, CRG.

Presenter biographies

Dr Iain Reeves

Dr Reeves is the lead clinician for HIV at the Homerton Hospital. He is an active researcher in the HIV field and has a particular interest in mental health. He is the chair of the NE London and Essex clinical network for HIV.

Robert James

Robert is a UK-CAB member. He teaches at the School of Law, Birkbeck College, and is a patient rep at the Lawson Unit in Brighton. He has a Masters in Research Methods and has experienced research as a subject of it, as a researcher doing it and sitting on advisory committees about it. He was also the UK-CAB community rep on the Data Safety Monitoring Board for the PIVOT trial of PI monotherapy.

Dr Colette Smith

Dr Smith is a Lecturer in Biostatistics and Epidemiology, working in the UCL Research Department of Infection and Population Health. She works as a medical statistician/epidemiologist, primarily in the HIV research field. Her work mostly focuses on observational cohort studies of HIV positive individuals, such as the Royal Free HIV Database and the D:A:D Study.

Dr Smith is interested in the long-term clinical, virological and immunological outcomes of antiretroviral therapy to treat HIV infection. A further research area is the potential long-term side effects of antiretroviral therapy. This frequently involves applying novel statistical methods in order to be able to answer clinically relevant questions.

Dr Smith is also involved in studies of viruses that may occur in adults and children who are immunosuppressed after solid organ transplantation, such as cytomegalovirus and Epstein Barr virus. She collaborates closely with my colleagues in the HIV Biostatistics and Epidemiology group, clinicians, virologists and scientists within UCL, at the Royal Free Hospital, and worldwide.

Elisabeth Crafer

Elisabeth is an independent NGO consultant and mentor, a former CEO of Positively UK and is currently a member of Women for Positive Action, a global initiative established to address specific concerns of women living and working with HIV.

Her particular interests are in equality, human rights and methods of achieving advocacy and representation. She is experienced in developing models for peer initiatives and gaining access to decision making at local and national level.

Silvia Petretti

Silvia is a woman living with HIV, Deputy CEO at Positively UK, and chair of UK-CAB. She has over 15 years' experience as a trainer and public speaker. She was the keynote speaker at the closing session of the United Nation High Level Meeting on HIV/AIDS in 2011 representing the Global Network of People Living with HIV (GNP+). You can watch her in action here:

<http://www.unmultimedia.org/tv/webcast/2011/06/global-network-of-people-living-with-hiv-2011-high-level-meeting-on-aids-95th-plenary-meeting.html>

Godwyns Onwuchekwa

Godwyns is a UK-CAB member. He is an HIV positive treatment advocate and a naturally gifted poet; he focuses on using poetry to inspire discussions on otherwise difficult and always unspoken issues of sex, romance and eroticism. Godwyns runs the annual Erotic Lounge poetry event on love and romance and has performed his poems in Whitechapel Gallery amongst other venues.

He is also a seasoned trainer with focus on the charity sector on issues including funding, governance, operation, service user engagement, social media and volunteering. Godwyns was the HIV patient rep at Homerton University for six years.

He currently runs the Shared Service Public Health HIV service users group for the Boroughs of Westminster, Hammersmith & Fulham and Kensington & Chelsea. Godwyns is an avid public speaker, blogger and an LGBT rights campaigner. He is a trustee of Changing Attitude, England; a charity campaigning for the full inclusion of LGBTI people in mission and life of the Church of England and he is also the founder of Justice for Gay Africans.

Garry Brough

Garry is a member of the UK-CAB Steering Group. He was diagnosed in 1991 at the age of 23. After starting treatment in 1997 and slowly recovering his health, he started volunteering and working in HIV support. He co-founded the Bloomsbury Patients Network in 1999.

Garry worked on the YMCA Positive Health Programme as the first paid patient rep in the UK at the Bloomsbury Clinic and developing and running the myHIV website for THT. He is currently London coordinator for Positively UK's Project 100, training peer mentors to deliver support in clinics and voluntary organisations.

Garry has been highly active within UK-CAB and BHIVA – sitting on BHIVA committees including the Treatment Guidelines, Primary Care Working Group, Conferences committee and most recently the BHIVA Executive Committee. Garry is also actively involved in both the London and national commissioning of HIV care and treatment via the HIV CRG and the London Clinical Advisory Group.