

United Kingdom Community Advisory Board (UK CAB) HIV treatment advocates network

Meeting Report CAB 32 - Advocacy Training Day 21 January 2010

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Presentations are all available to download for the January 2010 meeting at:
<http://www.ukcab.net/jan10/index.html>

Members attending

Name	Organisation	
Adela Mugabo	George House Trust	Manchester
Anca Nitulescu	Positively Women	London
Andrew Chuba	Black Health Agency	Manchester
Angelina Namiba	Positively Women	London
Ben Cromaty	North Yorkshire AIDS Action	Yorkshire
Brad Hepburn		London
Campbell Fisher	Waverley Care	Edinburgh
Charlotte Walker	HIV i-Base	London
Emma Hudson	The Brunswick Centre	Halifax
Godwyns Onwuchekwa	AHPN	London
Jeff Ukiri	Black Health Agency	Manchester
John O'Callaghan-Williamson	Tcell.org	London
Joram A Barigye	THT Woking	Woking
Karen Hamilton	Waverley Care	Edinburgh
Katie Walker		London
Kingsley Otoru	Inst for Int Health and Dev	Edinburgh
Memory Sachikonye	UKCAB	London
Nakamba Ng'ambi	Zambia Leeds Community Assoc	Leeds
Paul Clift	KCH Patients Forum	London
Roger Pebody	NAM	London
Samuel Serunjogi		London
Simon Collins	HIV i-Base	London
Virginia Cucchi	THT, Brent Mind	London
Winnie Sseruma	HIV i-Base	London

PROGRAMME

Morning Session: UKCAB structures and history	
10.00 – 10.05	Setting the scene for the day: a) Aims, expectations
10.05 – 11.00	UKCAB - Simon Collins a) How it started b) What we do: Community representation on Steering Committees, PCT, Trusts, BHIVA, etc. Responsibilities, networks, dissemination of information and how you are supported c) How we do it d) Strengths and weaknesses e) Denver principles
11.00 – 11.15	BREAK
11.15 – 12.30	Confidence building workshop – Winnie Sseruma a) Improving confidence through knowledge b) Challenging experts and status quo c) Support for your own care d) i-Base treatment advocates training model
12.30 – 14.00	LUNCH
Afternoon session: Skill-building session	
14.00 – 14.45	Advocacy Experiences a) Speaking on social issues – Godwyns Onwuchekwa b) Working as an advocate – Emma Hudson
15.00 – 15.15	NHS structures in the UK - Paul Cliff a) Primary and secondary care explained b) HIV in the UK – accessing care c) Polyclinics – effect on HIV care d) HIV Consultant and HIV Doctor – who's who?
15.15 – 15.30	Getting other advocates involved - Paul Cliff a) Forming a patient forum
15.30 – 16.00	What next – active involvement: a) Continued engagement of individuals and organisations: b) Advocacy - definitions, usefulness, limitations c) How do we keep everyone involved and supported? d) Issues for volunteers vs staff e) What can we ask of organisations, including the UKCAB?

This was a training day meeting led by experienced UKCAB members attended by 23 members, of which 9 were from outside London. The meeting's goal was to inform, engage and improve confidence of the new UKCAB members to be more engaged and remain active in CAB discussions on the forum and also in their own lives and areas of work.

The planned objectives for the day were: (led by Simon Collins)

- To have new members feel more confident to post/join discussions and maintain that momentum on the forum.
- To make all members understand they can use the forum as a resource - through other existing members.
- To address member needs to understand the history of UKCAB and how it works.
- To check whether members understand the meaning of advocacy.
- To build member-confidence and equip them with skills to deal with issues such as speaking out and challenging experts.

The meeting's aims, expectations were agreed on were:

- To develop a more active CAB membership
- Interactive sessions during the meeting for members to talk about personal experiences, limitations and areas of interest and the level of commitment they can offer to the CAB.
- Address the level of member activity, confidence
- Develop more expertise and confidence of members
- Allow enough discussion time for members to express themselves during sessions.

UKCAB structures and history

The first session was on the UKCAB structures and its history, which was led by Simon Collins. He started by finding out each attendee's length of involvement and experience with UKCAB. This turned out to be a range from those who have been involved from the start and those who had joined as early as two days before the meeting. He highlighted that the strength of the CAB is the individual members and its ability to help keep members in touch – reduces isolation. The CAB has developed a cohesion in its network that any representative is elected to feedback what is happening in the community at various committees – e.g. BHIVA, PCT, etc.

Discussion:

Q: About the CAB – what do you know about UKCAB?

A: Responses:

- *Focus is on treatment issues*
- *Provides training through meetings like this one*
- *Representation of the community of various boards, e.g. BHIVA, etc*
- *It has an email/message forum*
- *Provides networking for members across the country*
- *Advocates for positive people*
- *Currently approx 340 members from over 130 organisations*

How UKCAB started

The UKCAB was set up in 2002 to strengthen a network of people who were interested in learning about latest research in HIV-related treatments, especially for people working or volunteering in community organisations (although membership is also encouraged from individuals). At that time there was no structure for democratically nominating or election community representation on UK-based research or on the increasing set of guidelines panels. The CAB keeps people in touch via the email-based forum and is a cohesion in the network that any representation is elected to feedback what is happening in the community.

What we do: Comments and discussion

1. *Training, meetings, representation at various committees (BHIVA, MRC, etc), forum, email from message boards, networking, advocating for positive people, give information and sign-post, support for isolated positive people.*
2. *I make it a point of feeding back to communities in Yorkshire, would encourage everyone to do the same.*
3. *Community representation on Steering Committees, PCT, Trusts, BHIVA, etc*

Q: *Is it OK to challenge my consultant if I am not sure about something?*

A: *I would suggest everyone to have a second doctor for a second opinion if you need it to ensure your doc is up-to-date with treatment and other information.*

Comment: *We have the privilege of living in London, we forget they are other people in remote areas and do not have the choices we have.*

Members agreed that they find UKCAB useful and would sign-post it to other people.

UKCAB Forum

A handout on how to use the forum in the delegate pack was highlighted.

How do members use the forum; examples of how the forum is useful? What are the strengths and weaknesses? We would like to find a way of encouraging members to post.

Discussion

- *It drew me to want to know more, so I use it a lot.*
- *Recommended by a friend.*
- *See myself as a novice, am on learning curve and hope the CAB will be helping me as a frontline person in my job to signpost people to the CAB as a good resource.*
- *I have posted about 8 topics, the same numbers have replied.*

Comment: *I think twice before posting: is my post treatment-related?*

Why wouldn't you post?

- *Relevance; sometimes I wonder if its necessary to post things such as social care issues as I deal with that a lot.*
- *Technology; I find it a bit tricky. Its different from the old system*
- *Confidence issues:*
 - *Knowledge, if I am not knowledgeable about a subject I would rather not post*
 - *I am not sure whether is it not a wrong response to a post*
 - *I may feel the information may not relevant for the forum don't want to say something wrong or stupid (not relevant)*
 - *Fear of embarrassing oneself*
 - *Repeating what has been said before*
 - *Sometimes people do not read previous posts and repeat, should read and put additional information.*

Recommendations:

- Use of moderator if not sure to check your message before it goes out
- Members encouraged to try posting something - they could be surprised at the responses that may come.
- Check how many people are using the platform – membership is about 340 members from over 130 organisations.
- NHS cuts in support services will encourage more participation.

Denver principles – handout distributed in delegate packs, will be available on the CAB website.

Confidence building workshop – Winne Sseruma

This was a participatory session facilitated by Winnie and Angelina. They started off by acknowledging attendees’ levels of confidence, knowledge and experience:

Q: How long have you been a member?

- a. 0-3 weeks = 4
- b. 1-6 months = 1
- c. 7-12 months = 3
- d. 1 -2 yrs = 7
- e. 3 – 5 yrs = 2
- f. 6 - 10 yrs = 3

The next question looked at whether advocates are currently fulfilling their roles, and if not to find out what hinders them and also get pointers from those already fulfilling their roles:

Q: On a scale of 1-10 how confident do you feel as a treatment advocate? How can you get yourself to a 10?

Scale (no.)	To get to 10, I need:
Unsure (2)	<ul style="list-style-type: none"> • Personal interaction with experts in the area • Working with someone/patients
8-9	<ul style="list-style-type: none"> • I have a medical background, but need to know more about the inter-linking social issues.
8	<ul style="list-style-type: none"> • Talking to large groups, there should be more treatment advocates so I can slow down and do other things
7	<ul style="list-style-type: none"> • Effective network of treatment advocates/communication in specialised areas.
5 (5)	<ul style="list-style-type: none"> • Keep reading and updating my knowledge, want to be the next Simon! • More training • Engage with consultant/to be more assertive • Simplified information • Latest information on drugs and attitudes of patients • Lack of time and there are competing priorities
4-5	<ul style="list-style-type: none"> • Tips on retaining information/simplified information
3-4 (2)	<ul style="list-style-type: none"> • More treatment training • Need to do more talking, need more knowledge
3 (4)	<ul style="list-style-type: none"> • More information on a regular basis • Exposure on treatment advocacy • More information on the drugs and how they work • Writing information
2-3	<ul style="list-style-type: none"> • Sign-posting people/mentoring

1-2	<ul style="list-style-type: none"> • Need refresher courses on treatment information
1 (2)	<ul style="list-style-type: none"> • More information/confidence • To train in treatment/something to be done in understanding treatment

The last question was to address which experts advocates are likely to come across and what issues they need to challenge:

Q: Which/What experts do we need to challenge?

- PCT – funding prioritization
- NHS – treatment care pathways/jargon/PALS
- Bureaucracy – discrimination/rules
- Dentists – knowledge/awareness on transmission/accessibility/discrimination
- Drug companies – science (their version), ethics
- Doctors – lack of knowledge, drug interactions, testing, confidentiality
- Media – bias, responsibility to accurate reporting, treatment knowledge, interaction of health and media, offer training on HIV
- Social Workers – understanding of HIV e.g. they ask “ask you cured of HIV” during an assessment
- HIV positive people
- Organisations
- General population – faith groups

Support for own care, getting the best quality of life: This was a discussion on what issues are likely to come for the advocates and the experts and in general:

- Have an informed choice of treatment options.
- Challenge being bounced back and forth between doctors/experts on different disease areas.
- Have confidence to speak for own self, challenging doctors, self-awareness.
- Have professionals assess and acknowledge psychosocial issues.
- Have good listening skills.
- Knowledgeable about issues that affect them.
- Have a balancing act – taking care of oneself alongside other issues.

African outreach project update

This is an i-Base project run by Winnie to build treatment knowledge for PLHIV by training and developing a network of advocates who will be able to deliver sustainable treatment support for African communities and also develop a wider community awareness and confidence in treatment.

After the pilot in 2008, two more groups of advocates have been trained, some of whom have co-facilitated two treatment sessions. The last group’s focus was for advocates who already support people in their area of work; one-to-one treatment sessions, casework and treatment phone line.

The feedback has indicated the confidence gained through knowledge from this project, from support for own care to improving relationship with the doctor, and being able to support others in managing their treatment.

For this year, the plans include more training sessions for other community groups. For existing advocates monthly email update/support, quarterly update/support sessions, regular conference feedback sessions and phone line support.

Simon's Questionnaire

Attendees to think of three questions each that they have about HIV that they would want answered and three that they can answer, 17 written responses were received.

Questions members would want answered included:

- I need more information about CD4 percentages.
- Where can I get dosette boxes from?
- How can we get people living with HIV more interested in treatments?
- I'd like to know why sometimes they won't do CD4 tests?
- Why is it that sometimes my notes are not transferred to my GP or other specialists?
- Why do I have to tell my story after my HIV diagnosis, they want to know how it happened, etc (digging into my personal life)?
- Which drugs should I start treatment with?
- How do I know if a medication is not working for me – or how long should I put up with side effects before telling my doctor its not working; 1, 2 weeks, a month?
- As smoking has an effect on medication, would it be bad enough that you would need to change your drug regime?
- How safe is Kaletra monotherapy?
- If I have two blips (over 50 copies/ml) in a row, should I change straightaway or wait?
- Treatments/medication very complicated to understand, what can I do to retain information?
- There is so much going on in the sector, its difficult to keep up, how can I do this?
- How does smoking interact with medication?
- Why isn't there HIV education in schools?
- Why aren't there TV, radio adverts on HIV to encourage testing?
- How many strains to HIV exist?
- Can a heterosexual positive man have a child without sperm washing?
- Why is HIV referred to as disease/virus/germ?
- Why are all studies mainly based on men?
- Why are NAM, THT against each other?
- Why are there no variations in the dose of drugs we get, atripla in particular?
- What HIV treatments have a negative impact on the liver?
- Why do people get kidney stones?
- How many types of treatment are available for children?
- Why have our support organisations allowed funding to fragment their efforts to support us?
- Do alternative therapies work?
- Why has it proved difficult to find a cure for HIV?
- Why does the present treatment not lead to a cure since it could bring your viral load <5 copies/ml?
- Why haven't the Swiss guidelines been publicised in the media as a great milestone in the fight against HIV?
- What is still holding the vaccine?
- Is it true that if you have on HIV treatment you are not likely to transmit HIV to another person through unprotected sex?
- Does HIV reduce your life-span, what is the life-span of an HIV person in the UK?
- Does HIV treatment cause gall/kidney stones?
- Are there microbicides for HIV yet?
- What is the UK recommended CD4 count before treatment?
- Where did HIV originate?
- Organisational stigma in hospitals, how do we deal with it?
- What are the factors affecting access to ARVs amongst Africans?

- Why are GPs not confident in treating HIV patients?
- How are we going to deal with co-morbidities in the next two decades, in terms of patient care?
- How can we get more feedback/interaction around BHIVA reps and groups. Who is doing what? Regular feedback?
- How far have they gone with finding the HIV vaccine?
- Is there going to a cure for HIV?

Questions that members could answer: (Guess, Think, Know)

- I can answer most questions about transmission.
- How to provide good support for people living with HIV in rural communities
- How to support adherence strategies.
- When to start HIV meds in the UK (know)
- Some side effects of HIV meds (know)
- Importance of adherence (know)
- When should I start thinking about changing meds (think)
- That treatment is very individual (think)
- How exercise help with aches, pains and mental health (think)
- Questions around mother to child transmission (know)
- Assisted conception (know)
- How treatment works (know)
- Managing living with HIV
- Supporting others to make a decision on treatment
- Where to find support
- Can a positive woman have a negative child (know)
- I have HIV – can I be infected with another strain (know)
- Can I live to an old age with HIV (know)
- What's the difference between HIV and AIDS? (know)
- Why does the GP surgery send you a reminder for smear test insistently and not for other matters, e.g. flu jab?
- Which way is HIV transmitted?
- When you have an undetectable viral load, does that mean you don't have the virus in your organs?
- At what point is undetectable viral load equal to non-infective? (know)
- Is putting my health care between GPs and HIV clinics good for my health?(know)
- Where can I get objective advice about dental care for positive people? (know)
- I definitely know the standardized treatment for PEP.
- I definitely know the point at which someone needs to start treatment.
- I definitely know what treatment to use during pregnancy.
- Vaccine (know).
- Microbicides (know).
- GP, Primary health (know).
- Does poor adherence lead to resistance?
- Can a woman with HIV have a baby without HIV?
- What is PEP?
- There are different strains to HIV.
- There is no cure for HIV.
- Lack of adherence can lead to developing organ infections.
- An HIV positive mother on treatment can have an HIV negative baby.
- HIV has no cure.
- There are different strains of HIV.
- What causes AIDS?
- Ways of contracting HIV?

- Is there a cure for HIV?
- What ARVs are (know).
- Factors that affect access to ARVs in Africa (Nigeria) (know).
- When ARVs should be started (know)
- Pathogenesis of HIV transmission (biomedical mode) (know).
- How often do I take my drugs? (know)
- What drugs do I take? (know)
- When was I diagnosed with HIV? (know)
- Glands during sero-conversion.
- Viral load/CD4.
- Mother-to child-transmission (MTC).
- Basic HIV awareness and support.
- Solutions for people with adherence issues.
- HIV awareness and promotion.
- Importance of taking medication correctly.
- Pathways and signposting.
- How resistance develops.

Conclusion: This showed that all these questions could be posted to the CAB forum for discussion and could be answered by other CAB members. All members encouraged to use the forum for this.

Advocacy Experiences

Speaking on social issues – Godwyns Onwuchekwa

He shared his experiences of speaking at large audiences with very little time. One of his experiences was at the Labour Conference in 2009. There was no mention of HIV issues at the conference and felt he had to bring it up and emphasised the need to put the point first and there wasn't a lot of time. The response from the minister was that HIV care in the UK is not such a priority, so they do not do much. That's why there is need for advocacy in that area.

How do we improve confidence?

- Think positively
- Knowledge about the subject, do not argue,
- Knowledge not shared is useless.
- What was the expected outcome of your talk – need to know the objective of the audience and your own objective.
- Sample your opinions to a small group of people and get feedback.
- Structure your presentations, challenges and solutions, have a balance about what you want to seek and what your message is.

Q: Can you raise a controversial topic or do you just bring out HIV in general?

A: You should have enough evidence for your argument.

Q: Is it wise to decline your status when talking about HIV?

A: Depends on the situation, e.g. when you are talking to newly diagnosed people then it would inspire them to see that you can live OK with HIV.

Comment: Sometimes you are pushed to share experiences and you are not willing.

A: Get an expert, e.g. doctor to come and speak, know your audience.

Q: Suppose you are faced with the question: “HIV leads to sin which equals death?”

A: This could be difficult to deal with in religious settings.

Working as a advocate – Emma Hudson

Emma is a Community Development Worker with The Support & Advocacy Team at the Brunswick Centre that provides services to people who are HIV positive or who are directly affected by HIV in Calderdale & Kirklees. The aim is to support people living with HIV so that their physical and mental health/well-being is improved and maintained. She explained the support services offered and how she has advocated for her clients in different circumstances.

Q: Do doctors have a right to choose their patients? I know of a woman was having problems with her medication and complained; at next hosp visit she was assigned a new doctor.

A: Yes, but in practice I've not heard of any.

Q: Stopping medication – where do you draw the line as an advocate? Can you give up when you know the person is about to commit suicide?

A: I give all the relevant information and at the patient makes an informed decision about their life. I was supporting a HIV positive pregnant woman was convinced by her church that she did not need to take medication. After giving her information about another woman who had taken medication and had a HIV negative baby, she went on to take the medication.

Comment: You are supposed to be impartial.

Q: How long have you been an advocate?

A: I started HIV advocacy work in 2001 as part time, now I work full time.

Comment: Brunswick Centre are very fortunate, you do amazing work, wish there were more services like that around the country.

NHS structures in the UK: Paul Cliff

Apologies from Matt Williams who was supposed to co-facilitate this session with Paul.

Primary and secondary care explained

Primary care is the first point of contact, family doctor/GP, and involves the widest scope of health care, including all ages of patients seeking to maintain optimal health, and patients with multiple chronic diseases. Continuity is a key desirable characteristic of primary care, as patients usually prefer to consult the same primary care doctor for routine check-ups, and every time they require an initial consultation about a new complaint.

Common chronic illnesses, usually treated in primary care, include: hypertension, heart failure, and angina, diabetes, asthma, depression and anxiety, back pain, arthritis, thyroid dysfunction, etc.

Secondary care - are the specialists who generally do not have first contact with patients such HIV consultants, specialist registrars – cardiologists, urologists and dermatologists with link to fast-track to referrals to other clinics. Certain secondary care specialists do not

generally work in hospitals, such as psychiatrists, and some primary care facilities (notably the A & E) are located within hospitals.

NHS care is on the principle of universal healthcare free at the point of delivery'. However, 'universal' is compromised by immigration rules.

Polyclinics – effect on HIV care

Polyclinics are intended to offer a far greater range of services than can be offered by current GP practices and local health centres. In addition to traditional GP services they would offer extended urgent care, healthy living services, community mental health services and social care, whilst being more accessible and less medicalised than hospitals. A variety of models have been proposed ranging from networks of existing clinics to larger premises with several co-located GP practices, more extensive facilities and additional services provided by allied healthcare professionals.

Some opinions include the fact that with HIV now a long-term condition, polyclinics have a very important role in the delivery of HIV care. Many routine services, such as regular blood tests and check ups shouldn't require a trip to a hospital based clinic. Integrating services can only make life easier for people living with HIV so it's definitely a welcome move. Pilot still to be done for a poly-system clinic.

Comment: The view from the Department of Health is that HIV is now normalised like diabetes, why should it be different. As advocates we should counter this. NHS is going to have 5% cut in funding over five years for HIV services.

Comment: We held a 2-day training course for GPs, made it possible for an HIV positive person in that PCT area to access care across the board.

HIV Consultant and HIV Doctor – who's who?

Specialist Registrars are 'consultants in training' and therefore in a form of temporary placement while they 'skill up' to consultancy level.

Getting other advocates involved: Paul Cliff

Paul used to be the Patient Rep experience in Brighton and highlighted that an advocate or spokesperson of an HIV patients group will have a broad range of people to represent, and they have only one thing in common: at some point in their lives, they have been diagnosed with one particular infection. The key underlying principle to good advocacy is to avoid representing people like oneself, but to engage with the whole body of patients – gay men, women, African issues, etc. A patient advocate is aware of, alert to, the experiences of the broad range of patients he or she engages with and represents then without favour and prejudice.

Forming a patient forum

Paul spoke about how he was involved in developing a patient forum at the HIV clinic in Brighton that worked well and was right for its patients, anyone trying to set up one could use this as an example and adapt to suit their needs. The clinic consultant, e.g. Chelsea & Westminster, can start off a patient forum - Dr Martin Fisher started the one in Brighton. The lesson learnt from Brighton was the establishment of a meaningful patients' representation were patients can participate in the management of their clinic and that it is not threatening to the medical authority of their doctors. Some outcomes of this were:

- Changing clinic hours to meet patients' changing needs
- Evening clinic
- Early morning bloods
- Treatment with NewFill
- STI screening for HIV patients
- Telephone results of HIV antibody tests
- Relocation of services during rebuilding work
- Clinic for newly-diagnosed patients
- Home delivery of medications
- Development and implementation of patients survey
- Contributing to the case for increased clinic funding
- Access to care and treatment
- Retaining acute ward
- Stronger staff/cohort relationship
- Anecdotally, increased doctor confidence
- Stronger bargaining power - funding, PCT
- Patients survey (Brighton, with full support and resourcing from Hospital Trust including their specialist survey software)

Q: Is a patients' rep a paid role? We do not have one at Kobler. How do we start doing that?

A: Depends on the clinic, some clinics its voluntary – Bloomsbury and Kings College are paid, Homerton is voluntary.

Q: As a patient rep, many people feel they have the power to change things, how do you manage to make a group of people to feel their opinion matter?

A: Depends on the patient rep.

Comment: The problem is that if patient rep is paid, the hospital may as well make the rules.

Comment: Camden has been trying to set patient forum at Royal Free Hosp, but due to politics there it has not been possible. I feel I do not have the influence at my own hospital.

What next – active involvement:

Questionnaire - Simon encouraged all attendees to try posting at least a question on the forum from the forms handed out earlier to kick-start a discussion.

Continued engagement of individuals and organisations:

Attendees were asked to sign up for CAB subgroup in the areas they would like to develop expertise. The areas are:

1. Developing the email forum
2. UK CAB speaker group, could be subsidised by CAB
3. Producing pure advocacy resources
4. UKCAB representation on national committee, e.g. MRC, BHIVA and maybe have mentoring group
5. Patient Forums – members could form them at their own hospital
6. Media/PR for the CAB

UKCAB AOB

Comments on the day:

- There should have been a group tasks
- I enjoyed today; it felt like the kind of work I do, I sometimes do not use all the treatment information.

Q: As a gay white man, why should I attend the next meeting on African Treatment issues?

A: As advocates of a group of different communities, there are issues that run across the board which advocates should be well versed in.

A: African communities and gay are the most affected communities by HIV.

A: There are different services for different communities, but now patients are coming together in forums.

A: It is an opportunity to find out what other communities are doing.

A: As a advocate you should be able to advocate across a wide spectrum

A: There are African-related treatment issues (genetics)

A: You'll understand some social issues that affect Africans – immigration, isolation, stigma, etc.

Next meeting

Date: 19 March 2010

Topic: African Treatment Issues and Late Diagnosis

Pharma: Gilead Sciences