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

UK CAB 31
Meeting Report
Friday 23 October 2009

Contents:

Presentations from this meeting
are available from the UKCAB website at:
http://www.ukcab.net/oct09/index/html

PROGRAMME: *(amended Friday morning)*

09:30 -10:00	Registration, refreshments and expenses
10:00 -10:15	Welcome and UKCAB Updates – Brian West, chair
10:15 -11:00	**Session 1**
	UKCHIC Ageing Study - Caroline Sabin (30 mins)
	Chelsea & Westminster ageing study (30 mins) John J.J. O'Callaghan-Williamson Chelsea and Westminster Patient Group
11:00 -11:15	**Break**
11:15 - 12:15	**Session 2**
	Will we ever get to be old and wise? -Robert James
	BHIVA Autumn Conference feedback – Gus Cairns
12:15 – 12:30	Pre-Meeting for Abbott – Brian West
12:30 - 14:00	**Lunch**
14:00 -15:00	Community meeting update from Abbott
15:00 -15:30	Community Q & A session with Abbott
15:30 - 15:45	**Break**
15: 45 - 16:15	HIV and Ageing - Dr Martin Fisher HIV/Aids consultant at Brighton and Sussex University Hospitals
16:15 - 16:30	UKCAB AOB
16:30	Close

Members attending:

Adela Mugabo	George House Trust	Manchester
Angelina Namiba	Positively Women	London
Angeline Marang	HIV i-Base	London
Alastair Hudson	IPPF/Stigma Index	London
Andrew Chuba	Black Health Agency	Manchester
Annabel Mudyara	Our Project@ MESMAC	Bradford
Antony Tukai	Oxfordshire County Council	Oxford
Ben Cromaty	North Yorkshire AIDS Alliance	Yorkshire
Brad Smith	Our Project@ MESMAC	Bradford
Brian West	Waverley Care	Edinburgh
Caroline Sabin	UKCHIC	London
Eleanor Briggs	NAT	London
Eneya Chireya		Manchester
Fabiola Bayavuge	Black Health Agency	Manchester
Godwyns Onwuchekwa	AHPN	London
Gus Cairns	NAM	London
Jeff Ukiri	Black Health Agency	Manchester
John O'Callagham-Williamson	Frontline HIV Forum	London
Joram Barigye	Terence Higgins Trust	Woking
Kingsley Oturu	Inst for Int. Health & Dev	Edinburgh
Memory Sachikonye	UKCAB	London
Michael Marr	UKCAB Chair/Waverly Care	Edinburgh
Paul Clift	KCH Patients Forum	London
Richard Blackburn	Brunswick Centre	Halifax
Robert James	NAT	Brighton
Roger Pebody	NAM	London
Silvia Petretti	Positively Women	London
Walter Zonke	HIV i-Base	London

Apologies:

Badru Male	CHAT	London
Isabela Tolowonski		Tunbridge Wells
Matthew Williams	Monument Trust	London
Simon Collins	HIV i-Base	London
Winnie Sseruma	HIV i-Base	London

UKCAB Updates

- Apology from Matthew Williams who was going to be chair, Brian West took over as chair for the day. He welcomed all attendees and announced changes to the programme and that Dr Martin Fisher would do the HIV and Ageing session at the end of the day.
- Announced and congratulated Silvia Petretti as the BHIVA Community Rep

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Proposed Ageing Study

UK Collaborative HIV Cohort (UK CHIC) Study - Caroline Sabin

The presentation was to provide the general ideas that UKCHIC have for the study that it is still in the planning stage. With reduced mortality rates, an increasing number of people are living with HIV into older ages. 15% of HIV patients in the UK are over 50; the proposed study will look at the need to adapt the management of those living with HIV so that their clinical needs continue to be met as virtually nothing is known about the likely health care needs of the older HIV population.

The study will be done for a cohort of individuals aged 50yrs attending sites with the UKCHIC and Dublin HIV cohort to address questions relating to several issues; uptake and outcome of HAART in older individuals, ARV effects, cardiovascular disease (CVD), bone disease, CNS complications, musculoskeletal manifestations, women and the menopause, sexual behaviour, social and economic factors, CMV infection in compromising immunity during ageing and resource utilisation.

The study will be a fully consented with no intervention, with annual visits to study centres and there maybe separately funded sub-studies as necessary, e.g. sexual behaviour. She wanted to see whether the UKCAB can foresee any problems in terms of recruitment (i.e. what would make it an interesting study for patients to participate in), whether the community have suggestions about where UKCHIC could sample 'controls', and whether anyone would be interested in contributing to the study team.

Baseline visit would collect: demographic data, medical history, educational level, lifestyle factors, sexual behaviour, use of ART, ECG, thyroid function and concomitant meds (statins, etc). Annual assessments would be to update baseline data, syphilis and Hep tests, liver function tests, renal function, falls assessments, CVD risk, health use and any other clinical events such as diabetes, gout, etc.

Comment: There should be a thorough neuro-cognitive assessment at baseline visit.

Bi-annual visits would cover bone and CNS assessments, Therapeutic Drug Monitoring (TDM), pain assessment and immunology.

Q: Where are the mental health workers on the study team?
A: Alan Winston heading the neuro-cognitive side of the study.

Questions from Caroline:
Caroline: Is this a study that patients would be keen to participate in? If not what might make it attractive?
A: Generally yes.
Caroline: Are there medical issues that we should include?
A: i) *Social contact, isolation, support needs to be addressed.*
ii) Onset of cancer, would like to see more testing before people get cancers.

Caroline: There are lots of European studies looking at cancer, would like to target areas where there is less information.

iii) GPs and how they are supposed to pick up everything else – most people don't register with GPs, do not recognise HIV ageing issues and should be educated

Caroline: How do we find suitable control?
i) Robert suggested to remove haemophiliacs due to pain issues would skew results due to pain.
ii) HIV-negative controls could be found in sero-discordant couples
iii) HIV+ control group could be the different time starting HAART; they do not know how long they have been infected.

Caroline: We rely on statistical information.

Comment: Prime Time support group in Edinburgh has been doing a similar study on gay men, issues: CVD, dementia, bones. A control group is therefore important.

Q: How do come to identify these particular groups?
Caroline: clinicians would identify patients. Idea would be to take a whole spectrum of people to have a picture rather than a specific group and also look at different sickness patterns.

Caroline: Community involvement in the study team?
A: Yes, UKCAB is interested

Ageing with HIV: Project overview
Frontline HIV Forum - John J.J. O'Callaghan-Williamson

This is a patient-led research study at Chelsea and Westminster, the first major project with any NHS organisation utilising positive patients skills base. The NHS have been slow to change and broaden process to facilitate this form of research .

The research project resonates with the UKCHIC study and aims to obtain valid quantitative and in-depth qualitative data describing the growing and changing population of older adults with HIV. The criteria is to find and establish needs, construction by experienced patients to ensure relevant questions and areas are covered. It is partnered with the USA Acria Research on Ageing with HIV HIV study (ROAH) with some questions for comparison for UK/USA.

This is a study for HIV+ people over 50, pilot to be delivered by summer 2010 with the main study aiming to recruit 250 patients. This research is aimed at bringing out patient issues into focus; it is a first major ethical and medically accepted project of its type. It will help plan local health and social care outcomes as well as contribute to global understanding of Ageing with HIV.

Still seeking ethics approval, which was an oversight.

Q: Is this just for Chelsea and Westminster patients?
A: Yes, initially.

Comment: I would like to see sample of questionnaire.
A: Cannot share that at the moment, would like to protect the on-going work for now.

Q: **what support are you getting from the C&W staff?**
A: Directorate is very supportive; NHS have never done this before, we're having to negotiate each step.

Q: In the qualitative data, could you ask how people have resolved issues?
A: Have statistician working on the research to ensure they gather the right data.

Q: When people are taking part, is this going to be a C&W study or administered by the patient group?
A: It is going to be administered by patient group, in a partnership with C & W.

Feedback from BHIVA Conference

Will we ever get to be old and wise?
Robert James

This was his presentation from the BHIVA community Symposium. This was the positive people's response to cognitive impairment. It highlighted that cognitive impairment was not been seen in patient groups; it was not yet an issue for Health Trainers in London unlike other mental health problems. Recommendations are that patients should not rush to physiological diagnosis although there is fear that it is the start of HIV related dementia.

BHIVA Conference overview
Gus Cairns

He chaired the Community Symposium on cognitive impairement, and felt it went pretty well. His overview of the conference was that it wasn't educational and therefore not newsy. He highlighted on:

- Flick Thorley's workshop on Gay men and the consequences of party drugs; convinced that methamphetamine (crystal meth) has arrived in the London gay community in a big way, is causing harm, and it's time we wrote about it again.
- Prof. Gazzard gave a nice clear off-the-cuff talk on why 350 is the best CD4 count at which to start treatment.
- Dr Simon Rackstraw's HIV-related dementia presentation: How do you measure it? It is not simple test. There are battery- powered psychological tests but they isolate certain skills. Symptoms of Early Stage HIV related cognitive impairment include: difficulty concentrating, ddifficulty remembering phone numbers or appointments, slowed thinking, longer time required to complete complicated tasks. reliance on list keeping to help track daily activities, mental status tests and other mental capabilities may be normal, irritability, unsteady gait or difficulty keeping balance, poor coordination and a change in handwriting and ddepression.
- No evidence of this getting any worse, maybe a generalised thing that HIV does to the brain, related to your lowest CD4 count.
- Current CD4 is not related, but your initial CD4 puts you at risk, largest evidence is from US. They exclude other issues such as depression.

Q: Is anyone doing post-mortem brain studies?
A: Yes, but some HIV+ people have slightly reduced brain volume compared with HIV- people, but do not necessarily have brain impairment.

- Anti-depressants work even if you are not depressed.
- ABC penetrates the brain, TFV does not, and there is not a lot of evidence on effect of dementia.
- Hep C related brain dementia, not much evidence on cognitive impairment.
- Some clinics do not look for the symptoms

Comment: Important to have gender studies on all studies.

He noted that clinicians should be urged to do a simple baseline neuro-cognitive test for everyone is diagnosed and the importance of getting together a cohort of people prone to get dementia.

- Steven Deeks' talk on elite controllers. Elite controllers have HIV levels undetectable by standard viral load tests, without the use of antiretroviral drugs. There are probably fewer than one in a hundred individuals infected with HIV meeting this standard. Tried to find what they have in common, their CD8 cells have a fast response to HIV, but not all, still a mystery. May have an unfit virus, ongoing investigation.

Q: Was there anything about ethnic elite controllers?
A: Some research says there is more African-Americans.

Q: What about their social well-being? Is there any research to show any damage being done?
A: There are some indicators of immune chemical high count.

Q: Some African women in Manchester do not understand how treatment works and one had died, is that a mental problem?
A: Maybe not, need to update everyone's knowledge of HIV drugs

Comment: People afraid to side-effects such as CVD, lipodystrophy, etc.

A: You are better on HAART; there are studies to prove this. Do you want HIV or the drugs to kill you?

Comment: Some people believe you take meds when you are ill and stop when you are well. We need to help them change that.

Q: Which is the most important thing to encourage a person to start treatment – when CD4 is 350 or when they are ready?
A: Give information based on evidence from studies. Some professionals have said they would start as possible. Follow the current BHIVA guidelines.

Pre-Meeting for Abbott
Brian West

A discussion about Abbott's drugs was held. Brian briefed the attendees to bring up the issue of the price of the new ritonavir booster (novir).

Questions had been compiled and sent to Abbott in advance – *see Q&A session*

Community meeting update from Abbott
Tayo Erogbogbo – Community Relations Manager

He presented Abbott's work in the UK and in Africa, some highlights include:

Mental health
Engage the community such as UKCAB and ECAB, on issues across Europe and help with literature review of all HIV mental health data. Current response to the evidence shows:

- Why emotional/mental health issues are important – risk of HIV infection in the first place.
- A mental health survey showed that stigma is a cause of mental/emotional problems.

Q: Could you we have social data from UK or Europe, there is no consistency in the UK?
A: This is the data available.

Comment: Stigma index survey – to be launched 30 November 2009.
Comment: We need more recent data rather than data from 2004.

There is increased drug switching associated with psychological and physical pill burden. Switching reasons should be that is should be beneficial to you.

Comment: Suggest that you find reasons why people switch drugs, in the past it was side effects, drugs have got better and people switch for different reasons. You have touched on an issue doctors are not asking, its an important issue, need to see an study on intervention on mental health.

A: This could be an area that can engaged by a pharma/community, Abbott Diagnostics will be giving mental health diagnosis machines, still work in progress will meet with 45 centres in UK.

Q: Is mental health the same as emotional well-being; how do we measure that?
A: Emotional well-being is the an about the quality of life; maybe someone will produce some software to measure that, its not happening in the UK at present. If need is identified, there is no clinical pathway for support.

Comment: There are clinical psychologists within HIV teams in clinics.

Abbott Global Response to Africa:
- Sells kaletra and norvir HIV in Africa at cost. They also sell the Determine HIV test at cost on the continent.
- Distributed more than 100 million rapid HIV/AIDS tests at no profit or free of charge
- Served more than 700,000 children and families impacted by AIDS
- Improved HIV services at more than 90 sites across Tanzania, including building a new treatment centre and clinical laboratories at the country's largest hospital
- Undertaking modernization of all 23 regional hospital laboratories in Tanzania
- Supported a model paediatric HIV treatment program that reduced mortality rates by 90 percent; this model is now being expanded across Africa.
- PMTCT – helping pregnant women find out their HIV status, Abbott donates rapid HIV tests free of charge to qualifying programs in 69 developing countries, including all of Africa. Rapid testing allows women to learn their status in 15 minutes and increases the opportunity to receive counselling after the test. Local programs can then offer HIV-

positive mothers free and convenient therapy to prevent their child from being infected with HIV. Based on feedback from implementing partners, Abbott also has broadened the program to offer free rapid HIV testing to partners and children of women who test HIV positive.

Q: Why Tanzania?
A: We speak to governments and Tanzania was very engaging, it is a stable country, there is transparency.

Q: What is inflation rate compared to population, success rate?
A: 2-15%, success rate – impact from 100 to 1000 patients a day for voluntary counselling and testing.

Q: Stigma ideas – any programs to educate people on how to combat stigma?
A: *We can help programs that are already in place, we work through agencies.*

Q: How do you ensure your work is successful?
A: We have auditing systems in place to ensure we get valid feedback.

Comment: You need to engage with the grassroots to get that feedback, government feedback is usually biased.

Community Q & A session with Abbott

Q: Does kaletra penetrate the brain, and how does this compare with other drugs on the market?"
A: Yes, very well from available data.

Q: What will the new price of the new norvir be?
A: No price change in the UK, available from 03/10 and no increase in the rest Europe. We send more alluvia to Africa than the rest of the world.

Q: When precisely will this be available in the UK, EU and elsewhere?
A: The marketing strategy will be to phase out old tablet. Doctors not expecting complete switch, could be 12 months.

Q: Any new side-effects on the new drug?
A: Yes with food restrictions.

Q: What is the data update on the 100mg vs 50mg of the new norvir?
A: It will be100mg only.

Q: Adherence vs dosage; does it improve in single or twice daily dosing?
A: Adherence is better as with proved by Atripla sales, 18% improvement in once daily dosing.

Q: We generally know kaletra is a good drug in pregnancy, and would like to know more about pregnancy and conception, what is evidence is available?
A: Information on pregnancy register, recent data shows that's it works better, doing further research on breastfeeding as well.

Q: What are Abbott's pipeline drugs?
A: PI in development, not good, show 1000x rise in anaemia. There are good drugs on the market, Abbot is moving forward to focus on Hep C. Trials in phase 2 or 3, available 2012-13.

Comment: Other than the reformulation of kaletra, CAB is disappointed about no new drugs.

Q: Is Gilead working on a rival booster, may come out in 9 months, where is Abbott on this?
A: No interest from other companies on co-formulations

Q: Where is abbot on the pricing in Africa and Eastern Europe on the new formulation?
A: Africa US$5000/pt/yr, Europe US$8000/patient/yr

Q: Lab tests – are they free?
A: in Tanzania they are free, portable cd4 test being developed with different options. It is developed by Abbott and sold to another company - Inverness - now promoting testing in Africa.

HIV and Ageing
Martin Fisher – HIV/Aids consultant at Brighton and Sussex University Hospitals

This was an interactive session on HIV and ageing:
Q: What is old?
- Over 50, 15% in UK; 28% in Brighton

Q: Does ageing affect HIV?
- HIV progression faster, fast drop in CD4 and work less well, argument for starting early if you are older
- PCP, CMV likely to be common from CD4 of 200.

Q: Why do older people get diagnose late compared to younger people?
- Consider their risk factors as low; doctors do not talk about sex to older people. They are over represented.
- Infection in older age – not worry about contraception, prevention messages targeted at younger people, advent of Internet dating, new relationship, young blood!

Q: Age response to drugs? Young vs old
- VL response is the same; CD4 is slow to rise.
- HIV speeding up aging: - you should add 10-20 years on chronological age, but treatment helps with survival ages. Immune activation (over active) speeds ageing, results in cancer, neuro-cognitive, bone, liver, CVD
- Children born with HIV – not much known.
- Healthcare issues - cancers kick in from age 60: breast, prostate, colon, cervix, bowel, GP will need to call you in when you turn 50 for screening, should encourage for HIV patients to be screened early.

Q: Who should look after all of this?
- GP should be best, but not knowledgeable! London clinics trying to get a GP into HIV clinic.
- Poly-systems – a service with HIV consultants going into GP services
- HIV consultants and GPs should talk to each other!

- Patients should feed into national policy

Q: Why do HIV+ not disclose to their GPs?
- Patients worry about confidentiality – GPs and HIV consultants could read same records.

Q: Any GP training around HIV?
A: New graduates (from about10 years ago) includes HIV component training, older trained GPs do not have that.

Comment: GPs are trained in general practice, unless they have an interest in HIV, Scotland has a PC initiative for GP to train on HIV.

A: Too few HIV pts would want to justify time it costs for them to be trained and the cost of locums. Maybe there should be community-base HIV doctors.

Conclusion:
- Patients should to talk to GPs about screening for CVD, bones, physco-social needs such as a family to support, etc when they get to 50.
- Older patients Should start ART at no less than 500 if over 50,

Q: Should you be using different drugs TFV vs ABC debate?
A: Not one fits all, guideline say you should start 500 if you are over 50. And consider use of isentriss or maraviroc as second line therapy.

UKCAB AOB

Next meeting: 19 March 2010
Topic: African Treatment Issues and Late Diagnosis