

UK-CAB 43: Bone health and exercise 6 July 2012

Contents

Programme	2
Members attending	3
UKCAB updates	4
Bone health and exercise – Victoria Brown, YMCA	4
Bone health and Vitamin D deficiency – Dr Frank Post, Kings College	6
Pre-meeting for ViiV – Brian West	8
Company meeting: ViiV Healthcare	9
BHIVA community posters – Alison Barnes, Body and Soul	11
Next meeting	12

Presentations are all available to download for the July meeting at:
<http://www.ukcab.net/2012/07/cab43-bone-health-and-exercise/>

Programme

Chair: Angelina Namiba		Timekeeper: Fabiola Bayavuge	
09:30 – 09:50	Registration, refreshments and expenses		
09:50 – 10:00	Welcome, introductions, UKCAB updates		
10:00 – 11:00	Bone health and exercise – Victoria Brown, YMCA Positive Health Programme and Garry Brough		
11:15 – 11.30	Break		
11:30 – 12.30	Bone health and Vitamin D deficiency – Dr Frank Post, Kings College		
12:30 – 13.00	Company pre-meeting – Brian West		
13:00 - 14:00	Lunch		
Chair: Brian West		Timekeeper: Jonathan Ssentamu	
14:00 - 15:30	Company meeting: ViiV		
15.30 - 15.35	Break		
15:35 – 16:00	BHIVA Community poster: Body and Soul – Alison Barnes UKCAB AOB		
16.00	Close		

Members Attending

No	Name	Organisation	Destination
1	Angelina Namiba	HIV i-Base	London
2	Ben Collins	Int HIV Partnerships	London
3	Ben Cromarty	North Yorkshire AIDS Action	Yorkshire
4	Brian West	Waverley Care	Edinburgh
5	Fabiola Bayavuge	Black Health Agency	Manchester
6	Garry Brough	THT London	London
7	Glenda Gibbs	Personal	Wolverhampton
8	Gus Cairns	NAM	London
9	Jackie Ayuhi DeMasi	NAM	London
10	Jacqueline Stevenson	AHPN	London
11	Jeff Ukiri	Personal	Manchester
12	Jet Lengalenga	Personal	London
13	Jonathan Ssentamu	Waverley Care	Edinburgh
14	Memory Sachikonye	Personal	London
15	Michael Marr	Waverley Care	Edinburgh
16	Muirgen Stack	HIV i-Base	London
17	Nyambe Mukelabai	Leeds Skyline	Leeds
18	Paul Clift	King's College/UKCAB	London
19	Phyllis Okai	Central Middx Hosp - PPE	London
20	Rahab Maina	Leeds Skyline	Leeds
21	Rebecca McDowell	HIV i-Base	London
22	Roger Pebody	NAM	London
23	Roy Trevelion	Personal	London
24	Silvia Petretti	Positively UK	London
25	Simon Collins	HIV i-Base	London
26	Stewart Murau	GHT	Manchester
27	Tendai Ndanga	AHPN/Ffena	London

Apologies:

1. Rupert Jones
2. Damian Kelly
3. Robert James
4. Godwyns Onwuchekwa
5. Mark Platt
6. Pamela Kaseke-Mushore
7. Tsepo Young

UKCAB updates

- Michael Marr encouraged members to apply for the BHIVA Executive Committee rep post as Silvia Petretti's term is coming to an end at the BHIVA Autumn conference.
 - From November 2011 to June 2012, the UK-CAB organised an online community survey relating to changing treatment that had been introduced in April 2011, a summary report of the results was distributed in attendee packs at the meeting and also available on the UKCAB website in PDF format. A press release had also been distributed.
-

Bone health and Exercise - Victoria Brown

Victoria Brown changed her career five years ago as her passion for exercise resulted in retraining as a personal trainer at the YMCA Club at Tottenham Court Road. After volunteering and personal training at the Club she became interested in and trained in Exercise Referral. For the last two years she has worked as part of the YMCA's Positive Health team, which runs the unique Exercise Referral programme for people living with HIV. She coordinates the 12-week exercise programme, which supports those who are new to exercise or individuals who need support to get back to the gym.

The YMCA Positive Health Programme (PHP) was set up in 1997 to promote increased activity in HIV positive individuals. It offers a dedicated exercise referral scheme with a Positive Health team of staff who are able to understand and deal with the issues faced by individuals who are HIV positive. The aim of the scheme is to introduce HIV positive individuals who have an inactive lifestyle or who are suffering from a HIV related condition to exercise in a non-clinical setting. Members follow a 12-week programme and are given an initial fitness assessment and an individual exercise plan, which takes into account the various illnesses and conditions experienced. Through a wide range of activities, such as resistance and cardiovascular training, swimming and exercise classes PHP encourages participants to embrace a more active lifestyle. The scheme is also there to encourage interaction with a wide range of individuals to promote social inclusion.

Victoria explained that exercise not only makes you physically fitter, it also improves your mental health and general sense of wellbeing. Regular exercise can help protect you from heart disease and stroke, high blood pressure, noninsulin-dependent diabetes, obesity; back pain, osteoporosis, and can improve your mood and help you to better manage stress.

Exercise benefits bones in three ways:

- Exercise brings fresh blood to the bones and to the tendons and ligaments attached to them.
- Exercise brings more oxygen to the bone and surrounding tissues, and this helps to maintain the tissues and repair any damage.
- Exercise stimulates the existing bone and encourages it to grow new bone.

There are three basic types of exercise that benefit the bones: aerobic, weight bearing, and strength training exercises, and for strong, healthy bones a mix of these three types of workout is most beneficial. The aerobic exercises increase blood and oxygen supply to the muscles, bones and connective tissues; weight bearing exercises such as stair climbing, leg lifts, squats and push-ups use the body's own weight to strengthen the bones; and strength training workouts such as weight lifting use weights outside the body to strengthen the bones.

Weight bearing workouts help to build and strengthen the bones and slow the natural loss of bone density that occurs as we age. Weight-bearing exercises are those in which the body's own weight is used, such as climbing stairs, leg lifts or push-ups, rowing, or exercises in which weights are lifted.

Information about bone health and growth is in the slides presented by Victoria on the UKCAB website.

Osteoporosis is a condition that affects the bones, causing them to become weak and fragile and more likely to break (fracture). These fractures most commonly occur in the spine, wrist and hips but can affect other bones such as the arm or pelvis.

In childhood, bones grow and repair very quickly, but this process slows as people get older. Bones stop growing in length between the ages of 16 and 18, but continue to increase in density until the late 20s. From about the age of 35, a person gradually loses bone density. This is a normal part of ageing, but for some people it can lead to osteoporosis and an increased risk of fractures. There are often no warning signs for osteoporosis until someone experiences a fracture, often after a minor fall. The most common injuries in people with osteoporosis are wrist fractures, hip fractures or fractures of the spinal bones (vertebrae).

Other things that increase the risk of developing osteoporosis include:

- Diseases of the hormone producing glands – such as an overactive thyroid gland (hyperthyroidism)
- Family history of osteoporosis
- Long-term use of certain medications which affect bone strength or hormone levels, for example, oral prednisolone and menopausal women.
- Malabsorption problems
- Heavy drinking and smoking

If your doctor suspects you have osteoporosis, or are at high risk of developing the condition, you may be referred for a bone density scan (DEXA scan). This is a short and painless procedure which helps to assess your risk of a fracture.

A DEXA scan is a special type of X-ray that measures bone density. DEXA stands for dual energy X-ray absorptiometry is most commonly used to diagnose osteoporosis (where the bones become weak and fragile and more likely to break). They can also be used to assess the risk of osteoporosis developing. A DEXA bone scan can also help detect other bone-related conditions, such as osteopenia (very low bone mineral density) and osteomalacia (softening of the bones caused by a vitamin D deficiency). In children, osteomalacia is known as rickets.

DEXA test results are compared to the ideal or peak bone mineral density of a healthy 30-year-old adult, and are given a T-score. A score of 0 means the bone mineral density (BMD) is equal to the norm for a healthy young adult. Differences between your BMD and that of the healthy young adult norm are measured in units called standard deviations (SDs). The more standard deviations below 0, indicated as negative numbers, the lower your BMD and the higher your risk of fracture.

A T-score between +1 and –1 is considered normal or healthy. A T-score between –1 and –2.5 indicates that you have low bone mass, although not low enough to be diagnosed with osteoporosis. A T-score of –2.5 or lower indicates that you have osteoporosis. If negative number is high; then the more severe the osteoporosis.

Sometimes your bone mineral density is compared to that of a typical individual whose age is matched to yours. This comparison gives you a Z-score. Because a low BMD level is common among older adults, comparisons with the BMD of a typical individual whose age is matched to yours can be misleading. Therefore, the diagnosis of osteoporosis or low bone mass is based on your T-score. However, a Z-score can be useful for determining whether an underlying disease or condition is causing bone loss. This raises the question of long-term HIV medication as a risk factor.

Q: Why are particular ethnicities e.g. black African and Asian at higher risk of Vitamin D Deficiency?

A: Darker skin pigmentation has problems absorbing vitamin D.

Comment: Women exercising 20min a day for 10yrs before menopause offsets osteoporosis. Regular weight bearing increases BMD/offsets age.

Garry's (42) joined the YMCA gym after his HIV diagnosis to get strength back. He has been exercising for last 10years. He was referred for DEXA scan and had a T-score of -1.5 and wondered where this had come from. He had recently read about a US study on bone loss in young men who had switched to Truvada two years earlier and diagnosed with low BMD. He keeps asking himself if treatment had caused his problems. He recommended that everyone should be aware of the symptoms and a personal risk assessment, if you really worried, then talk to your doctor.

A show of hands in the meeting showed that the majority of participants had never had a DEXA scan or asked for one. Diet and exercise recommended as a limiting risk factor.

Roy (60+) had rheumatoid arthritis from age 7, treated with steroids to manage joints flaring up. He went to the gym and realised the benefit to his joint pain. He improved his diet with calcium rich foods, changed HIV treatment and has kept diary of joint pain. He had DEXA scan and diagnosed with osteopenia due to steroids. Exercise helped him retain higher BMD.

Discussion:

Comments:

- **Taking DEXA one scan does not determine BMD, some clinics are planning to take a baseline scan to have something to compare to in your 50s. Recommended that patients ask for baseline scan.**
- **Wondered what would have happened if Garry had DEXA scan at 33 on PIs? This would be recommended in the BHIVA guidelines on diagnostics. Community should push to BHIVA to include baseline BMD in guidelines.**
- **PI reference likely to be earlier drugs, do we need to be cautious?**
- **I have just learnt about the DEXA scan scores and had high calcium, I will be happy to start exercise.**
- **Osteopenia is mark of a lower bone density, not associated with fracture risk.**
- **T-score was developed about 30yrs ago from a healthy population and doesn't take into account current life styles including HIV. Osteopenia is an early marker of what will happen in 10yrs time, we should be aware.**
- **DEXA scan organised by HIV doc, GP refused due to costs. We should check who has been offered a bone scan amongst the people we work with.**

Q: How do you deal with someone who has never had a DEXA scan before they start exercising?

A: The PHP assessment and give appropriate exercise.

Q: Could you get a portable DEXA machine?

A: A clinic in Brighton (?) is piloting one.

Q: Has the US study on lower BMD for people on treatment shown anything any association with a particular HIV regimen?

A: It is all speculation at the moment. The SMART study on continuous treatment shows that people can have lower BMD; fracture risk was lower on people on treatment. Even compared to other risk factor its minimal compared to other risk factors such as smoking.

Q: Does dynamic yoga count as weight bearing?

A: Some moves in Pilates and yoga do benefit weight bearing, but need to be careful of some yoga moves, take each person as individual.

The session concluded with exercise recommendations for every fitness level to help with bone health. More information about bone mineral changes can be found in the HIV i-Base treatment guide:

<http://i-base.info/guides/side/bone-mineral-changes>

Bone health and Vitamin D deficiency in HIV positive patients - Dr Frank Post

Dr Frank Post is an Infectious Diseases Physician at King's College Hospital and Clinical Senior Lecturer in HIV Medicine at King's College London. His clinical and research interests include the effects of HIV and antiretroviral therapy on kidney and bone, solid organ transplantation in HIV infection, and mycobacterial infections including multi-drug resistant tuberculosis. Dr Post leads several multi-centre studies on HIV-associated kidney, cardiovascular and bone disease.

He is a member of the INSIGHT renal and tuberculosis interest groups, the UK CHIC and UK seroconverter register steering committees. He is also a member of the BHIVA guidelines writing group on HIV clinical follow up, the BHIVA treatment guidelines writing group and the BHIVA Audit and Standards subcommittee.

Vitamin D (VD) is important to good health. It is required for bone health and also plays an important role in the regulation of the immune system. VD deficiencies have been associated with low CD4 cell counts, an activated immune system and HIV disease progression. VD deficiency common in HIV positive patients, once detected it can be easily managed. The normal range is 30.0 to 74.0 nanograms per millilitre (ng/mL).

VD can be obtained from diet and is also produced by the skin when exposed to sunlight, which is not readily available in the UK. VD deficiency causes include ageing, low exposure to sunlight, and poor diet. HIV can also affect VD. Furthermore VD is metabolised by the body in the same way as many anti-HIV drugs, using the P450 pathway (common liver pathway that breaks down drugs), and some earlier research had suggested that protease inhibitors can inhibit the body's ability to metabolise vitamin D.

Dr Post gave an overview of the Vitamin D deficiency (VDD) from a London cohort that showed nearly 35% of patients were severely deficient with less than 10ng/L. Vitamin D deficiency is associated with cardiovascular disease, cancer, impaired immunity, HIV disease progression and MTCT. Kidney impairment leads to bone problems. The blood test used to determine how much vitamin D is in the body is called 25-hydroxyvitamin D (25(OH)D).

Should we be giving everyone VD; should a study be done? Efavirenz is associated with severe VDD levels in with patients with less than 10 ng/l. The clinical significance of these findings requires further investigation, given the widespread use of efavirenz and tenofovir in first-line combination antiretroviral therapy.

Several antiretrovirals including tenofovir, ddI, and PIs have been associated with greater reductions in BMD in cohort studies. The SMART study showed that continuous versus intermittent cART was associated with greater reductions in BMD and higher FRAX risk scores. The STEAL study showed that a switch to Tenofovir+FTC is associated with BMD reduction, and abacavir/3TC with improvement in BMD.

The parathyroid glands sit on the thyroid gland at the base of the neck and release parathyroid hormone, PTH, in response to low levels of blood calcium. This acts on the bones and kidneys to increase calcium by breaking down bone and reabsorbing calcium from the urine. PTH also leads to the activation of VD, which increases calcium absorption from the gastrointestinal tract. In the setting of high calcium, PTH is decreased and less calcium is transferred to the blood stream from the gastrointestinal tract and the kidneys. Higher PTH levels have been associated with greater reductions in BMD. PTH is raised by tenofovir, there should be an interest to study VD levels in all patients.

VD levels are lower in winter and higher in summer. Different studies show different results. There is no data linking VDD and fractures, other factors include old age, white ethnicity, low BMD, smoking, etc. VDD can be treated with 400-2000 units of colecalciferol daily or as prescribed.

VD supplementation (colecalciferol) 800-2k units/day is prescribed in HIV patients with low VD levels and may reduce PTH. VD and calcium supplementation is prescribed for the older population. Chewing calcium supplementation is associated with high CVD. VDD and PTH and low BMD common in HIV positive patients.

The clinical significance of reduced BMD is unclear especially in young people. Should the young cohort all get VD supplementation? If anyone has a high FRAX risk score, they should take more VD supplementation. FRAX risk score is associated with BMI; if lower, there is less risk.

Q: *Is HIV causing lower BMD than the general population?*

A: VDD may relate to low BMD with fractures as a clinical end point. In men and women from age 40 there is an increase in fractures, but the contribution of low BMD to these fractures is uncertain.

Q: *Is HIV a unique driver of VDD?*

A: This is still an open question to be answered.

Q: *Do we know how osteopenia changes with age?*

A: It's a benign picture, there are ongoing studies looking at natural history, little tendency to progress. Osteoporosis diagnosis could influence behavioural change.

Q: *If someone diagnosed today and is on current drugs, does the BMD lower then steadily rise?*

A: There is lack of current data. Age-adjusted fracture rates among HOPS patients were higher than rates in the general US population during the period 2000–2006. The WHIS study concluded that the effect of HIV upon bone loss is moderate, and highlight the role of traditional risk factors for loss of bone mineral density, such as age, tobacco use, and depression. Middle-aged women who use opioids (narcotics pills or patches for pain relief) may be at particular risk for low bone mineral density.

Q: *Should there be caution on calcium supplementation and CVD risk?*

A: This is largely assessed in people over 75, and testing for overloading of calcium in patients with advanced renal disease.

Q: *How much does a DEXA scan cost, £100? Currently there is a 'wait and see' attitude, should we establish a baseline for intervention?*

A: The 'wait till there is a problem' is not right, should be done ideally from diagnosis. It is a learning concept.

Q: *Will there more studies on whether HIV affects BMD or whether certain drugs are associated with low BMD?*

A. Pharma will be inclined in future to fund research, not funded by NIHR as not considered a priority.

Q: *What is the association and management of advanced CKD, PTH and low BMD?*

A: Management is complex and bone disease associated with CKD is composed of a number of abnormalities of bone mineralization. The major disorders are associated with high bone turnover and high PTH levels and low bone turnover and low or normal PTH levels.

Q: *Is there any study on whether older HIV patients over 50 start showing signs of being less stable of has a higher fracture risk?*

A: FRAX risk score hasn't been validated for HIV. The POPPY (ageing) study will assess frailty, but average age in study is 55 and so may not address fracture risk.

BHIVA is discussing the cost of testing for VD and cost of prescribing it (50p a tablet); there is limited data on VD supplementation in HIV patients that has shown it is effective in lowering the PTH but has no effect on BMD.

Pre-meeting for ViiV – led by Brian West

Brian gave a background about ViiV and the HIV drugs in use and those in the pipeline. The meeting agreed to ask for updates on:

- The new Integrase dolutegravir (which is also in development as a long-acting injection)
- The 3-in-1 dolutegravir+abavacir+3TC, including pricing (572-trii) - 3TC coming off patent and this should affect price

- Update on lersseviline and other compounds acquired from the Pfizer HIV merger
- Other pipeline drugs
- Plus perhaps why all their educational material is about bone
- Maraviroc in prevention trials – microbicides
- Non-inferiority studies – not doing big enough studies to show that one drug is better than the other.

Company meeting: ViiV Healthcare - Dr Andrew Benzie and Anna Lawson

A minute silence was observed in memory of those who did not benefit from the current treatment or have no access to life saving treatment.

Pipeline – Dolutegravir (DTG)

Dolutegravir (572) is a second generation integrase inhibitor in development. Studies have shown dolutegravir to be effective in patients with resistance to the only currently available integrase inhibitor, raltegravir. Clinical trials are underway to support dolutegravir in combination with abacavir and lamivudine, in a new fixed dose combination called 572-Trii. Twice-daily dosing was shown to work better in people who have viral resistance to raltegravir and the investigational elvitegravir in a short study, VIKING Cohort II, and a large phase 3 trials will look at the twice-daily dose.

SPRING-1 compared dolutegravir 10, 25 and 50 mg doses plus two nukes (abacavir/3TC or tenofovir/FTC) to the FDC efavirenz/tenofovir/FTC (Atripla). Results from the 96-week comparison with efavirenz, showed dolutegravir 50mg tablet to be effective at reducing viral load and raising CD4 count in integrase-naïve patients. Phase 3 studies will be done with the 50mg dolutegravir. Lipid changes were minimal, and laboratory abnormalities were relatively uncommon, with 5% of dolutegravir recipients experiencing raised creatinine levels, but did not increase by week 96. Dolutegravir inhibits secretion of creatinine, leading to small increases in serum creatinine without true renal toxicity. 2% - 3% experienced increases in ALT (liver enzyme) levels.

Initial results of a large Phase 3 study of dolutegravir, showed it to be non-inferior to raltegravir. Non-inferior is a scientific designation applied to study results meaning that the drug studied is not less effective than the one it is compared to. If approved, dolutegravir may be at an advantage because it is given once a day, while raltegravir is given twice daily.

The SPRING-2 study had about 800 HIV positive naïve individuals, half of them on a regimen with 50 mg dolutegravir once daily and half on a regimen with raltegravir (400 mg twice daily). Study reported that through 48 weeks, both groups achieved undetectable viral load; 88% of the study participants given dolutegravir vs. 85% of those given raltegravir. Dolutegravir is now available through an expanded access program (EAP), which allows for drugs not yet approved by the FDA to be provided free of charge to those in great need.

Spring-2 where are the SINGLE and Flamingo

There were no significant drug-drug interactions with ART. There are planned interaction studies with steroids, HCV?HIV co-infection treatment and oral contraceptives.

DTG paediatric programme

Child friendly formulations have been developed as granules. In PK studies, DTG granule exposures were all moderately higher than those of the tablet formulation, with or without liquids. Exposure was highest when the granule formulation was given with formula milk.

Expanded Access Programmes (EAP) essentially allow new ARVs to be made available before they are approved to people living with serious or life-threatening conditions who are unable to participate in clinical trials. They are permitted by regulatory agencies, such as the U.S. FDA, under special circumstances, where the potential benefits may outweigh the risks. To qualify, all patients must also have a viral load of at least 400 copies within three months of enrolling and have documented HIV resistance to raltegravir elvitegravir. EAP in Europe was open from April 2012.

Q: What does the pill look like?

A: It's about 112% size of Atripla.

Q: What are you doing to address the raised creatinine levels with DTG?

A: ViiV is working with researchers and nephrologists to identify and address what is really raising the creatinine.

Q: Whom are you consulting with to involve women?

A: Will welcome community suggestions from the community on how to address that.

Comment: How will promote DTG if it's non-inferior? NHS looks at price.

KIVEXA update

BHIVA guidelines now apply GRADE methodology to be inline with NICE guidelines. Kivexa is alternative NRTI backbone on the BHIVA guidelines. Kivexa is preferred vs alternative; efficacy is based on 3 studies comparing Kivexa and Truvada. It is to be avoided in all patients with high CVD risk, or alternatively modify risk where possible – such as smoking cessation or exercise.

Comment: Comparing CVD risk with abacavir in an RCT only run for 2-3 years will not give a true picture. This is better done with cohort study, eg DAD study. There is no plausible evidence on ABC association with CVD risk.

Ongoing studies:

Probono-1 Trial aimed to determine the prevalence and associations of low BMD and high fracture risk (FR) in an HIV cohort, suggest screening and management guidelines. FRAX score (10yr probability major fractures), and remaining lifetime fracture probability (RLFP) were calculated. Reduced bone mineral density and subsequent fracture risk was much commoner in patients with HIV compared to controls, especially, and those taking cART, and occurred across the age ranges. Hence screening for BMD and risk factors for fragility fractures is indicated in patients with HIV at a younger age than in the general population, especially if they are on cART.

Other studies include bone health, renal transporters and renal impairment.

Paediatrics – ViiV is collaborating with a generic drug company to submit registration for a new dispersible formulation of a fixed dose combination for paediatric Kivexa for patients in resource-limited settings.

Maraviroc (MVC)

Prevention:

- PEP studies in UK and Spain - open randomized PEP study comparing Truvada + Kaletra vs Truvada + MVC.
- PrEP (HTPN069) in MSM is currently enrolling

Co-infection: HCV or HBV – MVC may reduce liver stiffness

CNS – ongoing studies to check if drug is actually getting into the brain.

VIKING Cohort II had few ART-experienced patients with RAL resistance experience virological failure while receiving DTG 50 mg twice daily with an optimised background regimen that includes at least one active drug. Treatment-emergent IN resistance with an increase in DTG was detected in only 3 patients with integrase resistance-associated mutations at virological failure. These results support DTG 50 mg twice-daily use for a larger ongoing phase III study (VIKING-3) in this patient population.

Q: Have you seen an increase use of MVC since the UK now has tropism tests?

A: There has been an increase of MVC in the last 18 months.

Comment: MVC use in PI – most naïve pts in UK and Europe would not choose to go on a PI, maybe you should design future studies with new drugs differently.

Paediatrics – still working in correct dose finding, long term efficacy for various ages

Leseverine – study closed in phase one study after risk benefit analysis.

Compassionate access programme still ongoing.

Q: Does ViiV have a DTG pricing strategy? 3TC will be generic, what is ViiV's strategy? If it costs a more than current a FDC it wont sell. It is however nice to have alternative FDC other than Gilead.

A: Pricing is not discussed until near marketing, ViiV is aware it has to be a cost effective combination.

UNITAD patent pool: ViiV have own patent pool and have been working with other volume licensing companies on access in resource limited setting and compassionate access. This is a different concept from other patent pools.

Follow up:

- Creatinine clearance in DTG update.
- Protocol for the PEP study to be sent to the community.
- Keep us informed on the patent pool discussions and progress.
- Re-think on non-inferior studies, need superiority studies instead.

BHIVA Community posters – Alison Barnes, Body and Soul

For a number of years there have been posters at the BHIVA Spring Conference by community organisations. The UKCAB thinks this is a really good thing for community groups and advocates to do and wants to promote the idea so that more people and groups submit. It can be research teaching the medics something new that we have found out or evaluating the good things we do so that other organisations can find out about them. It also means we start to work in a way that produces strong evidence for our services and the activities we do.

Work is submitted as an abstracts, a short descriptions of the study or evaluation, then assessed by a BHIVA panel who do not get the authors names and the work is up against that produced by doctors and nurses. Every poster accepted at BHIVA is a big achievement, clinicians have theirs abstracts turned down every year. The authors of the best abstracts are asked to speak at the conference and this year was the first year that a piece of community research was an oral presentation, that done by i-Base HIV on testing in GU clinics.

The authors of the best posters are also asked to present briefly to the conference and two community organisations have had this honour. But to encourage more of you to submit abstracts the UKCAB decided that it would ask the author of the best community poster and to present their research at the next UKCAB meeting. The judges were Memory, Brian West from the UKCAB steering group and Robert Fieldhouse from Baseline. This is not a BHIVA thing, it is about the UKCAB spreading the knowledge we all generate and honouring the good work produced by people in the community. This year was a split decision but as the two posters were both by Alison Barnes from Body and Soul on the issues for adolescents we have invited her to present her research on adolescents with or affected by HIV.

Alison presented the Social Ecological Method used by Body and Soul to ensure it addresses multiple determinants of poor health in its highly vulnerable target population. The research produced posters on:

- Estimating the number of HIV affected children and adolescents in London
- Multiple risk factors for poor health outcomes in adolescents living with or affected by HIV

Gaps identified by this research:

- Very little non-clinical info about HIV positive teens in the UK.
- No studies on Body and Soul population.
- No established way of counting HIV positive children – only mother specific.

Results of the study showed that adolescents with or affected by HIV are engaging in sexual risk taking behaviours and therefore represent a population that needs accurate information and services to minimise risk. Youth should receive timely information on safer sex strategies and delaying sexual debut. Clinicians working with youth who have chronic health conditions should confidently incorporate age-appropriate sexual health education and screening strategies. This population should also be considered and included in strategies related to the reduction of mother to child transmission.

Comment: Recruitment for the study was from young people accessing services; this may bias the outcome of the research.

Q: Did the young people complete questionnaires?

A: Yes and those with learning difficulties had volunteers, with opt out option.

Comment: Language – risk assumes some urgency – maybe use words like ‘vulnerable’ when describing behaviours?

Next meeting:

Topic: Generics and drug development

Date: 19 October 2012