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

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Meeting Report
24 October 2008

Contents:

Presentations are all available to download from the website for the October 2008 meeting
http://www.ukcab.net/oct08/index.html

Programme:

09.45 - 10.00	Welcome and announcements and new look bulletin board
10.00 - 10.30	London Commissioners Drug Group and the Oversight Committee/D:A:D Research: Simon Collins
10.30 - 11.00	Mexico Feedback - Social issues: Paul Clift
11.30 - 11.45	Tea Break
11.45 - 11.55	BHIVA Education Scientific Committee Feedback: Elijah Amooti
11.55 - 12.15	BHIVHA/CHIVA Feedback: Matt Williams
12.15 - 12.25	Our Health, Our Say: Matt Williams
12.25 - 12.35	Update on the HCQ and PIVOT trials + any advance news of other research: Nick Parton
12.35 - 13.00	Q & A for all feedback sessions
13.00 - 14.00	Lunch
14.00 - 14.45	Transitional Care from Paediatric to Adult Services: A Clinical Care Perspective: Susan McDonald CNS, 900 Clinic, St Mary's Hospital London
14.45 - 15.00	Tea Break
15.00 - 15.45	Young People and HIV: A Social Support Perspective: Maria Phelan, Children and Young People HIV Network Coordinator, NCB
15.45 - 16.00	UK CAB Business
16.00	Close

Attendees

Andrew Chuba	Black Health Agency	Manchester
Angeline Marang	HIV i-Base	London
Anthony Aclet	UMOJA	London
Anthony Tukai	Oxfordshire Social Services	Oxford
Ben Cromaty	North Yorkshire Aids Action	Yorkshire
Brian West	ECAB	Edinburgh
Edwin Bernard	NAM	London
Elija Amooti	The African Eye Trust	London
Emma Hudson	Brunswick Centre	Halifax
Jeff Ukiri	Black Health Agency	Manchester
Joram Barigye	THT Working	Working
Kingsley Oturu	Inst. Of International Health & Dev	Edinburgh
Maria Phelan	NCB	London
Matthew Williams	UK-CAB	London
Memory Sachikonye	UK-CAB	London
Michael Marr	Waverley Care	Edinburgh
Nakamba N'gambi	Leeds Skyline Services	Leeds
Paul Clift	King's College Hospital	London
Roger Pebody	NAM	London
Rupert Jones	Leeds African Group	Leeds
Sarah Nicholas	Northwick Park Hospital	London
Simon Collins	HIV i-Base	London
Susan McDonald	900 Clinic, St Mary's Hospital	London
Svilen Konov	HIV i-Base	London
Taana Nimisha	Body and Soul	London
Tsepo Young	NHS (Skyline)	Glasgow
Winnie Sseruma	HIV i-Base	London
Yigletu Bisrat	Naz Project London	London
Yusef Azad	NAT	London

Chair announced the passing away Martin Flynn on 22 October 2008, a minute silence was observed.
A record is being made in these minutes of the passing away of Simon Mwendapole on 29 October 2008.
May their souls rest in peace.

New look Bulletin Board

Matt Williams

A demonstration of the forum**:** **http://www.ukcab.net/forum/help/quickstart.html**

- How to register, members encouraged to put question to retrieve password. Members can personalize profiles with a signature and picture.
- Browse and read and how to use the "notify" option so to be emailed messages as and when they are posted was explained. Read messages can be hidden.
- Posting replies to messages and starting a topic
- Personal email, board suggests names or look at the members list, member gets personal email informing them of email
- Search facility available

Q: Do messages go everyone?
A: First message goes to everyone.

Matt encouraged all members to send test messages after the meeting to demonstrate their understanding of how the forum works.

London Commissioners Drug Group & the Oversight Committee/D:A:D Research

Simon Collins

Mexico feedback main issues:

- All 'community-related' – sessions included key talks from HIV positive speakers
- New drugs – information presented in several sessions with more information on a new NNRTI called rilpivirine (TMC278), both in naïve and experienced patients. Short term monotherapy results from two other new NNRTIs were also presented.
    - abacavir, heart disease -
    - abacavir & high viral load
    - prevention: ARVs and viral load
    - nelfinavir contamination
    - other studies

Emphasis on track C, D, E covering:

- epidemiology, prevention, policy
- community involvement ' village'
- HIV-positive speakers
- issues for marginalised people (women, children, gender-based violence, IDUs, MSM etc)

Abacavir and heart disease D:A:D study

D:A:D is the largest study designed to look at heart disease and HIV treatment with over 33,000 people followed for over seven years. Researchers had found that the current or recent use of abacavir approximately doubled the risk of having a heart attack compared to using other nukes. Many people wanted confirmation of these results in other studies. They found risk was most significant in people with high cardiovascular risk – family history, lifestyle,smoking etc.

GSK study results from their own database of clinical trials did not find a link to heart disease. Reasons for this difference that need to be addressed were that GSK patients were much younger and healthier (10 years younger). Age increases cardiovascular risk. Patients with cardiovascular risk are often screened out from new drug studies. GSK database was not designed to look for or record cardiovascular events and therefore not powered to be able to see any link to abacavir use.

Framingham and CVD risk factors - HIV positive people need to check their risk of heart disease using the online Framingham calculators. If it is high, there is a 20% chance of a heart attack in the next 10 years and should use an alternative to abacavir.

Discussion:
After 7 years Abacavir was seen to cause heart disease after family history investigations. Study shows that stopping use, risk disappears. If a patient is high risk on Framingham, do not use Abacavir.

Swiss statement – background: Study on discordant heterosexual couple where the HIV positive partner is stable on HIV treatment, has undetectable VL for more than 6 months, adherent, no STIs, and monogamous, risk of HIV transmission is unlikely.

Prevention:
ARVs and Viral load: Basis - viral load drives transmission risk

Other issues raised are
condom break, pregnancy, PEP

Questions: anal sex? The study was not conducted on gay men.
Risk as continuous vs lower cut-off etc

New drugs:
- raltegravir 'naïve'
- rilpivirpine 'naïve'
- apricitabine
- other NNRTIs: IDX899, RDEA806
- paediatric formulations
- non-refridgerated ritonavir

Discussion:
- Resistance mutations is lower – Resistant NNRTI-Resistant Viruses (see slide RDEA806) side effects
- Monotherapy trial was in naïve patients
- Nelfnavir contamination – affected few people in the UK
- Cohort study from several countries 33k for 7 years, started in 1999 stored in one database
- Community orgs asked EMEA not approve drug after 2 years, observational at present.

Q: Should UKCAB write to EMEA?
Q: What about lipo for people starting treatment?
A: It should be managed properly due to the drugs available, guidelines show that it may not be necessary to switch.
Q: Side effects like neuropathy?
A: There will always be side-effects with all drugs.

Comment: TM278 drug trial – 5 years for trials to be approved

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Mexico Feedback - Social issues

Paul Clift

Paul's Mexico feeback was on the social issues at the Mexico conference. His observation was that gay men and MSM were 'readmitted' centre stage; African Gay & MSM highly visible; Challenges to (African) homophobia. The main themes were:
- Male Circumcision
- Criminalisation
- Gay men and MSM

Circumcision as prevention? TUAC03 - concern raised from the floor is that the effect of male circumcision on women was of great concern and according to the presenters is still largely unknown - THBS0104 Marge Berer (Reproductive Health Matters)

Benefit to MSM? Berer: Anecdotes

- "Many of the men I speak with think circumcision is like an AIDS vaccine." (doctor)
- Circumcision gives men an excuse not to use condoms. (Irin News, 31 July 2008.)
- Whose input was sought? HIV/AIDS NGOs; Positive people's organisations; Women's health advocates?

Berer: Conclusions

- Prevention needs major investment, especially condoms and antiretroviral prophylaxis.
- The snip alone won't do it; there must be a link between the penis and the brain.
- Partners of circumcised men have an equal right to protection.
- Safer sex is needed now more than ever.

In other words, circumcision is not a purely clinical intervention; significant non-clinical aspects have to be considered also.

Criminalisation

- Small number of prosecutions in UK; but >100 investigations
- There is a slow 'creep' of increasing criminalisation across the [53] countries being studied
- "Criminalisation has, for me, re-stigmatised HIV when it was becoming normalised" Participant, Living 2008

Presentations from:

- Edwin J Bernard: Selective global responses to HIV 'crimes' - July 2007 - July 2008: criminal HIV exposure or transmission prosecutions reported in 12 countries; new laws criminalising exposure or transmission passed in, or proposed for, a further 16 (incl. 13 in Africa) http://www.criminalhivtransmission.blogspot.com

- Edwin Cameron: Why criminalise? African lawmakers and policy-makers look for strong remedies; many African countries face a massive epidemic with agonising social and economic costs; women experience the heaviest burden of AIDS.

- Clayton et al: Criminalising HIV transmission: is this what women really need? The N'djamena African Model Law (2004)
  - Requires disclosure of HIV status to a spouse or regular sex partnerwithin 6 weeks of diganosis;
  - Permits mandatory testing of pregnant women and when necessary solve to solve a marital dispute;
  - Creates an offence to wilful transmission through any means with full knowledge of status and can cover MTCT!

Efforts should be made to address the root causes that drive the demand for criminalization in Africa to:

- Protect women against violence; promote equal status of women in marriage; address cultural practises
- Gender Based Violence - 13-45% of women are assulted by intimate partners

African Gay Men & MSM

- >50% African countries criminalise MSM activity
- Limited amount of data on prevalence of MSM activity and characteristics, particularly in Sub Saharan Africa, MENA, Caribbean, some data beginning to come through.
- **Togo study key findings**: first male sex ranged from 9-20years; 48% had had intercourse with women prior to male sex; 32% reported having two or more concurrent sex partners. Condom use – 32% reported condom use during first male intercourse, 60% last condom use in male sex, 21% systematically used condoms. Reasons for non-use – trust in partner, condoms not available, lack of pleasure, partner refusal, negative beliefs

Discussion:

- Tanzania? HIV transmission carries a life sentence
- Sierra Leone – women criminalized for giving birth to positive babies
- The whole criminalization issue in Africa is a mess; women feel they have been deliberately infected by their husbands

BHIVA Education Scientific Committee Feedback

Elijah Amooti

- Encouraged all to become BHIVA members to access more information, only community member on the committee
- Has been advocating for interested people to be allowed to study for the diploma in HIV Studies
- Speakers can be provided by BHIVA to give talks
- 5 studies currently going on – to be emailed to the forum
- Recommended to sub-committee to have community session for each BHIVA conference
- UKCAB to respond to Scottish Consortium for turning down Pfizer drug

Comment: No community session at the next BHIVA conference; will be incorporated in future conferences.

Q: Is studying for the diploma free?
A: No

Q: There is need to have patients attend the course for the diploma
Q: is it a requirement for each doctor to take the diploma course?
A: It is a requirement for new doctors; maybe there is need for a refresher course for GPs every 5 years
Q: Could you ask BHIVA to put up treatment guidelines as HTML not PDF
A: This will be taken to BHIVA

BHIVA/CHIVA Feedback

Matt Williams

Community session: undetectable = uninfectious?
This was to discuss the science behind the recent Swiss statement on risk of transmission when viral load is undetectable and offer a community response.

Matt thanked Gus Cairns and his co-chair for leading an incisive and much appreciated session at the BHIVA autumn conference. There were presentations from Dr Bernard Hirschell, Geneva and Dr Steve Taylor, Birmingham. Disagreements seemed more on detail than the broad principle that treatment is highly protective in terms of transmission.

Particular thanks go to Edwin Bernard, NAM and Silvia Petretti, PW/PozFem UK for their intelligent, real and humanising presentations (after much discussion of genital tract sampling for viral load by the docs…).

The feedback from several eminent figures (doctors) was that this was an “essential”, “important” and “impressive” session. For Matt, the session raised more questions than it answered on current treatment/prevention paradigms.

Silvia’s feedback from women on Swiss statement:
- Complex issue, questions on criminalisation, questions on stigma and discrimination, relieves anxiety, increases difficulty to negotiate safer sex.

Cons:
- Confusing after so many years of condom promotion
- Makes negotiating condoms more difficult
- Assumptions on the sex heterosexuals have…
- Not encouraging a holistic approach to sexual health
- Problems with chronic herpes
- How does it apply to drug users?
- Sense of false security

Pros:
- Supports existing practices
- Easier to conceive
- Motivating to improve adherence
- Decreases pressure to use PEP
- Decreases fear of condom breaks
- Issues for discordant couples to the forefront
- Informed risk taking
- Supports increase access to treatment and VL testing in less developed countries

Bernard's feedback from gay men on Swiss statement:
- Different response – denial, anger, bargaining, depression, acceptance.

Denial: "I was actually rather surprised to see this statement made especially considering everything I've read in the past suggests completely the opposite."
Anger: "[The Swiss statement] is morally unconscionable!! There is no doubt that many men who have read it simply jump for joy, throw condoms to the wind, and have unprotected anal sex. The consequences are beyond belief!!!!"
Bargaining: "As someone who's been positive for eight years, has faithfully taken meds every day, and remained undetectable and very healthy, I am hopeful that some day I will be able to freely engage in unprotected sex with my negative (receptive) partner. More [studies are] needed, clearly. It would be wonderful to be able to truly feel the connection, rather than feeling that we're in separate rooms."
Depression: "So, basically I got nothing from this … Am I infectious to my lover or not?..."
Acceptance: "I tested positive for HIV the first time I tested 23 years ago. I have tested "undetectable" for years. I have consensual condom free sex often. NONE of my partners have seroconverted."

Some final observations:
- Is this expert opinion or scientific fact?
- Does it apply to me, or only to others?
- How do I feel about condoms, and condomless sex?
- How do I feel about risk?
- Who is responsible?

Slide sets with full comments from Silvia, Bernard and Dr Hischell's brief version of the science behind the Swiss statement are on the UK-CAB website: http://www.ukcab.net/resources/presentations.html

Q: Is there an argument for starting treatment sooner than current guidelines recommend?
A: Yes, perhaps. British Columbia has a model for treating everyone which eliminates the epidemic in 30 years. Also good personal reasons, eg to protect partner.

Q: What to do with people identified as having frequent unsafe sex, could they get daily directly observed treatment?
A: Difficult, perhaps unworkable long-term, questions about whether this counts as medical treatment as a punishment (not allowed) or a public health measure (maybe allowed). Also, how do you prove someone is doing what you think they are doing?

Q: Has Swiss statement affected criminal prosecutions [in Switzerland]?
A: It has got worse. To some extend the statement was designed to mitigate prosecutions. Swiss courts have now decided that you can be prosecuted if you are or might be HIV-positive, whatever the risk involved.

Comment: Need to individualise prevention message around treatment being protective.

Q: Adolescent transmission – can they be prosecuted?
A: There have been no cases yet.

Other feedback

1. Health tourism
A new NAT report that "separates facts and evidence around migration from fears and misinformation" argues that there is no evidence to demonstrate that HIV health tourism to the UK exists.

2. Untested children, late presentation and delayed diagnosis
A small but significant number of vertically infected (mother-to-child transmission at birth) adolescents have survived childhood undiagnosed and untreated. London: recent death of an adolescent whose HIV status was missed during childhood, and who presented with TB and died soon after. Audit identified 42 adolescents aged between 13 and 20 who had acquired HIV vertically. 50% had symptoms at the time of diagnosis. Median CD4 count was 210 cells/mm3 (range 0-689).

3. Gay men, Africans and undiagnosed HIV
- 4/10 gay men in the UK who have HIV are undiagnosed. Main reason: not testing often enough rather than refusing to test.
- 6/10 Africans in the UK who have HIV are undiagnosed. Main reason: never tested in their country of origin. Often have low CD4 counts and tend not to test until they have symptoms.
- Professor Andrew Phillips presentation: why don't gay men test? Possible reasons: already know but refuse test; anxiety; incidence among group most at risk so high that occasional testing (eg annually) not often enough. Modelling suggests last of these most likely.
- Scottish survey: 56% of men who were in fact HIV-positive despite having had a previous negative test described themselves as "HIV negative" – more than the proportion who said "don't know". Significant fears around testing – 1/6 of said they were "too frightened" to go for a test (or another test), 1/9 said saying they "didn't want to know".

4. Prebiotics
Prebiotics – like probiotics (Actimel etc) but work in colon, not small intestine. Gut is the largest immune system organ in the human body. Soon after an individual becomes infected with HIV, the virus directly infects gut associated lymphoid tissue (GALT) where 70-80% of all immune cells exist, destroying up to 80% within a month of infection. Prebiotics seem to assist with restoration of gut health. Small study by Dr Mario Clerici, Milan University Medical School + Danone Research Centre, Netherlands.

The main theme of the meeting was transitional care of children to adult services with clinical and social care perspectives. Transition was defined as:

> *" The purposeful, planned movement of adolescent and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems "*
>
> *(American Society for Adolescent Medicine, 1993)*

Transitional Care from Paediatric to Adult Services: A Clinical Care Perspective

Susan McDonald CNS, 900 Clinic, St Mary's Hospital London

UNAIDS/Who statistics:
- 2.5m new infections in 2007, 50% <25years; 4 young people infected with HIV every minute
- Demographics: (n=654) 52% female, 76% Black Africans, 57% born outside UK/Ireland
- Presentation: 143 (23%) aged 10+; 9% with AIDS; 41% mild CDC A/B; 39% post-diagnosis of family member; 2 teenage pregnancies at antenatal testing
- Adherence issues, 78% undetectable

Planned transition: well planned improved clinical, educational and social outcomes; poor transition increased risk, non-treatment adherence and loss to follow-up.

CHIPS - a collaboration between the National Study of HIV in Pregnancy and Childhood (NSHPC), 52 clinical centres in the UK and Ireland and the MRC Clinical Trials Unit; includes all children in follow-up since 1996 in

the 52 participating centres; annual prospective follow up since 2000 with prior retrospective data collection.
CHIPS summary: Half the children in cohort have survived to adolescence; 103 have transferred to adult services.

Q: To what extent can the CD4 counter maker be used as an indicator?
A: Children generally have high CD4, becomes clearer when they are older.

Q: What is it like working on the frontline?
A: They are amazing young people, reality is some of the medication are difficult to take such as ritonavir. *You have to offer holistic support – peer support, try to work with them and help them through changes.*

Q: Are there any medical trials for adolescences, or are they taken for granted?
A: None going on at present

Q: Are there other factors affecting adherence?
A: At Body and Soul there is a large group of young people, have worked as peers to those with adherence issues.

Q: What does St Mary's do for people who come out of town?
A: We provide residentials so they can meet with other people, Barnados in Manchester has a project.

Q: What about body image – have any young people had fillers?
A: We have not had facial lipoathy, but lipo. One child in a case study would like to have surgery

Q: What about untested kids in families?
A: CHIVA conference in December: Don't forget the children, would encourage UKCAB to have strong representation.

Q: Education and GPs – do they know about children's needs?
A: GPs are variable; most children are linked with GPs. MDT is composed of doctor, nurse, social worker and patient has access to all. It is a one-stop shop with access to family planning nurse, no social worker, Citizens Advisory Bureau. We have links with Connexions and do referrals. NCB has facilities for 1-2-1 consultations.

Discussion:
- GPs often left out of transitional care process.
- Schools – one parent was called up to secondary school as their child's HIV information was passed on from primary school without consent.
- NAT is telling agencies to produce HIV guidance for children in schools

Q: Is there a helpline for families with children, seems no specialist service is available?
A: NCB's website is a good information base.

Young People and HIV: A Social Support Perspective

Maria Phelan, Children and Young People HIV Network Coordinator, National Children's Bureau (NCB)

NCB aim to give a voice in policy and practice development to children and young people who live in the UK and are infected by HIV.

Issues young people identify:
Relationships, being independent, living a 'normal life', talking in families, wanting to know their story, difficulty with lying and keeping secrets, managing medication around life, loss and bereavement and the future.

Challenges
Guilt and shame instilled into children, they are on complex regimes – drug resistant strains from their parents, need different support for adherence, need to talk to someone they can trust/or someone like them, family setting – some it's a secret, cant talk to friends for support, isolation – mental health problems, no policy on HIV disclosure in DDA pack given to schools – working with NAT and the media not being friendly to HIV.

Q: Criminalization – children who do not know their status, is there a case?
A: Not sure, child protection issue, are we accelerating disclosure?

Comment: HIV world is dominated by adult care, should kids' needs be met? There is the future – college, family etc.

Concerns: Being judged about the origin of their HIV, building new relationships with new professionals.

Comment: There is no HIV clinic for young people in Yorkshire.
A: It is difficult to replicate in other areas – recommend build up a relationship with the adult care over time.

Discussion:
- Relationship with doctors – paediatrician doctors don't move as much as adult doctors
- Difficulty with issues like sleepover at friend's house, parent cannot pass on meds to strangers.
- Psychosocial support: important, discussion held at CHIVA.
- It is difficult to demonstrate impact of peer support services for children
- There is a need for huge areas of research, children will be on treatment for longer than adults, there are issues relating to CVD, lipo, bone health etc. A study may be funded to do brain CT scans of young people with HIV on treatment.

Q: What about long-term side-effects of HIV such as cancer, brain development?
A: There should be service provision during transition with adequate services such as an evening clinic, adapt adult services to suit young people.

UK CAB Business

Topics for future CAB meetings:
- Please fill in feedback forms or send suggestions to Memory/steering group ASAP, as programme currently being compiled for 2009

Yellow card scheme feedback:
- Meeting held with MHRA and 10 000 yellow cards distributed most were distributed in HIV Treatment Bulletin (i-Base) and HIV Treatment Update (NAM).
- Some will be put into each bag of meds at pharmacy at King's Hospital.
- King's Hosp concern that Yellow Cards are currently printed only in English (they had asked for some other languages e.g. French and Swahili as well). They were told that MHRA can arrange for responses in other languages to be translated into English, though how a non-English speaker/writer fills in the form which is printed only in English remains unanswered.

BHIVA Executive Committee membership:
- Vacant memberships - notices to go on forum and applicants will need to explain why they think they should be on a committee, an application process will be developed.

Steering Group Member selection process:
- Members can put themselves forward, should be elected, to transit from ad-hoc

Suggestions for community presentation at BHIVA autumn conference:
- Access to care for immigrants communities

UKCAB Chair
- Michael Marr announced he is the new chair for a temporary period of one year.