



## **Minutes Hypnet meeting 26/01/2010**

**Chair:** Dr Caroline Foster

**Minutes:** Djamel Hamadache

Attendees; Djamel Hamadache, Debbie Levitt, Shetal Patel, Alice Armstrong, Daniella Chilton, Colin Ball, Jayne Griffiths, Maria Phelan, Tomas Campbell, Ondoreira Voke, Sophie@bodyand soulcharity.org, Ali Elgalib, Alisa Richardson, Sarah Bernays, Michael Evangeli, Katia Prime, Caroline Foster, Sarah Fidler, Sabine Kinloch, Pat Tookey, Sheila Donaghy, David Cox

### **0. Voluntary Sector and the NHS**

Apologies from Elaine Pearson who could not attend the meeting

#### **1. Social science research- Sarah Bernays**

Sarah Bernays from London School of Hygiene and Tropical Medicines led the discussion on the qualitative sub-study of the Breather Study (HAART 5 days on / 2 days off).

Independent sub-study looking at adolescent's experience of treatment interruption and their adherence to treatment regimen.

Recruitment: 20 young people (10-21 years old) (10 in continuous arm, 10 Short cycle therapy (SCT)). The sub-study will consider age, gender, family background, treatment administration in household, etc.

Use of audio diaries (for 2 weeks at week 4 and later) / interviews (x3). Also focus groups at end of study to provide feedback to subjects and designing youth targeted resources.

6 key areas for investigations:

- How young people who know their diagnosis present / reflect on their identity
- Treatment experience (e.g. medical affect, healthcare settings, influencing factors)
- Adherence
- Transition (adolescents, change of treatment settings...)
- Young people's expectations
- Child experience

Thoughts around doing sub-study in Uganda where BREATHER will also take place.

Panel discussion on expanding the sub-study to other African countries where a lot of work has already been done around young people and treatment (e.g. South Africa) where existing network.

New ideas to look at structured life for YP, who they rely on, etc.

Impact of such a study on adherence in those who do not recruit but hear “weekends off are fine” such as in peer support setting?

## **2. CHIVA Africa – Colin Ball**

Recognised as a charity in 2009. Launch took place early November at the South African Embassy in London with guest appearance Leleti Khumalo and Anant Singh (involved in movie called Yesterday).

UK healthcare professionals volunteer to teach, assist and support local health teams in Kwazulu Natal (KZN). 11 adolescent workshops took place in 2009. Healthcare Topics: Treatment in adolescents, adolescent services, sexual health, teenage pregnancy/ improve communication, access to services.

Continuous need for volunteers (GU practitioners, health advisers, nurses, etc).

Formal lectures, workshops, feedback meetings. Teaching 4 days then long term network via emails.

Ideally volunteers should dedicate 1 week own time every 6-12 months with the idea of repeated interventions (flexible according to individuals)

Wish to extend intervention to Eastern Cape

If you are interested in volunteering and would like more information, please contact [colin.ball@kch.nhs.uk](mailto:colin.ball@kch.nhs.uk), [caroline.foster@btinternet.com](mailto:caroline.foster@btinternet.com) or visit [www.chiva.org.uk](http://www.chiva.org.uk)

## **3. Literature for YP- Katia Prime**

Katia Prime (St George’s team) presented several leaflets on condom, PEPSE, “passing it on”.

The leaflets have been written by YP who thought about what they should have known at an early age. The leaflets are tailored, specific, short, simple info for teenagers in paediatric units.

New ideas on creating a leaflet on contraception, etc

Central stock at St Georges, Have the budget for printing. Possible future PDF access on [www.chiva.org.uk](http://www.chiva.org.uk) after panel review

Mortimer Market did a survey on services and info. They found out that YP would prefer info on prevention and health promotion on USB rather than hard copies.

Following discussion, it was agreed that the use of both format would be more appropriate to reach wider group

Survey to be sent to HYPNET

## **4. AALPHI – Sabine Kinloch**

Research study: Adolescents and Adults Living with Perinatal HIV. CHIPS cohort, will follow-up 400 perinatally HIV-infected young people, and 300 uninfected siblings, to measure health outcomes over a five year period.

Awaiting final funding decision from Sainsbury Trust

**5. The next generation pregnancy audit paper (see attachment) – Caroline foster**

Abstract has been submitted to BHIVA for the April conference. Will check if these young people are included in NSHPC data

? extending the audit asking young women attending clinical centres if they have been pregnant during audit period. The idea would be to include those who have experienced miscarriage or termination.

**6. Guidelines**

**7.1. Sexual health**

Have been reviewed and will be on the web by mid-February

**7.2. Adherence workbook for professionals working with HIV infected children (0-24)**

Questionnaire on young people adherence to treatment was sent to many centres across the UK. 73 questionnaires were collected.

Time period extended to end of March – aim 100+.

Centres are being asked to make sure all young people attending their unit have returned their questionnaire. Please send the questionnaires to Susan McDonald (St Mary's Hospital, London)

Collaboration CHIVA (0-13) – HYPNET (13-24). Multidisciplinary working parties in need for more people (Psychologists, pharmacists, nurses, etc) Please contact Debbie Levitt (Hypnet) [debbie.levitt@royalfree.nhs.uk](mailto:debbie.levitt@royalfree.nhs.uk) or Djamel Hamadache (CHIVA) [djamel.hamadache@chelwest.nhs.uk](mailto:djamel.hamadache@chelwest.nhs.uk)

**7.3. Adolescent Care guidelines (BHIVA, CHIVA, HYPNet, BASHH)**

Anyone with burning desire to join the writing process, please contact [caroline.foster@btinternet.com](mailto:caroline.foster@btinternet.com)

Should be ready by December 2010

**8. Hypnet meetings**

Due to restricted budget and wish to prevent unnecessary expenditure, it was agreed that hypnet meeting venues would be as follow:

- 2 meetings in health centres (St Mary's Hospital, St Thomas Hospital or Mortimer Market) where meeting rooms are free and relatively easy to access
- 2 at Body & Soul (support from pharmaceutical companies)

CHIVA has bank account that can be used by HYPNET

## **9. Department of Health e learning- Katia Prime**

To create educational resources (30 slides Power point presentation) for Gps / Sprs...

HYPNET to provide info (key points, content, references, case studies, etc) on HIV (vertical & horizontal transmission) and adolescence

Katia Prime to email HYPNET group with more info. Anyone wishing to be involved in the writing process, please contact [katia.prime@stgeorges.nhs.uk](mailto:katia.prime@stgeorges.nhs.uk)

## **10. AOB**

National Children's Bureau: study day on immigration 18/02/2010  
[www.ncb.org.uk](http://www.ncb.org.uk)

UPDATE; Due to funding and other considerations Transition will now probably be the subject of the CHIVA parallel sessions at the BHIVA Autumn conference rather than a stand alone event.