

Minutes HYPNet 23/9/2015

Present

David Cox (DC)	Health Advisor SGH (Chair)
Jacqueline Flynn	CNS GOSH
Margaret Clapson (MC)	CNS GOSH
Marthe Le Prevost (MP)	Research Nurse MRCCTU (Nursing Rep)
Karlien Groenwald	Social Worker, Croydon Adults in Need
Floyd Cuffie	Social Worker, Croydon Adults in Need
Colin Ball (CB)	Consultant Paediatrician KCH (Treasurer)
Alison Barbour (AB)	SPR SGH (SPR Rep)
Rachel Hill-Tout (RHT)	SPR SGH (SPR Rep, minutes)
Nadia Ahmed	SPR MMC
Liz Hamlyn (LH)	Consultant GUM/HIV KCH (Vice Chair)
Katia Prime (KPP)	Consultant GUM/HIV SGH
Sabine Kinloch (SK)	Senior Lecturer Royal Free
Michael Evangelis (ME)	Psychologist

Apologies

Daniella Chilton
Caroline Foster

Introductions

Thanks to VIIV for sponsorship

Discussed chairing of group- DC happy to continue until Daniella returns from Maternity Leave. DC to continue for now as chair.

CB reported that balance of HYPNet account is £1850. He has renewed web-hosting of the website for another year and has been reimbursed.

Discussed need for another member of the group to have knowledge of how to update the website. MP will contact James Stevenson re website and will check website links are working

Newsletter

AB volunteered to coordinate but only had one submission from ME. Agreed it would be worthwhile to have a newsletter- could be in the form of an annual report summarising the minutes from each meeting. KPP said that it would be important to have an annual report to account for the group's activity. AB will continue to coordinate items for the newsletter.

Direction of HYPNet in future.

DC suggested: is there enough difference from CHIVA to make it worth attending both meetings?

CB- having both adult and paed clinicians and members from voluntary sectors has been very valuable and has allowed several very useful audits to be carried out, however need to adapt to the changing landscape re YP and children living with HIV.

KPP- one of the strengths of HYPNet is that it is independent of BHIVA or CHIVA

CB- Current issues in CHIVA are transitioning rather than MTCT or toxicity. Deaths audit carried out by HYPNet was very powerful. Death rates in YP living with HIV higher than HIV negative YP and not improving.

LH- We should follow up children and YP as they grow up to look at outcomes

SK- benefit of HYPNet is ability to act quickly and independently

MP/CB/KPP- Suggested shared meetings with CHIVA. Agreed would be useful to have shared educational meetings with CHIVA every three months. They are held at the same venue as our meetings. Better than trying to tag on a HYPNet meeting onto national conferences and would also avoid the cost of this option. CB said that we would need to adapt the content of the educational meetings to make it relevant to clinicians seeing adolescents.

LH- Would like to check if there is a copy of the original Terms of Reference for HYPNet. KPP will check old emails for this.

DC- Would be useful to have more case presentations.

MC- Finds it difficult to see what her role is in HYPNet as not contributing to any audits but has lots of experience.

CB- Said that her experience was very important and valued and gives a deep understanding of background of YP living with HIV.

MC- there used to be a Paeds CNS subgroup but very few specialists now in this area and no longer meeting.

KPP- Rebecca Hope did an audit showing high achievement at A-Levels of YP LWHIV

DC- Agreed to carry on meetings in current format, 3-4 per year plus consider joining educational meetings with CHIVA

MP- AALPHI Update

No funding for 3rd year. Monument Trust has closed and they have been unsuccessful applying for NIHR grant. They will reapply for NIHR funding next year.

Closed Yr 1 AALPHI in April and now doing data analysis.

They have presented at several conferences this year-

- BHIVA Brighton
- 7th International Conference Vancouver
- AIDS Impact Amsterdam

Next steps- looking at self harm and sexual health. Initial results show low levels of reported sexual activity which was questioned by other members of the group. May be issues about generalisability of data.

Will reapply for NIHR grant for a smaller project and find funding for a research nurse. Continue registration and start data collection at AALPHI sites.

Will get independent ethics for CHIPS+ and roll out R+D to all sites. KPP asked if would need to re-consent patients if independent ethics obtained- MP said this would not be necessary.

Trying to get Paeds teams to consent

KPP said when Paeds consent they allocate an SC number and email adult teams with this when patient transitioned but adult teams unable to identify patient from SC number hence need to re-consent patient . MP will look into this.

Audits

LH- would like to follow up YP after leaving school/ Uni. Could audit outcomes in >25s. KPP said there would be very few in this age group, most around 18-20 years.

Agreed could look at 18-25 year olds outcomes using the CHIPS+ database

LH and SPR representatives RHT and AB to discuss audit plans further and take this forward

MP will liaise with LH re audit in under 18s re accessing CHIPS database.

CB presented Sophie Herbert and AB's malignancy audit at CHIVA- Oral presentation received very well.

Need to write up audits, KPP will remind Ellen Dwyer to write up mental health audit and AB to write up sexual health/ contraception audit.

ME- has been funded by VIIV to evaluate CHIVA camp this year.

ME- would be useful to present conclusions of PHD studies he has supervised involving YPLWHIV as many have relevant clinical recommendations.

AOB

Agreed that DC will continue to chair until Daniella returns from Maternity Leave. DC happy to continue. KPP thanked DC for his hard work in chairing the group.

Nav from MRC will continue to organise events from the MRC

Next meeting 18th Jan 2016.

Presentation from Croydon- joint clinical and Social Work presentation for next meeting.