

13<sup>th</sup> Annual Conference of the  
National HIV Nurses Association (NHVNA)



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Young people and reported  
adherence to antiretroviral  
therapy: A HYPNet survey.

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## Background

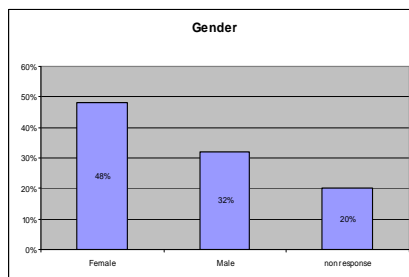
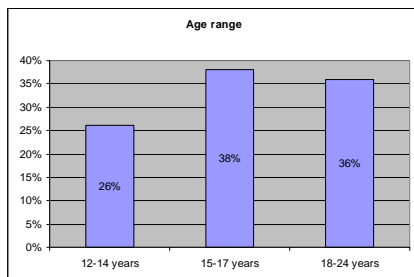
- HYPnet survey
- Aim: Assessment of young peoples (12-24yrs) views on adherence to further develop adherence guidelines/tools for adolescents/young adults
- Background: Limited UK data, USA: Cross sectional data identifying barriers to adherence and impact on viral suppression *Bret et al (2009)*, *Flynn P et al (2007)* *Murphy et al (2003)*
- Cross sectional snap shot – **views of 12-24 year olds currently on HAART**



## Method

- Design
- Ethics – service evaluation
- Questionnaire reviewed by 10 MDT professionals
- Piloted with 2 YP in clinic
- HYPnet/CHIVA/Contacts – distributed to 29 sites
- 14 sites responded
- Anonymous questionnaires returned by post
- Data entered and analysed using excel
- Next step will be to use SPSS for further analysis

## Respondents = 138

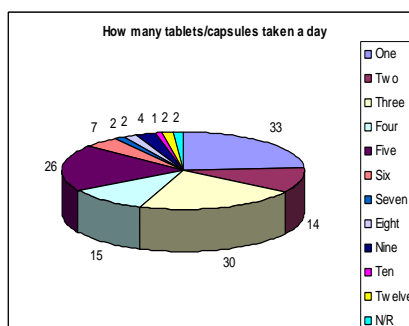
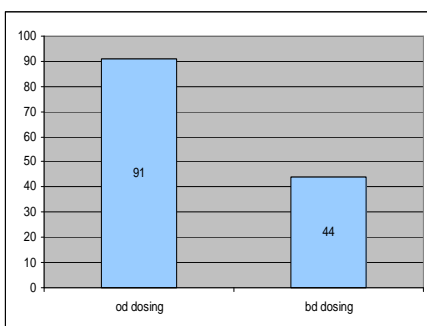


83% live with family.

Length on treatment: 133/138 11% (n=15) don't know, 33% (n=44) < 4 yrs, **56% (n=74) > 4 yrs of which 68% (n= 50) report > 8 yrs**

6 respondents had used a gastrostomy at some point

## Dosing and pill burden



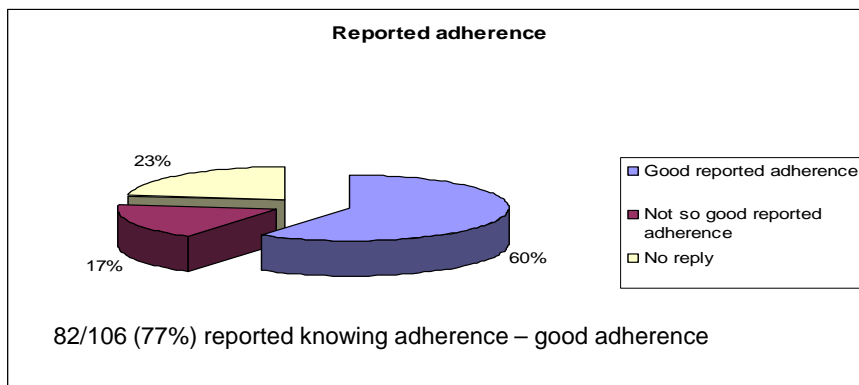
137/138: 91/137 (66%) taking meds once a day

136/138: 76/136 (43%) taking 4 or more pills a day, 9/76 (12%) report taking more than 8

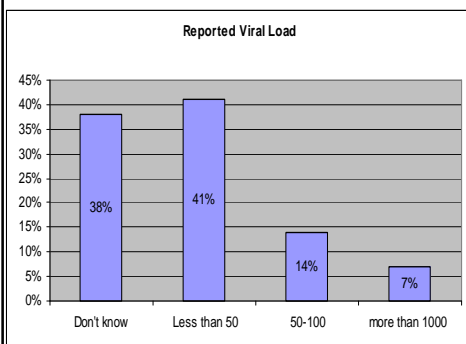


## Self reported adherence 132/138

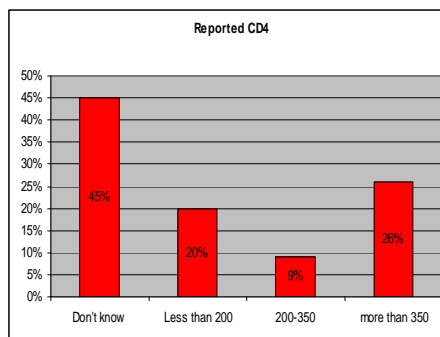
Paterson et al (2000) >95% adherence rates (“good”) = optimal viral suppression



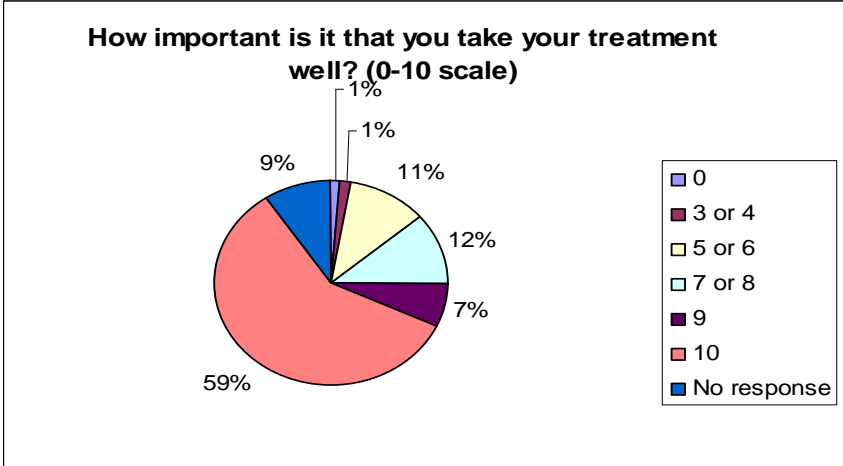
## Reported CD4 & Viral load 127/138



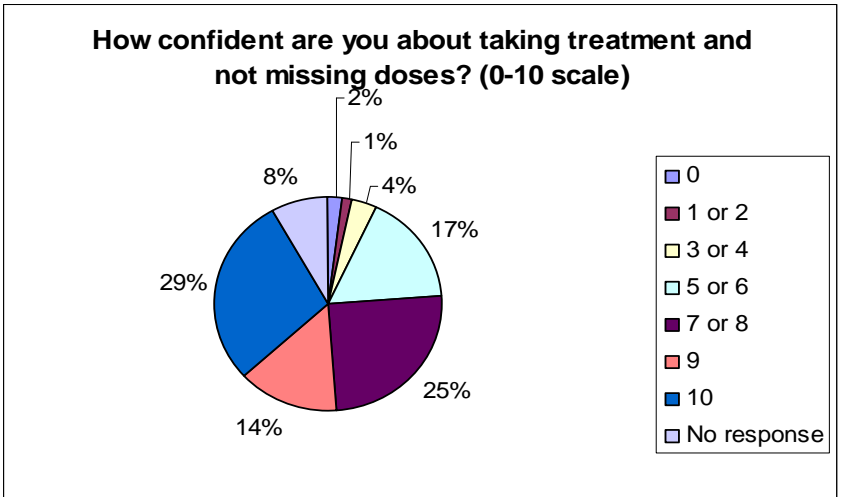
52/79 (66%) reported VL < 50



34/72 (47%) reported CD4 over 350



68% rating a range of 9-10/10



43% rating 9-10/10 for confidence.

## Treatment Interruption (53/126 reported TI)



Don't know	<b>17% (n=9)</b>	Part of trial	<b>4% (n=2)</b>
Doc stopped it	<b>32% (n=17)</b>	Didn't want to take it	<b>23% (n=12)</b>
Side effects	<b>21% (n=11)</b>	Pill burden	<b>11% (n=6)</b>
Pill fatigue	<b>30% (n=16)</b>	Didn't think it was helping	<b>4% (n=2)</b>
Felt well	<b>9% (n=5)</b>	other	<b>19% (n=10)</b>

42% (n=53) report treatment interruption 57% for <1 yr 36% >1 yr 23% DNK

*"Thought and still think that Christ is my healer and has healed me"*

*"Feeling depressed and there are times when you don't feel like taking them because you feel well and when you take them you feel ill"*

## What helps you to take your HIV treatment? (135/138)



I just remember	<b>43% (n=58)</b>	Family/carer reminds me	<b>44% (n=59)</b>
Having a routine	<b>28% (n=38)</b>	Health benefits	<b>20% (n=27)</b>
Mobile phone/alarm	<b>16% (n=22)</b>	Pill box	<b>16% (n=22)</b>
Keeping them in a place that reminds me	<b>16% (n=21)</b>	Having a specific goal	<b>6% (n=8)</b>
Carry them with me	<b>4% (n=6)</b>	Friends remind me	<b>3% (n=4)</b>
Reminders from clinic	<b>2% (n=3)</b>	other	<b>4% (n=5)</b>

## Reasons for missing doses 134/138



Did not miss any	<b>18%</b> <b>(n=24)</b>	forgot	<b>48%</b> <b>(n=64)</b>
Side effects	<b>15%</b> <b>(n=20)</b>	Busy with other activities	<b>29%</b> <b>(n=39)</b>
With family/friends (secrecy)	<b>18%</b> <b>(n=24)</b>	Didn't have meds with me	<b>15%</b> <b>(n=20)</b>
On school/college trip or holiday	<b>14%</b> <b>(n=19)</b>	Pill fatigue	<b>14%</b> <b>(n=19)</b>
Reminds me of HIV	<b>10%</b> <b>(n=13)</b>	Felt well	<b>4%</b> (n=5)
Don't know	<b>7%</b> (n=10)	Feel different	<b>8%</b> (n=11)
Don't want to take it	<b>5%</b> (n=7)	other	<b>6%</b> (n=8)

## Comments



*“can't be bothered sometimes”*

*“The smell of the medicine affects the mood but I try hard to take it because it helps me a lot”*

*“rushing for school”*



### What could further help adherence 127/138

Once daily regimen	<b>38% (n=48)</b>	Less meds	<b>37% (n=47)</b>
Smaller meds	<b>26% (n=33)</b>	If I didn't have to keep them a secret	<b>25% (n=32)</b>
No side effects	<b>23% (n=29)</b>	If I was able to share this with friends	<b>13% (n=17)</b>
Somebody to remind me	<b>10% (n=13)</b>	If I could see the benefits	<b>8% (n=10)</b>
Having my own goal	<b>9% (n=11)</b>	Text reminder	<b>9% (n=12)</b>
Talking to somebody on treatment	<b>9% (n=11)</b>	Better Understanding of the benefits	<b>4% (n=5)</b>



- 122/138: 56/122 (46%) access peer support
- 97/138: Those that access/have accessed peer support 62/97 (64%) report this helping adherence





## Conclusions

- Majority report taking meds well with good adherence strategies
- Family play important role
- Peers play important role
- Once a day/less tabs reported as helping adherence
- Daily activities and simply forgetting identified as the main barrier
- Needing to keep diagnosis secret impacts on adherence
- Most understand the importance of good adherence but report lower levels of confidence in taking treatment



## Limitations

Drug and alcohol use was not addressed

Partners not included

- Not validated
- Self report
- Self-selected group –only those on HAART
- Missing data
- Questions – may have not been clear/misunderstood



## Implications for practice

- Engaging YP
- Building up self – efficacy (therapeutic approaches such as Motivational interviewing)
- Positive affirmations
- Easier access to peer support
- Supporting family/carers
- Individualised and MDT approach
- Simplifying drug regimens



## Massive thank you!

- Caroline Foster, Jayne Griffiths, Nimisha Tanna, Debbie Levitt and HYPnet
- Christine Norton
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- Body and Soul, London
- Cardiff and Vale NHS Trust paediatric dept
- Chelsea and Westminster Hospital family clinic and YP clinic
- Dublin hospital paediatric dept
- Georges paed/adolescent clinic
- Great Ormond Street Hospital
- Mortimar market YP clinic
- Newcastle Upon Tyne Hospitals paediatric unit
- Newham family clinic/adolescent clinic
- St Mary's family clinic and 900 clinic
- St Thomas' paediatric/adolescent clinic