



Adolescents and Adults Living with Perinatal HIV Cohort (AALPHI) update

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Outline

1. Background and study aims
2. Methods and accrual
3. Characteristics at interview 1 and 2
4. Interview 1 analyses conducted so far:
 - a) Cognition
 - b) Anxiety and depression
 - c) Adherence
 - d) Sexual health
5. Future plans for AALPHI and CHIPS+



Methods

- Two waves of interviews two years apart over 5 years; two hour face-to-face interviews
- Young people with/without perinatal HIV
- Inclusion criteria:
 - **PHIV+ (n=300)**: Age 13-21 yrs, paediatric care in UK, aware of their HIV status, willing to give a blood sample
 - **HIV- (n=100)**: Age 13-23 yrs, willing to have an HIV test, awareness of HIV in the family
 - 46% have HIV+ mother and sibling
 - 49% have HIV+ mother only

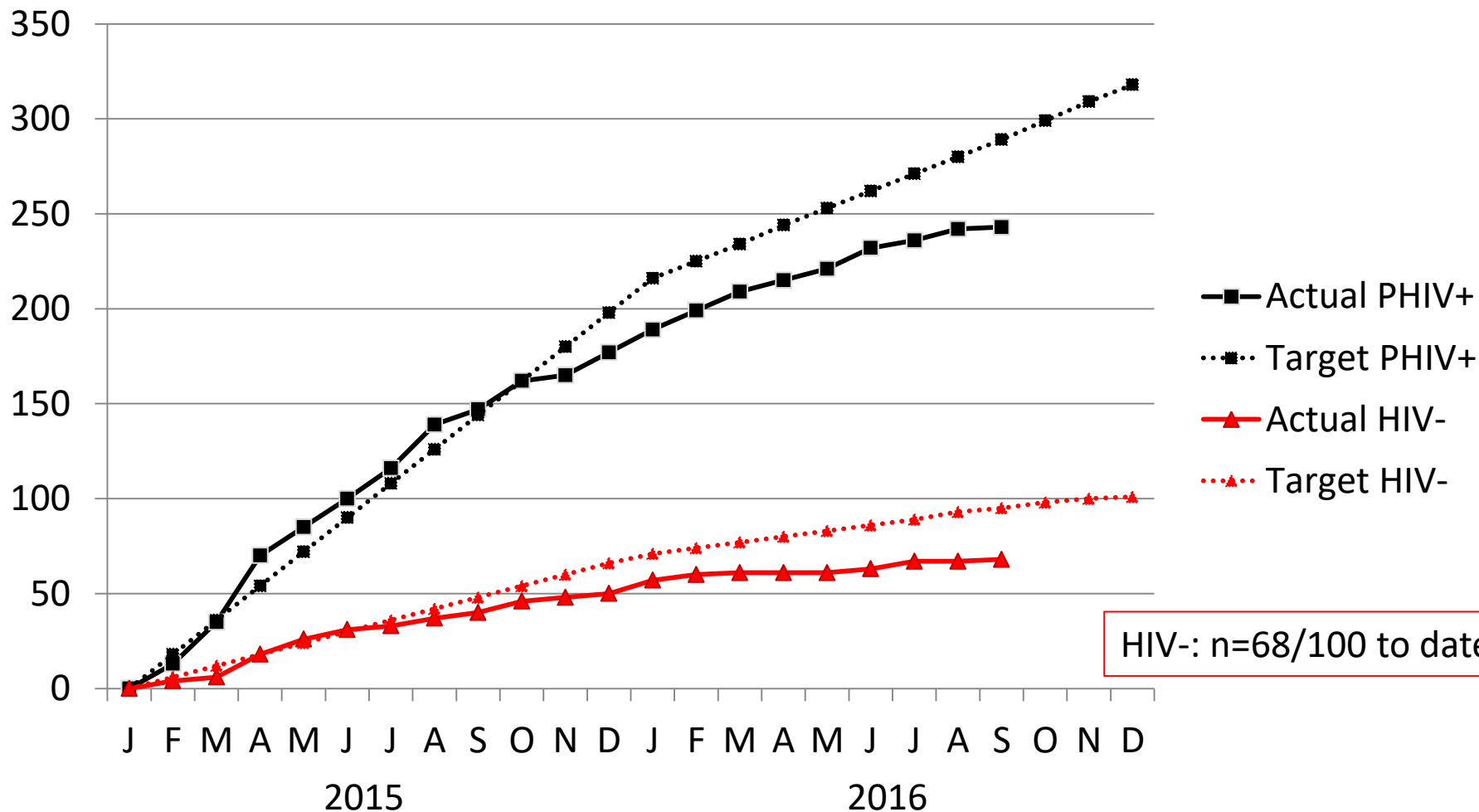


| | Interview 1 | Interview 2 |
|--------------------------------|---|---|
| Psychosocial health | Social Factors Living situation, employment and education, family | Social factors Living situation, employment and education, family |
| | Cognition | Cognition |
| | Anxiety and depression | |
| | Quality of life, self esteem | Quality of life, self esteem |
| | Self harm | Self harm |
| | Alcohol, smoking, drugs | Alcohol, smoking, drugs |
| | Adherence | Adherence & health beliefs |
| | General health | Health |
| | Life changes | Coping |
| | HIV naming / disclosure | |
| Sexual and reproductive | Growth, sexual health, pregnancy/ births | Growth, sexual health, pregnancy/ births |
| Transition experience | | Transition |
| | | Service use |
| Cardiac function | | Pulse Wave Velocity |



Follow-up interview progress

PHIV+: n=244/317 to date



HIV-: n=68/100 to date



Analysis of interview 1 data

- Outcomes

- **Cognition** (NPZ-6)
- **Anxiety/ depression (HADS)**
- **Sexual health**
- **Adherence** (3 day recall)

- Predictors:

- **Socio-demographic:** PHIV+ v HIV-, age, sex, ethnicity, born outside UK
- **Family:** parent death, fostered/adopted, who living with, whether parent in work, deprivation
- **Psychosocial:** current education/employment, Rosenberg self-esteem, self-harm, ever felt life not worth living
- **Lifestyle:** alcohol, smoking and drugs
- **PHIV+ only:** year 1st presented, nadir/current CD4, age starting ART, current ART status, ever/current EFV use



Characteristics of PHIV+ and HIV-

| | PHIV+ (n=295) | HIV- (n=90) | CHIPS (13-21yrs) |
|------------------------------------|-------------------|----------------|---------------------|
| | % or median [IQR] | | |
| Male | 42% | 31% | 52% |
| Age | 16 [15, 18] | 16 [14,18] | 16 [14,18] |
| Black ethnicity | 85% | 72% | 81% |
| Born outside UK | 78% | 60% | 64% |
| Occupation | | | |
| School | 80% | 70% | |
| Employment | 14% | 26% | |
| Neither | 6% | 4% | |
| Live with parents | 91% | 88% | |
| Death of one/both biol. parents | 36% | 26% | |
| Fostered/adopted | 11% | 0% | |

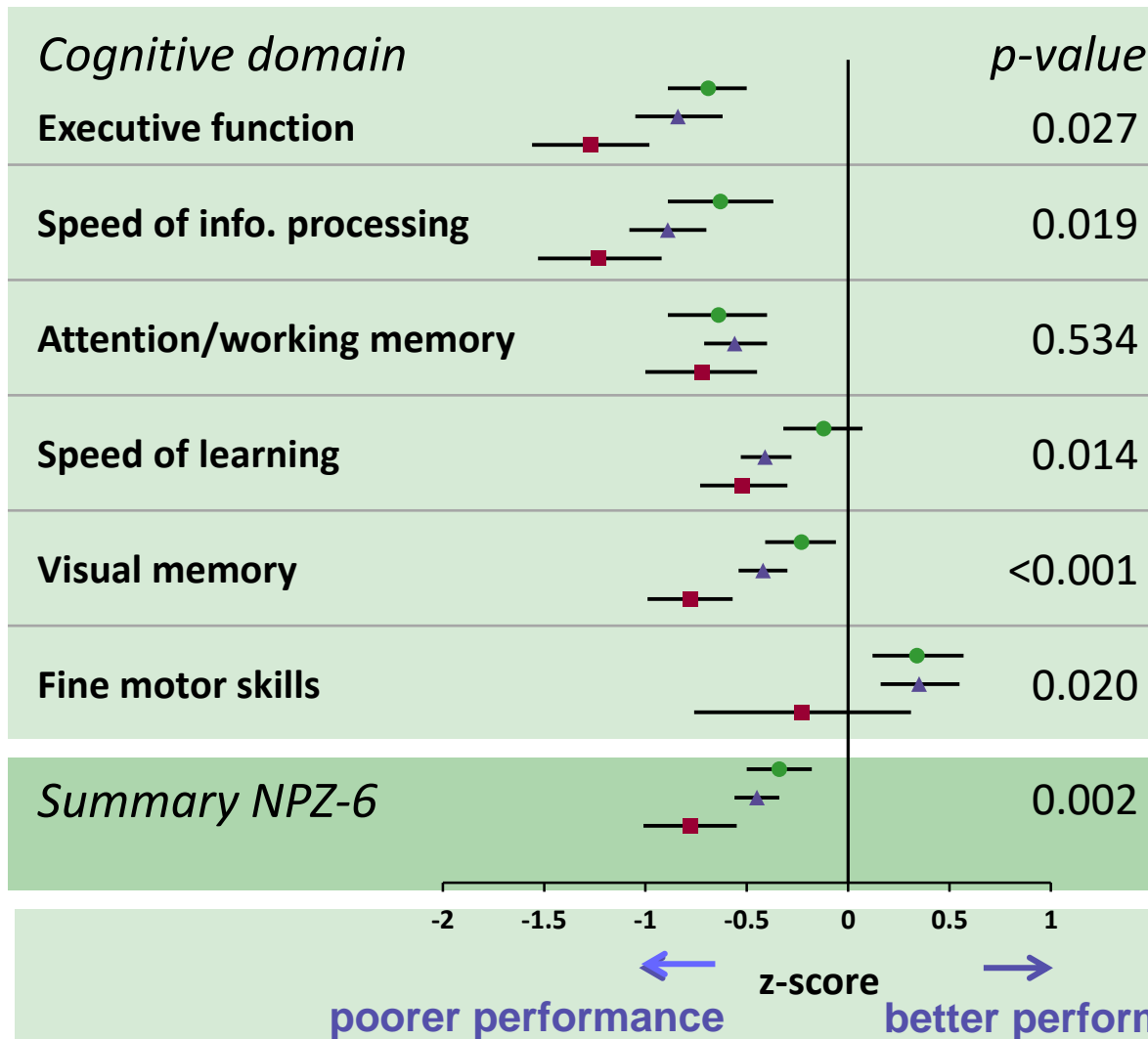
HIV-related health



| | No CDC C (n=218) | CDC C (n=76) |
|-------------------------------------|-------------------|----------------|
| | % or median [IQR] | |
| Year 1 st in UK services | | |
| Pre-1996 | 16% | 21% |
| 1997-2000 | 20% | 34% |
| 2001 + | 64% | 45% |
| Age at ART initiation | 8.0 [5.2, 12.0] | 3.8 [1.4, 6.2] |
| Age at first CDC event | - | 3.0 [0.5, 6.4] |
| ART status at last visit | | |
| Naïve | 12% | 0% |
| On cART | 83% | 95% |
| Off cART | 5% | 5% |
| VL>50 at last visit (on cART) | 21% | 32% |
| CD4 at last visit | 582 [408, 769] | 641 [422, 873] |



a) Cognitive performance

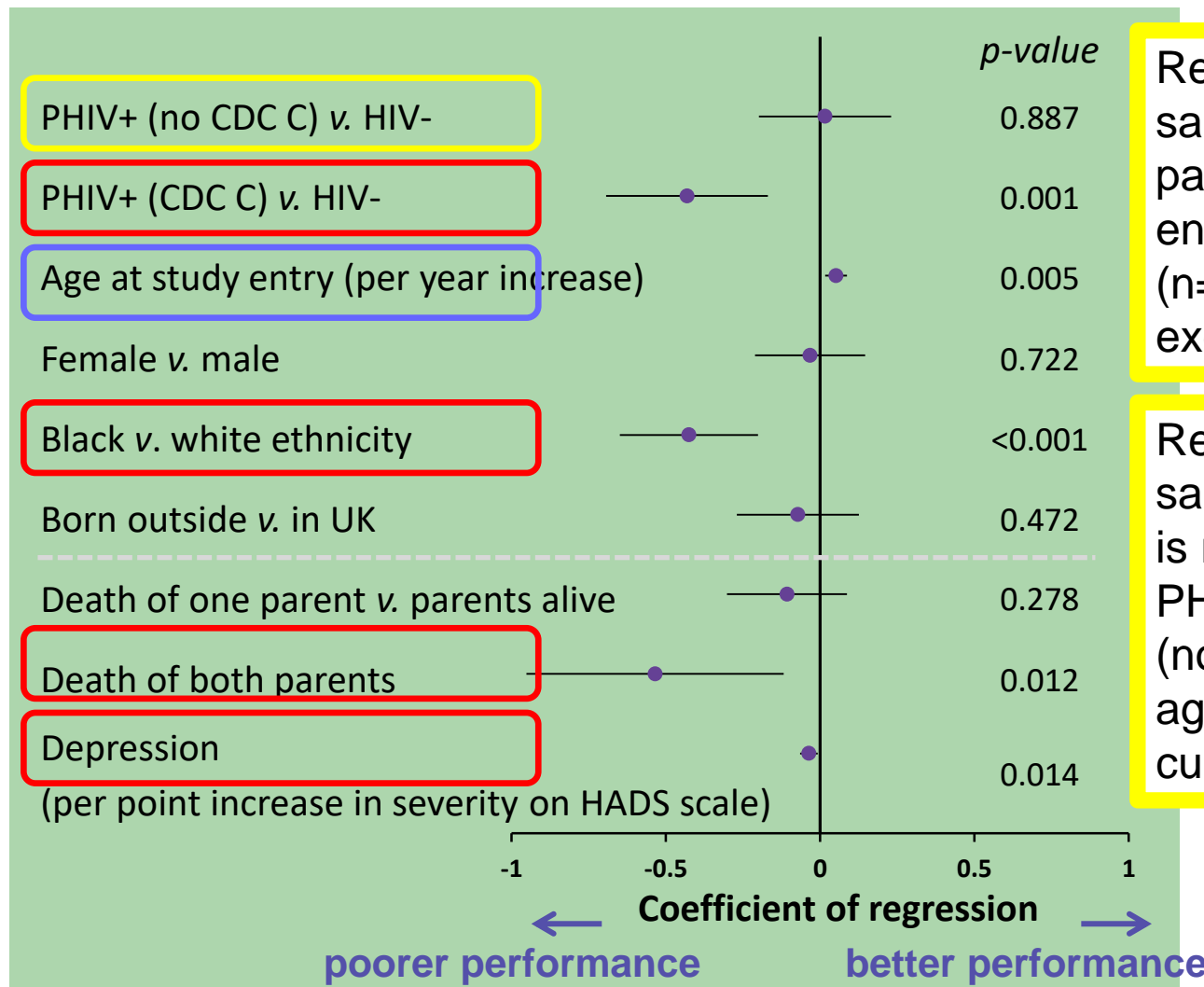


- HIV-
- ▲ PHIV+ (no CDC C)
- PHIV+ (CDC C)

Data are mean z-scores with 95% CIs



Multivariable predictors of NPZ-6



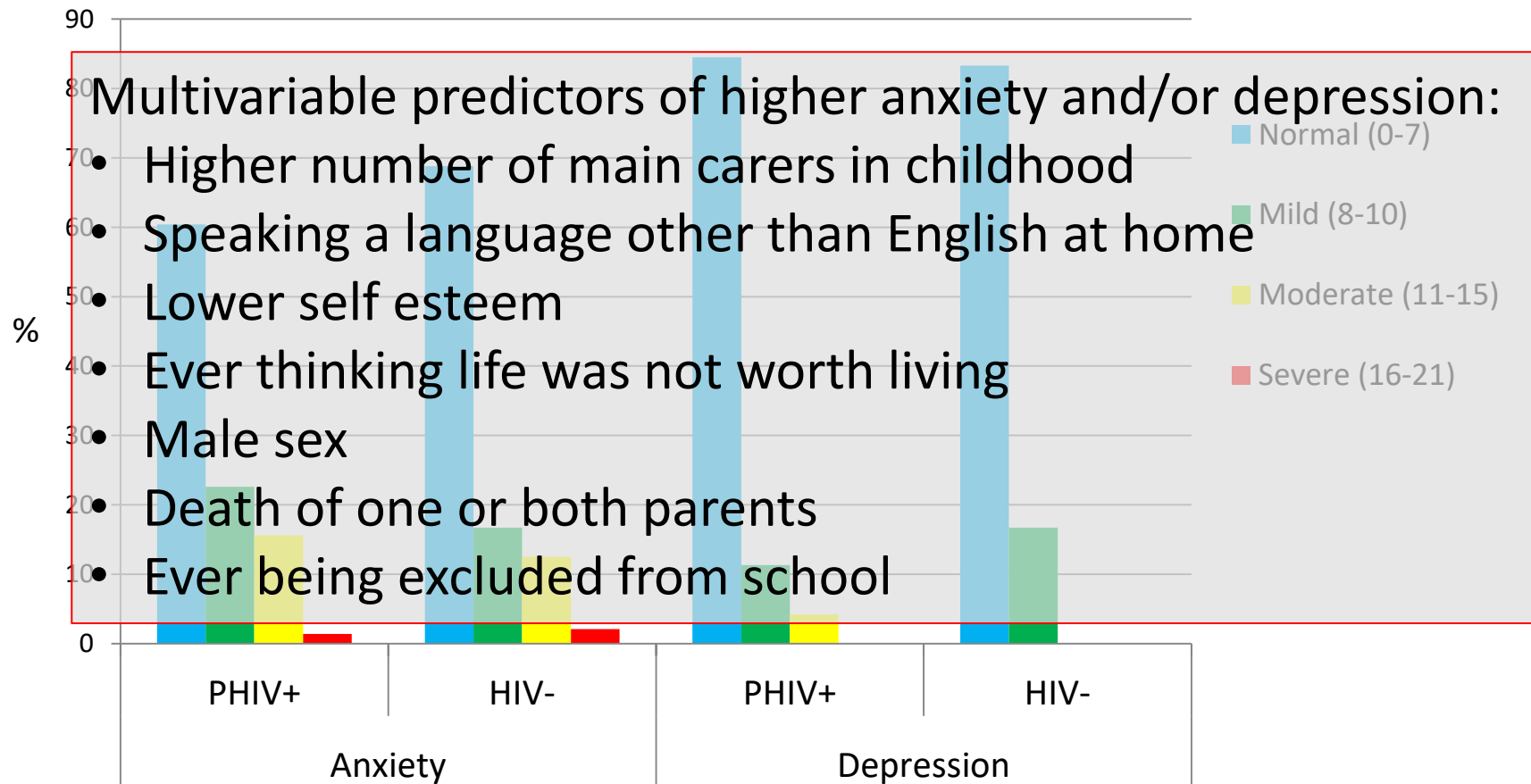
Results are the same when patients with encephalopathy (n=11) are excluded

Results are the same when model is restricted to PHIV+ only (no effect of CD4, age started ART, current EFV use)



b) Anxiety and depression

No difference between PHIV+ and HIV- or norms





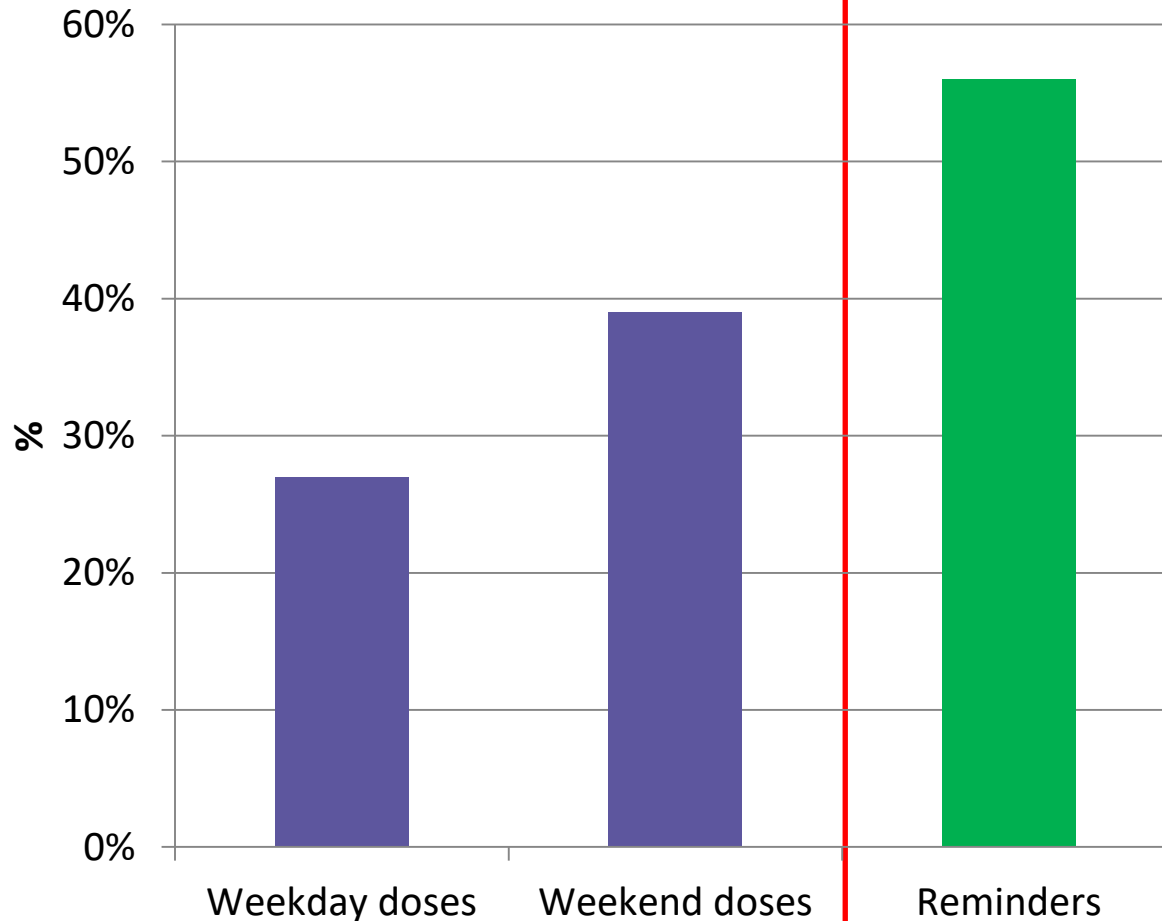
c) Adherence for those taking ART

- 88% (261) took ART at the time of interview

| Socio-demographics | | HIV related variables | |
|----------------------------|-----------------|---------------------------|-----------|
| Male | 111 (43%) | CDC stage C | 72 (28%) |
| Black African | 220 (84%) | Viral load ≤ 50 c/ml | 204 (78%) |
| Median age | 16 [IQR 15,18] | In adult HIV care | 50 (19%) |
| Parent(s) died | 87 (35%) | | |
| In FT education | 242 (93%) | | |
| Live with parents | 236 (91%) | | |
| Moderate/severe anxiety | 17% | | |
| Moderate/severe depression | 5% | | |
| Mean NPZ-6 | -0.58 (SD 0.86) | | |

I find it difficult to take....

I use reminders...



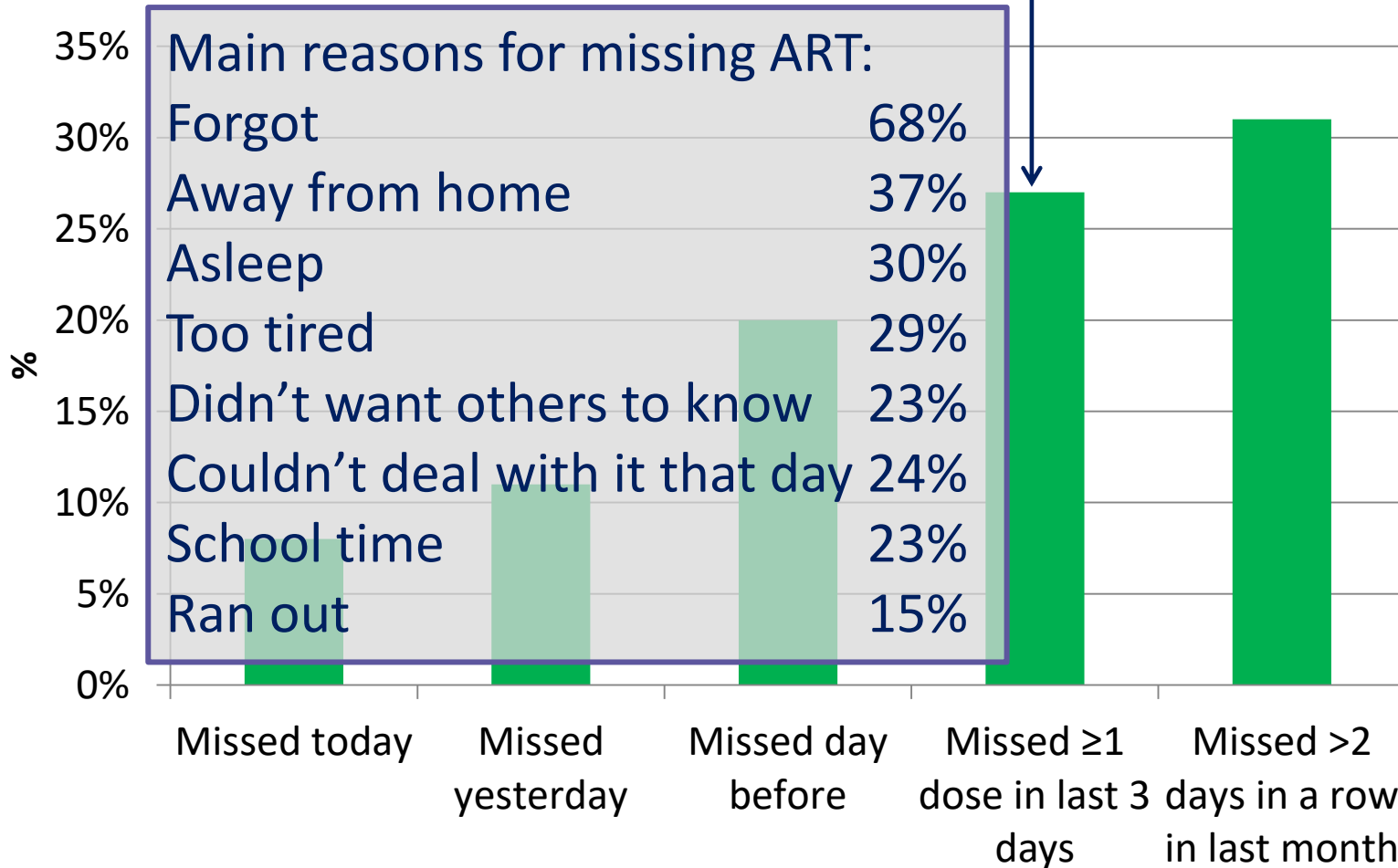
Most popular:
Family 73%
Pill box 20%
Timer 20%
Daily routine 10%*
Text message 7%
Friend 7%

* Eg breakfast time/ TV show



Missed doses

20% PHIV+ with VL \leq 50/ml
51% PHIV+ with VL $>$ 50c/ml





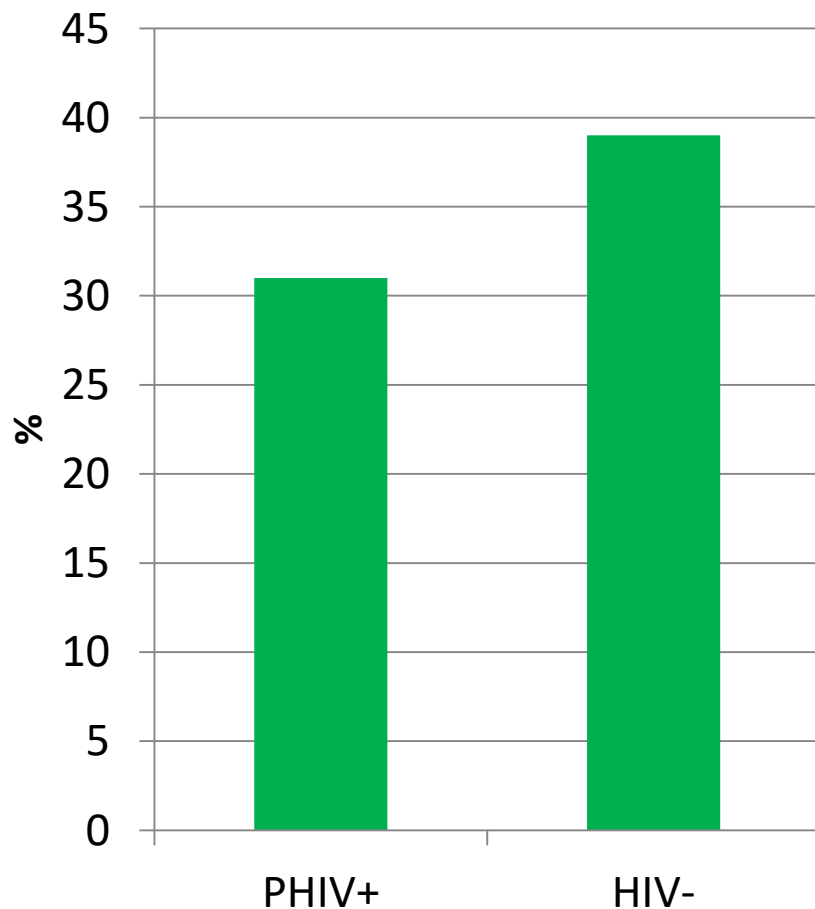
Predictors of 3 day non-adherence

- ≥ 1 missed dose in last 3 days

| Variable | | Adj OR (95%CI) | P value |
|-----------------------------|----------------------------|----------------|---------|
| Quality of life (PedsQL) | Per 100 units decreased QL | 1.1 (1.0, 1.2) | 0.029 |
| Ever smoked cigarettes | No | Ref | 0.010 |
| | Yes | 2.7 (1.3, 5.7) | |
| Perception about having HIV | Per 5 units worse score | 1.1 (1.0, 1.2) | 0.043 |



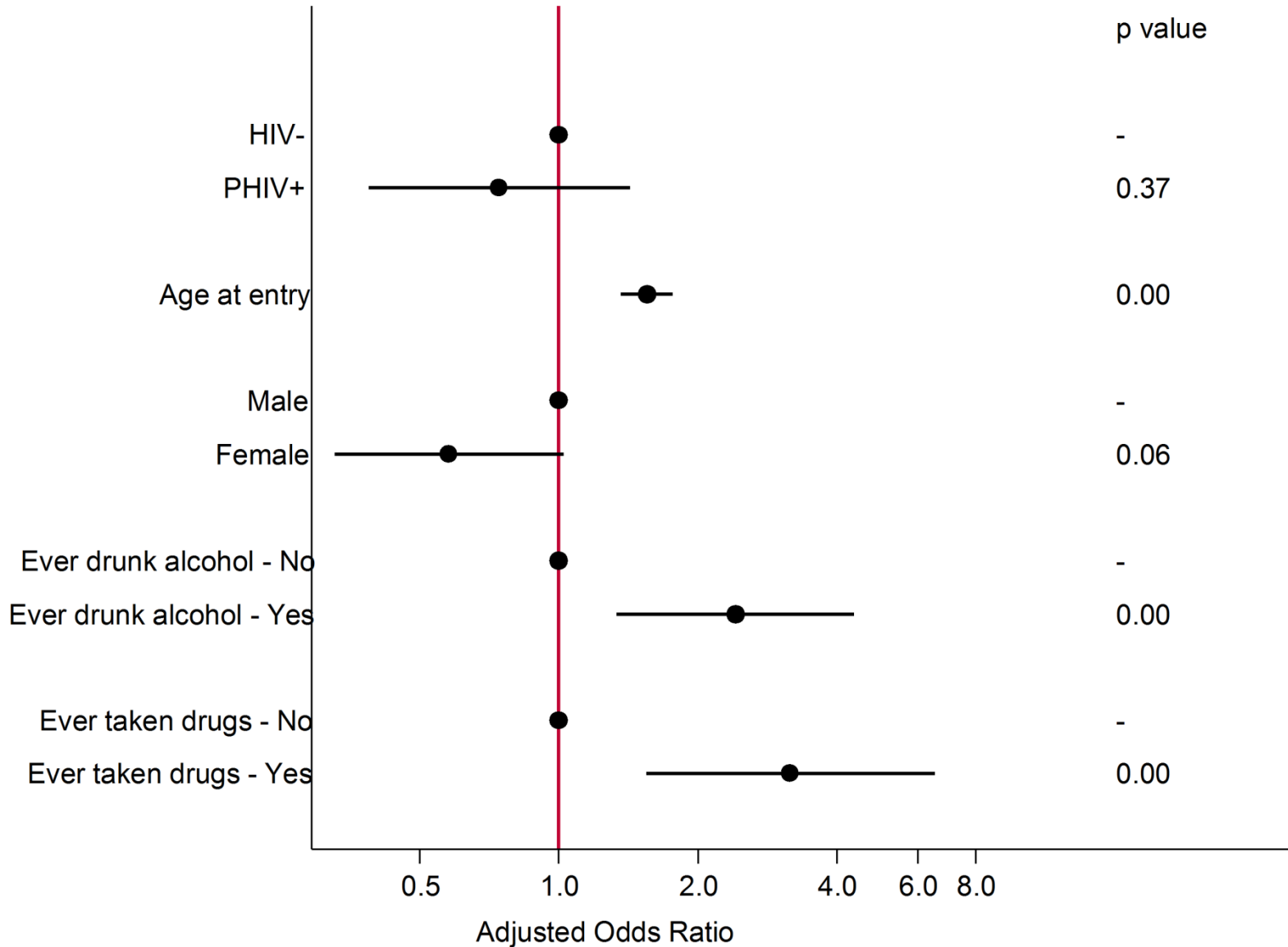
d) Prevalence of vaginal/anal sex



| | PHIV+ (n=90) | HIV- (n=37) |
|-----------------------------------|-----------------|----------------|
| First sex <15 years old | | |
| Vaginal | 20% (17/87) | 19% (7/37) |
| Anal | 6% (1/17) | 17% (1/6) |

| Condom use in last 12 months | PHIV+ (n=90) | HIV- (n=37) |
|------------------------------|-----------------|----------------|
| Always | 68% | 38% |
| Usually | 18% | 22% |
| Sometimes | 11% | 27% |
| Never | 3% | 13% |

Multivariable predictors of ever sex





Reasons for not having sex

248 never having sex cited the following reasons (multiple reasons per person):

- 67% (++) not ready yet
- 29% fear of HIV transmission (35% PHIV+, 7% HIV-)
- 22% religious beliefs



AALPHI conclusions so far...

- Cognition:
 - PHIV+ with CDC C performed less well
 - Performance similar between PHIV+ no C and HIV-
 - Mild impairment compared to normative data
 - Domain-specific differences are apparent and need further analysis
- Anxiety and depression:
 - Levels similar between PHIV+, HIV- and normative data
 - 40% had at least mild anxiety; 15% at least mild depression
 - Predictors of higher anxiety and depression can guide who to target for interventions
 - Self esteem needs further analysis



AALPHI conclusions so far...

- Adherence:
 - 1/4 to 1/3 reported poor adherence in last month
 - Role of mental health factors
- Sexual health:
 - Similar proportions of PHIV+ and HIV- had ever had sex
 - Levels are comparable to Natsal-3

The future



- CHIPS+ will follow all PHIV+ in adult care
 - Full application went to NIHR in July; decision any day!
 - clinical outcomes
- New proposal for AALPHI 2017+
 - Web-based CASI interview in 2017/18, to complement CHIPS+, including:
 - Transition process and preparedness
 - Mental health, adherence, quality of life
 - Education outcomes, employment
 - Use of NHS services
 - Patient involvement in all aspects to make sure questions are relevant to adolescents' changing and expanding lives



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