**Penta Breather – Phase 1- Draft topic guide**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Key area of investigation** | *Rationale* | **Themes** | **Example questions** | **Explanatory notes** |
|  |  |  |  |  |
| **Discussion about participation in trial** | *This may be the easiest place to start- as it is something that they will know a little about it.*  *But hopefully it will help them discuss adherence and treatment in a general way before going onto talk about their specific experiences.* | * Knowledge about trial and their expectation of it. * Decision to participate in the qualitative study * Initial talk about the personal experience of treatment adherence | * How did you hear about the trial? * How was it introduced to you? * What do you understand about it? * Why did you choose to participate? * Why did you choose to take part in the qualitative substudy? * What do you think about the intervention? * It will be randomised, but if you could choose do you know which arm you would like to be put in? Why? * Do you think that young people your age need support with adherence? Why? | *It’s important that this is not seen as a test in anyway and so it needs to be open and focus on their thoughts and ideas.*  *If a participant has very few ideas this section need not be laboured.*  *By exploring their expectations this will be useful for comparative analysis alongside their phase 2 and 3 interviews* |
| **Tell me about yourself,**  **e.g. talk about what you did yesterday** | *This may not be necessary, but this is to move the conversation from the more general discussion around the trial towards their own experiences. The function of this stage is to encourage young people to talk about themselves, for the interviewer to demonstrate interest in them individually and to provide some context to facilitate the treatment history map.* | * Explore background circumstances: Household, schooling community and friendships.      * Whether mention HIV treatment as part of their daily lives and routine. | * So, we’ve spoken a bit about X (before interview/ start of interview) but just so I can know a bit more about your day to day life, can you tell me a bit about yourself? * Can you tell me about what you did yesterday? * Is this a fairly typical day? * Good/ bad bits? * Who did you spend time with? * Tell me a bit about when you take your treatment and how that goes? | *This stage is intended to:*  *Demonstrate interest in their lives.*  *Encourage participants to start talking relatively freely.*  *Allow young people to talk about HIV treatment as one component amongst many that constitute their daily lives.* |
| **Experience of living with HIV - drawing life and treatment history map** | *This is to be able to plot a timeline of their lives- (use a simple sheet of paper with timeline sketch to fill in).*  *Found that young people often appreciate having something else to look at whilst talking- the timeline map provides a relatively neutral focus for both the interviewer researcher and the participant.*  *The aim of this is to facilitate discussion around contextual factors which may influence adherence and to be able to talk about particular events or periods in their lives in which adherence has been more difficult and why.*  *It will also provide a more detailed description of the circumstances in which they have been negotiating living with HIV.* | * Important life circumstances: Household, family health and own health. * Education * Disclosure * Awareness pre-disclosure * Treatment experience (when began treatment, treatment changes) * Involvement in support groups | * So that I can understand a bit more about what it has been like taking HIV treatment I’d like us together to draw a timeline, so that we can talk about what’s been going on in your life since you started taking treatment?   **Questions to be adapted to be sensitive to each individuals’ circumstances**   * Who do you live with at the moment? (if not already known) * Have you lived anywhere else before then * When did you find out about your HIV status? * Did you have any idea of this beforehand? * When did you start taking treatment? * Changes since then? * Education/ employment/ relationships * Key events that are missing from this timeline? | *Gain greater contextual understanding of life circumstances by mapping out key life events. Looking at how HIV treatment adherence interacts with multiple other factors, so need to encourage lots of detail on the treatment map.*  *We have found that many young people appreciate the opportunity to have an activity to support their talk.*  *Explore in greater details periods of poor adherence.* |
| **Adherence experiences** | *Explicitly reflect on adherence routines and the multiple factors which may coincide to create adherence problems or adherence support.*  *By not only focusing on the present it may make it easier to talk about times in which adherence was not good. This should differentiate the interview from any adherence discussions with the counsellors which may focus on the now and the imperative of optimum adherence.*  *Explore challenges in talking honestly about adherence problems with carers, doctors and anyone else.* | * Adherence routines * Factors which disrupt routines * Management of adherence- self-care, supervised * Transitions in care but also more broadly in priorities and concerns as young people get older. | * *Pointing at particular points on the map-* ask about times when taking treatment has been particularly difficult? Why? Times when it was a bit easier- why? * *Looking back on this –* can you identify periods when your adherence was less than everyday? * What does having good adherence mean to you? * What is good enough adherence? * Taking your treatment- what’s it like? When you’re holding it in your hand what are you thinking? * How would you describe what it’s like taking treatment to a friend? * Would you explain it differently to your doctor?   ***If the previous conversations have not yielded much discussion about their own adherence problems – a different tactic would be to discuss challenges to adherence amongst young people.***   * Most people have days when it is more difficult to take treatment. Why do you think that (a similar description in age and gender to themselves) might be it difficult? (relationships, boredom, illness, inadvertent disclosure)   ***Revisit their own experiences.***   * Can you tell me about a few times that it might have been more difficult for you? * Slip-ups in past few weeks? * Do you discuss these with any clinic staff? Why/ not? * How do you think clinic staff would react to you? * How would you like them to react? * What might make it easier to talk to them about these challenges? | *This section will start broadly and follow up with other questions, such as how difficult/easy, what makes the difference, how important etc.*  *The life and treatment history map will provide an overarching perspective on their treatment lives so far, prompting discussion about different adherence times.* |
| **Help, support and care experiences and needs** |  | * Additional important elements of life not associated directly with HIV | * Tell me about times when you are not thinking about HIV * Or when it is not at the forefront of your mind? * Plans for the next few years? * What would you like your experience of HIV treatment to be like during this time? Think it will? | *Explore positives in life to ensure appropriate closing of interview but also for further information to follow up in next interviews.*  *Add to the life and treatment history map.* |
| **Closing** | *Close on less emotive subjects- prepare them for follow up.* | * Experience of trial so far * Explain follow up and audio diaries | * We’re nearly done, but can you just tell me about your experience of the trial so far? * Would you like to keep an audio diary? * (after explanation) do you think that there might be any particular subjects that you’ll talk about in the audio diary? | *This question is left until last, rather than asked at the beginning, as it may be that they are more relaxed to talk about it by the end of the interview.* |