**Phase 2- YPLHIV interview**

This interview will be conducted during the second half of the trial. The key concern to bear in mind is that we will be aiming to follow-up on what we already know to explore it more in-depth. We will not be repeating the same ideas of questions, but adapting them to generate further insights. Integrate the individually relevant issues and questions throughout the interview- rather than leaving to the end.

Begin with rapport building, following up on non HIV related issues that have been discussed in phase 1 through the interview itself or the fieldnotes. This does not need to necessarily be in the interview, but should be detailed in the fieldnotes. This will save time when it comes to transcribing and translating the data.

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| **Key area of investigation** | **Themes** | **Example questions** | **Explanatory notes** | **Individual questions/ issues to add in – in preparation for interview** |
| **Discussion of the Breather trial** | * Experience of trial
* Changing adherence patterns, attitudes and behaviour through participation in the trial
* Experience of clinic when in trial as compared to standard clinic patient (waiting times, relationships with healthcare staff, attendance etc).
* Views on SCT
 | Clarify which arm they are in and adapt your questions accordingly. * How did you find it this week?
* Has this changed since the beginning of the trial?
* What’s it like coming to the clinic now that you are in the trial? Best bits? Worst bits?
* How does this compare to coming to the clinic when you weren’t in the trial?
* Do you know anyone else in the trial? Do you see them? Talk about the trial? Talk about other things/
* (Even for those on Cont arm) What are your thoughts on SCT? Do you think it is safe? What do you base this on?
 | *This is in part still a warm up part of the interview. Ask questions in a short timeframe in the first instance to help ensure that they are answerable.* *You can then move on to clarifying their understanding of the trial and to further exploring their motivation to participate in the trial.* *Interested in their general perspectives on SCT (deliberately only thinly explored in phase 1) and whether this has changed at all since the start of the trial and why. Opportunity to explore how they understand this trial- as an ongoing experiment or a foregone conclusion.* *Although these latter questions may be more appropriate for the older participants, it is worth trying to explore them with younger participants to ensure that they have an opportunity to express any ideas/ opinions that they may have on these topics.*  |  |
| *Research/ hope* | * Awareness of recent medical developments in the treatment and management of HIV (ie past year)
* Influence of any awareness on their own expectations of the future and their treatment behaviour.
* Whether participation/ engagement with research shapes their hopes for the future and influences how they manage their present.
 | * You are in this trial, are you aware of any other research going on about HIV (not ltd to JCRC)?
* Have you ever heard/ read about medical research about HIV or any breakthroughs? Tell me about them.
* What do you think when you do hear about developments? Why?
* Do you think about your treatment in exactly the same way now?
 | *Many young people have spoken about how they are motivated to participate in the trial because of altruism and interest. Are they aware of the medical developments which have taken place in USA and Paris (and others)? Has this shaped how they think about research, possibilities of a cure, their own treatment behaviour etc?* *We can also use this opportunity to explore the relationship between research and hope more fully. Does it make any difference to how they think about the future knowing that research is going on/ that they are participating in this study? How and why?*  | This may not work for all participants, but it is particularly targeted at those individuals who have taken a keen interest in ‘research’ and talk about how it in part sustains their hopes. We want to know if this is limited to the Breather trial and how connected they may be to more global research developments (thinking primarily about breaking news stories about HIV).  |
| *For those on SCT* | * Explore differences and acceptability
 | * What did you think when first being offered SCT?
* How are you finding having time off treatment?
* Can you tell me about the days which you have off?
* How do you feel when you come to start up again?
* How does SCT work for you? Do you prefer it?
* What do you think the effects are?
* Have you spoken with other young people about SCT? If so, what about?
 | *This is to record their reflections on the randomisation process as well as their experience of the particular arm that they are on.* *We are particularly interested in whether they are in contact with others on different arms.* *This will lead into a discussion of adherence and the possible influence that the trial may be having.*  |  |
| *For those in the control arm* | * Explore differences by participating in trial
 | * Have your attitudes towards adherence changed in any way since you have been participating in the trial?
* Similar to questions above adapted for the control arm
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| **Adherence** | * Effects of trial participation as well as being in a particular arm on adherence and treatment behaviour
* Influence of awareness of SCT on attitudes towards missing doses
* Any other changes which may have affected their adherence since the last interview- may be nothing to do with the trial (changes in routine, school, household, friendship groups)
* Experimentation with drugs dosage and taking
* Truth economy around adherence
 | * We’ve spoken a bit about how you have found being on X arm. Do you think that being in the trial itself has made any difference to how you think about your treatment? How you take your treatment?
* Now you know that some people/ you are interrupting your treatment in this trial, does it make it any difference to being able to talk about skipped doses? I.e. to talk about non-adherence/ slippages etc.
* If someone/ you did miss a few days of treatment, which was unscheduled, do you think you would now think about this differently because you know that SCT is being trialled?
* If you could choose, which I’m afraid that you can’t, which arm do you think that you would prefer to be in? Is this the same as you had thought before you began the trial?
* *For those who mentioned being upset about their allocation*- how do you feel about this now?
* This trial is trying to work out good ways for you to take your drugs. Have you ever done any types of experiments to see what affects you and how you take your drugs?
* Why do you think that SCT is needed? (to be asked of those who are not experiencing adherence problems themselves)
* Why do you think people/ you are often not honest about adherence?
* What do you think might help them to talk more honestly about non-adherence?
 | *As with all sections this needs to be adapted to the individual that you are interviewing at the time.*  |  |
| **Disclosure of HIV status** | * Experience of disclosure
* Expectations of disclosure (where learnt from)
* How assess whether/ whom to disclose to. Ie: their own disclosure rules
* Advantages of disclosure
* Expected or experienced disclosure to partners
 | * Have you disclosed to anyone/ anyone found out about your status since the start of the trial? Tell me about that. Follow-up with detailed probes about their experience.
* What do you imagine it would be like if X (peers), e.g. your friend/ sibling/ found out?
* Why do you think that they would react this way? How did you come to think this?
* What do you think it would be like once x people knew?
* Can you imagine ever telling them? Why/ not?
* Is there anyone that you think that you will/ should tell? Why?
* How do you assess whether it would be OK to tell someone?
* Do you think that there are any advantages in telling someone your HIV status?
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| **Attitude towards parents post-disclosure** | * Experience of being disclosed to
* Extent of discussion with carer about HIV, child’s status and the parents’ HIV status
* Attitude towards the way the carer disclosed to them- suggestions for improving the experience
* Attitudes towards being infected through birth and subsequent relationship with carer.
 | * We have spoken a little about your experience/ expectations about disclosing to other people. Can you tell me a bit (adapt this depending on what was learnt from their phase 1 interview) about your experience of being disclosed to yourself?
* How did you discuss this with your carer? Have you ever discussed how you yourself were infected with them?
* How would you have liked to have been disclosed to?
* (adapt to individual circumstances, depending on whether they know their parent/s HIV status) Has knowing how you were infected had any effect on how you think about your parent/s? Your relationship with them?
* If you could discuss this issue with them, what would you say to them?
* Do you think that they are aware of how you feel?
* Why don’t you discuss it?
 | *In the case of vertical transmission, one of the reasons given for delayed disclosure to children by carers is the assumption that children will have a negative reaction towards them. However this has rarely been explored from young people’s perspective.* *This has been starkly outlined in the theme column. However obviously, it is a very sensitive issue and may not be appropriate to explore in detail with all participants, for example those who are still somewhat confused by perinatal transmission. But where feasible we would like to gently discuss this. It also needs to take into account whether their biological parent/s are still alive, whether they are aware of the HIV status of their carer etc.*  |  |
| **Transitioning through adolescence** | * Moving from supported to autonomous treatment taking and responsibility for adherence- and the effect that this may have on their adherence
* Any changes that have been happening in their lives that have affected their experiences-e.g. change in school, household, peer friendship groups
* Information, resources and discussion of sex (in anticipation of and/ or direct experience of) from clinic, household, school, peers, support groups etc
 | * We’ve spoken a bit about how X reminds you to take your drugs. Can you imagine a time when you will be doing this on your own? Can you tell me a bit about when you think that might happen? And how that might be?
* OR/ have you always taken primary responsibility for taking your drugs? What was it like before? How did it come about that you took on this responsibility?
* What effect do you think it might have on your treatment taking/ adherence?
* We spoke before about what it might be like for you when you are in a relationship. Where do you find out information about sex and relationships at the moment? What do you think might make it easier to get hold of the information that you would like?
* How do you think you would go about disclosing to a partner? Is there anyone that you can talk to about this?
* Do you talk to the staff at the clinic about sex and relationships? Do you think that it makes any difference that they have known you for X years/ since you were X years old? What do you think might make that easier?
 | *Clearly these questions are particularly in need of individual adaptation, depending on the stage/ age/ experience of each individual.* *What we are particularly interested in how is they anticipate it will be, are experiencing it or are reflecting back on the process.*  |  |
| **MEMSCAP** | * To explore the experience of participating in the Memscap study
* Interaction with the Breather trial
* Experiences of and impressions of monitoring of adherence
* Awareness of flaws/ limitations
 | * Tell me, are you in the Memscap study?
* Why did you choose to participate?
* How have you found it?
* Do you think that it has made any difference to how you take/ think about your treatment each day?
* How do you feel about this little bottle being a way of monitoring your actions? Do you think it is an effective way of monitoring whether someone actually takes their treatment?
 | *You should know in advance whether a participant is involved in the Memscap study. This was not discussed at all at Phase1 and is an entirely new subject for phase 2.*  |  |
| **Follow up issues discussed in audio diary and those that emerged from phase 1 analysis- integrate into the topic guide throughout** |  |