**FOCUS GROUP with BREATHER TRIAL PARTICIPANTS**

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| **Section** | **Activity / aims** | **Suggested questions** |
| **OPENING UP:** | Greetings  Explanation of purpose of FGD and schedule for the session (they will have snacks, talk in pairs, talk in group etc etc)  “Rules” (incl. recording, notes, confidentiality, planned breaks, interruption, leaving if not comfortable etc.) |  |
| **WARM UP EXERCISE:** | Guess each other’s favourite sport/music/film... |  |
| **PAIR WORK** | *In pairs, participants can discuss their views and understandings of the trial results. Stella/ Winnie can observe and help out then one person from each pair could feedback to the group for broader discussion. You can ask them to sit next to someone they don’t know to try and observe whether they interact and know each other more than we thought from the interviews.*  *The questions in this section should be framed against the background of the dissemination event – so the participants are clear we are referring to the ‘trial results’ as explained during that day.*  *Here we want them to first communicate with each other and also to establish that they all (more or less) understand what the topic of the FGD is and why they are here.* | **1. Views and understanding of the trial results**  *What did you understand BREATHER to be about?*  *What did you understand the findings are?*  *What did they understand will happen in the trial now?*  *How did you feel when you left the dissemination event?*   * (These could be feelings about JCRC, or themselves as participants, or about research in general?) |
| **GROUP DISCUSSIONS** | *The following questions/topics are to be discussed with the whole group, as always ensuring everyone gets a chance to participate and give their views.*  *We want to understand their experience of the dissemination event so we can design better events in future if there is going to be broader dissemination to young people not in the trial. We also want to know whether they have learnt more about BREATHER than what they had understood during the trial itself, which would be an interesting area to explore for us in terms of understanding their participation and consent in clinical research.* | **2. Dissemination event**  *Did they enjoy it? / was it useful?*  *Can it be improved?*   * How do they suggest it should be done?   *Did you learn something about BREATHER you did not already know?* |
|  | *Here we want to know about their response to the trial results (we need to somehow stress these are ‘preliminary’ as of course they are still in the follow-up so it’s important to remind them the study is not entirely completed).*  *We want to know about those on CT whether they feel any different now they know that SCT could be ‘safe’. But even more we want to know how they feel hearing those on SCT speak of their experience of the intervention. Does this make them curious? Would they like to try it too? This is important because it gives us an idea of how other YP might react once they find out about SCT. It’s also important for us to understand whether hearing of the experiences of their peers changes their opinion compared to hearing clinicians talk about something like SCT.* | **3. SCT results (for them)**  *What do those on SCT think of SCT now they know the (preliminary) results?*  *What do those on CT think about trial results?*  *What do those on CT think when they hear those on SCT speak about their experience of the intervention?*  *Would they like to stay/go on SCT?* |
| **SNACK** | 5-10 mins max. They can take their soda with them and keep on snacking/drinking as they move into the next section (so it feels informal). |  |
| **Stand up exercise** | *Once they start answering the first question, you can split them into two groups (those who think SCT is for everybody and those who do not). You can then go up to them (and Winnie to the others) and ask them a but more about the reasons why they think what they think; and also why they think the others’ are ‘wrong’.*  *You can then ask them to sit back on their chair and have the remaining questions sitting down.*  *The important thing is to make sure they feel free to choose whatever side they want and do not feel like they should all follow the others, but if they all go to one side then you can just ask them to sit down again and continue with the questions.*  *These questions are designed to make us understand better how they feel about other young people finding out about SCT, whether they see any risks or benefits and how they see the intervention being rolled-out (under what conditions etc etc).* | **4. SCT (for others)**  *What do they think should happen next to SCT?*   * Should SCT be for everybody or only for those with undetectable VL and good adherence?   *What do they think about other young people (who were not in the trial) being told about trial results?*  *What do they think about other young people who may find out about trial results and/or SCT?*  *Do they think other young people (outside the trial) may try to go on SCT?*  *What may they need to know?*   * How can this be best managed? |
| **Group discussion** | \*\**Would they like their stories to go in a book like these? [Show them the storybooks and mention they will get a chance to read later. And of course reassure them they’re not the real life stories of actual children].*  *Here we want to know about their feelings about the qualitative data and how they think we can help, if possible.*  *We also want to tease out the reasons why we may have different stories about adherence in the interview data than what the trial questionnaires have been able to collect (their data points to very little missed doses and little side effects whereas we have lost of stories of missed doses and of side-effects). We need to understand what makes the interview a method that allows them to be frank so we can design better integrated methods in future research. We also want to continue investigate the reasons why YPO may find it difficult to talk about non-adherence with clinicians. But we do not want their own personal stories in the FGD, rather their general views about why one method may elicit different answers than another. So we ask them indirectly to comment on patient-clinician relationships.* | **5. Qualitative study results**  *What do they think should be done with the results of the qualitative study? (their interviews as well as the focus group)*  *How would they like us to use their stories? \*\**  *Are those in the FGD who were not part of the qualitative study interested in hearing more about these findings?*  *Why do they think we sometimes find differences between the results of the adherence questionnaires (given to the triallists) and findings on adherence (and non-adherence) from qualitative interviews?* |
| **Groups discussion** | *Here we want to find out a bit more about their networks and peer support. We have found little evidence in the interview of them socialising with others of their age/clinic. So we want to know whether they enjoy it and whether we should continue to recommend these happens more often.*  *We also want to know whether they see themselves (as trial participants) as different from other YP in the clinic. Are they a special group? Are they particularly ‘good’ patients?* | **5. Getting together**  *Was the dissemination event helpful for them to get together?*  *And the focus group discussion?*  *As a group, do you think you are the same as everyone else in the clinic?*  *Would they like to get together more often?*  *(if yes) How / why would they like to do this?* |
| **OPEN QUESTIONS** | *Here of course we need to be ready to answer what we can but also to be quite clear that any questions about the trial (future, follow up, switching therapy etc etc) need to be addressed to the trial team. We can offer to refer them and make sure someone is there to talk to them (Annet) or to get back to them with any further information they might want.* | *Is there anything else they want to discuss?*  *Do they have any further questions?*  *Would they like to be referred to anybody else who could answer their questions?* |
| **CLOSING REMARKS** | *Here you can discuss what the plans for the quali study are, for example that we are moving forward with carers’ interviews, and that we have dissemination plans for quali study which include going to conferences to talk to others, and helping clinicians improve the care they give to YP. And also using their ideas discussed in the FGD to take our work forward etc.*  *We should also offer for them to get in touch with us if they want to know more about what we are doing.*  ***This is also a good time to remind them of the confidentiality of the FGD discussion.*** |  |
| * **Distributing comic books** * **Reimbursements etc..** * **Thank yous and LUNCH!!!!** |  |  |