

Haus Study – Stage 1 Focus groups topic guides – non-specialists

Date:

Facilitators' Initials:

Location:

Materials needed:

- Payment / and payment record sheet
- Sign in sheet
- Images
- Participant info sheets in hard copy
- Light refreshments
- Pens
- 2 digital recorders (and back up batteries)
- Note paper for observations
- Stickers for name tags
- Consent forms printed
- ****NEW – Participant Number Cards***

Introduction (10 mins)

- We are..... [names / institutions and research background BRIEFLY]
- The information sheets gave you a lot of detail about our study – so we will just give you a short background before we start.
- Many people with HIV in the UK do not know they are infected and are missing the chance to benefit from drug treatments that can prevent the development of AIDS, allowing people to live healthy lives.
- A lot of these undiagnosed people are from African backgrounds, preventing them from accessing beneficial and effective treatments to keep them, and their partners, well.
- Health services in the UK must increase the numbers of people of African background who are regularly taking HIV tests.
- One of the ideas is for people to take a blood sample themselves, either at home or another private place, then send this away to be tested. We think that this might make HIV testing more convenient and hope it will increase the numbers people who take a test.
- Today we would like to hear your views on this, to look at the test kits, to talk about whether you think that people might like to use them and to talk about how to give them the test kits, the sort of support people might want and how they might like to hear about the test results and be helped to access treatment and care.
- We are most interested in how people talk to each other about things and to find out where you all agree and disagree. We are happy to answer any factual questions at the end but are really interested in how the group discusses the

topics. It is our job to try and make sure everyone take parts and sticks to the agenda. Nothing you say will be traced back to you, and everything discussed in this room is entirely confidential.

- We will switch on the digital recorders soon. That is because we can not write down everything you say as quickly as you say it. Only those working directly on this study will have access to those recordings, and when it is all written down we will completely remove any mention of names or other details that might possibly identify an individual.

Any Questions?

[All consent forms collected before starting.....]

Ice breakers (5 mins)

- A. Before we talk about these things we'd like to ask you each to introduce yourselves to the group (first name only)

Recording starts

- B. Now that the recorders are on, can you please go around the room and state your participant number (using card in front of them), and then just say one place you know of where you could get an HIV test if you wanted one, or where would you tell a friend to go if they wanted one?

As group feeds back, focus on the contrasting and similar responses and group them (largely) into the following categories (quickly):

Clinic:

- *Hospital or clinic based test – because you have asked for one*
- *Hospital or clinic based test – because you are unwell*
- *Routine unanonymised testing (ante-natal) **but not blood donation, nor all clinic blood samples*

Community:

- *Community organisation*
- *GP*
- *Draw out the different waiting times that people are aware of, as well as various sampling methods / requirements*

Introduction to HSK (25 min)

Introduce the HSK – using two **VIDEOS** - please speak instructions aloud for TINY vial video

Give out sample TINY kits, ask participants to explore how they look / feel / operate

1. What do you think about these kits?

Prompts:

- *Issues related to self-sampling and collecting a small vial of blood*

- *Perceptions of accuracy / efficacy - any different than conventional blood test for HIV?*

- What would be the advantages / disadvantages compared to current ways of getting an HIV test?
- Who would struggle with these kits? Why?
- Who would use them?

2. What would you like a kit to look like?

Prompts:

- *Is there anything about the look and packaging that would make people more or less likely to take it and use it?*
- *branding*
- *setting*

Distribution: Acceptability/practicalities of community distribution of testing kits (20 min) CD

3. Where do you think these kits should be available?

***hand out labelled photos/or printed scenarios of different locations to initiate talk*

Ask about best place/worst place

- advantages/disadvantages
- Any others places you think might be good?
- Should people have a choice about where to go?

Why is this important?

Prompts:

What is most private?

Most Trustworthy?

Most professional?

4. Do you feel that in each of these places, someone needs to be there to actively give out the kits and answer questions?

Prompts:

GP

Pharmacist (boots)

Dentist

Hairdresser

University staff

Faith leader

Community outreach worker

5. Would it be better for a person to give out the kit or for people to be able to pick it up without talking to anyone?

6. For the next part of our study, we will actually have to ask people about taking part, and agreeing for us to follow up with them to find out what they thought about using the kit. For that purpose, what personal details other than a name and contact number do you think people would be happy to provide when they collect the kit?
 - *identify any firm boundaries / no-go areas?*

Self-sample collection – preferred venue (5 min) CD

7. Once someone has the kit, where do you think that most people may want to actually collect their sample? Will that always be back at home?
***Use image cards to provoke discussion:*

- *Might there be issue with doing the sample at home?*
- *in a community venue?*
- *somewhere else?*
- *Why?*

Return of sample – preferred method CD

8. What do you think is the best way to get the sample back to the lab?
Prompts:
 - *post the sample personally*
 - *return it to the venue where they got the kit?*
 - *Why? – privacy and confidentiality*

Communicating and confirming HIV test results (15 mins) EM

Explain what the possible results are:

- *What does it mean to get a negative result*
- *What does it mean to get a reactive result*
- *The risk and meaning of false positives*

9. What might be the best way to explain all of this to people considering the sampling kits, particularly the idea of false positives?

Currently many sexual health clinics will use HIV test results where the result is given instantly, in person. If they have to send the result to a lab, they may need to ask the person to return for another appointment to get their result, or they may agree that any negative results will be communicated by text, or a phone call, but all HIV positive

results are given in person. There are home sampling schemes in operation now that give HIV negative results by text, and that call those whose test result is reactive. There will be a clinic in charge of each patient receiving news of a negative or a reactive result – just in case they need more information, a confirmation test, or further support.

10. What is the best way for people to be told about the result of their test?

Prompts if needed:

- *Text with actual results*
- *Text saying the results are ready*
- *Home visit*
- *Phone*
- *Secure web login*
- *Posted letter*
- *Other: What?_____*

11. What kind of language should be used to communicate test results?

12. If a person was receiving a negative result, saying they did not have HIV, do you feel that is all they should be told? Is there anything else you might expect them to get in terms of information /advice?

13. If a person was receiving a reactive result, indicating that they may have HIV, what sort of support should they receive?

- Should this information be passed on the same way no matter what the result?
- What kind of follow on information, support, advice should they receive?
- Is that appropriate to do on the phone? Or is it best in person?

14. If someone has a positive test with the home sample kit they would need to have another test to confirm that they are HIV positive. How and where should that be done?

15. Do you feel that people who you know might be interested in using one of these kits? Why / Why not?

Marketing (5 mins) EM

Mock up packs have already been distributed to the group.

16. Should there be anything else included with the kit when people collect it?

Prompts:

- *Condoms?*
- *Additional testing kits*

- *HIV prevention / information?*
- *Support information / contact details?*

Group Closure (5 mins) EM

17. If you had to say one thing about Home Sampling Kits what would you want to say?

Just before we close, is there anything you wanted to add that you did not get a chance to, or things you feel we should have discussed?

- Thanks for your time / honesty.
- Explain process for rest of Phase 1.
- Website / Twitter for ongoing updates about progress.
- Sort out payments / receipts etc.

<END>