

Appendix G: Focus Group Discussion Patient information leaflet



Information for participants taking part in interviews

I am inviting you to take part in a research study called: APPLE

Please take time to read the following information carefully. Discuss it with friends and family if you wish. Take time to decide whether or not you wish to take part.

It is up to you if you do or do not want to take part in this research study. If you choose not to take part, this will not affect the care you get from your own HIV clinic in any way.

Ask us if there is anything that is not clear or if you would like more information.

Thank you for reading this information. If you decide to take part you will be given a copy of this information sheet and asked to sign a consent form. You'll get a copy of that as well.

What is the project about?

I am doing a study on young people's experiences of attending HIV clinic appointments. I want to find out about how young people find having regular hospital visits and what issues help or get in the way of attending these clinic visits.

What I am trying to find out?

I am trying to understand the reasons young people do or do not attend their HIV appointments. I hope that this study may help to improve services for young people with HIV by better understanding these issues.

Why would I like to talk to you?

You are being asked to take part in this study because you use HIV health services and I am interested in hearing your experiences and your views. There are no right or wrong answers. This study is also a sub-study of the Adolescents and Adults Living with Perinatal HIV (AALPHI) study which is another research study you have already taken part in.

Who am I?

My name is Marthe Le Prevost. This project is part of the studies I am carrying out at The London School of Hygiene & Tropical Medicine.

What will be involved?

How many interviews?

If you take part, you will be interviewed two times over the next year. The two interviews would be at least 6 months apart.

The reason I want to carry out two interviews is because I know a lot can happen in your life in a few months. And so I would like to hear your views on these new experiences

What will the interview be like?

For each interview I would like to talk to you for about an hour at a place and time that you choose. I would like to talk about your experiences of attending your HIV clinic appointments and how you manage this in the context of the rest of your life. You do not have to talk about anything you do not want to talk about.

I would like to make an audio recording of the interviews so that I can remember what you said.

Where will the interviews take place?

Interviews need to be carried out in a quiet room. They can be carried out at:

- an HIV support group
- your home
- my office in Holborn.

Is the research confidential?

YES! Any information that you share with us will only be used for research. All information will be stored securely. I will take care to protect your personal identity at all times and nothing you talk about will be linked to you.

I might use some of your quotations (words), and any diagrams which may be drawn during the focus group, but I will never use your real name or any personal details. Anonymised data (without names, so no one can tell who said what) will be stored for a minimum of 10 years in a data repository and may be used for other studies, but will only be seen by researchers authorised by me. Also if you tell me something that makes me worry about your safety (if you are under 18 years old) or the safety of someone else under 18 years old, I would have to share this with another professional. I would always tell you if we are going to do this and there is no other reason I would ever tell anyone what you said.

What will I gain?

You will probably not gain anything directly from participating. However your experiences may help other young people with HIV, and this is an opportunity to make sure your voice is heard.

What are the possible risks?

There is very little risk to taking part in this research study. There is a small risk that something upsetting may come up while we are talking. If this happens, I will ask you if I can contact anyone to help support you, and I will give you information about appropriate support groups.

Will I be compensated?

Yes, I will give you a £20 voucher for each interview to say thank you for your time.

More information about taking part

Do I have to take part in this study?

No, it is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form. If you decide not to take part in this study, this will not affect the care you receive at your HIV clinic.

Can I stop taking part after I've joined the study?

You can stop taking part in this study at any time and without giving a reason.

What will happen to the results of this study?

I will publish findings from this study in publications and reports so that anyone who is interested can see them. You can ask me for a copy of any publication. Your identity and any personal details will be kept confidential. No named information about you will be published in any report of this study.

Who is funding and organising this study?

My PhD is funded by the Medical Research Council and is receiving support from the Adolescents and Adults Living with Perinatal HIV (AALPHI) study.

The London School of Hygiene & Tropical Medicine is the sponsor of the study and has overall responsibility for the conduct of the study. They are responsible for ensuring the study is carried out ethically and in the best interests of the study participants.

Who has reviewed this project?

This project has received ethical approval from the East Midlands – Leicester Central REC and the ethics committee of the London School of Hygiene & Tropical Medicine.

How to contact me

If you have any questions or need any more information, please contact me on:

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How to withdraw your consent?

You have the right to object to the use of your information and can withdraw your consent at any time. Please contact the data protection officer at DPO@lshtm.ac.uk if you have any questions.