

UNIVERSITY OF DERBY

**COMPETING REALITIES,
DIVERSE NEEDS:
AN INTER-DISCIPLINARY APPROACH TO RELIGIOUS
ENGAGEMENT WITH HIV PREVENTION AND CARE**

VOLUME II

APPENDIX

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Doctor of Philosophy

2012

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THE SPINE IN THE
ORIGINAL THESIS**

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Tree Nodes

APPENDIX A1

What is HIV?

HIV is a virus. Viruses infect the cells of living organisms and replicate (make new copies of themselves) within those cells. A virus can also damage human cells, which is one of the things that can make an infected creature become ill. People can become infected with HIV from other people who already have it, and when they are infected they can then go on to infect other people. Basically, this is how HIV is spread.

HIV stands for the '*Human Immunodeficiency Virus*'. Someone who is diagnosed as infected with HIV is said to be 'HIV+' or 'HIV positive'.

Why is HIV dangerous?

The immune system is a group of cells and organs that protect your body by fighting disease. The human immune system usually finds and kills viruses fairly quickly. So if the body's immune system attacks and kills viruses, what's the problem?

Different viruses attack different parts of the body - some may attack the skin, others the lungs, and so on. The common cold is caused by a virus. What makes HIV so dangerous is that it attacks the immune system itself - the very thing that would normally get rid of a virus. It particularly attacks a special type of immune system cell known as a CD4 lymphocyte. HIV has a number of tricks that help it to evade the body's defences, including very rapid mutation. This means that once HIV has taken hold, the immune system can never fully get rid of it.

There isn't any way to tell just by looking if someone's been infected by HIV. In fact a person infected with HIV may look and feel perfectly well for many years and may not know that they are infected. But as the person's immune system weakens they become increasingly vulnerable to illnesses, many of which they would previously have fought off easily. The only reliable way to tell whether someone has HIV is for them to take a blood test which can detect infection from a few weeks after the virus first entered the body.

What is AIDS?

A damaged immune system is not only more vulnerable to HIV, but also to the attacks of other infections. It won't always have the strength to fight off things that wouldn't have bothered it before.

As time goes by, a person who has been infected with HIV is likely to become ill more and more often until, usually several years after infection, they become ill with one of a number of particularly severe illnesses. It is at this point that they are said to have AIDS - when they first become seriously ill, or when the number of immune system cells left in their body drops below a particular point. Different countries have slightly different ways of defining the point at which a person is said to have AIDS rather than HIV. AIDS (*Acquired Immune Deficiency Syndrome*) is an extremely serious condition, and at this stage the body has very little defence against any sort of infection.

How long does HIV take to become AIDS?

Without drug treatment, HIV infection usually progresses to AIDS in an average of ten years. This average, though, is based on having a reasonable diet. Someone who is malnourished may well progress to AIDS and death more rapidly. Antiretroviral medication can prolong the time between HIV infection and the onset of AIDS. Modern combination therapy is highly effective and, theoretically, someone with HIV can live for a long time before it becomes AIDS. These medicines, however, are not widely available in many poor

countries around the world, and millions of people who cannot access medication continue to die.

How is HIV passed on?

HIV is found in the blood and the sexual fluids of an infected person, and in the breast milk of an infected woman. HIV transmission occurs when a sufficient quantity of these fluids get into someone else's bloodstream. There are various ways a person can become infected with HIV.

- *Unprotected sexual intercourse with an infected person*
- *Contact with an infected person's blood*
- *From mother to child* HIV can be transmitted from an infected woman to her baby during pregnancy, delivery and breastfeeding. There are special drugs that can greatly reduce the chances of this happening, but they are unavailable in much of the developing world.
- *Use of infected blood products*
- *Injecting drugs*

It is not possible to become infected with HIV through :

- sharing crockery and cutlery
- insect / animal bites
- touching, hugging or shaking hands
- eating food prepared by someone with HIV
- toilet seats

Is there a cure for AIDS?

Worryingly, surveys show that many people think that there's a 'cure' for AIDS - which makes them feel safer, and perhaps take risks that they otherwise shouldn't. These people are wrong, though - there is still **no cure for AIDS**. There is antiretroviral medication which slows the progression from HIV to AIDS, and which can keep some people healthy for many years. In some cases, the antiretroviral medication seems to stop working after a number of years, but in other cases people can recover from AIDS and live with HIV for a very long time. But they have to take powerful medication every day of their lives, sometimes with very unpleasant side effects.

There is still no way to cure AIDS, and at the moment the only way to remain safe is not to become infected.

AVERT.org has more about:

- [The global AIDS epidemic](#)
- [HIV transmission and testing](#)
- [Prevention of HIV transmission](#)
- [HIV/AIDS treatment and care](#)

Adapted from information at www.avert.org

APPENDIX A2

HIV/AIDS INFORMATION, ADVICE AND SUPPORT

Health Advisers
Dept GU Medicine, Leicester Royal Infirmary
0116 2585208

Faith in People with HIV
Rev'd Trevor Thurston-Smith,
Chaplain for People Affected by HIV
0116 2733377

Leicestershire AIDS Support Services
0116 2559995

NHS Community Drug Team
0116 2256400

Leicester Rape Crisis
0116 255 8852

NHS Direct
0845 4647

APPENDIX A3

Address for correspondence:

Reverend Canon Margaret Morris

Home address

XXXX

XXXX

XXXX

XXXX

Dear Colleague

A REQUEST TO HELP WITH RESEARCH ON RELIGIOUS CONTEXTS OF HIV/AIDS IN LEICESTER

I have worked in the field of HIV support and hospital chaplaincy for many years. After stepping down as the Bishop of Leicester's Chaplain for People Affected by HIV in 2005 there is time to undertake an academic study which I hope will further our understanding of some of the issues around religious belief and HIV/AIDS.

In collaboration with the University of Derby, faith networks of Leicester and Leicester Royal Infirmary, I am conducting research into religious contexts of public health HIV prevention and care policy and provision in Leicester. Due to constraints on resources (financial and human) it has been decided to focus the study on the three largest faith communities in Leicester - Muslim, Hindu and Christian. I am writing to ask for your help by spending a few minutes completing the enclosed questionnaire. Anonymity and confidentiality are assured.

The research findings will be analysed and it is intended that they will

- inform our understanding of the role of religion in the delivery and development of HIV prevention and care services in multi-faith Leicester;
- point to ways in which HIV prevention and care services can meet the needs of more people in our communities;
- identify the contributions of faith groups and communities in Leicester to HIV prevention and care.

At present such information is not available.

There are three main sections of the study which involve local participants.

1. Postal questionnaire to local faith group leaders, teachers and/or representatives (those who have responsibility for teaching and the formation of opinion in their faith group or community) with questions about their religion's teachings in response to HIV/AIDS.

2. Exploring with small groups of lay members from the participant faith communities how they understand the teachings of their religion and how their beliefs affect their responses to HIV/AIDS.
3. Finding out from people living with HIV/AIDS how religious teachings and beliefs affect their experience of HIV/AIDS.

I am hoping you will take part in section 1 of this study by

- passing the enclosed questionnaire and request to complete it to the person in your faith group who has responsibility for helping the congregation or community understand their religion's teachings and to whom people may go for guidance when they have problems;
- completing the questionnaire yourself if you are that leader/teacher;
- returning the questionnaire to me in the stamped and addressed envelope provided.

To reiterate, anonymity and confidentiality are assured.

This research is not designed to test how much knowledge of HIV/AIDS you or your colleagues have, but I have included a brief information sheet. If you would like to know more about HIV/AIDS and the support that is available to local people please contact one of the organisations on the enclosed list.

It is anticipated that in due course a summary of the research findings will be made available. Information about this will be circulated via the local faith networks. No information identifying individuals will be used in the study report.

I enclose

- questionnaire,
- basic information about HIV,
- a list of local HIV information and support agencies,
- stamped and addressed envelope for return of the completed questionnaire.

Please do not hesitate to contact me if you require further information

In anticipation of your help, thank you.

Yours sincerely

Canon Margaret Morris

APPENDIX A4

Research Study

Religious Contexts of HIV Prevention and Care in Leicester

QUESTIONNAIRE

Please answer all the questions, or as many as you can, as concisely as possible. Feel free to use another sheet of paper if you need more space.

I would be grateful if you could return the completed questionnaire as soon as possible, but by the end of October 2007 at the latest. I enclose a stamped and addressed envelope.

If you decide not to take part in the study it would be helpful if you would use the reply envelope to let me know why you felt unable to participate.

Please give below the name of your religion and, where applicable, the denomination or group – I do not require your name or contact details.

1. In your opinion what are the main factors contributing to HIV transmission

(a) around the world?

(b) in the UK?

(c) in Leicester?

PTO

2. Do you think that HIV/AIDS is a cause for concern as a public health issue?
Please tick 'Yes' or 'No' and give reasons for your answers.

(a) around the world

Yes

No

(b) in the UK

Yes

No

(c) in Leicester

Yes

No

(d) in your faith community

Yes

No

3. Describe what you understand your religion's teachings and beliefs say about

(a) HIV/AIDS

(b) about people who have HIV

4. Please give a brief outline of your religion's beliefs and teachings about intimate relationships.

5. How far do you think people in your faith group/community conduct their intimate relationships according to their religion's teachings?

6. Do you think the teachings and beliefs you have described (questions 3-4) influence the responses of your faith group/community to

(a) HIV/AIDS in general Yes No

Please tick 'Yes' or 'No' and give reasons for your answer.

(b) people who have HIV? Yes No

Please tick 'Yes' or 'No' and give reasons for your answer.

7. Do you think the teachings and beliefs you have described (questions 3-4) influence the responses of people **outside** (via media reports, books, conversations, attitudes etc) your faith group/community to

(a) HIV/AIDS Yes No

Please tick 'Yes' or 'No' and give reasons for your answer.

PTO

(b) people who have HIV

Yes

No

Please tick 'Yes' or 'No' and give reasons for your answer.

8. Do people in your faith group/community talk to one another about HIV/AIDS?

Please tick 'Yes' or 'No'.

Yes

No

9. Do **you** in your role as religious leader/advisor talk to anyone in your faith group/community about HIV/AIDS?

Please tick 'Yes' or 'No'.

Yes

No

10. Do you think that your religion's teachings and beliefs influence whether or not

(a) people in your faith group/community talk to one another about HIV/AIDS?

Yes

No

Please tick 'Yes' or 'No' and give reasons for your answer.

(b) people in your faith group/community talk with health professionals, school/college teachers about **information** on HIV/AIDS?

Yes

No

Please tick 'Yes' or 'No' and give reasons for your answer.

(c) people in your faith group/community talk with health professionals, school/college teachers about information on **testing** for HIV?

Yes

No

Please tick 'Yes' or 'No' and give reasons for your answer.

11. Have your religion's teachings and beliefs influenced whether or not **you** in your role as a religious leader/advisor have talked with

(a) anyone in your faith group/community about HIV/AIDS?

Yes

No

Please tick 'Yes' or 'No' and give reasons for your answer.

(b) health professionals, school/college teachers about having **information** on HIV/AIDS?

Yes

No

Please tick 'Yes' or 'No' and give reasons for your answer.

(c) health professionals, school/college teachers about information on **testing** for HIV?

Yes

No

Please tick 'Yes' or 'No' and give reasons for your answer.

12. Do you think anyone affected by HIV in your faith group/community would feel able to talk to someone in the faith group/community about their concerns?

Yes

No

Please tick 'Yes' or 'No' and give reasons for your answer.

PTO

13. Has anyone in your group/community approached **you** to talk about HIV?

Yes

No

Please tick 'Yes' or 'No'

If 'Yes' please describe your response

14. What can/does your faith community offer people affected by HIV/AIDS?

15. In your view what would be appropriate support and care for people affected by HIV in your faith group/community?

16. Can you suggest how that support and care for people affected by HIV could be provided

(a) in or by your faith group/community

(b) by other organisations in Leicester

17. Do you know personally anyone with HIV?

Yes

No

Please tick 'Yes' or 'No'

If 'Yes' please indicate, if you wish, whether you know the person as friend, family member, colleague, neighbour, member of your faith group/community or other.

18. Do you know of anyone with HIV?

Yes

No

Please tick 'Yes' or 'No'

If 'Yes' please describe how you know of him/her.

19. In your opinion what should be the two most important messages to prevent HIV/AIDS

(a) in your faith community?

(b) in Leicester?

20. Please give a brief outline of your views on sexual health and relationships education in schools.

PTO

21. Do you think it matters what faith groups and faith leaders believe and say about HIV/AIDS?

Yes

No

Please tick 'Yes' or 'No' and give reasons for your answer

22. If you wish please add any other comments about the relationship between HIV/AIDS and religious teachings and beliefs which have not been covered by the questionnaire.

Finally, it would help inform the analysis if you could provide some information about yourself.

Gender.....
Age.....
Ethnic background.....
Role or position if any in your faith group/community.....
Country of birth.....
Education level/Qualifications.....

Thank you very much for taking the time and trouble to help with this research study. It is greatly appreciated. Please return the questionnaire in the stamped and addressed envelope provided.

A summary of the study's findings will be available in due course and circulated via the faith networks of Leicester. It is hoped that a presentation may be arranged for anyone interested in the results of the study and other issues covered by the research. Some direct quotes may be used but no information which identifies you will be used in any presentation or report.

Thank you again for your help.

Canon Margaret Morris

APPENDIX B1

CONSENT FORM

Title of Project: Competing realities, diverse needs: a multi-disciplinary approach to religious contexts of HIV prevention and care in Leicester.

Identification Number for this study:

Name of researcher: Margaret Morris

Please initial to confirm

- I have read and understood the information about this research study.
- I have had an opportunity to ask questions about the research study and discuss it with the researcher and friend, family member or supporter.
- I understand the purpose of the research study and how I would be involved.
- I agree to the interview being tape recorded and understand that tapes will be stored securely and will be destroyed after the study has been examined.
- I understand that any information collected in the research study will be held in line with the requirements of the Data Protection Act (names, codes, transcripts and tapes, paper copies and/or disks will be separated and stored in locked and secure places.
- The terms of confidentiality have been explained to me.

Continued over

- I understand that my participation in the research study and the information about me is confidential but that any indicators of self-harm or harm to others will have to be reported through the appropriate channels and I understand that some direct quotes may be used in study reports, but that no personal details which could identify me will be included in any finished or published work.
- I confirm that I will be taking part in this research study of my own free will. I understand that I may withdraw from it at any time and for any reason without my medical or other care or my legal rights being affected.

I agree to take part in the above research study. I am over 18 years of age.

| | | |
|---------------------|-----------|-----------|
| _____ | _____ | _____ |
| Name of Participant | Date | Signature |
| _____ | _____ | _____ |
| _____ | _____ | _____ |
| Researcher | Signature | Date |

When completed 1 for participant; 1 for researcher

Adapted from standard COREC form and Sample Research Form for Research Study
www.rdfunding.org.uk/flowchart/ConsentForm.htm

INFORMATION SHEET

Study Title: Competing realities, diverse needs: a multi-disciplinary approach to religious contexts of HIV prevention and care in Leicester

Introduction

Between March 2007 and March 2008 I shall be conducting research into the relationship between religious beliefs and HIV. This is part of a PhD research programme with the University of Derby. The staff of the Department of Infection and Tropical Medicine (IDU) and the Department of Genito Urinary Medicine at Leicester Royal Infirmary and at Leicestershire AIDS Support Services (LASS) and Faith in People with HIV have agreed to give information about the research to people living with HIV.

Invitation

You are being invited to take part in this research study. Before you decide whether or not to accept the invitation it is important that you understand why the research is being done and what it will involve. Please take time to read the information in this leaflet and discuss it with others if you wish. If there is anything that is not clear or if you would like more information please contact me. You will find my contact details towards the end of this leaflet.

What is the purpose of the study?

To help in understanding and identifying

- whether religious beliefs (their own beliefs and/or the beliefs of others) affect a person living with HIV;
- whether religious beliefs affect HIV prevention and care services;
- whether any recommendations for changes to prevention and care services can be made;
- any contributions to HIV prevention and supportive care which faith groups and communities can make.

Which religions?

In Leicester the largest religious groupings are Hindu, Muslim and Christian. It has been necessary to select these religions because the researcher's resources are limited and a wide-ranging study covering all the religions of Leicester would not be possible. So the study is concentrating on people who have connections with Hindu, Muslim or Christian religions.

Why have I been invited to take part?

A major part of the research programme involves finding out from people living with HIV/AIDS whether their religious beliefs and/or the beliefs of others have affected their experience of HIV/AIDS. The staff in the Department of Infection and Tropical Medicine (IDU) and the Department of Genito Urinary Medicine at Leicester Royal Infirmary and at LASS and Faith in People with HIV have agreed to pass on the information about this research project to people diagnosed with HIV. The staff members are not involved in the research in any other way.

Do I have to take part?

No. Taking part in this research is entirely voluntary. It is up to you to decide whether or not to take part. You are free to ask for any information you need to help you decide. If you do decide to take part you will be asked to sign a consent form but you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time or a decision not to take part will not affect the standard of care you receive.

Do I have to be religious to take part?

No. Whether or not you practice your religion, if you are from a Hindu, Muslim or Christian background your views and your experience are important to the research study.

What will happen if I decide to take part?

I would like to meet with you to talk about your religious beliefs and your experience of HIV. Please contact me using the details at the end of this leaflet. A meeting will be arranged at a time and a place convenient to you. There will be some questions which I shall use to guide the interview. An audio tape recording will be made of our meeting. This will be written up and the taped and the paper records will be kept in separate and secure places. After the study is completed and has been examined the tape recording will be destroyed. The paper record of the interview will be stored securely in line with NHS regulations.

Will my taking part in this study be kept confidential?

Before the interview begins I shall explain the purpose of the research and clarify the arrangements for confidentiality. It will be important to understand, for example, that I would have to report to my manager and supervisor any indication of self harm or harm to others that came to light during an interview. You will be asked to read and sign a consent form which I shall go through with you point by point. No personal details which may identify anyone will be presented or published. Some direct quotes may be used in the study report but these will NOT identify you. The interview will last no more than an hour and you can withdraw from taking part at any time if you wish to do so.

What will happen to the results of this research study?

The research study is part of an investigation into the ways religious beliefs of people in Leicester may affect

- people living with HIV,
- HIV prevention and supportive care services,
- contributions faith groups and communities can make to HIV prevention and supportive care services in Leicester.

The study's results will be written up and summaries made available to all those who take part and wish to receive a copy. Please note the point made above – some direct quotes may be used in the study report but they will not identify you or any other participant.

Who is organising and funding the research?

I am undertaking the research as part of a PhD programme with the University of Derby's Faculty of Education, Health and Sciences and with the help of the Department of Infection and Tropical Medicine and the Department of Genito Urinary Medicine at Leicester Royal Infirmary and also of LASS and Faith in People with HIV. I am self-funding and no doctor or health professional or other staff members are being paid to participate.

Who has reviewed the study?

All research that involves NHS patients or staff or uses NHS premises or facilities and at the same time involves users of other services must be approved by an NHS Research Ethics Committee before it can go ahead. Approval means that the committee is satisfied that your rights will be respected and that you have been given sufficient information with which to make an informed decision. This study was reviewed and given a favourable opinion for conduct within the NHS by the Derbyshire Research Ethics Committee. The study has been registered with the University of Derby.

If you would like to have independent information about being involved in a research study you may contact

NHS Patient Advisory Liaison Service (PALS)

Leicester Royal Infirmary

Infirmary Square

Leicester

LE1 5WW

Telephone: 0116 2586344

or

The Research Office

University Hospitals of Leicester NHS Trust

Leicester General Hospital

Gwendolen Road

Leicester

LE5 4PW

Telephone: 0116 2588246

Who do I contact if I have a complaint?

If you have any complaints about any aspects of the conduct of this research please contact

The Research Office
University of Derby
Kedleston Road
Derby DE22 1GB
Telephone: 01332 591060

What do I do if I decide to take part or if I want more information?

Please contact me. My contact details are

The Reverend Canon Margaret Morris
Home address
XXXX
XXXX
XXXX
XXXX

Telephone: Home telephone

If at all possible, I would encourage you to talk over this invitation to take part in the research with a friend or a family member.

Please contact me by telephone if you would like to take part and arrange an interview. I enclose also a reply slip and a stamped and addressed envelope if you prefer to let me know by post that you wish to take part. I will then contact you by telephone or by post. Alternatively you can hand the envelope to a member of staff when you next attend clinic or go to LASS or Faith in People with HIV and they will forward it to me.

If there is no convenient way to contact you by telephone and you would prefer not to receive letters about your participation in the research, I can meet with you at clinic, at LASS or Faith in People with HIV to discuss arrangements if you let staff there know you would like to take part.

About the researcher

I am an Anglican (Church of England) priest who has been involved in HIV support work for many years. In January 2005 I stepped down as the Bishop of Leicester's Chaplain for People Affected by HIV. This allowed time to conduct this research programme, the results of which I hope will help health and social care professionals as well as faith groups to understand better the role of religion in HIV prevention and care. I am a member of the Chaplaincy team at Leicester Royal Infirmary.

Thank you for reading this. I look forward to hearing from you.

APPENDIX B3

Research Study: Competing realities, diverse needs: a multi-disciplinary approach to religious contexts of HIV prevention and care in Leicester

Interviews with People living with HIV

Participant Code Number eg 01/ Religion code/ date eg 010507/place eg h-home, ch-chaplaincy/ time eg 2.30/ gender/ m or f

Interview Location

Time

Date

Information about the research project will be given verbally and in written form

Attention to be drawn to audio recording and terms of confidentiality
Consent forms to be completed and signed

Interviewer's Questions

1. Do you attend a place of worship?
2. Did you attend a place of worship before you were diagnosed with HIV?
3. Please give the reasons for any changes there have been.
eg If 'Yes' at 1. and 2., is it the same place of worship? If not, why has it changed?
If 'Yes' at 1. and 'No' at 2. or *vice versa* why the difference?
4. Are you actively involved in your faith group? (*teaching, prayers, music, etc*)
5. Were you actively involved in your faith group before you were diagnosed with HIV?
6. In your opinion what are the main factors contributing to HIV transmission
 - (a) around the world?
 - (b) in UK?
 - (c) in Leicester?
7. Do you think that HIV/AIDS is a cause for concern as a public health issue
 - (a) around the world?
 - (b) the UK?
 - (c) in Leicester?
 - (d) in your faith group/community?

Please give the reasons for your answers.

8. Describe what you understand your religion's teachings and beliefs say about

- (a) HIV/AIDS
- (b) people who have HIV.

9. Give a brief outline of your religion's beliefs and teachings about intimate relationships.

10. How far do you think people in your faith community conduct their intimate relationships according to their religion's teachings?

11. Do you think the teachings and beliefs you have described influence the responses of your faith group/community to

- (a) HIV/AIDS?
- (b) people who have HIV?

Please give reasons for your answer.

12. Do you think that the teachings and beliefs you have described influence the ways people outside (via media reports, books, conversations etc) your faith group/community respond to

- (a) HIV/AIDS
- (b) people who have HIV?

13. Do people in your faith group/community talk to one another about HIV/AIDS? Give reasons why. Do you talk to anyone in your faith group/community about HIV/AIDS. Give reasons why.

14. Do you think that your religion's teachings and beliefs influence whether or not people in your faith group/community talk to one another about HIV?

Please give reasons for your answer.

15. Have the beliefs and teachings influenced whether or not you talk about HIV to someone in your faith group/community? Give reasons.

16. Do you think that your religion's teachings and beliefs influence whether or not people in your faith group/community talk to their religious leader(s) about HIV?

Please give reasons for your answer.

17. Have your religion's beliefs and teachings influenced whether or not you talk to the religious leader(s) in your faith group/community?

18. Do you think that your religion's teachings and beliefs influence whether or not people in your faith group/community talk to health professionals, school/college teachers about information on

- a) HIV/AIDS?
- (b) testing for HIV?

Please give reasons for your answer.

19. Did your religion's beliefs and teachings influence whether or not you talked with health professionals, school or college teachers about information on

- (a) HIV/AIDS?
- (b) testing for HIV?

Please give reasons for your answer.

20. Have you disclosed your HIV status to anyone in your faith group/community? If 'No' please give reasons. If 'Yes' please say to whom and why and describe his/her response.

21. Do you know another person with HIV? Or of another person?

22 Do you know anyone else with HIV in your faith group/community? Or of anyone?

23. What do you receive from your faith group/community? Do you think that would be the same whether or not you have HIV, or whether or not you are known to have HIV?

24. Please describe any experience you have of how your faith group/community responds in practise to people affected by HIV. Is this how you think your faith group/community should respond? If not, how should it respond?

25. Describe the kind of HIV information, support and care you are receiving from

- (a) your faith group/community
- (b) Leicester agencies providing HIV information, support and care
- (c) other

Can you suggest ways you think HIV information, support and care services could be improved?

26. Suggest two messages each for (a) and (b) which could help ensure support and care for people affected by HIV

- (a) in your faith community
- (b) in Leicester

27. What should be the two most important messages to prevent transmission of HIV

- (a) in your faith community?
- (b) in Leicester?

28. What are your views on sexual health and relationships education in schools?

29. Do you think it matters what faith groups and faith leaders believe and say about HIV/AIDS? Please give reasons for your answer.

30. Are there any other comments you would like to make about HIV/AIDS and religion which we have not covered during the interview?

Biographical outline

Gender

Age (over 18 years),

Religion (plus denomination/group)

Ethnic background

Country of birth

Educaton/qualifications

Thank participant for taking part in this research study.

APPENDIX B4

Address for correspondence:

Reverend Canon Margaret Morris

Home address

XXXX

XXXX

XXXX

XXXX

An invitation to take part in a research study

Study Title: Competing realities, diverse needs: a multi-disciplinary approach to religious contexts of HIV prevention and care in Leicester

Religious contexts of HIV prevention and care in Leicester

As part of a research study at the University of Derby and with the help of Leicester Royal Infirmary's Department of Genito Urinary Medicine, I am looking at some of the religious contexts of HIV prevention and care services in Leicester. The available resources do not permit a study involving all faith groups so the research will concentrate on the three largest of Leicester's faith communities, Christian, Hindu and Muslim.

A major part of the research programme involves finding out from people living with HIV/AIDS how their religious beliefs or the beliefs of others have affected their responses to and experience of HIV/AIDS. I am writing to ask whether you would be willing to take part in this research which is intended to help us understand better any contributions to HIV prevention and supportive care which faith groups and communities can make. At no time will any information be presented or published which will identify you.

If you come from a Hindu, Muslim or Christian community or background, are over 18 years of age and live in Leicester I would like to meet with you to talk in confidence about your religious beliefs and your experience of HIV. A meeting can be arranged at a time and a place convenient to you. There will be some questions which I shall use to guide the tape recorded interview. The audio tape, along with any paper records of our meeting, will be kept in a secure place. When the study is completed the tape will be destroyed. No personal details which may identify you will be presented or published. Before the interview begins I shall explain again the purpose of the research and ask

you to sign a consent form. The interview will last no more than an hour and you can withdraw from taking part at any time should you wish to do so.

I encourage you to talk over this invitation to take part in the research, if at all possible, with an advisor, a friend or family member. Please contact me direct by telephone (01509 412092, the number on the information sheet) if you would like more information or would like to arrange an interview. I enclose also a reply slip and a stamped and addressed envelope if you prefer to let me know by post that you wish to take part. Alternatively you can hand the envelope to a member of staff when you next come to GUM. If there is no convenient way to contact you by telephone and you would prefer not to receive letters about this, I can meet with you at GUM to discuss arrangements if you let staff know.

I enclose

- an information sheet with details of the research and information about myself
- a reply slip if you wish to contact me by post
- a stamped and addressed envelope for your reply
- a leaflet explaining the NHS Complaints Procedure

In due course a summary of the research findings will be made available to participants.

If you require further information please do not hesitate to contact me. I look forward to hearing from you.

Reverend Canon Margaret Morris

Study Title: Competing realities, diverse needs: a multi-disciplinary approach to religious contexts of HIV prevention and care in Leicester

REPLY SLIP

Give only as much information as you wish eg telephone number only if you prefer not to give name and address.

Name

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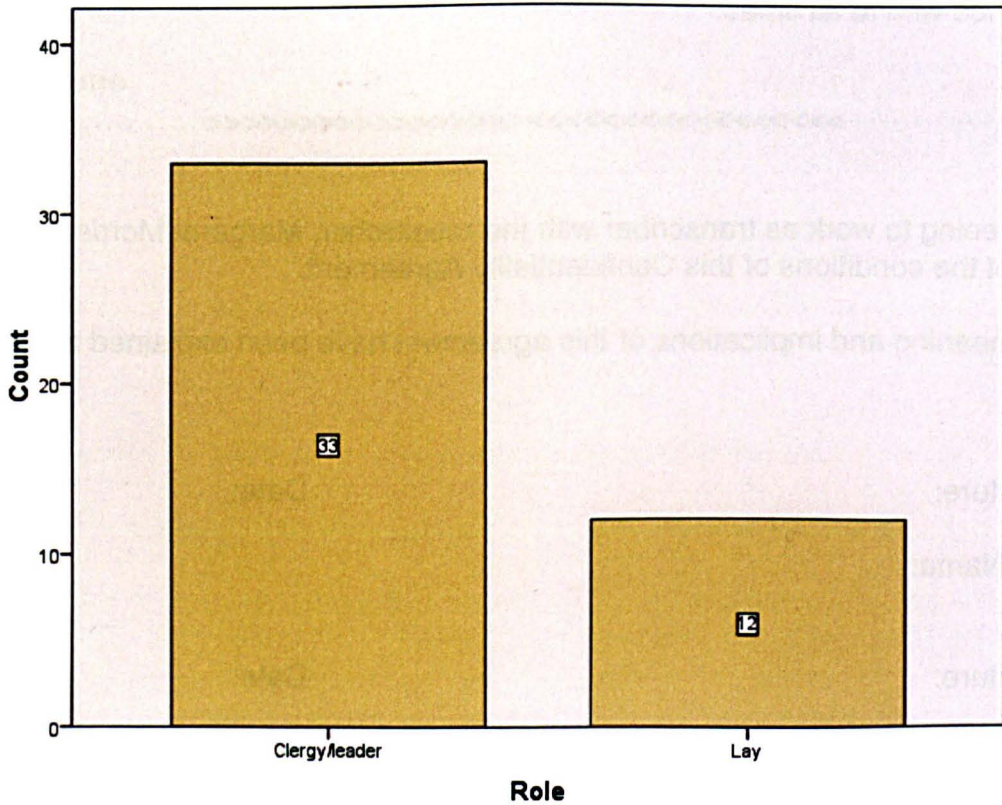
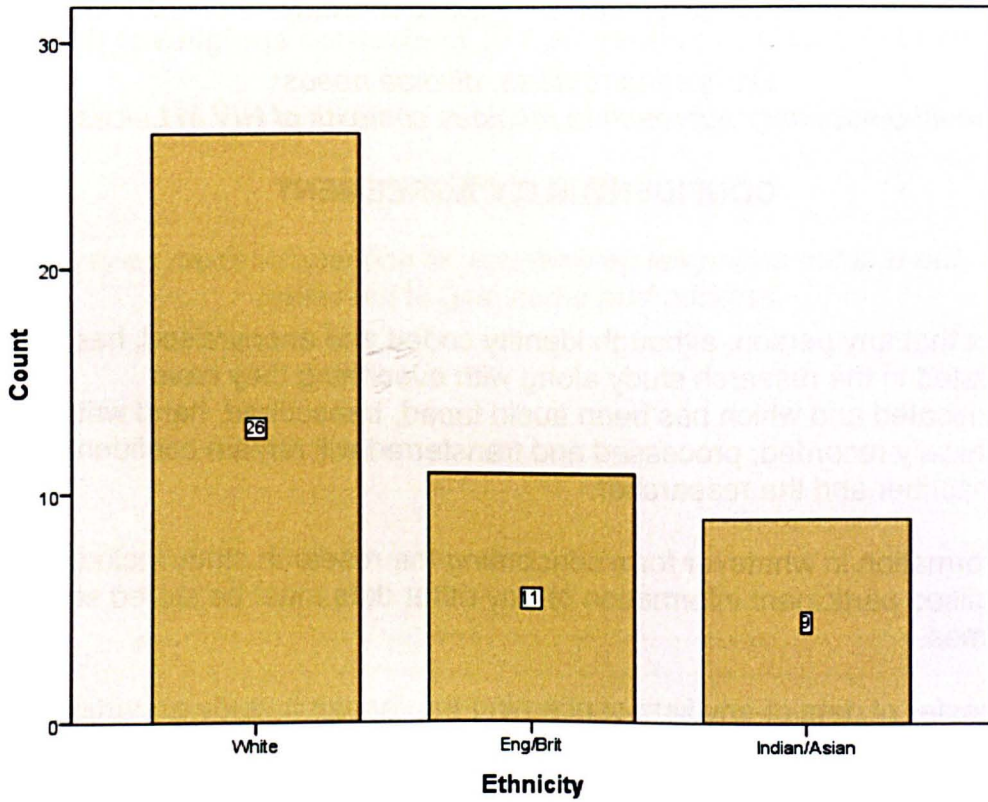
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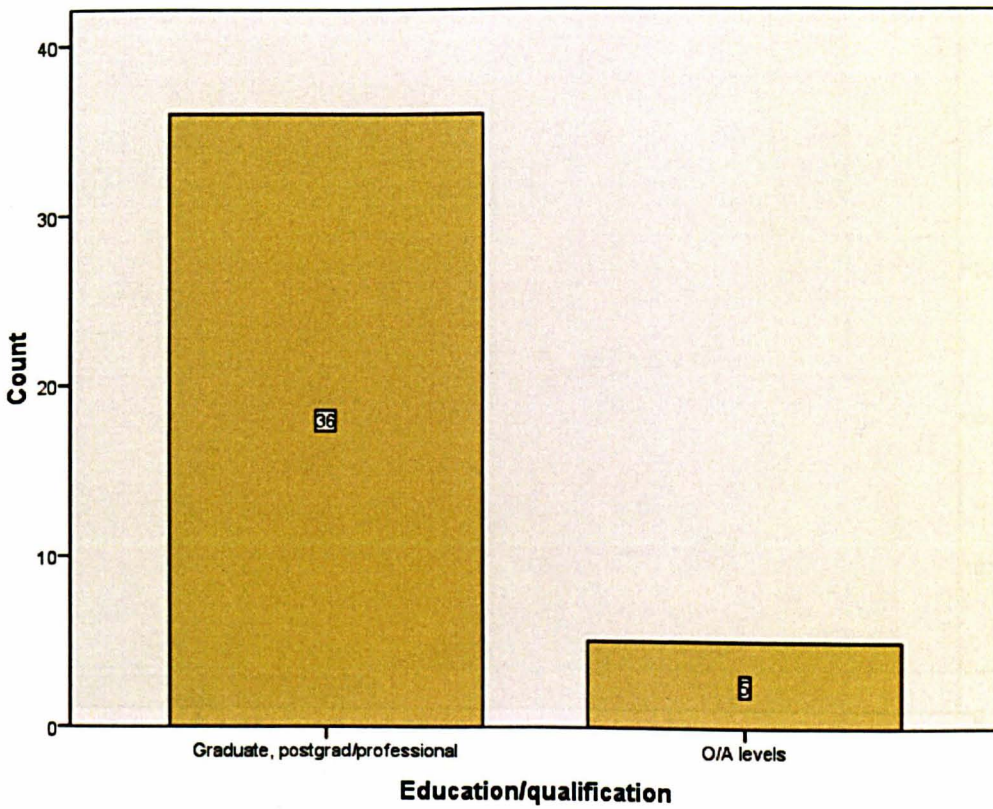
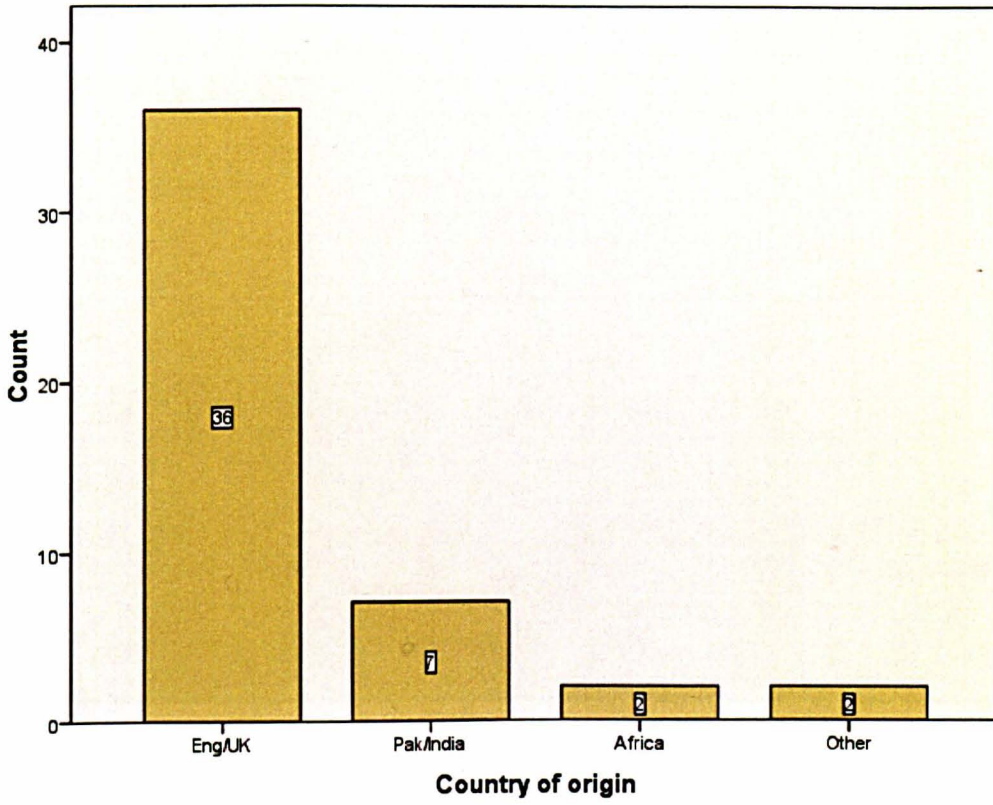
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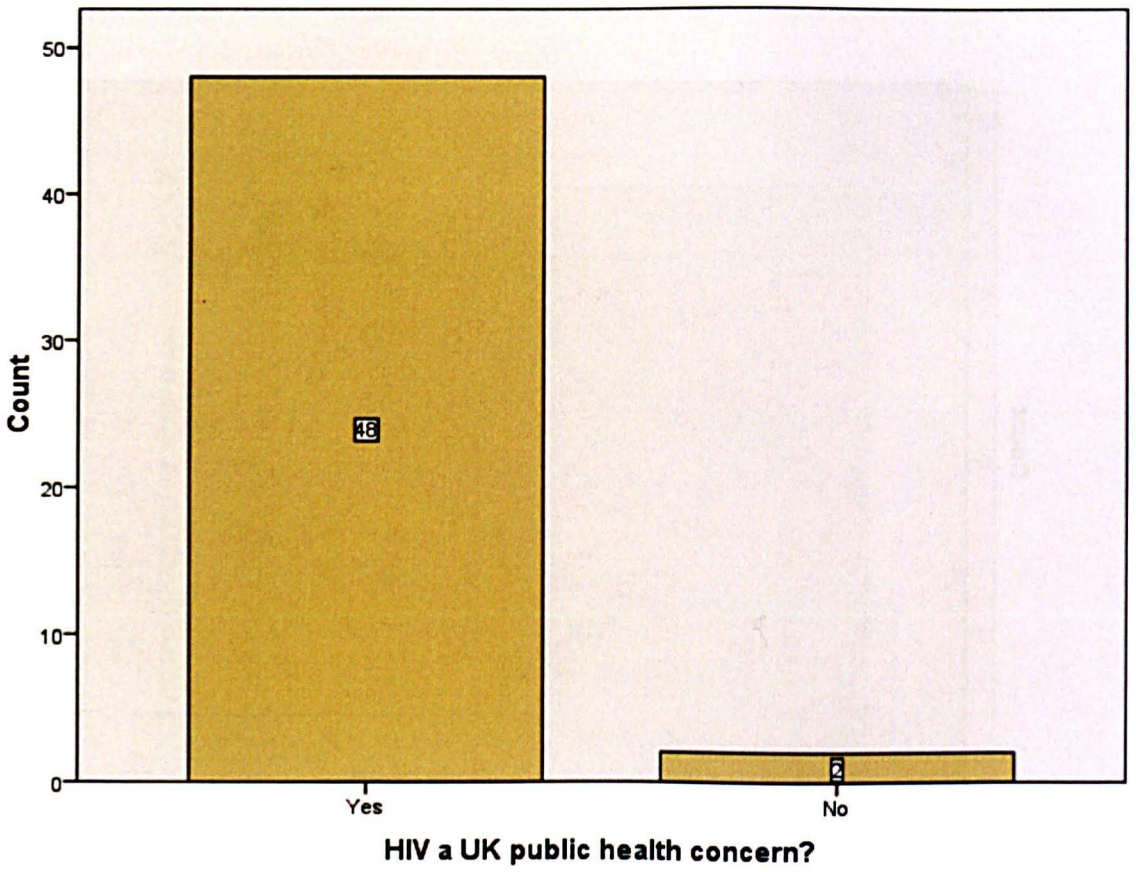
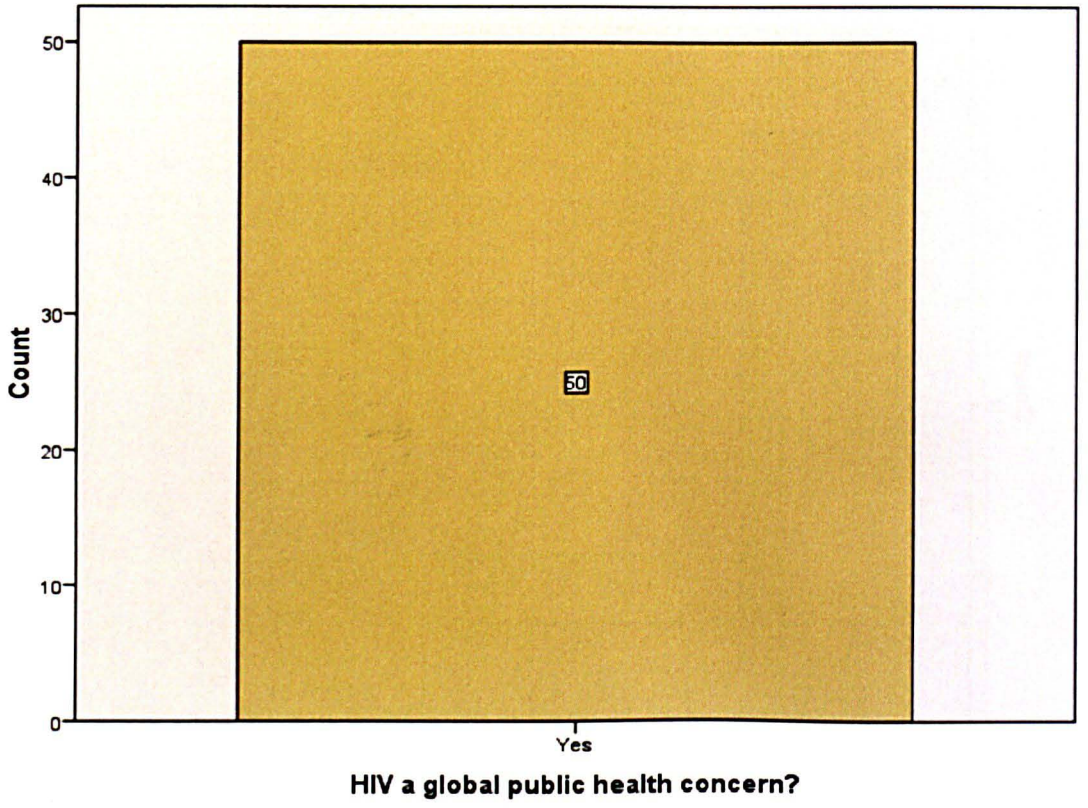
APPENDIX D1a

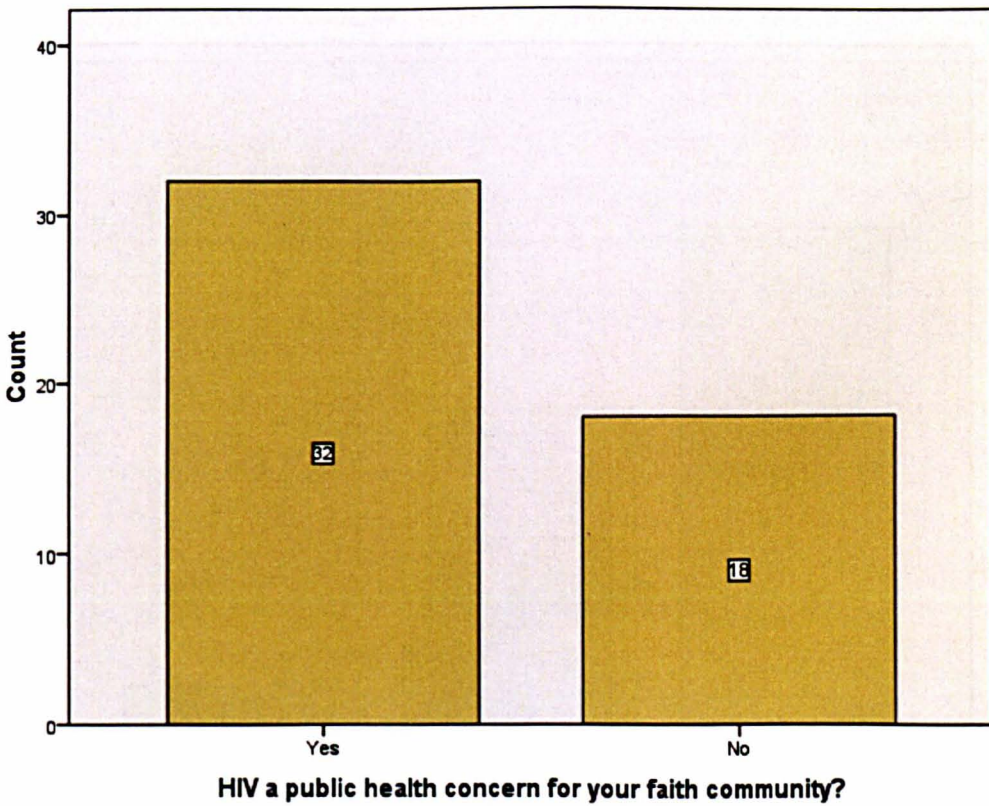
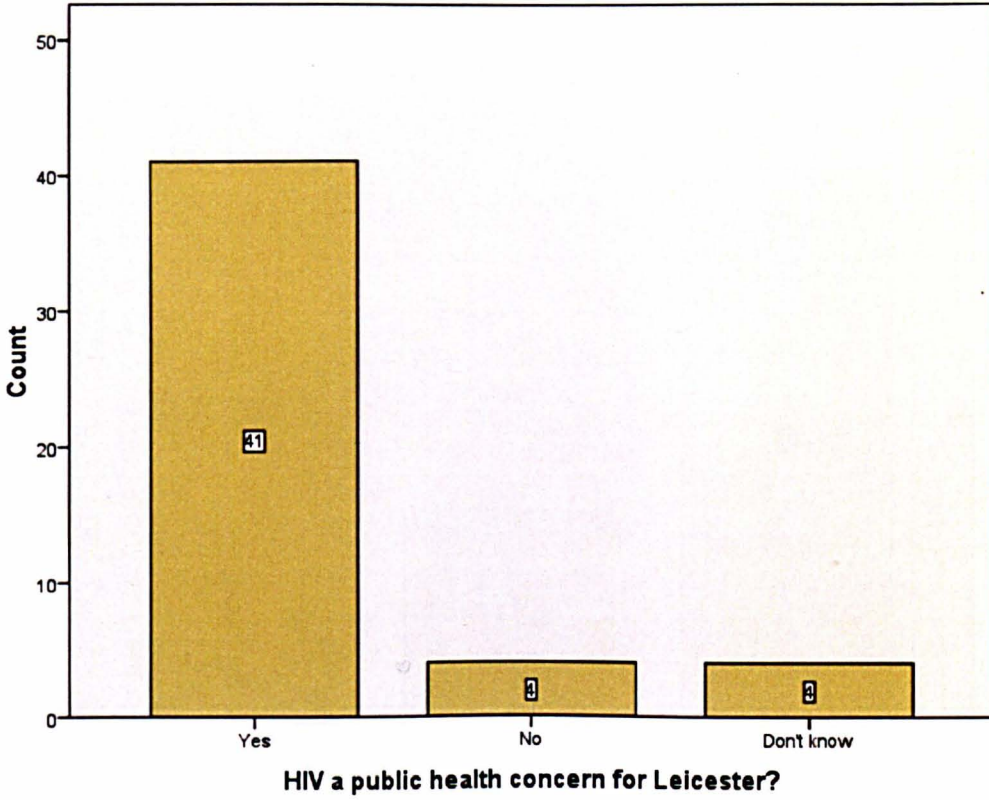
QUESTIONNAIRE RESPONSES

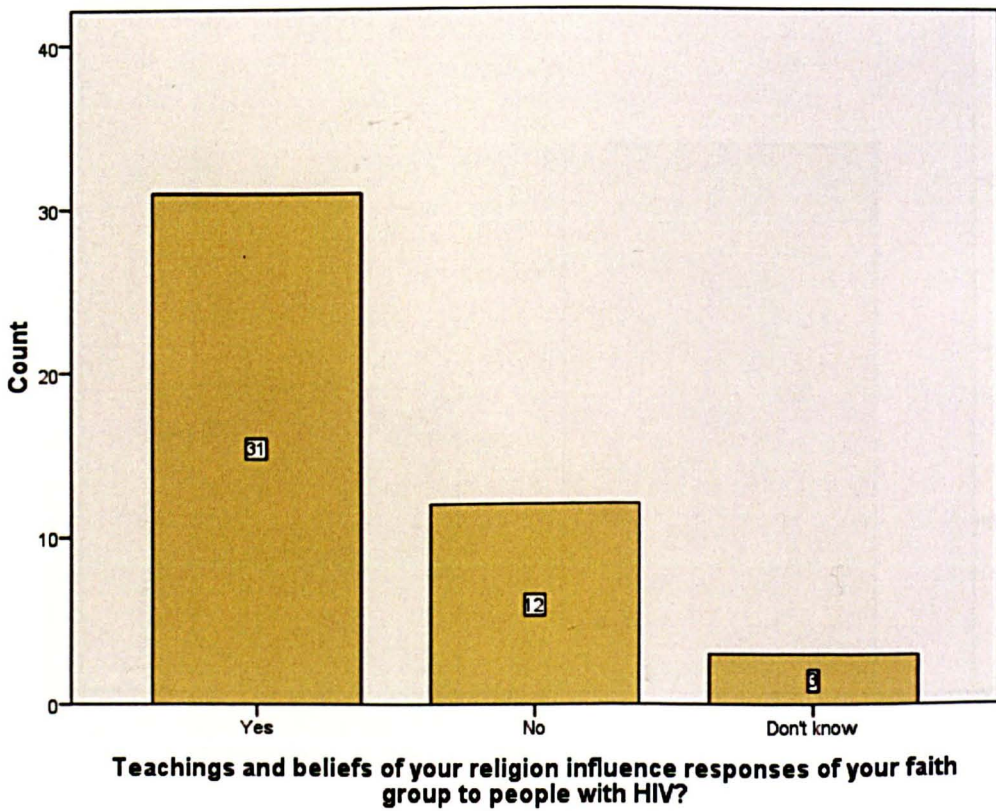
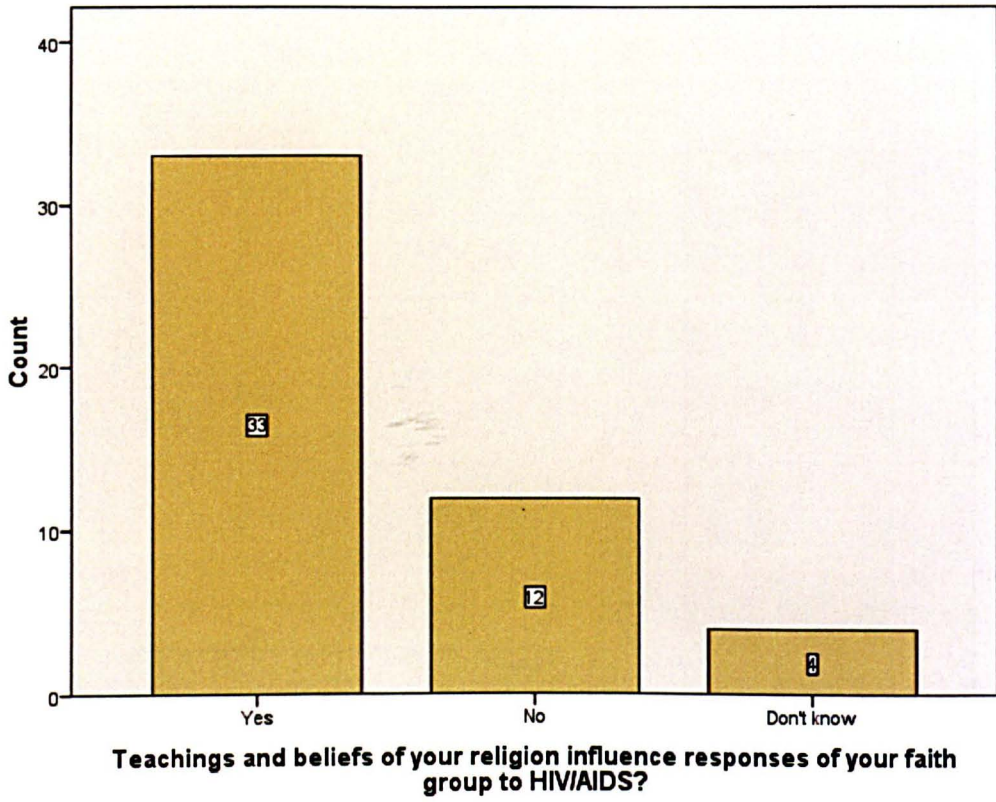
Closed questions: Bar Charts

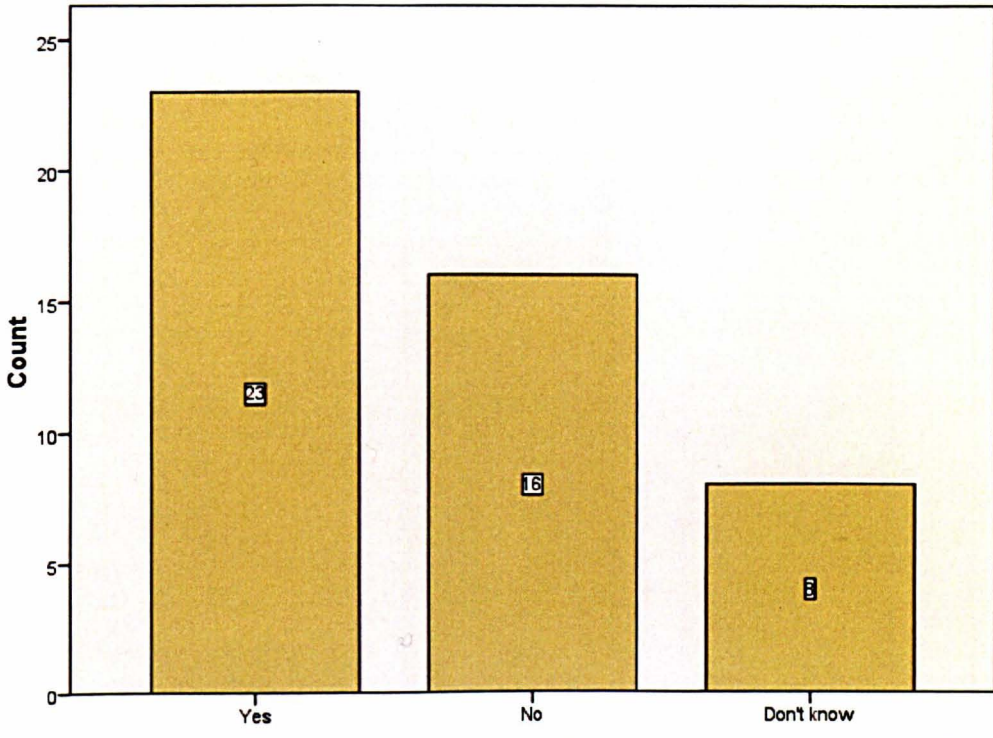




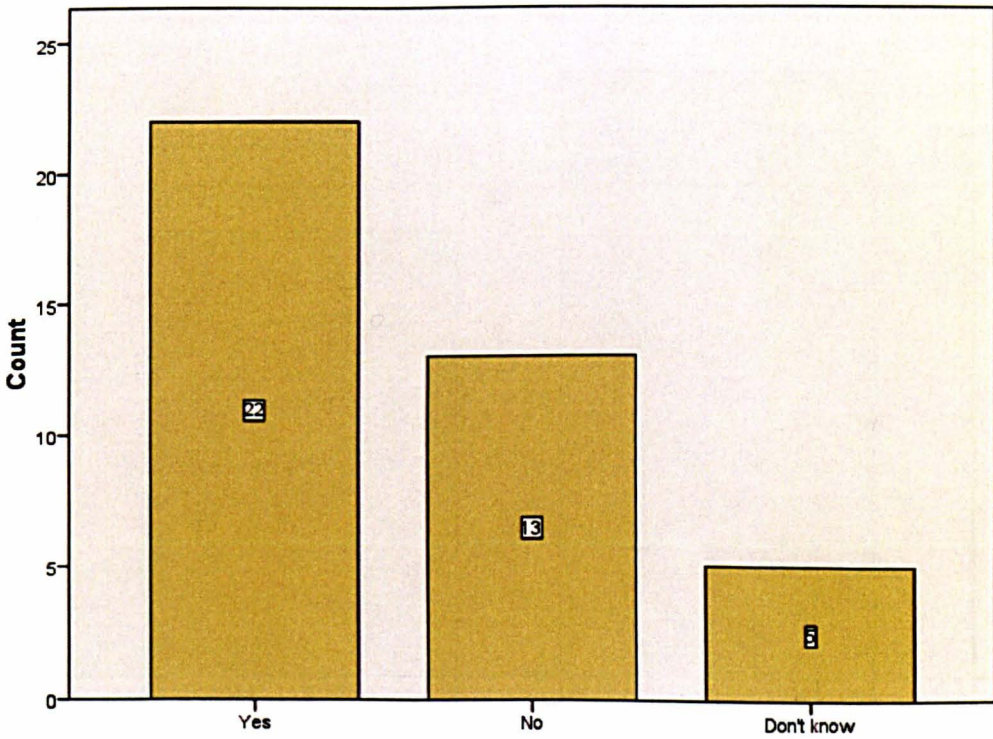




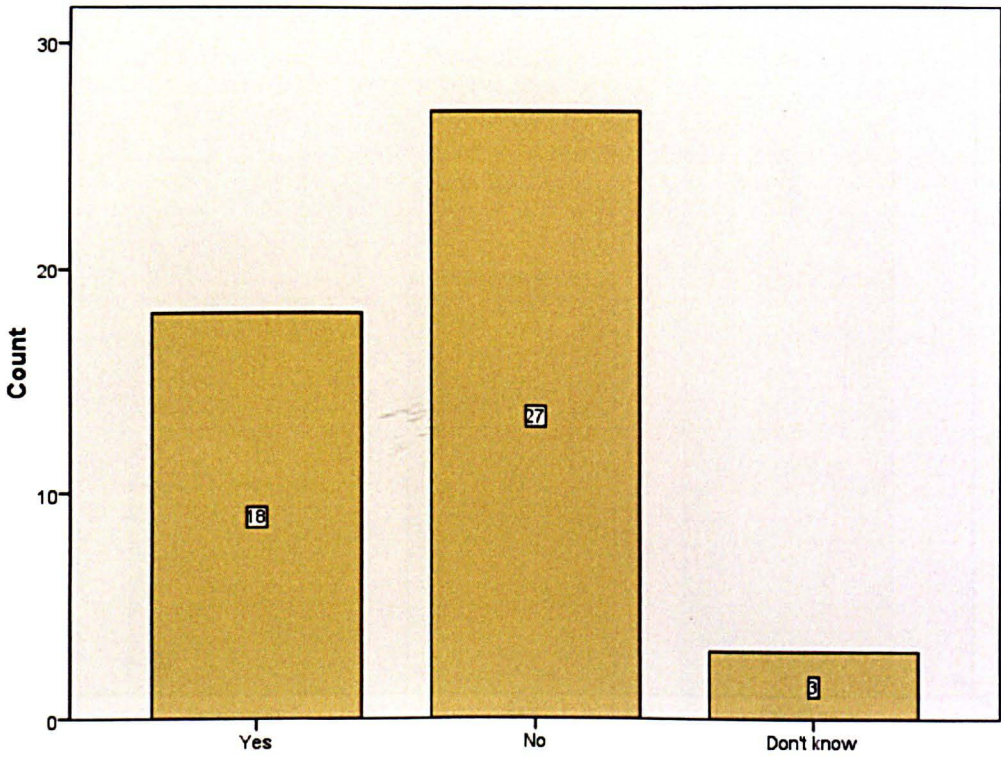




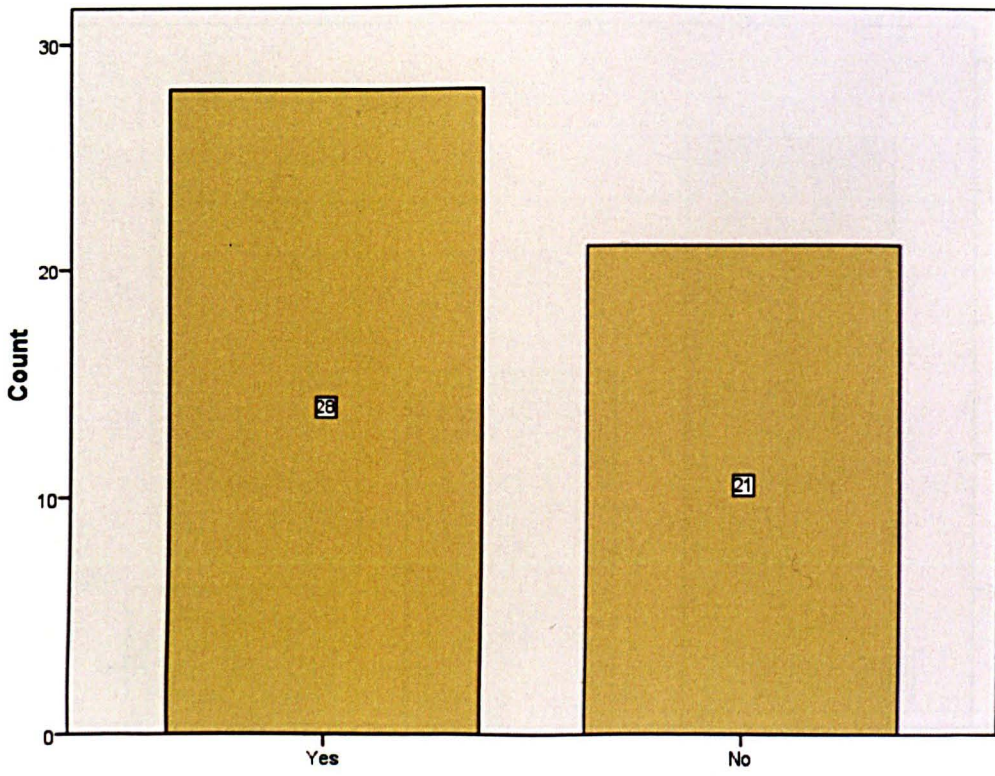
Teachings and beliefs of your religion influence responses of those outside your religion to HIV/AIDS?



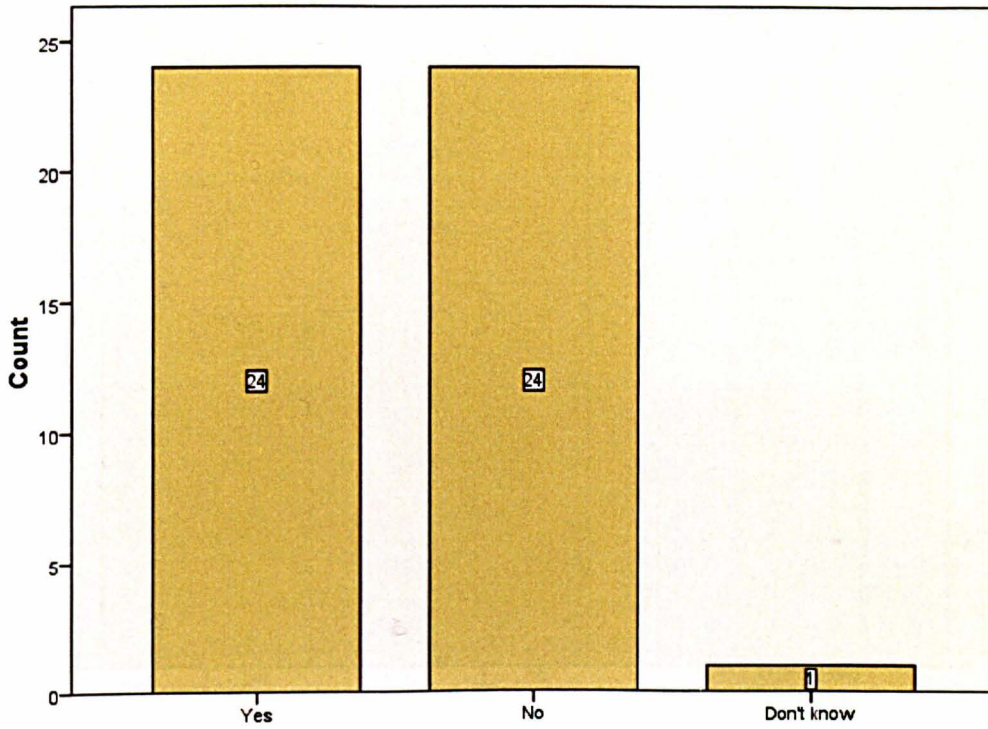
Teachings and beliefs of your religion influence responses of those outside your religion to people with HIV?



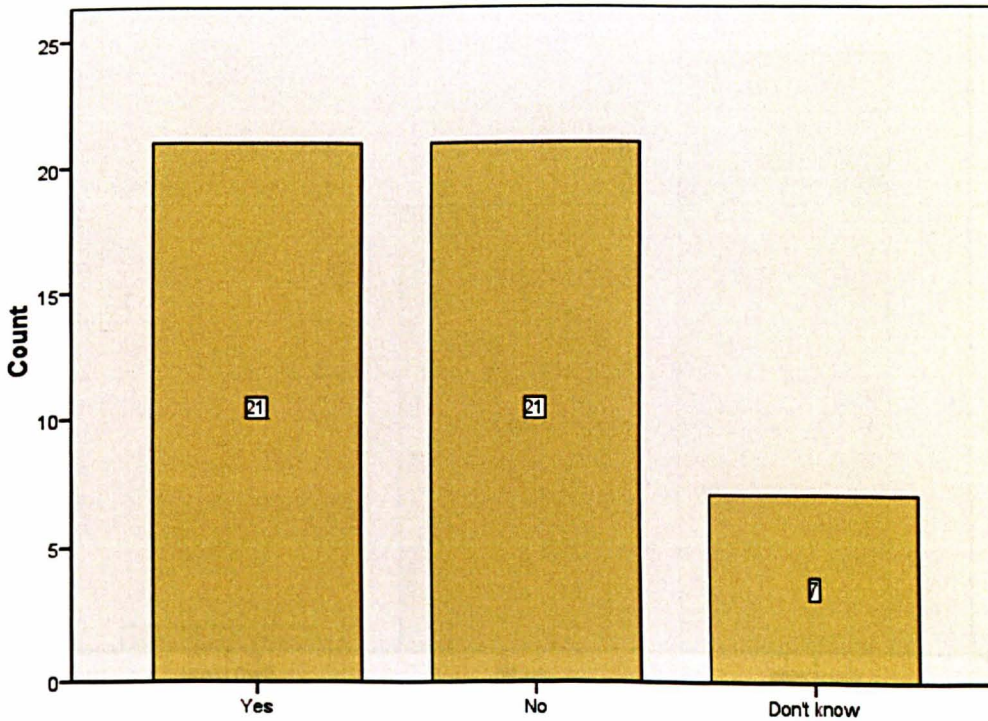
Do people in your faith group talk to one another about HIV/AIDS?



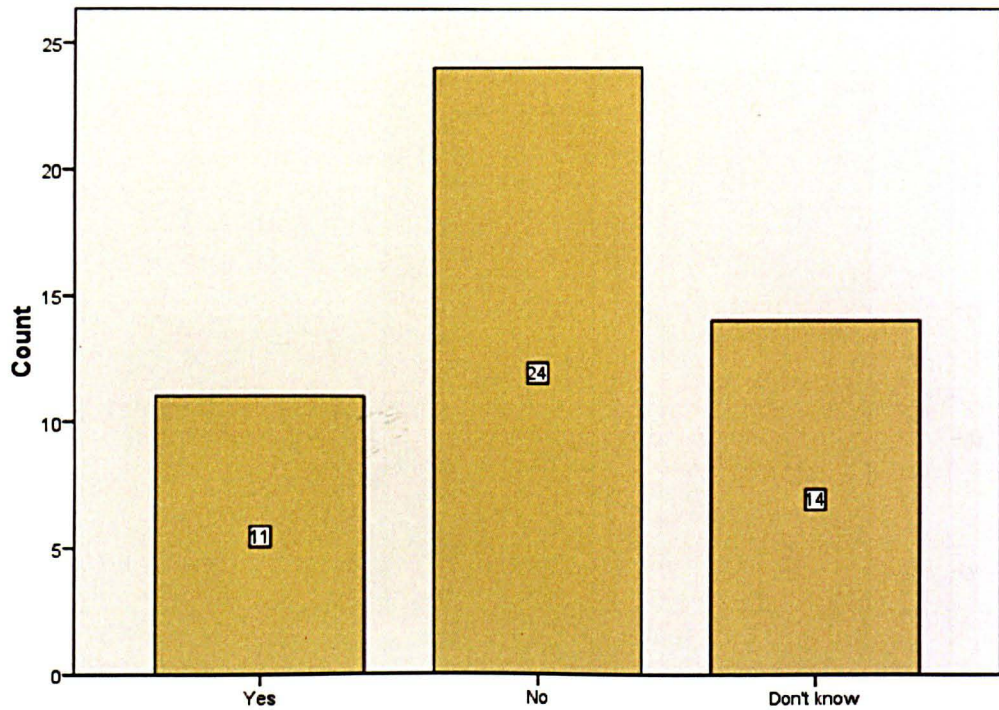
Do you talk to anyone in your group/community about HIV/AIDS?



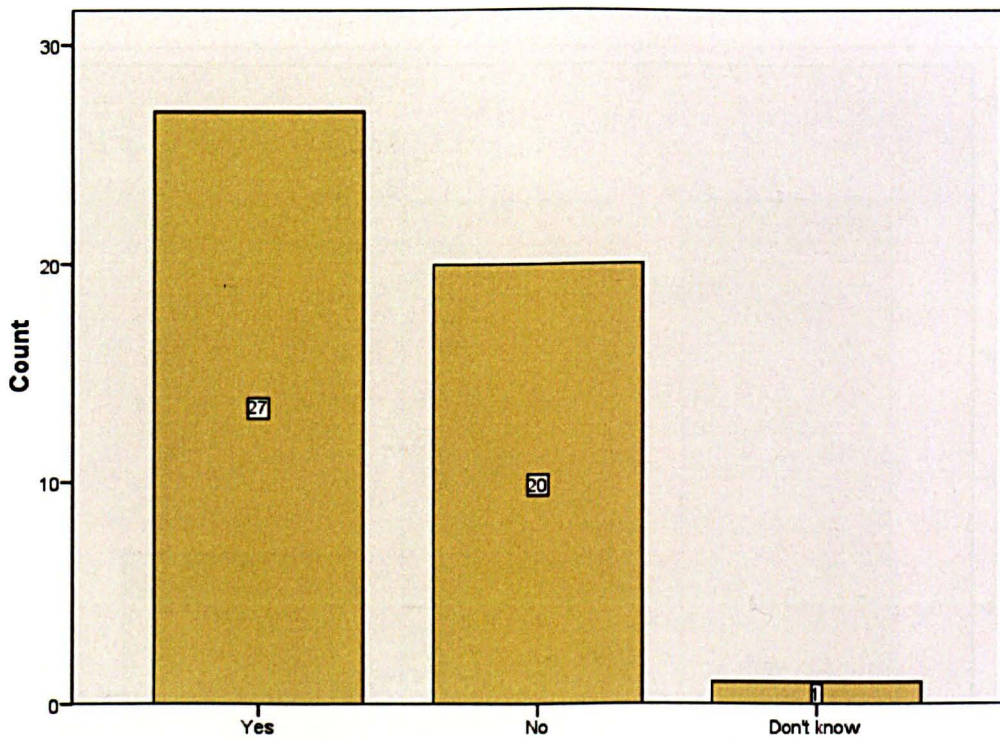
Do your religion's teachings and beliefs influence whether or not people in your faith group talk to one another about HIV/AIDS?



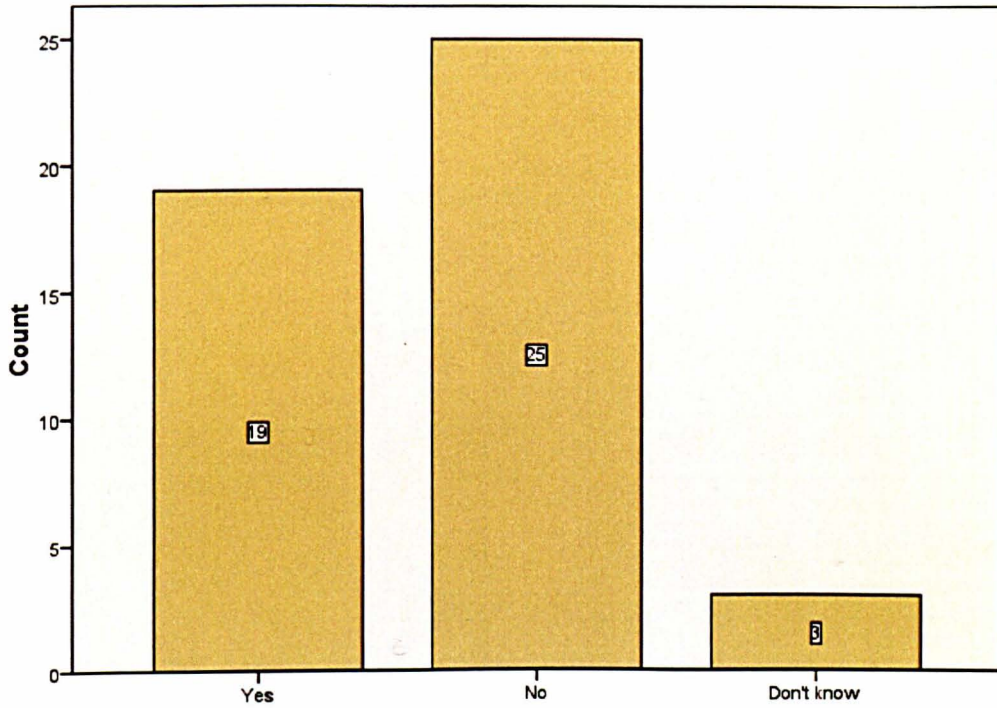
Do your religion's teachings and beliefs influence whether or not people in your faith group talk with health professionals/teachers about information on HIV/AIDS?



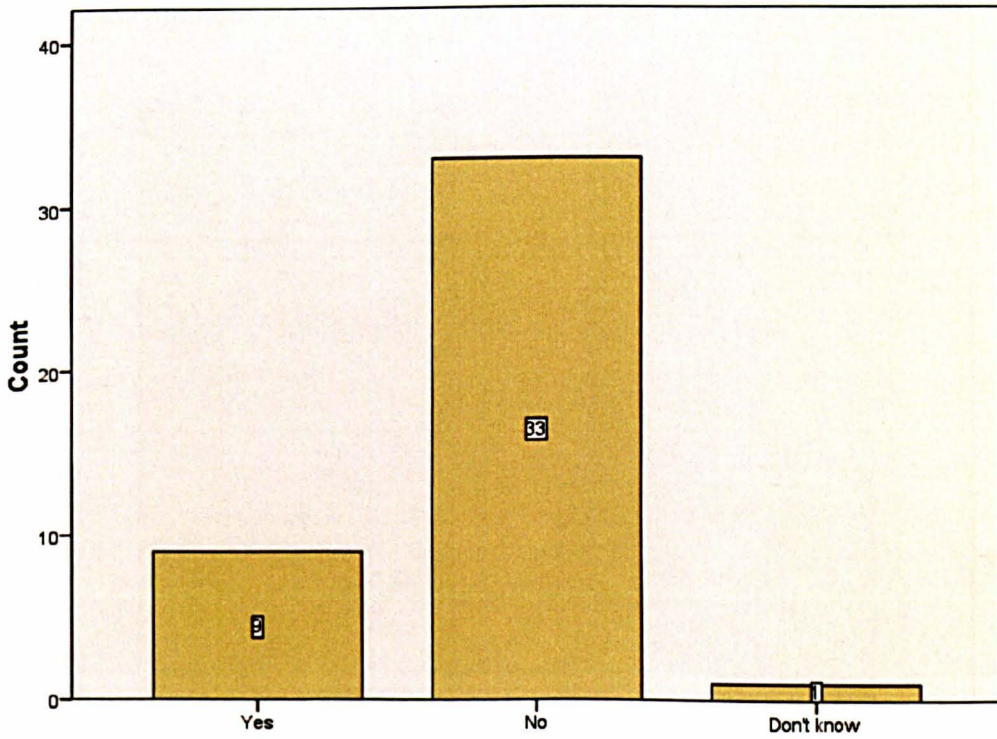
Do your religion's teachings and beliefs influence whether or not people in your faith group talk with health professionals/teachers about testing for HIV?



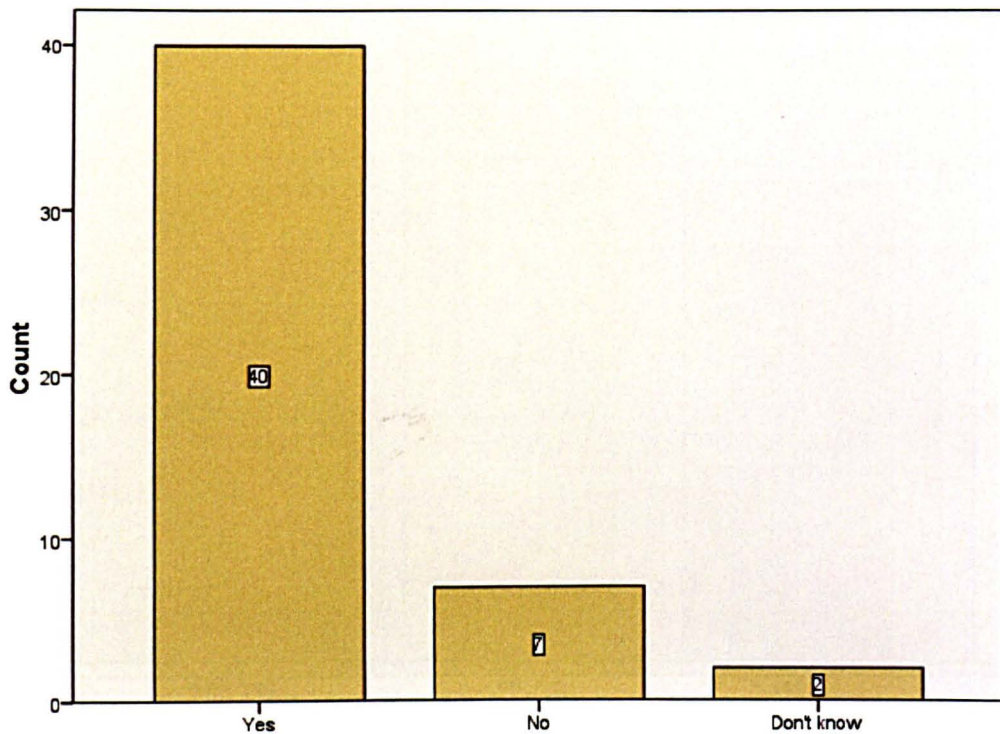
Have your religion's teachings and beliefs influenced whether or not you have talked with anyone in your faith group about HIV/AIDS?



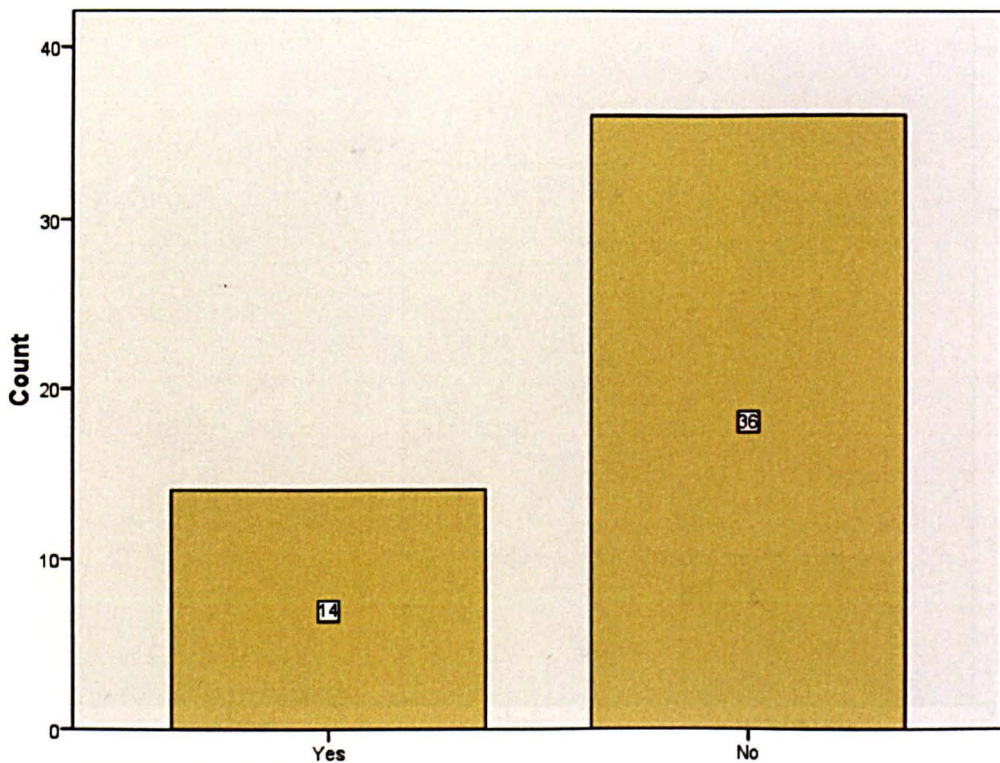
Have your religion's teachings and beliefs influenced whether or not you have talked with health professionals/teachers about information on HIV/AIDS?



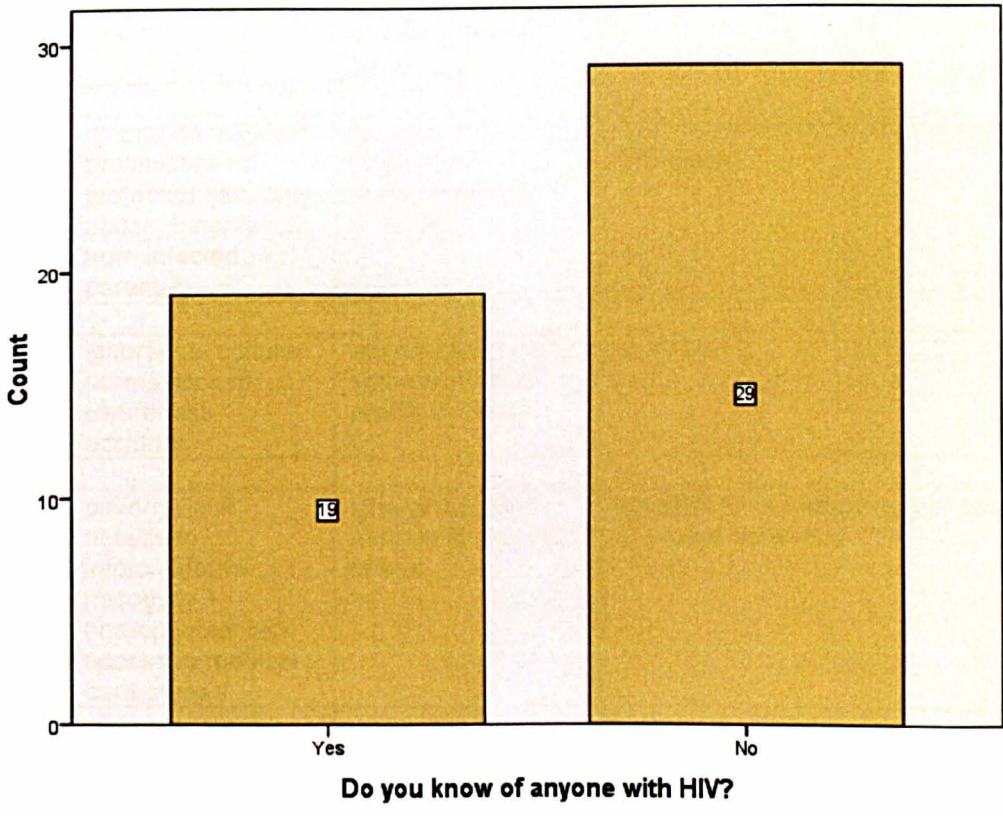
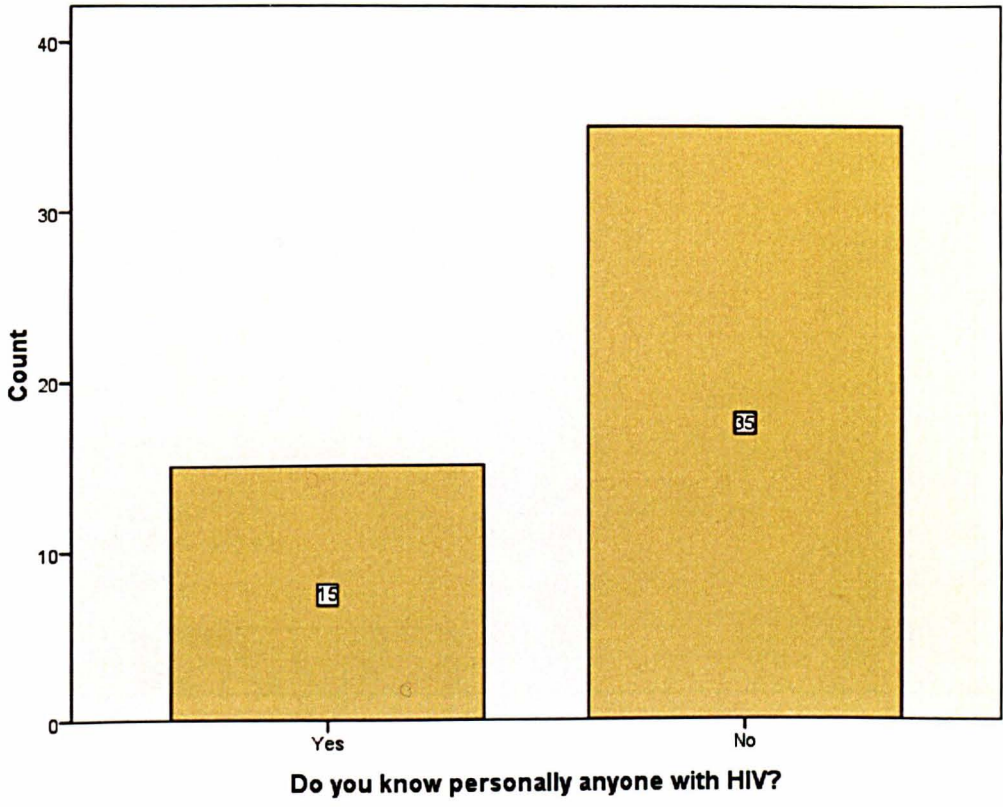
Have your religion's teachings and beliefs influenced whether or not you have talked with health professionals/teachers about testing for HIV?

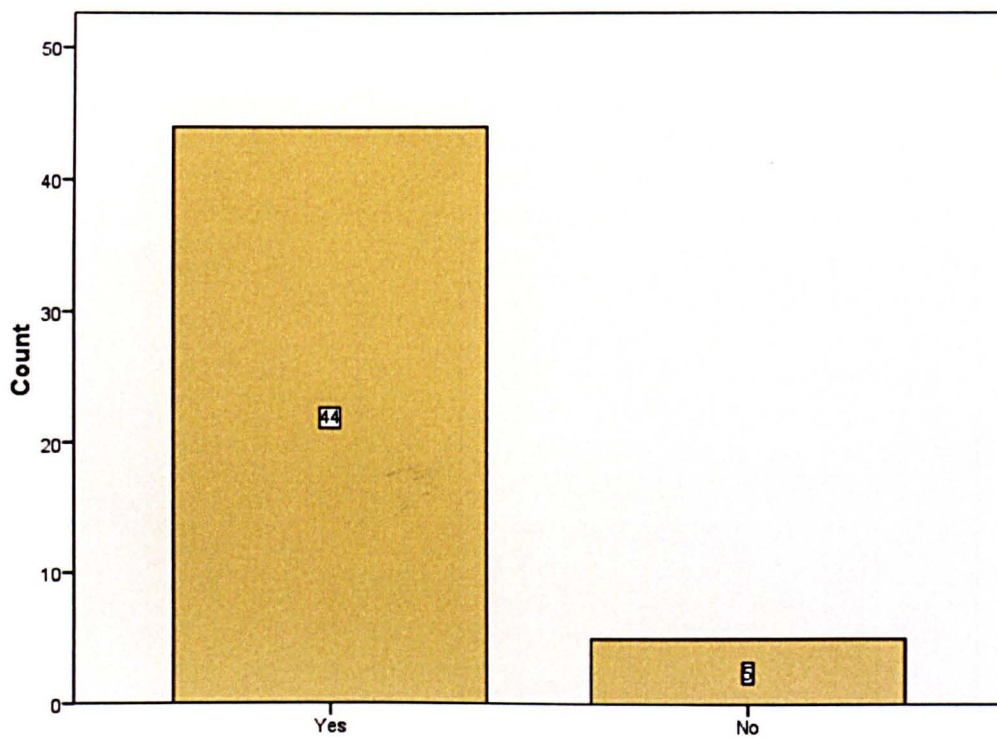


Would anyone in your faith group affected by HIV feel able to talk to someone in the faith group about their concerns?



Has anyone in your group/community approached you to talk about HIV?





Do you think it matters what faith groups and faith leaders believe and say about HIV/AIDS?

APPENDIX D1b

QUESTIONNAIRE RESPONSES

Open Questions: Question 1

| QUESTIONNAIRE RESPONSES | | | |
|--|---|--|--|
| 1 Main factors contributing to HIV transmission? | | | |
| Name | 1a World | 1b UK | 1c Leicester |
| QC01 | Birth to HIV+ parent husband to wife men forced to live separately from wives for long periods, in drug culture | birth drugs gay community | really don't know, only lived here for 6 mths but assume birth, drugs, gay community |
| QC02 | multiple partners lack of protection in sex | multiple partners needle sharing for drug users | not sure as UK? |
| QC03 | blood, sexual contact birth | blood, sexual contact birth | blood, sexual contact birth |
| QC04 | unprotected sex | unprotected sex, sharing needles | as b |
| QC05 | poverty, poor sex ed ignorance of hith issues | att to sex, multiple partners, ignoring safe sex practices, unaware already have HIV | most of a, b, also blood products from past |
| QC06 | ignorance religious prohibitions of protected sex, drug abuse, inheritance from infected parent(s) | ignorance & neglect of unprotected sex drug, abuse. | don't know but think it could repeat UK scene |
| QC07 | ignorance, cultural norms, lack of awareness accident, | sexual promiscuity ignorance lower profile in media | as in UK |
| QC08 | poverty: lack access to info/condoms misogyny + homophobia: lack access to medical care, drugs | ignorance; can't happen to me; fear of sex | conspiracy of silence re real patterns of sexual behaviour |
| QC09 | promiscuity | careless use of drugs | don't know, probably as UK |
| QC10 | ignorance, contraception issues, RC | ignorance, arrogance casual attitude, drug issues, prostitution | As in UK |

| | | | |
|------|---|---|--|
| | teaching prostitution, | sharing hyperdermic needles | |
| QC11 | sexual promiscuity: inheritance; blood transfusions | same as (a) though possibly in different order | the same... |
| QC12 | poor education/ awareness | complacency | avoidance of issue/ complacency |
| QC13 | ignorance, fear, poverty | ignorance to a degree, apathy | As c (before) |
| QC14 | lack of sex ed, lack of preventive measures & resistance by men to use them | change in moral attitudes-sexual promiscuity between both male & female relationships drug use now common place | short term sexual relationships without prevention methods Drug use common place lack of money for new needles. General lack of self respect thro' lack of guidance at young age |
| QC15 | lack of understanding & education, poverty | lack of knowledge of partner | as for UK |
| QC16 | low moral standards - lack of care for the other', poor direction from 'the church' | as (a) | as (a) |
| QC17 | unprotected sex, from mother to child, infected blood products & needles | unprotected sex, infected needles | unprotected sex |
| QC18 | conduct contrary to biblical teaching on hygiene & sex | conduct contrary to biblical teaching on hygiene & Sex | conduct contrary to biblical teaching on hygiene & sex |
| QC19 | | see Jeremiah 8.9 our national condition is much the same as in Jeremiah's day <i>Researcher - Your wise men are put to shame they are confused & trapped They have rejected my words what wisdom have they got now?</i> | |

| | | | |
|------|--|--|--|
| QC20 | unprotected sometimes promiscuous sex, contaminated blood transfusions. | unprotected sometimes promiscuous sex, contaminated blood transfusions | unprotected sex |
| QC21 | sexual intercourse without condoms | as above | as above |
| QC22 | Poverty, causing instability in family relationships as people move to seek work | lifestyle choices (relationships/ drugs) linked with lack of other opportunities | as above |
| QC23 | Often includes poor medical practises & sexual abuse | drug abuse & sexual permissiveness, mainly | As in UK plus asylum seekers from around the world |
| QC24 | Promiscuous sex, children born with it. | Multiple partners & children born with it. | Children born with it |
| QC25 | sexual promiscuity, drugs | sexual promiscuity drugs, | sexual promiscuity drugs, |
| QC26 | Unprotected sex, intravenous drug abuse, contaminated blood products | unprotected sex, iv drug abuse | unprotected sex, iv drug abuse |
| QC27 | Extra-marital unprotected sex | ditto | ditto |
| QC28 | Lack of education; lack of money for adequate health care; not using condoms | lack of education; apathy - I'm all right Jack it will never happen to me. Not using condoms | as above |
| QC29 | sexual promiscuity by men with men/women | ditto | ditto |
| QC30 | Polarisation of rich & poor | Blood products & unprotected sex | As in (b) plus immigration from Africa |
| QC31 | Poverty | lack of education/ Promiscuity | Poverty & Multi-cultural issues |
| QC32 | Sexual promiscuity (unprotected); ignorance; bad advice | promiscuity; 'it won't happen to me'; sharing drug paraphernalia | no Leicester-specific information |
| QC33 | Entrenched cultural values & practices | Unprotected sexual activity - | As above |

| | | | |
|------|---|--|--|
| | 'unprotected sexual activity | homosexual & heterosexual | |
| QC34 | Ignorance, poverty, denial, religion | Irresponsibility, ignorance, religion, | a/a drug abuse |
| QC35 | open sexual activity | open sexual activity | open sexual activity |
| QC36 | heterosexual sex, mother to child transmission | heterosexual sexual intercourse homosexual intercourse | as above, occasional blood borne |
| QC37 | poverty | lack of sexual education and understanding | |
| QC38 | Ignorance of contraception + lack of contraception | Complacency, casual encounters | as above in UK |
| QC39 | Ignorance, cultural blocking of problem, sexual licence | Sexual promiscuity, blood transfusion | Sexual promiscuity |
| QH01 | no idea | no idea | no idea |
| QH02 | Sex | Sex, sexual freedom | Sex- sexual permissiveness, live for today |
| QH03 | Awareness of HIV is not made enough | people are not using protection when travelling | No awareness |
| QM01 | Lack of sex education | Sex outside marriage more, sexually active | as above (B) |
| QM02 | Lack of morals - lack of religious teaching | ?permissive attitude, media & films - false sense of liberty | As above |
| QM03 | Freedom and carelessness | ditto | ditto |
| QM04 | Too much freedom and irresponsible attitude | do | do |
| QM05 | Illegitimate sex & unnatural sex | as A | As A |

| | | | |
|------|---|-----------------------|-----------------------|
| QM06 | Use of unsterilised needles, unprotected sex, blood transfusion | As above | As above |
| QM07 | unprotected intercourse by infected individuals | risky sexual activity | risky sexual activity |
| QM08 | unprotected sex | unprotected sex | unprotected sex |

QUESTIONNAIRE RESPONSES

2a HIV a cause for concern as a public health issue around the world?

| | | |
|------|------------------|--|
| QC01 | Yes | taking out so many young adults in Africa |
| QC02 | Yes | greatest present global public health issue surely |
| QC03 | Yes | spreading fast in some countries |
| QC04 | Yes | decimating societies & families hardship |
| QC05 | Yes | w/w travel risks re casual sex women & war/rape cultural practices |
| QC06 | Yes | if ceased to be ph issue less urgency & less public funds |
| QC07 | Yes very much so | pandemic in Africa |
| QC08 | Yes | nos speak for themselves esp in Africa |
| QC09 | Yes | results in more orphans in poor countries |
| QC10 | Yes | Pandemic & claims untold nos |
| QC11 | Yes | widespread& indiscriminate sexual activity |
| QC12 | Yes | because of devastation of working pop+ families |
| QC13 | Yes | |
| QC14 | Yes | African countries seeing huge increases in HIV - orphans, lack of every basic necessity - water, medical, contraception, drugs |
| QC15 | Yes | huge no. of deaths & amount of suffering |
| QC16 | Yes | diverts resources for other illnesses |
| QC17 | Yes | epidemic proportions in some African countries, lack of effective drug s, many infected, children etc |
| QC18 | Yes | like all diseases it restricts & stops people reaching their full potential |
| QC19 | Yes | by media |
| QC20 | Yes | large number of orphaned children |
| QC21 | Yes | Males in particular need to understand that |

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|------|-----|--|
| | | permissive sexual activity spreads HIV/AIDS |
| QC22 | Yes | seriously affects population of many countries |
| QC23 | Yes | a major issue |
| QC24 | Yes | Families left with no parents, child deaths |
| QC25 | Yes | It destroys lives and relationships. It is becoming endemic It orphans and infects children. |
| QC26 | Yes | Big problem in sub saharan Africa |
| QC27 | Yes | Thousands of children being born with HIV/ AIDS eg in Africa where it is believed to have reach ed 'epidemic proportions |
| QC28 | Yes | because it is spreading - particularly in areas of Africa |
| QC29 | Yes | Affects employment, health, education, population growth |
| QC30 | Yes | Becoming pandemic in some parts |
| QC31 | Yes | It affects every aspect of human growth cultural economic social moral |
| QC32 | Yes | Terrible scourge in Africa & elsewhere in developing world. |
| QC33 | Yes | Africa appears to be subject to an epidemic or worse |
| QC34 | Yes | Physical, social economic health (orphans) |
| QC35 | Yes | |
| QC36 | Yes | Mortality & morbidity in economically & socially vulnerable |
| QC37 | Yes | Whole generations being wiped out - leading to orphans and child- led families |
| QC38 | Yes | So much misery and gross unfairness to the unborn |
| QC39 | Yes | Death thro ugh HIV/ AIDS is epidemic |
| QH01 | Yes | in certain countries |
| QH02 | Yes | damaging health |
| QH03 | Yes | |
| QM01 | Yes | better religious and sexual education |
| QM02 | Yes | Humanity is suffering |
| QM03 | Yes | Because it is incurable |

| | | |
|------|-----|---|
| QM04 | Yes | Because it is a killer having no cure |
| QM05 | Yes | It is spreading uncontrollably around society |
| QM06 | Yes | |
| QM07 | Yes | major burden esp in developing world |
| QM08 | Yes | |

APPENDIX D1d
Question 4

QUESTIONNAIRE RESPONSES

| QUESTIONNAIRE RESPONSES | |
|---|---|
| 4: Brief outline of your religion's beliefs and teachings about intimate relationships | |
| Name | |
| QC01 | Official line is no sex outside hetero marriage Recognised that doesn't always happen Recognise some are born gay - current discussions about that- but official view of today. No genital contact |
| QC02 | sexual intimacy for committed marital relationships between one man & one woman. |
| QC03 | sex in heterosexual marriage is norm. |
| QC04 | sexuality best and ought to be express'd in marriage |
| QC05 | Biblical guidelines re chastity & loving rel for wider good of whole community as well as individuals |
| QC06 | Formally not outside marriage. Informally, not outside loving commitment |
| QC07 | Sex for marriage enshrined formally, many marriages conducted in Meth ch between cohabiting couples. Homosexuality celebrated but 2nd class citizens |
| QC08 | People like to think Bible v clear, but truth is it is v confused esp re sex outside marrge, re male homosexuality Shld be taught as life affirming + joyful, but not good at being honest about it. |
| QC09 | We follow the Bible precept: Marriage is honourable in all & the bed undefiled: but whoremongers & adulterers God will judge (Heb 13:4) |
| QC10 | sexual intimacy shld be exclusive to people in committed relationships that intend to be permanent |
| QC11 | Intimate rel shld be conducted in context of respect & commitment - normally this means within marriage |
| QC12 | Christianity offers marriage as the ideal, as a model of faithful permanent partnership There is historical trad valuing of celibacy as a vocation. However, Jesus meets people where they are. |
| QC13 | security of covenant relationships provides the best available on this side of heaven |
| QC14 | As 3. Sexual relatns given to enhance & cement marriage rel-atnship where union wld be a child, to allow that offspring to be secure. |
| QC15 | that they shld be loving & truthful; that promiscuity, rape, abuse, prostitution are wrong. We are officially ambivalent about gay relationships but in any case I think people now understand HIV/AIDS is not a gay issue. |

| | |
|------|--|
| QC16 | promiscuity - is forbidden, love between 2 people is acceptable |
| QC17 | fairly conservative line ie sex is for hetero sexual marriage relationships. However, social awareness - inclusive 'core value' allow for & recognise diversity & other behaviours |
| QC18 | sexual relationships according to our understanding of the bible are allowed between one man & one woman in the covenant of marriage. All other sexual activity with another living being are taboo |
| QC19 | No sex outside marriage. Marriage is for life: see Malachi 2. 14-16. researcher: You ask why he no longer accepts them. It is because he knows you have broken your promise to your wife you married when you were young.... although you promised before God that you wld be faithful to her. Have children who are truly God's people... I hate divorce' says the Lord God of Israel.. |
| QC20 | should be faithful to one person whether hetero or homosexual there are good reasons for this: emotional spiritual, practical |
| QC21 | promiscuous sexual intercourse is wrong |
| QC22 | Full sexual intimacy reserved to marriage which is by definition between a man and a woman. |
| QC23 | Among Christians should be reserved for the union of marriage. We accept unbelievers as they are, but would encourage commitment in relationships once someone has found a saving faith. |
| QC24 | One man & one woman in a marriage is best. Outside of marriage - no sex. |
| QC25 | See 3(a) |
| QC26 | sex should be within a loving stable relationship. |
| QC27 | See previous comments |
| QC28 | It depends what strand of Christianity you come from. Some would say that marriage is the only relationship a man & woman should have. But if a couple are committed to one another in a loving relationship whether heterosexual or homosexual our loving God would not condemn them. |
| QC29 | Intimate relationships belong within marriage. There is no Biblical justification for approving other sexual acts but sinners are forgiven when they repent. |
| QC30 | Sex is a gift of God and finds full expression in committed relationships. Unclear about homosexuality |
| QC31 | A biblical relationship is exclusive, faithful, loving, life giving - personally this can be seen in same sex relationships as well as marriage. |
| QC32 | Ideal is 'monogamous lifelong faithful' ie marriage. Different standards in Church of England for clergy & others. Some accept |

| | |
|------|--|
| | homosexual genital activity; others reject it. |
| QC33 | Should be in a heterosexual loving relationship between two committed people. |
| QC34 | Upholds married life and intimate relationship within married life. |
| QC35 | These should only take place in the context of a legally recognised marriage situation |
| QC36 | that human bodies are significant. That sexuality is a gift and that sexual relationships are to be regarded as precious and to be protected. That sex is not to be used wantonly or inadvisedly |
| QC37 | Intimate relationships flourish best within the structure of marriage |
| QC38 | Should be explored sexually inside a committed (i.e. married) relationship |
| QC39 | People are made in God's image and should be accorded dignity & respect. There's ambivalence about the body and therefore intimacy, which is both precious and a source of dangerous emotions |
| QH01 | our religion do not allow this |
| QH02 | See 3a |
| QH03 | No intimate's before marriage |
| QM01 | Religion does not encourage relationships outside of marriage In fact prohibited |
| QM02 | Islam has a clear boundaries & clear structure for intimate relationships. It's not only for fun & pleasure responsibilities goes hand in hand |
| QM03 | The religion says it is against the nature to have irresponsible sexual behaviour |
| QM04 | Intimate relationship is definitely prohibited and it is described as great sin. |
| QM05 | Islam forbids & makes unlawful all intimate relationships outside of marriage. Islam promotes marriage to safeguard society. |
| QM06 | Only one partner (no sexual relationship unless married to the person) |
| QM07 | inside marriage intimate relationships are permissible |
| QM08 | No sex before marriage |

APPENDIX D1e
Question 10a

QUESTIONNAIRE RESPONSES

QUESTIONNAIRE RESPONSES

10a: Religion's teachings and beliefs influence people in faith group/community talking to one another about HIV/AIDS?

| Name | 10aYes | 10aNo |
|------|--------|--|
| QC01 | | No only in sense it's not high on my agenda or the church's & therefore unlikely to be generally. |
| QC02 | Yes | gen we don't like to talk about sex, think bec so oft out of kilter with our teaching. As partly STD - seen as taboo |
| QC03 | Yes | taboo or doesn't happen here! |
| QC04 | | No largely in the dark |
| QC05 | | No sweep under carpet unless raising awareness |
| QC06 | | No people fairly open British reserve re talking of sex, nothing religious about it |
| QC07 | | No more influenced by own concerns & news Attentn to Jesus bias to outcast & AIDS orphans may bring to fore |
| QC08 | Yes | See above. Know many who think they shld be more loving, open minded etc but aren't. HIV is one of range of sexuality issues where this is general positn. |
| QC09 | Yes | gen beyond people's experience some parents talk to their children re danger |
| QC10 | | No isn't a problem' as far as most personally concerned |
| QC11 | | No Think there is widespread ignorance & therefore Christians whilst being sympathetic lack confidence |
| QC12 | Yes | observe WAD as part of our calendar of concern & |

prayer for the world

QC13 Yes

QC14 Yes

only when crops up in conversatn or a visiting speaker from 3rd world cntry

QC15 Yes

if we understand perfect love casts out all fear' then we can be brave enough to talk about any thing in a loving, safe environment There'd be no taboos

QC16

No

doesn't generally come up in conversation.

QC17 yes

some might be cautious in ex pressing what might be seen as a 'liberal' or non- moral response

QC18

no

HIV/AIDS is just one of many illnesses & we tend not to pick on individual groups to target -'all have sinned Christ died for all'

QC19

Our teaching as in Q3 and Q4 above covers this researcher ie incl refs Isa 53.6, 1 Tim 1.15, Malachi 2,14-16.

QC20 Yes

We rarely talk about sex at all- homosexuality esp ecially is a very contr- oversial issue with regard to Anglican Communion at the moment and we don't like to have arguments!

QC21 Yes

more willing to talk in theory rather than what actually happens

QC22 Yes

Possibly makes people reluctant to talk because of fear of others passing judgment

QC23 Yes

Our faith encourages openness and accountability and prayer about all our needs and fears

| | | | | |
|------|-----|--|----|--|
| QC24 | | | No | It's in the same category as cancer was 30 plus years ago Fear, unknown, little anyone can do. |
| QC25 | Yes | Because it is part of being a caring community | | |
| QC26 | | | No | Because we haven't come across it we don't really talk about it. |
| QC27 | | | No | These are difficult questions for lay people to answer. HIV/Aids is not an everyday topic of conversation for most people. I am sure that at a higher level these things are discussed in reference/discussion groups but most of us are not involved. |
| QC28 | Yes | As part of wanting to care | | |
| QC29 | | | No | |
| QC30 | Yes | Connection with New Testament themes | | |
| QC31 | | Unsure | | |
| QC32 | | | No | There are many possible subjects & only limited time. Tendency to focus on issues paramount in lives of hearers/ congregation. |
| QC33 | Yes | I feel it is an uncomfortable subject for many and rarely raised as a subject. | | |
| QC34 | Yes | Girls & Boys Brigade | | |
| QC35 | Yes | Because prejudice is avoided | | |
| QC36 | Yes | eg as an example of inclusion of untouchables | | |
| QC37 | | | No | people talk to each other if they have come across people with HIV/AIDS or know the situation. |
| QC38 | | | No | It's just not perceived as an issue. |
| QC39 | | | No | HIV/AIDS is thought of as a condition for people in developing countries. |
| QH01 | | | No | not much knowledge in our community |
| QH02 | Yes | | | |

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| QH03 | Yes | | |
| QM01 | | No | Probably more of culture element |
| QM03 | | No | Mind your business attitude is a problem |
| QM04 | Yes | | responsible people do take notice. |
| QM05 | Yes | | |
| QM06 | | No | Since this is a sensitive topic it is not discussed with every one. Any one who has concerns would go to their GP |
| QM07 | | No | |
| QM08 | | No | |

APPENDIX D1f
Questions 14, 15

QUESTIONNAIRE RESPONSES

| QUESTIONNAIRE RESPONSES | | | |
|--|--|--|--|
| 14 What can/does your faith community offer people affected by HIV/AIDS? | | | |
| 15 What would be appropriate support and care for people affected by HIV in your faith group/community? | | | |
| Name | 14 | | 15 |
| QC01 | walking alongside being there my community cld offer practical stuff but limited by few members& great age | | really don't know.- if it happens we'll be reactive rather proactive |
| QC02 | belonging, touch, affirmation, forgiveness if req, care, hope, understanding, listening etc | | inclusion in reg activities of ch. educatn of ch congr re how to respond to them, care in illness should AIDS develop |
| QC03 | support - pastoral | | acceptance, support thro diffclt times, understanding. |
| QC04 | on individual basis would offer love and friendship | | hope all treated as human being not as blanket label |
| QC05 | support at time of fear& loss, comfort, hope, encourged testing not sure acceptance would happen in communit y | | acceptance, love, hope, support teaching, raising awareness in other |
| QC06 | support in prayer & friendship depending on need practical, positive, prayerful above all accepting not patronising | | same as offered to others in need: prayer friendship, availability - willingness to stand back |
| QC07 | same support & care offered to anyone who s ill | | People have appointed pastoral visitor, others also involved in support as appopr medical care offered, minister visit reg. Ideally noone to feel alone when ill. |
| QC08 | Prayer, themed services esp wad place of safety + welcome but that not as true as I want it to be Initial shock sadness they waited so long to disclose, willingness to be involved in any way nec | | To be treated like any other member of community, to be listened to when needed, visited if necessary, involved in normal life of church, not made to feel different |
| QC09 | Prayer support as with any other illness | | medical assistance& nursing as needed |
| QC10 | compassion, prayers | | friendship, practical help, |

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| | | | acceptance | |
| QC11 | V little institutionally, but many Methodists support HIV/AIDS charities etc wld be disappointed if, despite expressed opinions on subject, people thought I wld be condemnatory | | That we should press for adequate treatment and care | |
| QC12 | locally - open, inclusive, welcome & clear signs (posters, prayer) that we care. Regionally - a chaplain for those affected by HIV | | the same as that offered to any person suffering from illness or disadvantage; prayer, counselling + practical support | |
| QC13 | the same care & pastoral suppt as anyone is offered when faced with disease & suffering sadness | | listening, prayer directed by the person | |
| QC14 | friendship, advice, contact with local group with expert counselling | | acceptance | |
| QC15 | personal relationships where it is fine to be yourself & safe environment & an accepting one. have kept in touch re progress, the people are in touch with relevant professionals | | I think it is good in Leicester. Maybe. suppt groups in different local spaces. | |
| QC16 | Compassion N/A | | pastoral support | |
| QC17 | N/A but would like to feel we would offer support + appropriate advice | | acceptance, friendship, prayer, other professional advice | |
| QC18 | Salvation through Christ Jesus | | we would love & support according to our resources | |
| QC19 | As Q3 (b) ie the gospel recipe for us all - Isaiah 53. 6, 1 Tim 1.15 | | | |
| QC20 | a welcome, reassurance, support, friendship, a small group to be open with; no assumptions or judgements. not lately - in the past yes | | conversation, understanding, pastoral care if ill, confidentiality or not (their choice), physical contact (hugs) (education for church if needed) | |
| QC21 | Faith in a loving God | | acceptance in our faith group | |
| QC22 | We have good provision for all those who are ill and we would offer support to HIV/AIDS people in that context | | As above | |
| QC23 | Listened, encouraged, prayed with. Sought specific advice/info- rmation from local organisation and the internet. Love, acceptance, faith, prayer | | The above plus all practical support and help particularly if AIDS progresses. | |

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| QC24 | But only in terms of general world-wide or overseas projects. Child care in Africa, hospice in Asia plus 2 medics | | If someone on staff got HIV, that would create an interesting dilemma | |
| QC25 | Acceptance, care, comfort, counselling | | see above | |
| QC26 | support - spiritual/moral | | moral support - encouragement to seek medical help. | |
| QC27 | Moral/pastoral support | | regular visiting, invitation to share in communal gatherings, family meals etc etc. | |
| QC28 | A listening ear. I listened and was able to point the person to help | | To listen, to care, to support | |
| QC29 | | | | |
| QC30 | Through XXXX work in this area overseas. I hope it could be acceptance and support | | personal friendship & agency of 'Faith in People with HIV'. | |
| QC31 | In other Parishes. It doesn't offer much | | Yes | |
| QC32 | Listening ear; prayer; on-going support; access to specialist chaplaincy. | | as with any other serious/life threatening illness. | |
| QC33 | Nothing as yet. I am sure support would be offered in the event | | Talking, listening, sharing - advice | |
| QC34 | | | | |
| QC35 | Sympathy, understanding | | get in touch with correct authorities | |
| QC36 | support - pastoral , social, liturgical, spiritual; education + research, signpost for professionals | | | |
| QC37 | Support | | Non judgemental attitude, listening | |
| QC38 | Understanding + prayer. A willingness to help practically | | as above | |
| QC39 | At present, nothing, except asympathetic ear from some individuals. | | Demonstrating inclusive activities, and reassuring people infected that we understood how HIV/AIDS worked. | |
| QH01 | No knowledge | | Nobody has approached us so far so don't answer this | |
| QH02 | Sympathy | | Would want to help but can't | |
| QH03 | Support, pray from them and listen to there problems | | mental support should be given as it works like panacea for them. | |
| QM01 | Support and counselling from religious perspective | | Probably support group and one to one advice | |
| QM02 | confidential support/advice& help, | | Confidential help line & sympathetic attitude | |

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| | comfort & prayers | | | |
| QM03 | A good sound advise and moral support - they feel guilty | | To assure them and ask for forgiveness from God | |
| QM04 | Help and support and consolation Do – because they feel ashamed | | Ask them to repent | |
| QM05 | Advice, care, support | | | |
| QM06 | Since this is a medical thing they get help from hospitals /doctors As above – Since Islam prohibits illicit intimate relations this issue would not be discussed with a religious leader/adviser but with medical staff | | As above - Since this is a medical thing they get help from hospitals /doctors | |
| QM07 | | | | |
| QM08 | | | | |

APPENDIX D1g
Questions 19a, 19b, 20

QUESTIONNAIRE RESPONSES

| QUESTIONNAIRE RESPONSES | | | |
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| 19a, b: Two most important messages to prevent HIV in (a) faith community, and (b) in Leicester. | | | |
| 20: Brief outline of views on sexual health and relationships education in schools. | | | |
| Name | 19a | 19b | 20 |
| QC01 | safer sex | safer sex | not up to speed with it. When I left teaching in 1989 there was pitifully little on relationships barely more on sexual health & - no correlation made between the two. |
| QC02 | abstinence faithfulness in sexual relationships drug avoidance | safe sex drug avoidance | educate children early de-mystify the mechanics but incr emphasis on mystery of sex as emotional & spiritual force empower yp to say 'no' to unwanted sex & drug use rather than starting one is sexually active. |
| QC03 | precautions in sex | precautions in sex | should be done in school, kids more likely to be open than family/church |
| QC04 | | sexual hygiene, use condoms, don't share needles | knowledge better than ignorance children need age-related info |
| QC05 | safe sex, changes to attitudes re casual sex, safe health care | as (a) | Schools try hard to promote good values re rel and safe sex but society has let things slip too far, now hard for yp to make good choices. Young never think of death or it could happen to you. |
| QC06 | keep praying for those suffering, at risk, for enlightenment, for those in research. be far more aware of responsibilities | Be sure of risks & how to avoid them, do not keep your agony to yourself. | cleanliness - development of loving responsible relationships more likely if keep clean. Sex outside love no more than cheap thrill. Encourage need to accept responsibility, respond appropriately and with love. |
| QC07 | safe sex, care with blood | safe sex, care with blood | 2 pronged approach - facts eg safe sex, lots of relationships ed, time to talk about situations to be faced, think & hear about feelings& options to consider when may want to have sex (age, how long together, marriage, lifelong partner, what does that really mean? |

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| QC08 | love responsibly; treat others as beloved & respected children of God, not your personal property; learn to see as Christ sees. | Grow up & be honest about sex. Tell truth to yourself even if bear can't to share it, don't make others pay for your dishonesty. | Essential, pref before they get to be sexually active, so it is ingrained by the time they are. |
| QC09 | abstain from casual relationships & from taking drugs | same as (a) | It is asking for trouble to encourage young children to experiment with each other. Present trend for discussing this at v young age is pernicious and anti-social |
| QC10 | always wear protection. No one is safe. | As before | still too much a taboo subject(sex). Relationships awareness/ training is too narrow. |
| QC11 | (a) sexual fidelity (b) 'safe' sex | As before | Have difficulty in accepting idea that condoms etc shld be provided in schools - it seems to give permission' for indiscriminate sexual activity - but yes to education, education, education!!! |
| QC12 | respectful & honest relationships | that HIV/AIDS affects all communities | needs to build up self-esteem + respect & to be honest about realities of under-age sexual relationships (& homosexuality) |
| QC13 | | | |
| QC14 | no sexual promiscuity always use prevention methods | | Unable to say I have no real way of knowing |
| QC15 | faithfulness within relationships | as (a) | I think it's v important to have good level of open conversatn as well as high level of information. As a parent I know that my children (14, 16) have been given lots of education in the form of informatn about scientific facts but hardly any conversation about emotions & relationships |
| QC16 | sex education, good moral conduct | as (a) | too much given too soon. Children shld be allowed to be children. Information shld be given when they can respond maturely |
| QC17 | encourage safe sex + education, acceptance of the fact of HIV/AIDS in society | ditto | facts need to be taught. Moral questions need to be discussed & taught with all views given equal weight ie safe sex, 'just say no'. |
| QC18 | 1) return to biblical principles 2) safe sex | as above | should be taught with a moral input |

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| QC19 | As Q3 (b) ie the gospel recipe for us all - Isaiah 53.6, 1 Tim 1.15. | As Q3 (b) ie the gospel recipe for us all - Isaiah 53. 6, 1 Tim 1.15 | Best education is by the parents. Education in schools concentrates on the mechanics of sex which often leads to experimentation: it should teach sex within the marriage bond. |
| QC20 | faithful sexual relationships (homo or hetero) | ditto | Should be open, honest, should promote faithfulness to one partner, should be strong enough to say no to sex too young or to promiscuity - our children need to learn to respect themselves and each other, to be confident, mature, independent of peer pressure |
| QC21 | safe sex and resist promiscuity | safe sex and resist promiscuity | A very good idea |
| QC22 | Faithfulness in marriage, appropriate relationships outside it | Choose a safe lifestyle (of which the above is one!) | Should be accurate information presented in a moral context |
| QC23 | Some of us live in a community situation so we have to encourage care in sharing of things/toiletries where spread could occur. | don't know | I have no knowledge of how adequate this is. |
| QC24 | safe sex | as above | Very little good teaching. An assumption that everyone says yes pre-marriage. |
| QC25 | Chastity. Avoid drugs | | The ideal place for this is in a loving home environment according to the age and capacity of the recipient. |
| QC26 | protected sex - always use sterile medical equipment. | protected sex, clean needles | Not really familiar with this issue as taught in schools |
| QC27 | 1) no sex outside of marriage 2) no unprotected sex | as above | Not too familiar with extent of educational programme as existing but feel strongly that 'no holds barred' approach required with probable results of 'immoral' behaviour in human relationships unequivocally demonstrated. |
| QC28 | Safe sex, respect for yourself & your partner/s | | |
| QC29 | sexual discipline | safe sex | In many schools facts are taught without much background in human relationships & morality by |

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| | | | teachers who are not specialists |
| QC30 | Abstinence is a counter-productive message | Awareness of the virus in our community | Should be clear, informative and taught alongside emphasis on committed relationships |
| QC31 | Sexual health Care & Person value and love | As above | I don't know about current practise |
| QC32 | if you are sexually active, be safe! | as above | Like to see much more prominence given and from a younger age. |
| QC33 | have one sexual partner | have protected sex | Do not know enough to comment |
| QC34 | Education and personal responsibility | | |
| QC35 | Keep intimate relationships within marriage | Same answer | Too much emphasis is placed on sexual relationships rather than abstinence |
| QC36 | 1 even greater openness. 2 continent sexual relationships 3 women's empowerment. | ditto | should be as open and frank as possible, within a value-laden context (biased in favour of stable relationships) |
| QC37 | Effective health education | As above - plus support to get out of poverty | Should be discussed openly and more advice offered. |
| QC38 | Education + complacency | as above | I agree with any education that helps pupils to understand the physical, emotional + social consequences of sexual relationships |
| QC39 | Be clear about causes of HIV/AIDS. Practice safe sex | as above | It remains inadequate by being restricted to practical effects and the perceived need to be non-judgemental with regard to values or cultural & religious factors. |
| QH01 | Information leaflets should be distributed | same as 19a | Should be given to children after age of 16 |
| QH02 | Routine testing | No sexual relationships with unknown people. Not to allow mixing - keep separate | Should not start so early giving education about sex. If they know about it they want to experience. |
| QH03 | Do not get involved in any ridiculous stuff. think with patience before you take any step. | | Nowadays this has become necessary to give in schools as young generation should be aware before they proceed for this kind of relationships |

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| QM01 | Better moral and religious education Outline issues and causes of HIV. | People need to adopt better moral standards and educate people against sex outside of marriage | Normally very good, from past experience but should be supplemented past ten years |
| QM02 | Follow God's commands & ways shown by God's messengers | Open debate & discussion without being politically correct' | Must be promoted but with great care & responsibility |
| QM03 | Belief in religious teaching and sex outside marriage to be punished | ditto | I don't know |
| QM04 | Educate people about religious morals and beliefs | do | I don't know |
| QM05 | To follow commands of Allah in all aspects to abstain from what is forbidden | As 19(a) | |
| QM06 | Follow the teaching of strictly religious faith. Follow all what Islam says about this(1) Seek medical advice (2) | Same as (a) | |
| QM07 | education | education | generally good |
| QM08 | | | |

APPENDIX E1a
TRANSCRIPTS – GROUPS
Group: CG03

MARGARET: It's going. As I say, we may need to just speak up a little bit please. The first question is what are the main factors contributing in your view to HIV transmission around the world, in the UK and Leicester?

INTERVIEWEE: Um, well, what I'd heard and understood was that in our Western society, it's more um by drugs, like sharing needles or, you know, and unclean needles and things rather than, um, passed on by sex, whereas in maybe in the third world it isn't so much about drugs. It was more about unprotected sex.

INTERVIEWEE: I think you'd already just said that in the developing countries, the issue is more about, um, transmitted sexually and that's, as I say, what would – what are the most thing I hear about it is via the news and everything, and um, the cases and obviously in the developing countries there's a lot of cases of rape and goodness knows what so, um, yes, it's tragic really that, um, -

INTERVIEWEE 2: But are we happy to think that ours is all from drug related and not sexual in this country? Is that a wrong perception that we have? Is that more acceptable to us to think that it's drug related?

MARGARET: No, in fact, it's not drug related, not in this country. It is in some European countries.

INTERVIEWEE 2: So it is in this country, it is sexual?

MARGARET: Yes.

INTERVIEWEE 2: Yes, but what – that's what I'm saying –

MARGARET: The majority.

INTERVIEWEE 2: - that we as people are happier to think that it's drugs. You know, we don't like to think that it's – sexual

INTERVIEWEE: I think I was thinking in this country even it's sexually transmitted hence the need for education about the sexually transmitted diseases at an early age for the children to understand that, you know, it is – it is very dangerous.

INTERVIEWEE 2: It's a responsibility too.

INTERVIEWEE 3: Yeah, a great responsibility too.

MARGARET: And do you see that happening in schools? Do you think there should be an emphasis on sexual health education in schools or do you think, um –

INTERVIEWEE: I think there is a programme in the schools, certainly that I'm involved with, the schools that I'm involved with certainly all have a quite a good education programme.

INTERVIEWEE 2: Yeah.

MARGARET: As I understand it, it's not a compulsory programme, is it?

INTERVIEWEE 3: Students can withdraw from the programme or parents can withdraw them from it should they want to. Parents are given that option, but as far as I'm aware, most schools do have part and parcel – yes, I think it's part of the curriculum now and regard to Every Child Matters and everything else that's going on because it's – it's in their best interest but like religious education, parents have the right to withdraw children from that as they do from the personal social health education issues that take place.

INTERVIEWEE: Is it – is it sort of emphasized about, um, in schools about HIV and AIDS or is it just about being pregnant or...?

INTERVIEWEE 3: It – it depends. It's age appropriate, I think. That's how it's dealt with as far as I'm aware. Yes, certainly at secondary school they – they talk more on the issues of AIDS, but not in primary school. AIDS is not discussed in primary school, um, but certainly secondary it is.

MARGARET: Along with other sexually transmitted infections.

RRS: (murmurs of agreement)

INTERVIEWEE 3: And drugs as well. Alcohol, drugs and everything else.

MARGARET: Yes.

INTERVIEWEE 4: I teach at a college and we have to do it with them as well when they first start even though they're like eighteen. They know more about it than I do. We had to do a sex education lesson with them which discussed, obviously AIDS and other transmitted diseases and it asked them what they knew about it and what names they used for it, you know, all this sort of business. Um, and as I say, they knew more than me! Very disconcerting, really, I have to say. But um, even at that age, we have to do it.

MARGARET: And generally, do you feel supportive of that? Do you think as – as Christian women you feel inclined to support sex education programmes for young people in schools?

INTERVIEWEE: Yes.

INTERVIEWEE 2: Yes, I'd be for it anyway.

INTERVIEWEE 3: Yes, I – I think – I think I would also like a little bit more of the responsibility that – um, how can I explain it? For the children to be aware of not just the implications of getting the disease, but their whole – them as a person being worth something because there's this culture of – um, well it was the same when we were at school where you were, you went on with the crowd almost and you didn't want to be different and I think in some cases there's almost an acceptance that, um well when you have sex rather than, um "if" and if you don't want to – but I'm not familiar with the sex education now. I only know when my children were at school so we're going back a few years now. Um, so I don't know in what context it is –

INTERVIEWEE: I think the sad thing is that not all parents take responsibility for the children for both their moral development and I think this is half the problem so I think it's vital that in schools they get it from somewhere because some parents and – well.

INTERVIEWEE 4: I mean the trouble is in schools is that it's done by a teacher.

INTERVIEWEE 3: I was going to say who delivers it?

INTERVIEWEE 4: Very often the teacher is not the person that should be doing it because the teacher actually – well, I mean you know you see the child every day, so if they have issues, they're not going to raise that with you, are they, because actually you see them all the time and you're for ever going to be thinking of that so and sometimes, I mean, at whatever age they're at, particularly boys but girls as well are a bit silly, aren't they? You know, the moment you start talking about sex, it becomes – and I think somehow perhaps – yeah, you know and they giggle and they laugh about it, you know, and maybe a better way is

to have sort of specialists who go in who the children don't know and therefore there's a bit more respect for someone who goes in as, you know, as a like an outside person. They will listen to them more. They will respond to them more and – and maybe there should be more thought, you know, like visual images are very good, not about sex, but about the causes of AIDS and HIV so you know, if you actually saw children in Africa who didn't have both parents because of AIDS or whatever and you actually saw the consequences of illnesses, then I think that might have more impact upon people than just talking about, you know, how to avoid it because I think it very much it's a laughable thing in schools. Well, it just happens because they're that age, and that's what they do and I think perhaps there needs to be a different focus, and like I say somebody coming in and – and refocusing on perhaps the consequences of doing that. Um, and that just might make them think a bit more, you know?

MARGARET: What about those children, young people, who are withdrawn from those classes, um, and sometimes it is on the grounds of religious conviction and – and belief, isn't it? Do you – have a view on that?

INTERVIEWEE 4: Yes. Well I – I – I work in the middle of Leicester, and obviously in my class there's like Muslims and Asians and, you know, not many Christians, but you know a whole range, and of course the Muslims can leave if they want to. So at the beginning of the session, we have to ask if anybody wants to withdraw, but it's mainly the Muslim girls and boys to be fair that actually withdraw, um, and so they don't actually hear it. Now, some of them stay, actually, but they are given the opportunity to withdraw, and then they don't hear it.

INTERVIEWEE 3: Is not everyone given the – everyone's given the –

INTERVIEWEE 4: They're all given the opportunity but it tends to be the Muslims who actually will say, "I actually don't want to be in this," because a lot of the Muslim girls in particular, um, they're brought up, aren't they, not to have sex before marriage, so – and – and so in that sense they don't want –

INTERVIEWEE 3: So they say it doesn't apply to them?

INTERVIEWEE 4: Yes, and they don't want to talk about it because obviously you bring the condoms out and things and they don't want to actually talk about it or anything to do with it because they've not come across it before, so they will tend to leave. Otherwise, they're embarrassed. So it's to avoid that, really, but then they don't get to hear the other side of it then, do they?

INTERVIEWEE 3: Unless they teach it in their own religion, do they?

INTERVIEWEE 4: I – to be honest, I don't know the answer to that question, actually.

MARGARET: So do you think that HIV then is a cause for concern, a public health issue?

RRS: (General murmurs of agreement)

MARGARET: Locally and globally?

RRS: (General murmurs of agreement)

INTERVIEWEE 3: It impacts on everyone doesn't it?

INTERVIEWEE 4: In one way or another.

INTERVIEWEE: Yet you don't see it, do you?

INTERVIEWEE 3: No.

INTERVIEWEE 4: No, well, that's another thing we're going to talk about soon, I suppose, isn't it?

MARGARET: So what do you think a Christian view of HIV and people affected by HIV might be? What do you think, um Christians might teach about HIV or how might we approach HIV and people affected by HIV?

INTERVIEWEE 4: The only word I actually can think of is compassion, really. It – you know, I think about what Jesus would have done, you know? And it's very easy to condemn people, isn't it, for their lifestyle or whatever, but at the end of the day, I think Jesus would have had compassion on them.

INTERVIEWEE 2: I think what comes to my mind, again, is not to judge but to have compassion because it would be very easy to judge and we don't know why they've got it but you assume it's through – yes – yeah, but it – as I say, sometimes it's through no fault of their own and that's the thing, yeah.

INTERVIEWEE 3: But surely we as Christians really to understand this person, we should learn more about it, know a little more of it. I mean what can you suggest to the person, anyway, if you don't know anything about it, what opportunities there are for them to get help or whatever. I mean there's the LASS organisation, isn't there, that helps.

MARGARET: Yes. There is. Yes. What would be a Christian view in your opinion, um, about how we conduct our most intimate relationships? I suppose what I'm asking is what does Christianity in your view say about sexual relationships?

INTERVIEWEE: Fidelity

(General agreement verbalisations) Faithfulness. Yes

MARGARET: Within a marriage situation or...?

INTERVIEWEE 4: Mm hmm. Yes.

MARGARET: You would want to include marriage in that as –

(General agreement)

MARGARET: It's not just about a long-term faithful relationship? It has to be, you're saying are you, within the context of marriage or...?

INTERVIEWEE 4: Well, yes.

INTERVIEWEE 2: On a personal level, yes, I would say.

INTERVIEWEE 3: Yes.

INTERVIEWEE 2: But again, we're not to judge.

INTERVIEWEE 4: No.

INTERVIEWEE 2: If somebody chooses different – differently to us, but it –

INTERVIEWEE 3: We talked about that the other week, didn't we, about the woman being the man's missing rib?

INTERVIEWEE: Yes. Yes, you did, yes.

INTERVIEWEE 3: You know, and part of *****.

INTERVIEWEE: Yeah.

INTERVIEWEE 3: But that's what it says, doesn't it? A man shall, you know – the woman shall leave her family and cleave to her husband and if – if you literally read the Bible, it does say that, doesn't it, you know that if they're together, then they should be married, and that is – that is almost a Christian viewpoint, really, except that society's changed and – and as a Christian, do you – it's very difficult, then, isn't it, as a Christian to say, "Right. Am I so fundamental that I'm going along with what it says in the Old Testament and the New Testament to a certain extent," or do I say, "Times have changed and have I the right to judge?" You know, should I be saying to everybody, "Right. You should all marry."

INTERVIEWEE 4: But I think people know that don't they. People who you know, even if they choose differently, they still know. You don't have to like be all condemning and that. People know what you've – you've ***** don't they?

INTERVIEWEE 3: I just – yes –

INTERVIEWEE 4: That if they – if they choose differently, then that's their choice, isn't it? It's not for us to –

INTERVIEWEE: No.

INTERVIEWEE 3: I also wonder that when our children are grown, will they have a diff – it will be harder for them, won't it because there'll be more people integrating with HIV and AIDS and, um, just because you get married doesn't mean to say you're not – you know, it's not there.

INTERVIEWEE 2: No.

INTERVIEWEE 3: So it'll probably impact further on – on them.

INTERVIEWEE: It's interesting. My son is seventeen and we had a discussion once about, um, sex before marriage. And he said to me, "Oh," he said, "No." He said, "I'm going to wait until I'm married." ***** I said, "Right. Okay." Um, but he then said that a lot of girls that he knew had actually already had sex and him and his friend who's a Christian as well were actually saying, "Ooh, no, we don't want any of them because they're all second-hand goods!" We don't want any of them, and I had to smile, but that – that was his view and in a way, I thought, "Oh, well thank goodness for that. You've done me proud there, really." Um, now he's only seventeen, it might change. Let's hold onto what we've got now, shall we? Um, but I – I – I wasn't sure if we should have actually discussed it, but obviously him and his friend were discussing this particular issue, you know. I don't know why but they were, and that was – that both of them had come up with that conclusion

because they were both Christians and actually believed that it was wrong to actually have sex before marriage, and I thought he was making himself a bit – he was standing out, wasn't he, really, and I'm just not sure how easy that is for somebody. And I don't know that he said that to the girls, but with his friend, he could perhaps say that. And he felt he could discuss that with me, but I think it is very difficult for young people, actually, today really.

INTERVIEWEE 2: Well, I suppose as well we don't really know the percentage of children that do or don't because there'll be some who will say they do.

INTERVIEWEE: And they haven't, that's right, to go along with the rest.

INTERVIEWEE 2: I mean how – how do – you ever know

INTERVIEWEE: I think it all boils down to upbringing to an extent. I mean I've talked to my daughter about it. She's thirteen and it's quite interesting because we've talked about sex because the frightening thing is, some of the people she knows have had sex and to me, I'm like horrified. And it's like, "Oh, N, it's the most precious thing." And I use the analogy with regards toys. I said, you know, I says, "What I would hate you to feel is you're the odd one out because all –" Because at school there are popular kids and not popular, and the popular ones are the ones with all the boys and they're doing these things. And I says, "And how do you actually feel about that?" "Oh, I don't agree with it or I think it's, you know, tarty." And I said, "Well, yeah," I says, "but you know, think about it. If – if at the end of the day you had toys –" And I used that analogy, you know, if somebody had all these toys before you and you got it at the end, it's not the same as new. And I says, "You know, when you do decide to, um, you know, have sex with your – hopefully with your husband, you know, it is a precious thing." And we've had really long conversations about it, but I think if children feel within their home that they can talk about it, it's not an issue. You know, it's a sound thing and it's not something to be fright – and it's not just about sex. It's about more than that.

INTERVIEWEE 2: It's much more than that, sex is, isn't it?

(People talking over one another)

INTERVIEWEE 4: That's what I was saying about sex education earlier. To isolate it is wrong, isn't it?

INTERVIEWEE: Yes.

INTERVIEWEE 3: It is. It's not just about –

INTERVIEWEE 2: I'm thinking of these teens like N and your daughter. I'm sort of out of touch with teenagers, really, but do they talk about the consequences, you know, HIV and other diseases and that, or is it just –

INTERVIEWEE 4: Or becoming pregnant?

INTERVIEWEE: Pregnant, I think, is what the younger ones think of first and foremost.

(Talking over each other)

INTERVIEWEE 2: And then we go down the road. I've said, it's very, very sad for some children because I – we always have discussions when children have done things at school, we'll say, "Aw, there must – I wonder what issues they have at home? They're obviously very unhappy." You know and we don't judge them, and um, I says, "You know, imagine how children feel that are not wanted," you know, because we have a laugh. I'm a little bit protective to say the least and she'll say, "Oh, there's something going on. Guess who's not going. I'm not allowed." Because – and one of her friends says the other week, "Well, what's the security like at your place now? Are you allowed out on your own?" Because I won't let her go around the streets and that. And I said, "It's because I love you. I care for you," and all the rest of it and some of her friends says, "I wish my Mum cared like you do." And I said, "Well, she does, but you know, I just show it in a different way," but – but it's quite interesting. And then I – when we talk about children having – teenagers having babies, I says, "You know, it's about how those children would feel not wanted because then the mothers would want a life. They want to be going out, doing things. They want to be out on the town and all the rest of it." And so I've discussed all that with my daughter with regards to the effects of having children young on the children. And how you feel. You know, you've got an older Mummy and Daddy who adore you and spoil you rotten. They've done what they want to do and they've grown up, so I mean, and again the sex issue revolves about not just the act of having sex. It's everything else that goes with it and –

MARGARET: Do you have a sense of how far people conduct their most intimate relationships, um, whether they do so according to, um, our religious beliefs and so on within our churches?

(Lots of talking over each other, but mostly uncertain.)

INTERVIEWEE 2: In an intimate place like this, maybe we could, but don't just chat to anybody about it or relationships

MARGARET: You don't really have a sense of that? There's a sort of barrier. Or it's just not spoken of?

(General agreement.)

INTERVIEWEE: I don't know. Yeah, I suppose –

INTERVIEWEE 3: The interesting thing I think with probably a lot of my daughter's friends, I'm sure if they wanted to talk about sex, they'd all probably come to me and talk to me about it.

INTERVIEWEE 4: They wouldn't go to their mums, would they probably?

INTERVIEWEE 3: I don't think they would. I mean my daughter would because at the moment she'll tell me anything. Like I say, we discuss everything ***** but I'm sure – I think the fact that you go to church regularly and you're with – you know, you're with children and friends. I think they see you as a figurehead. I mean I'm not – I mean I just attend on a regular basis at church. Obviously I'm not – I don't preach or anything, but I think some of the children, because I'm a Christian might feel they can talk to me about sex. I don't – I don't know, but –

INTERVIEWEE 2: They've not got preconceptions then?

INTERVIEWEE 3: No, I don't think so. No.

MARGARET: So if we're – if we're saying that, um, our teachings about sex, um – sexual relationships tell us that sex is to be confined to a marriage relationship, do you think then that that has any influence on attitudes towards people in – influence in our churches on attitudes towards people affected by HIV, um, given that so much HIV is sexually transmitted and the suggestion is that that sexual activity that has put a person at risk of HIV has happened outside a marriage situation?

INTERVIEWEE: I personally wouldn't think that because you don't know how they've, you know, how they've contracted it and there's so many – well, there's various ways they can contract it through no fault of their own so I wouldn't at all assume that anything. No.

INTERVIEWEE 3: I think that ***** I think that the older generation, um, find it very difficult to talk about sex anyway. Um, and I think because they're more, um, structured into you know what the rights and wrongs of being married and – and keeping to one sort of relationship, I think sometimes it – I'm not saying in my own church, I'm saying generally in

churches, I actually think that maybe the older people would perhaps be more prejudiced, shall we say, towards people who perhaps caught HIV, assuming that they'd caught it through sexual activity which perhaps they thought wasn't right. Do you see what I'm saying? I think that -

INTERVIEWEE: Yes. It's only – yeah *****

INTERVIEWEE 3: You know, I'm in a situation where I don't consider myself old although I probably am really now, but I don't consider myself old and I – because I work with young people, in many ways I'm, you know, I'm tuned in almost to what young people think and – and believe, but I can see that there are in a lot of churches there are older people who perhaps would, I don't know, would have a preconception about people who'd got AIDS.

INTERVIEWEE 2: No, because they wouldn't know a lot about it, would they?

(Several people talking at once)

INTERVIEWEE 3: Of course, we don't talk about it because –

INTERVIEWEE 5: ***** , I'm nearly 8X, and I mean in my day of course, there was nothing, nothing like this at all. I mean you work with younger people and it's all foreign to me. You know, what goes on in the schools and what you're teaching them and what you're telling them. Well, there was nothing of that whatsoever.

INTERVIEWEE: No.

INTERVIEWEE 2: No.

INTERVIEWEE 5: Well, ***** you didn't speak about anything –

(General disagreement from others.)

INTERVIEWEE: Years ago to have children out of wedlock was very *****.

(General murmurs of agreement.)

INTERVIEWEE 2: Well, you got put in an asylum, actually. There were people at Carlton Hayes Asylum who'd had babies out of wedlock.

INTERVIEWEE 4: ***** wouldn't even explain how – I know my mother told me she didn't even know where the baby was coming from when she was expecting. It just – such a wide ***.

(Male voice offers tea/coffee. It is declined)

INTERVIEWEE: I think that's what I was trying to say.

(General agreement)

INTERVIEWEE: I wasn't being critical.

INTERVIEWEE 5: No, but then again.

INTERVIEWEE: I was just saying that *****.

INTERVIEWEE 5: It's a different generation *****.

INTERVIEWEE: ***** can't see at the same time N somebody who's got that that you'd be saying, *****.

INTERVIEWEE 5: We were brought up strictly, right?

INTERVIEWEE: Mm hmm. Yes.

INTERVIEWEE 5: And been grateful for it.

INTERVIEWEE: Yes.

INTERVIEWEE 5: Then again you see what's on television, don't you?

INTERVIEWEE: Well, yes, that's right. Some of the – yes.

INTERVIEWEE 2: Yes, the turn off button.

INTERVIEWEE: Yes, a lot of people don't turn it off, do they? That's the thing.

INTERVIEWEE 4: Or even the Internet these days and that sort of thing, these chat shows and things.

INTERVIEWEE 3: I think it just makes us feel comfortable if we can think it's mostly from abroad and –

MARGARET: Yes.

INTERVIEWEE 3: Yes, then it – then it gets in the system, that kind of thing, but I think we're happy thinking that it isn't.

INTERVIEWEE: Yes, and to ignore it almost. And let's not talk about it because –

INTERVIEWEE 2: Yes. Yes.

INTERVIEWEE: I mean when – when I was working in school, I think it was in the 1980s was it when the first explosion hit. Endless staff meetings talking about this, but we were led to believe then that it was all – it was just same sex, sex sort of thing. There were no heterosexuals. Nobody thought it came from that at all. So it's – you sort of got these visions now of – Diana, now she's been dead ten years, hasn't she, going around hospitals talking to these AIDS patients. And have we moved on in the twenty years really?

INTERVIEWEE 2: Well, I don't really know much more –

INTERVIEWEE 3: A lot of people wouldn't like, you say touch people.

(General agreement)

INTERVIEWEE 4: Because they thought it was catching and have a drink from the same cup.

MARGARET: Do you think that's still the case, that might still be the case?

INTERVIEWEE: Yes.

INTERVIEWEE 2: I think in a lot of cases, yes.

INTERVIEWEE 3: I think that's your point, isn't it, really that for a lot of people, we haven't moved on from that. You know, or they haven't moved on from that, yes.

MARGARET: So when you're saying, um, we're unlikely to talk about sex, in the same way we're unlikely to talk about HIV?

INTERVIEWEE 2: Oh yes. Mm hmm. I don't think people would –

MARGARET: Even though, for instance, imagine around World AIDS day, there might be programmes on the TV, you know, about situations in Africa or on the Comic Relief programmess or whatever, you know, when they're looking at particular projects, or something. Um, does – does that ever sort of filter through into conversations at church?

INTERVIEWEE 4: No, I think in my XXXX class, I don't think they – they talk about it, quite frankly, not when we all got round talking, would we.

INTERVIEWEE: I've talked about it with people.

INTERVIEWEE 2: Not at my ***** I don't think.

INTERVIEWEE: No, but yeah, I've talked about it.

INTERVIEWEE 2: I think on a more intimate basis maybe, but perhaps not with a group of people.

INTERVIEWEE 3: But I think to our shame we don't discuss it as a church, do we?

(General agreement)

INTERVIEWEE 3: You know, we don't actually – when it's World's AIDS Day, we never actually have anything up in the church, do we?

INTERVIEWEE 2: No.

INTERVIEWEE: But why not? But we could, couldn't we? Why can't we?

INTERVIEWEE 2: Perhaps we ought to.

INTERVIEWEE 3: I don't know why not.

INTERVIEWEE: No, it – that's what –

INTERVIEWEE 2: Perhaps we think it doesn't affect us.

INTERVIEWEE: Well, that's what I'm saying. Perhaps – perhaps .

INTERVIEWEE 2: Perhaps we could come in touch with anybody with AIDS or how do we get it or *****

INTERVIEWEE: We don't know, do we?

INTERVIEWEE 2: I mean you can get it through a blood transfusion, can't you?

INTERVIEWEE 4: Yeah, ***** how – how

INTERVIEWEE: We're not going to know, are we?

INTERVIEWEE 4: One of us here could have it.

(General agreement)

INTERVIEWEE: And how would we know?

INTERVIEWEE 3: Who would – yeah

INTERVIEWEE: ***** because I thought that, actually, when you going through those questions and I thought, "Do you know," I mean I go around and visit a lot of people and actually, there is one church member I do discuss sex with actually, but that's beside the point, but um, no one has ever said to me, "I've got HIV." But would they tell me if they had?

INTERVIEWEE 3: You know what we've had to do? We had a church thing, and I know it's probably going off the subject slightly, but with regards to taking communion, we were told by our vicar categorically that we should and always receive the bread in our hand, take it and then have the wine. Well, some members in our community take the bread, dip it in and do it and he was saying, you know, this is not the correct way to take it. In hospitals, they even do it which they don't, they even take it by hand and drink it, blah-de-blah-de-blah because you can't catch anything because it's 100% alcohol. Well, it's not because it's watered down and it's a silver mug, and blah-de-blah. Well, um, but I'm sure there are people in our church that do it that way for the fear of catching something. Now whether that's, I'm sure it's probably not AIDS, but who knows, but they still have this fear of catching something by drinking out the same cup. And, um, it's just an interesting point. I mean my point is with regards taking, you know, Holy Communion. It's – you know, so long as you receive it, I don't think God would mind whether you dipped it in or took it one way or the other. I mean years ago, they didn't have a silver cup for Jesus. I mean at the end of the day, but our vicar was saying, you know, we must stick to the doctrine. You shouldn't take it any other way and blah-de-blah.

But, you know, thinking about people's worries, fears, anxieties maybe we should be addressing why they want to do it that way and what is it that they're frightened of?

INTERVIEWEE: I always assumed when you dipped it in it was because you got a cold or something that you didn't want to pass on to someone else.

INTERVIEWEE 3: Yeah, absolutely. Yeah. Yeah.

MARGARET: I can perhaps say something about that, but at the end, you know. It's probably not appropriate just now.

INTERVIEWEE 3: Sorry for that. But it's just that fear of people are frightened of catching things, even whether it be a cold, HIV or anything else, so...

INTERVIEWEE: I've never thought about that before.

INTERVIEWEE 2: And I think in the '80s you're right. There was a great fear about catching AIDS and things. It's like *****There was all these pictures on TV wasn't there of tombstones and things? It was very scary really, wasn't it?

INTERVIEWEE: And if you cut your finger, *****

INTERVIEWEE 2: Yes, it – it was. It was ***** And like you say, we've moved on from there, haven't we, but we don't – you don't get those same adverts now, do you?

INTERVIEWEE: No.

INTERVIEWEE 2: You know what I mean and yet it still is rife, isn't it?

INTERVIEWEE 4: ***** use plastic for everything. Got your gloves on for everything now, *****

INTERVIEWEE: Well, that's –

INTERVIEWEE 3: So we actually haven't move on *****

(Multiple voices talking)

INTERVIEWEE 3: It's totally different to what it was.

INTERVIEWEE: Yes.

INTERVIEWEE 4: *****thought about it but you're right.

MARGARET: Yes, those practices have changed completely because of HIV. I mean there are other infections that are – that we should have been doing it for before.

(General agreement)

INTERVIEWEE 4: I mean you got people where they were refusing to give mouth-to-mouth resuscitation, weren't they? I remember one course we went on and, um, somebody always carried a little bag around with them, you know, a special thing to put over their mouth to *****

INTERVIEWEE 3: I'll tell you one thing that I think about. You know mosquitoes, whenever you get bit, I always have that fear. Or you know, when you go abroad, if –

INTERVIEWEE 2: Yeah, exactly

INTERVIEWEE 3: Yes, that does cross my mind, I must be honest, when I go abroad. I do think, "Oh, is there a possibility if you get bitten you can trans – have something like that transmitted?"

INTERVIEWEE: I think we've sort of acclimatised to it certainly in certain respects, don't we? And – and I think XXXX mentioned a few moments ago. I – I was only jolted this Comic Relief with the tragedy of these children.

(Murmurs of agreement).

INTERVIEWEE: You know, and if it's born with AIDS, but there are drugs that can sort of keep them going, provided they can afford them. It's absolutely heartbreaking.

INTERVIEWEE 3: Yes.

INTERVIEWEE: And, um, I mean I'm totally ignorant of what's going on around here, but I've seen those awful pictures in Africa. It's just amazing that um –

INTERVIEWEE 2: Well, I think the only work we're aware of is the things like Elton John and the pop stars that do concerts in AIDS, but that's in this country apparently the only person who really makes a big show of supporting AIDS.

MARGARET: Those high profile events.

(General agreement)

MARGARET: Do you think, um, given that sort of climate, do you think that, um, somebody who was concerned – suppose somebody in your congregation had had an HIV diagnosis or a member of their family had had a diagnosis and they were, you know, immensely sort of worried. They felt in some sort of crisis. Do you think they would be able as a person with HIV or somebody who was worried about somebody close to them with HIV, do you think they'd feel able to go to the minister?

INTERVIEWEE: Depends on the minister.

MARGARET: Depends on the minister, yes. Mm hmm.

INTERVIEWEE: *****

(laughter)

INTERVIEWEE 3: It's a very private thing, isn't it?

(General agreement)

INTERVIEWEE 3: But again, don't you think attitudes toward vicars have changed? I mean years ago vicars were *** and there's been so much bad press about priests and goodness knows what with one thing and another that over the years, they've lost probably some of the respect that they had.

INTERVIEWEE 2: Well, definitely yes in the Roman Catholic faith with all this, the cover-up over....

INTERVIEWEE 3: Yeah, so again...

INTERVIEWEE: But I think part of the problem is that actually if you've got something like that and as you were saying, it's very personal. You might not want to go to someone who's going to stand up every Sunday and look out at you.

(General agreement and voices talking over each other.)

INTERVIEWEE: ***** do you know what I mean? And just in case the person thought XXXX was getting at them, do you know what I mean? That's a very big responsibility, isn't it, then on the minister or whatever. Because like I'm saying, just think, you would have to be so careful what you said, wouldn't you? Even if you weren't using it for them – ***** I would like to think they would, but in many ways, it's easier to go to somebody who you don't know and tell them.

INTERVIEWEE 3: Do you think it would be different if there were probably more cases of it or –

(General agreement)

INTERVIEWEE 3: Because I'm not sure whether many people would come out and say they were gay in our community.

INTERVIEWEE: No. No.

INTERVIEWEE 2: No, ***** at all *****.

MARGARET: And do you think, um, there might be a reluctance to go to anybody if you were concerned about HIV? Would – would you – *****?

INTERVIEWEE: I think you'd probably go to an HIV charity, an HIV specific place, they would go, but other than that, probably no.

INTERVIEWEE 2: I think I could – I think I could go to people I know.

INTERVIEWEE 3: Friends?

INTERVIEWEE 2: Yes. Yes, I do.

INTERVIEWEE 3: Yes, you see, I could go to friends.

INTERVIEWEE 2: I – I think I could.

INTERVIEWEE: I'm not saying I could go to anybody in the church.

(Several people saying no)

INTERVIEWEE 4: But there are other people you could go to.

INTERVIEWEE: But – but yes, there are people that I could go to.

INTERVIEWEE 3: Yeah, and I'm not saying they're not in the church either.

INTERVIEWEE: No, that's right. No.

INTERVIEWEE 2: My mother's family, I mean, no problem.

INTERVIEWEE: Yes, I mean, you're right. There might be people in the church that you would tell.

INTERVIEWEE 2: There possibly would be within the church as well. And I suppose as well it would be dependent upon how you got it.

INTERVIEWEE 3: That's right.

INTERVIEWEE 2: Yes, it would.

INTERVIEWEE: But also in the church, you don't really want to put your burden on somebody else, do you?

INTERVIEWEE 2: No.

INTERVIEWEE: You know, you might think, "Oh, I'm really suffering here, but..."

INTERVIEWEE 3: But what – what would be the issue? Why wouldn't they tell people? Is it because of their fear of being judged by the people, the fear of being rejected by the people, the – I mean –

INTERVIEWEE: Yeah, they might catch it in some way.

INTERVIEWEE 3: I mean yeah, what would be the barrier?

INTERVIEWEE 4: Well, I think it's an embarrassment that you've got it. I think that's probably what a lot of it is that people will begin to say, "Well, how did they get it then?"

INTERVIEWEE: Yeah.

INTERVIEWEE 4: You know what I mean? It – it would be that, wouldn't it, I think?

INTERVIEWEE 2: And also I think it still would be that some people would be frightened.

INTERVIEWEE: Would be frightened *****

INTERVIEWEE 2: **** of having a cup of tea with them.

INTERVIEWEE 4: I do think there are people around who would still would be frightened of it.

INTERVIEWEE 2: It's like years ago when you had TB. I had TB in our family and I didn't dare tell anybody in my grammar school's form because I felt dirty. You know, I couldn't tell anybody.

INTERVIEWEE: Oh.

INTERVIEWEE 3: Yes. Yes.

INTERVIEWEE 2: My father died of it and my sister nearly did and I nearly did, so you know it – that was the dreaded ***

(Voices talking over one another)

INTERVIEWEE 2: I mean that was a dreaded isolation hospital with three sisters in at the same time.

INTERVIEWEE: I mean not everybody will even talk about anxiety and depression, will they?

INTERVIEWEE 2: No.

INTERVIEWEE 3: No.

INTERVIEWEE: You know, and that's –

INTERVIEWEE 4: Most people don't want to know, do they?

INTERVIEWEE: You know, to be – within a church setting, you'd still be careful who you said that to.

MARGARET: Mm hmm. Yes. But you know nobody with HIV, nobody either in church or beyond?

INTERVIEWEE: I know somebody. I don't know them personally but I know they have it.

INTERVIEWEE 2: Oh, I see.

INTERVIEWEE 3: I'll have to say I don't. Not that anybody's ever told me, no.

MARGARET: And if there was somebody in your church with HIV, and disclosed that, do you – what sort of reaction do you think they'd have? What might they receive from your church?

INTERVIEWEE: In general?

MARGARET: Mm hmm.

INTERVIEWEE: Love you'd hope.

(General agreement)

INTERVIEWEE: I think it'd be pretty varied, wouldn't it? I think initially it would be a shock, wouldn't it, actually and I think sometimes people's first reaction isn't always how they – they would feel if they had time to think about it before, do you know what I mean? And – and I don't know.

INTERVIEWEE 3: I think what you said earlier, the older people would probably be more frightened of it than the younger generation within the church, um, and again issues of communion would –

INTERVIEWEE 2: Well, that's not an issue for us, you see, because we have separate glasses anyway.

INTERVIEWEE 3: Right. Okay.

INTERVIEWEE 2: So for us, that wouldn't be –

INTERVIEWEE 3: I think that might be an issue with some members of our church if they were aware of somebody who had AIDS, then I'm sure it would be an issue. And again, without being disrespectful, probably older people more so than the younger generation within the church, but again I think you'd get mixed responses depending on people's understanding of AIDS basically.

INTERVIEWEE 4: Yeah, I don't – I mean I'm older generation and I feel that, um – I don't think I – I would. But I think probably some younger people would be more frightened than - if it actually came to it because I think when you're younger, you've got almost, um, nothing-can-hurt-me kind of thing that – it's like when you talked about sex education. When you think back to when you were younger, you thought you were invincible anyway, and – and I mean we talked about – I mean smoking was the thing when we were younger and if somebody talked about what could happen to you, you'd say, "Well, when I'm old, it don't matter, does it?" And that's how you – I wonder if it's a little bit like that with some of the sexual things until they get it or somebody else *****

(General sounds of agreement)

INTERVIEWEE 4: Yeah, until they're faced with it and then I'm not sure how they would be, whether they would be quite as – you know, they might be just as frightened of being... I don't know. I mean I think it's an age thing perhaps in our perceptions and like N was saying with the upbringing and all that, but I don't necessarily think it's an age thing as regards the compassion.

INTERVIEWEE 3: No, I think the older ones would be probably more compassionate than the younger ones.

INTERVIEWEE: I'm sitting here mentally going through the congregation.

(Laughter)

INTERVIEWEE: And as I'm going through it, I actually think, "Oh, they'd be okay about it. Yeah, I think they'd be all right." And actually, as I go through it, there's a vast majority of that congregation that I think would actually show great love to the person, actually. I'm not saying they all would. Um, but I think as I think about it and I think about the personalities behind those people, there's a genuine love, actually, and care for one another and I actually think that once you got over the shock, I think that – I know what I'd like to think, but I also genuinely think that there's a lot of – I do believe there's a lot of love in our church and I think that - and I think that – and I think that – you know, as I think round, you know, if you – I end up going, "Yes, yes, yes." I think that they would.

MARGARET: By and large, the person would feel that church was a supportive place to be, supportive and safe place.

INTERVIEWEE: Yes.

INTERVIEWEE 2: Because it's a parish church, it's a little bit – bigger and it's also – I also think it has more people, ...

INTERVIEWEE: More transient ***** , doesn't it, yes?

INTERVIEWEE 3: It's quite interesting. So we have some disabled people come to our church and over the time –

(Audio tape stopped)

MARGARET: I need to turn that over, don't I?

INTERVIEWEE 3: It's interesting to watch people's reactions because – towards the disabled people and eventually when they get used to them. I don't know whether it's used to them ***** whatever. Initially, it's though they daren't touch them. Some of them, people shake their hand and then others just walk past like that, and it's really interesting to see the different, the way people receive them or not as the case may be. Um, but because we've got such a different variety –

MARGARET: Yes. We're nearly at the end, so um if you – what would be your message to prevent transmission of HIV? Is there anything that you could say if you were to produce a kind of slogan or something, a key thing that you'd like to emphasize in terms of preventing transmission of HIV.

INTERVIEWEE: That's a bit crude what I was just going to say.

INTERVIEWEE 2: Use a condom.

INTERVIEWEE: Think before anything goes into your body.

INTERVIEWEE 3: Yes.

INTERVIEWEE 4: Yes.

INTERVIEWEE 3: You see, I think that's -

INTERVIEWEE: Whether it's a needle or anything else.

INTERVIEWEE 2: Oh yes, well, I was thinking something like, "Honour your body," or something but they wouldn't understand that, would they, perhaps young people nowadays, but *****

INTERVIEWEE: Not just the young people *****?

INTERVIEWEE 2: That's true. But, you know, I'm just thinking about if you honour your body then you would be careful about what you were doing about it, wouldn't you?

INTERVIEWEE: Don't let anything enter your body that

INTERVIEWEE 5: I was thinking more of being concerned for other people as well with it, be responsible. Um, think – thinking of people who don't worry too much about their sexual activities and they've got somebody at home and then they're going off and out and then they come back and they're not really realising what they're doing that they're passing things on. I don't know – I can't think of a slogan for it though.

MARGARET: It's about behaving responsibly, yes?

INTERVIEWEE: Think before you act.

INTERVIEWEE 3: But I mean even in hospitals and that or anywhere. I mean before – I mean when you're in hospital they come and inject you, but really again, it's – it – things happen in hospitals don't they, blood transfusions and everything else, so it's –

INTERVIEWEE: ***** can't it?

INTERVIEWEE 2: ***** I suppose we've all got our first thoughts of where it comes from perhaps because I've got plenty of literature from abroad. Most of it seems to be pointed at men who, um, live in Africa who, um, are not faithful to their wives and then they're bringing it home and their wives are dying and it's leaving grandmas, now whether again, it's like whether that's just my perception again. Um, it's – it's – it's a wrong perception because as you say, it's being transmitted here as well and I think that's making us think a little bit more tonight it's wider than ****.

INTERVIEWEE: Because the only images I've got and it sounds like you as well, N, are – is in Africa are all these tragic cases where it spreads like a pyramid.

INTERVIEWEE 3: Yeah, we see the effects of that.

INTERVIEWEE 2: And you see that. You don't see that here. *****

INTERVIEWEE 3: No, we see – and we see concerts

INTERVIEWEE 2: Nobody sees a programme on what's happening in Leicester, do they?

(General agreement)

INTERVIEWEE 3: Probably that's what we ought to do.

INTERVIEWEE: So probably *****. So you don't know who you're sitting next to on a bus, do you? They could be somebody with HIV.

INTERVIEWEE 2: Where is it more prevalent, you know, in this country? Is there any sort of – is it in Birmingham or...?

MARGARET: London. London is a main, um – there are more cases in London.

INTERVIEWEE 3: Is that through prostitution as well?

MARGARET: I've made a note of that because I think, you know, after we're finished recording. Do you – do you think it matters at all what religious leaders say about HIV or what we, as church members, say about HIV?

INTERVIEWEE 2: Think it matters to whom?

MARGARET: To – to those of us in our own – in our own Christian context, or the wider community.

INTERVIEWEE: Yeah, it has that ripple effect doesn't it, like from the – from the minister to the people, then it's to your congregation. It's – you know, that compassion spreads out.

MARGARET: So, um, it matters if the focus is compassion?

(General murmurs of agreement)

INTERVIEWEE 3: And again, it can have a negative effect on how people view it depending on how it's put over, so it's important that the message– the right message is given. I think the right message is better than – hang on – it's better to give no message in some ways than to give the wrong one.

INTERVIEWEE 4: Perhaps these ministers should have a course on it or something to – to, you know, educate them more about AIDS and its consequences.

INTERVIEWEE 5: But I suppose as ministers, as a Christian she has got to say what she believes is the proper way to – to live, but at the same time have compassion for those who don't live that way.

(General agreement)

INTERVIEWEE 2: And the balance – and that is a very difficult message to get across isn't it?

INTERVIEWEE: Yeah.

INTERVIEWEE 2: I mean we've got a situation that needs a lot of help and, you know um, to try and stop it and that's a lot of things needed, aren't there? Um –

INTERVIEWEE: I don't personally think it should be preached from the pulpit. I think it should be in groups and things of that nature.

(Lots of agreement and talking over one another)

INTERVIEWEE: Because you wouldn't get the reaction either from that.

INTERVIEWEE 2: No, that's right. And – and yes, and you can't gage what people are thinking or not thinking, so no. No, but nevertheless, yeah it's – it's been good that we've talked about it, I think though.

INTERVIEWEE 4: It is, really, isn't it? Yes.

INTERVIEWEE 2: So you certainly think you know a little bit more about it, you probably will talk about it more to other people and see what they know about it?

INTERVIEWEE: Yes, because we've all got to go home now, won't we and I'll probably say, "Oh, yeah, we had this dis-" you know, and – and so that – that's like automatically, it's got like everybody else talking about it because we'll go home and say won't we?

INTERVIEWEE 3: Yes.

MARGARET: And is there anything that you feel we perhaps ought to say before we stop the recording that we haven't covered?

INTERVIEWEE: Maybe in church – um, in school, when the ministers go into schools, that could be part and parcel of um –

(Laughter)

INTERVIEWEE: - one of the assemblies.

(Laughter)

INTERVIEWEE: Just a thought.

MARGARET: Shall we close?

INTERVIEWEE: Yes.

This was a group of 7 women – all from a Protestant Free Church tradition apart from one who was an Anglican (not all have been identified in the transcription, but all participated and voiced opinion at some point).

APPENDIX E1b
TRANSCRIPTS – GROUPS
Group: FG06

MARGARET: All right, I just want – so there are no names on the paperwork that I keep at all. I just want a code which I shall – can I just check with you – you would describe your religion as Muslim?

INTERVIEWEE A: Yes. Islam, yeah.

MARGARET: You'd rather say Islam?

INTERVIEWEE A: Islam, yeah.

MARGARET: Okay. Yes. And is there a particular group, Islamic group?

INTERVIEWEE A: Sunni.

MARGARET: Sunni, okay. So this is just the code for the –

INTERVIEWEE A: Okay.

INTERVIEWEE B: So we are Muslims, Sunni aren't we, if you only just –

INTERVIEWEE A: Yeah.

INTERVIEWEE B: Yeah.

MARGARET: So if I say –

INTERVIEWEE B: It's easier to say as Muslims.

MARGARET: Okay.

INTERVIEWEE A: Yeah, I didn't realize you were talking in the – asking in that context, that's why.

MARGARET: So the code for the recording is XXXX.

INTERVIEWEE A: Okay.

INTERVIEWEE B: Okay.

MARGARET: So what I'll do is go through a series of questions and it's not about knowledge, a test of knowledge or anything like that, but um, just to get your views, um, and – so there are no right answers or wrong answers or anything like that. And wherever we sort of go with it is absolutely fine. Um, I'll just use the questions as a guide to gather perhaps the kinds of, um, the particular data that I'm – that I'm hoping for. So, um, in your view, um, what are the main factors contributing to HIV transmission around the world? Do you know how HIV is transmitted or the kinds of things that do lead to the transmission of HIV?

INTERVIEWEE A: There's, um, sexual transmission.

INTERVIEWEE B: It's basically unprotected sex and having multiple partners in my opinion.

INTERVIEWEE A: I think it's unprotected sex, also could be, you know, someone's got HIV and they use a needle and it then goes on to someone else. It could be – two people– it could be – it's more blood. Like if someone with HIV has got blood and someone who doesn't and somehow they've both got cuts and they pass that blood on to one person to the other.

MARGARET: And do you see that that might be the case in the UK and in Leicester or – or not?

INTERVIEWEE A: Um, you often hear about it in, you know, Africa it being very widespread. In terms of Leicester, I've not come across it, come across anyone who has – has HIV, so in terms of knowing anyone with HIV and how it's transmitted, well no, I don't know of anyone personally. But I've heard of cases in London, um, but that wasn't through sexually – that was a XXXXXXXXXXXXXXXXXXXX female student XXXX in her final year of dentistry, she was actually – um, she'd given someone who suffers from HIV an injection and it accidentally then went into her arm and now she's awaiting the results on if she may or may not have HIV, so that's the only case that I know of someone who may. The results are yet to be confirmed as I understand it.

MARGARET: And that's, um, that's the same as that transmission route that you described with the injecting needles and the –

INTERVIEWEE A: Yeah, she's a young Muslim girl. Um, Muslim girl, so that's something that she's got to now deal with, yeah.

MARGARET: It's a worry.

INTERVIEWEE A: It is, yes.

MARGARET: And do you think HIV is a cause for concern as a public health issue globally and locally?

INTERVIEWEE A: I think globally, yes. I'm not too sure about locally. Like she said earlier, I've not heard of anything within Leicester, but you do hear a lot about it in the news and the newspapers, even in like articles that you get for women like Heat Magazine. There's always an article in there.

INTERVIEWEE B: Also soaps. Yeah, you get –

INTERVIEWEE A: Eastenders, there's a Mark –

INTERVIEWEE B: Yeah, British soaps. You get it in Hollyoaks. Um, and I think it is there for an awareness that – and usually, most of the time in the media it's usually through sexual –

INTERVIEWEE A: Yeah, bodily fluids.

INTERVIEWEE B: Bodily fluids.

MARGARET: Yes.

INTERVIEWEE B: So that's how it's always seen as only through like I – well, I mean, yeah it's mixing with a bloke, I think things like that, so that's how I understand it, yeah.

MARGARET: So you – you – you, um, are aware of it being a public health issue in global terms or –

INTERVIEWEE B: Well, it's – it's – it's in – in some places.

MARGARET: Or somewhere other than the UK?

INTERVIEWEE B: Yeah, somewhere other than UK. In the UK, it doesn't seem, I think – I don't think it seems to be a significant problem, especially in Leicester. Again, you do hear it in the news, but –

INTERVIEWEE A: Quite a lot.

INTERVIEWEE B: Quite a lot, but I don't know how representative that is of what a concern it is.

MARGARET: Do you mean local news or do you mean when you hear it in the news, do you mean –

INTERVIEWEE A: National

INTERVIEWEE B: I've not come across it in the local news.

MARGARET: What do you understand might be your religion's teachings about HIV?

INTERVIEWEE B: Um, that's a tough one. Um, I –

MARGARET: Given how you've described it being transmitted *****.

INTERVIEWEE B: Well, it doesn't seem to be – I think it's the way in which you get HIV would be where people may clamp down and say, "Oh, that's not acceptable." And that's having multiple partners or having sex outside of marriage. Now in Islam, you only have sex with one partner which is your hu – wife or –

INTERVIEWEE A: *****.

INTERVIEWEE B: Yeah, and you don't have multiple partners. Adultery is forbidden. So in terms of transmitting it that way, it will be seen as incorrect. But in terms of, for example, if it's done in other ways outside – outside of sex, if it's done in other ways, then no, I don't think it's something that's discriminated against in the community or – in – I mean in Islam, I don't see how it would be an issue, Islamically.

MARGARET: Hmm. And would that apply as well to the – Islam's teachings about people affected by HIV and people with HIV? What – what might that, um, connection be?

INTERVIEWEE B: In all honesty, it's not something that's been discussed in mosques or in Islamic circles that I've ever attended personally. In fact, I've never discussed it in the religious context. It's only been in the social context and it's usually watching soaps or it might lead to a discussion amongst my friends, but never in – from a faith context. And it's never something I've come across in the books I have. But it's not something that it creates an awareness of.

MARGARET: So – so it's, um, in your experience, it's something – it's an issue that is apart, set apart from anything that is spoken of within the context of Islam?

INTERVIEWEE A: Yeah.

MARGARET: Or experienced within the context of Islam?

INTERVIEWEE B: Yes.

MARGARET: Locally? Would that be locally just or are you – is that –

INTERVIEWEE B: I mean I – I mean I – I mean I do. I travel to places like Pakistan. I don't know how common it is there, but it seems like it's not common at all. People think that, you know, it's something that people are unaware of. Again, locally, within the Sunni community, it's very unheard of unless it's like a doctor or medically that it's been transmitted with no, you know, no fault of their own. Again, when I say – use the word "fault" it's because – um, it's understood within the Muslim community that if you get it through sexual transmission, then that is, you know, should-have-been-more-careful type of thing, should have been more aware, but outside of that it shouldn't be an issue.

MARGARET: And that it has been contracted as a result of behaviour that is forbidden
*****?

INTERVIEWEE B: That's right. Yes.

INTERVIEWEE A: Yeah.

MARGARET: In the context of Islam?

INTERVIEWEE A: Yeah.

MARGARET: What, um – what would, then – we'd touched on this really, but what would Islam say about, um, intimate relationships? Um, you've spoken about husband and wife, um, can you say a little bit more about that? By intimate relationships, I mean a sort of close, sexual relationship.

INTERVIEWEE B: Well, marriage – it's actually only allowed in marriage.

INTERVIEWEE A: Only allowed in marriage, yeah.

MARGARET: So – so no sexual relationships outside marriage?

INTERVIEWEE A: Yes.

MARGARET: And what about, um, - does – does a sort of polygamous marriage feature at all?

INTERVIEWEE B: Um, well, for men Islamically they may marry more than one. They may have more than one wife. It's very rare in the UK because of the laws that we have, and my understanding again is that under the Islamic rule, the Sharia, you comply by the laws that you – the laws of the country that you're living in. Therefore, as far as I am concerned if the British law doesn't apply right, then Islamically it shouldn't be done either. But in places like Arab, Saudi Arabia, it's really common.

INTERVIEWEE A: ***** more than one wife.

INTERVIEWEE B: Again, it doesn't – HIV doesn't seem to be a concern amongst Arabs. It – I mean it's more common with Arabs than it – well, I don't know, actually. I can't say if ***** I'm making a very generalisation there myself. Um, but it just – um, it just doesn't seem to be a concern of the Muslim community.

MARGARET: And so it's no sexual relationships outside the marriage

INTERVIEWEE A: Marriage contract.

MARGARET: Yes. And so how far do you think, um, that people within the Islamic community conduct their relationships - I mean this is difficult. It's about your perception, really, or you know it might be about your – your personal sort of knowledge and experience, but how far, um, people within the community conduct their relationships, intimate relationships according to the religious teachings.

INTERVIEWEE A: It depends how religious they are.

INTERVIEWEE B: Yeah. I think now – amongst of my friends in my generation, and now I'm like 2X, and most of my friends do not have relations outside of marriage. But now, my understanding is it's becoming more and more common-

INTERVIEWEE A: Common, yeah.

INTERVIEWEE B: -amongst 18/19/20 year olds. Young Muslim girls are becoming – are basically – they are more –

INTERVIEWEE A: Sexually active.

INTERVIEWEE B: Yeah, outside –

INTERVIEWEE A: Of marriage.

INTERVIEWEE B: Yeah. I mean it is becoming more and more but not at the time when I was at college or university, it wasn't. But it has def – become more so now and this I know from my XXXX, and XXXX went to college and XXXX says it's a totally different, you know, generation of culture to how me and my friends are. And again, it's like N said. I agree with N. It depends on how practicing you and that may –

INTERVIEWEE A: I think inhibition, in a way, does play a part, but then again it depends on views and opinions. It's like myself. Um, even with girls my age, like, ones I went to school with, um, we never like even considered it. Fair enough they had boyfriends, but they didn't take it that far. But the people that I know now, even though they're my age, it depends on their upbringings and some are sexually active, so I would in a way agree and disagree like the generation gap. It depends on yourself and how you perceive Islam. And it depends on the people around yourself as well and the media. Because in the news at the moment, when they do talk about HIV, they don't really talk about it from a cultural or a faith point of view. They just give you, um, like the age and that's mainly it, just that it's contracted and especially in this day, and every time you put the news on, they say more and more young people, especially from school age, are more and more sexually active and unprotected sex. So everywhere you go, you do see posters and they are trying to make it aware so it does hit people that there is such thing as HIV because we personally don't know anybody with HIV. If we did, I think – well, it's a bit hard to explain. It's different if you actually know somebody in person than rather than seeing it on the news or somebody's actually been through it. If somebody's actually contracted AIDS and HIV and you can see what they're going through and maybe they can share their experiences with other people, I think that that will have an effect. And youngsters nowadays, um, they just – um, they hear it and I don't think it affects them that much because they don't think, "Oh, I will get it." And with HIV, it's really hard, like, you don't know if anybody's got it or not so it's quite difficult. And it's not just through – it's not just sexually transmitted. It's through drug users as well. If like they find a needle and they just, um, use it and you can contract it through that as well, so you don't have to be sexually active in order to contract HIV or AIDS.

MARGARET: But you do think that younger people are able to access information about it, but perhaps because it's sort of beyond their, um, immediate experience in terms of not knowing somebody affected by HIV, they're perhaps not able to transfer that information about HIV and how it's transmitted and so on and how to protect themselves, into their lifestyle and their relationships and so on. Is that a fair –

INTERVIEWEE B: Um, I think the facilities are there if they want to access it, um, because as I work in a XXXX I have got many girls coming and going and quite a majority of them are Muslims, and they do say that, "Oh, we've had unprotected sex." So we take them down normally to XXXX and in there when you go, you don't see many Muslims. But then again, they don't wear head scarves so I'm not too sure if they're Muslims or not so I don't really know, but you can get advice. You can see a nurse and a doctor. And you can have condoms and the pills from there. So it is available to them, but I'm not too sure about their knowledge, the awareness, if they know it is accessible or not. But nowadays in school, I think they do teach you from a young age about sexually-transmitted disease because I think it is a growing concern now as girls are starting to get sexually active at a very young age.

INTERVIEWEE A: I think there's more of an awareness of teenage pregnancies, so there's an awareness that they need to have protected sex for – to avoid pregnancy or something –

INTERVIEWEE B: Or STDs.

INTERVIEWEE A: Or STDs, but I think if, um – I mean you could be sexually active without becoming pregnant, if you know what I mean in doing it in different ways. And then they may think, "Oh, okay, well I don't need to because *****" Or they may think, "Oh, I'll take the pill," which is unprotected sex. So I think there's – um, I know myself – I know people who thought they may have been pregnant at the age of fourteen, and this is going back ten years ago. Um, and I think – many people – most people would know someone or hear of someone who may be, you know, pregn – teenage pregnancy. Again, it's like N said, we've never heard of anyone contracting HIV. We don't know anyone. And that makes it very – or it could happen to everyone there but it may not happen to me. I think it's that type of attitude.

MARGARET: And so, um, so do you have a view on how far then that the teachings and the beliefs about sexual intimacy and so on, sexual relationships, um – um, how far they influence or may influence the responses of Muslims to HIV and people with HIV? How do you think Muslims respond to HIV and people affected by it?

INTERVIEWEE B: Again, if it was done through sex outside of marriage contract, the view would be, "Well, you've been given guidance from Allah, God, um and you didn't take that

guidance and this is what happens if you don't take guidance." I think some people would take that perspective. Not all. I think the older generation would take that perspective. Um my parents' generation, my grand – they would take that perspective. Um, in terms of my personal perspective, I – you see, it's a difficult one. It's not something that I've thought about and it's something that you're making me think about. You're making me think about myself and I don't think I would sit there saying, "Oh my God," you know, "You've done this and that's it. You deserve that." No, not at all. Um, I do myself adhere to those strict rules that Islam has given me, but I am not one to judge someone else for, you know, a mistake - ***** make because that is their choice. Um, I – I – you know, I'm not one to say, "Oh well." "Oh dear." You know, I – I would support someone. You know, hopefully give them the correct guidance. If it – I – you know.

MARGARET: So there would be a range of views? You think –

INTERVIEWEE B: Definitely. Oh, definitely.

MARGARET: What you've described is sort of representative of the – the – the kinds of views that would be around within the community?

INTERVIEWEE B: I mean when we grew up, it was very much, um, "Well, if you abide by these laws, then you are less likely to have these problems such as STDs, such as teenage pregnancies, such as these." And when you do go to places such as – to other Muslim countries that are predominantly Muslim, you don't see those. You don't see that happening. You don't see, um, people with STDs, of – not just HIV, any sort of STD. You don't – well – either that or ***** it's not talked about. It's a taboo subject. Or you don't see teenage pregnancies, and – and I think especially my parents' generation, they will compare it. They'll be like, "Well, you don't see it there, and you know, here in this country where people are more sexually active and there is more sex –" They will say, well, you know, that's bound to happen. What do you expect when this is what's going on and this is how people are behaving.

MARGARET: And you think part of that is to do with living in a more diverse community where there are different influences on behaviours and so on?

INTERVIEWEE A: I think that does play a part in a way because like N said, if you go to Islamic countries like Pakistan or Saudi Arabia, it's literally unheard of. I'm sure it does happen, but –

INTERVIEWEE B: *****

INTERVIEWEE A: Yeah, it does happen but it's not spoken of. So I think that does, in a way, does play a part. There's more a fear of getting, you know, it's like because you don't hear other people doing it in very – the predominantly Muslim countries, um, there's a – it plays a part like – Oh okay, we won't encourage someone to do it. Whereas in this country, I don't think it's the community. I think media plays a very strong part. And I don't think that's – I don't think that's a Muslim concern. I think it's a community concern.

MARGARET: A wider concern, yes, for wider society?

INTERVIEWEE A: Yes.

INTERVIEWEE B: Yes, and I mean a simple advert would – you know, you can have a food advert and, you know, sex sells like they say. ***** and I think those things really play – especially young, you know, people, especially young people and I think that leads to a lot of carelessness, a lot of lust, a lot of – you know, that people are not thinking, "Well, what could be the consequences and how should we deal with this and it could happen to you." They think, "Oh, it happens in Africa, it may not happen here." And I think that's what it is.

MARGARET: That it's a problem somewhere else?

INTERVIEWEE A: Yes.

INTERVIEWEE B: Yeah.

MARGARET: It's not a problem. It's nothing I need to think about? And do you – do you think at all that any of the what we might describe as Islamic responses to HIV and people affected by it have any influence in the wider society or do you think it's just within a Muslim context?

INTERVIEWEE A: I think this is kind of Muslim *****. It's really difficult to say because it's never spoken about within like Muslims within Muslims, not because of a taboo subject because it's just something I, myself, have never had – been in a position to discuss. Again, it's not known. If it comes up, or like I say if it's on Eastenders or Coronation Street, yes, you know you might think, "Oh, look what's happened." It's sort of like educating you to a certain degree about other people's prejudices and it makes you realise, uh for me, I think through media in – whether it's films or soaps, it's made me realise, "Oh, okay, well they're humans and they're being treated, you know like you know you can't share the same drink with them and that's how people treat them." And this – um, and that sort of like shows you that, well, you know, they're – that's not how you treat people. So if I did come across somebody with HIV, I think I would – I would be more cautious to treat someone in that

manner. Um, but in – like I say, it's – I don't think it's – um, not discussed with Muslims. Even my non-Muslim friends, um, have never really discussed it.

(Not sure whose voice: *****)

INTERVIEWEE A: Yeah. Not at university. Not at college. It's a topic that's never come up.

MARGARET: Sorry, N. I should have asked if you'd wanted a drink or something.

INTERVIEWEE A: Oh no, I'm all right, thank you.

MARGARET: Are you sure? Or something to eat?

INTERVIEWEE A: Oh no, I'm positive.

MARGARET: You're okay. Um, so we've covered this really. You were saying – um, my question was going to be do people in your community talk to one another about HIV and you were saying no.

INTERVIEWEE A: Yeah, again, I think it – and I don't think it's um, like for example if you have a group of Muslim women, it's not a taboo subject within a group of Muslim women to talk about it. It's just that there's no need. It's just never come up. It's just one of those things that has never come up. Um –

MARGARET: Yes, and so part of the reason for it not coming up, you don't see it as being specifically to do with the religion itself, nothing to do with Islam or anything.

INTERVIEWEE A: No, it's just not a concern, a community concern.

MARGARET: It's something. Yes. Yes. Um, and my other question was, you know, do you talk to anyone in your faith group about it, um, but you've – you've described that you would if it came up, but it's not something that you would necessarily raise unless there was, you know, perhaps it had become a topic of conversation and that you had perhaps had heard of somebody with HIV or something like that. Um, so you can't sort of identify any specific barriers to talking about it?

INTERVIEWEE A: No, there's no barriers.

INTERVIEWEE B: Um, even today there wasn't – no one actually said, "Oh, I'm not coming," or "I don't want to come because it's about HIV." I didn't get that response at all. Uh, the

responses I got was, "Oh, I don't know what to say," because they'd never discussed it or talked about it so they just felt that they didn't have anything to offer HIV information, and

INTERVIEWEE A: You see, that's the same with my friends because I tried to bring a couple along with me and they did the same thing. The same responses that I got from themselves.

MARGARET: Don't know anything –

INTERVIEWEE B: But it wasn't a taboo subject. It wasn't like, "Oh my God, I can't talk about it."

MARGARET: No.

INTERVIEWEE B: I don't think that exists.

MARGARET: No. What about, um, talking to a religious leader about it? Would that be difficult to do? Suppose somebody was concerned about HIV. Um, either somebody who'd had a diagnosis and they were upset and felt they needed to talk to – needed spiritual guidance or something, or perhaps I don't know, say somebody was concerned that they might have been exposed to HIV in some way or another. Um – would somebody feel able to go to talk to their religious leader or do you think it would just not be something that would – that would –

INTERVIEWEE A: I think it would depends on the person. The person themselves, so I can't really say. Some people might be more comfortable speaking to them if they think – actually, it would depend on – it would seriously depend on the person. It could be that maybe they do know a religious leader like a personal friend and they would feel comfortable talking to them, or maybe they just wouldn't. It just depends on the person.

INTERVIEWEE B: I think me, if I were to, God forbid, think about me myself personally, I don't think I would go to a religious leader. I think I'd go to a doctor or go to a counsellor, someone who has the professional skills to help me. I don't think religious leaders are equipped in their knowledge to understand or unless I already knew, for example, if there was a Muslim chaplain who worked at a hosp – in a hospital setting, yes, then I may because I would think that they work in a hospital setting. They may – you know, it's a subject that may have come up for them. They may have an understanding of it. I wouldn't go to someone religious or non-religious if I don't feel that they had an understanding of what HIV was.

MARGARET: Yes.

INTERVIEWEE B: And I think – my personal friends, again I can't talk about the Muslim community. I can talk about my friends. Again I think if they felt that the religious leader, the Imams, someone had sufficient knowledge, if they didn't have sufficient knowledge, why would – you know, because if that person didn't have sufficient knowledge, he could easily make you think it – situation worse, you don't know. But –

MARGARET: Yes. And will that apply, um, you know, somebody who had a diagnosis say of cancer or something, um, and as I understand it, whilst there might be taboos around HIV and how its contracted and so on, there wouldn't so much be the taboos around cancer. Um, would a person feel comfortable talking to their religious leader about, you know, their anxieties about the progress of their cancer disease or in a – in a different sort of way from how they might feel able to talk to their religious leader about the progress of their HIV disease?

INTERVIEWEE A: Oh most probably. I mean I think someone with cancer would be quite open to talk about what they're dealing with. It wouldn't be something that they're trying to hide from someone whereas with someone with HIV may not want everyone to know. Again, I think when we – I mean, I can't speak for you, N, I can only speak for myself. Because I went to a religious leader to be seeking guidance, it would be asking them for their prayers. So whether it's HIV or cancer, if I needed their prayers, yes, I'd go to a religious leader. But in terms of talking about, um, what I'm going through, a ***** friend.

INTERVIEWEE B: Yeah, it'd be a friend or a family support.

MARGARET: Yes.

INTERVIEWEE B: Family support. I mean, in terms of going to a religious leader – I have been to a religious leader in situations where I don't understand something theologically or something that's very clear in Islam that I think, "Okay, they would have knowledge of that situation in Islam." But I think things like HIV isn't something that is in any of the Islamic text or something that an Imam would have actually studied, so it'd be whoever's the best person for that subject.

MARGARET: Yes, and if you were asking for prayers, you wouldn't necessarily disclose why you were asking for prayers because of the subject?

INTERVIEWEE A: But you could – but I think you've hit a point as well. Would someone with HIV – I mean if someone were with cancer, they may say, "Oh, I've got cancer. Could you pray for me?" Someone with HIV, would they say they've got HIV? I don't know. It's a very

difficult, difficult – I couldn't answer that. Um, I could only speak for myself which I did which is that I would – I would go to a doctor or a counsellor.

MARGARET: Yeah. Yes. So you think, um, you think perhaps that would be the route for other people that, um, they wouldn't be constrained from approaching health professionals at all if they were concerned that they had been exposed to HIV? You think they'd feel okay about going to the GP or –

INTERVIEWEE B: To a GP or a health centre.

MARGARET: Or a teaching or –

INTERVIEWEE A: Yes, someone who's got knowledge.

INTERVIEWEE B: And the trust too, you know, confidentiality.

MARGARET: Yes. Um, and – yes, and that applies to sort of going to inquire about having a test for HIV or something like that. Now has anything ever sort of come up about um, testing for HIV prior to being – getting married or anything like that? You've never heard anything spoken of that sort –

INTERVIEWEE A: No, it's just assumed, um – it's just assumed that that person, even though they may have had a sexual partner, it's assumed that –

MARGARET: They won't have –

INTERVIEWEE A: They won't have because – unless they say they have had.

MARGARET: Come into the relationships as virgins and without having been sexually active, yes.

INTERVIEWEE A: But um, in terms of – Sorry, I was just going to bring a point to where XXXXXXXXXXXX the needle went into her arm. It's – I mean I don't know this person and yet I've heard about it XXXXXXXXXXXX. Now, if she had contracted HIV through sexual means, it's very likely that I wouldn't be sitting here giving her as an example because I wouldn't know about it. So I think that is quite significant in how one contracts it. That would be – that is – they'd be more open. If she – maybe she will sort of be more open about it if they'd – when I say ***** , I mean I'm talking non-sexually, um, contracted it. But if someone has sex and contracted it, then maybe they wouldn't be so open about it. I – I think it's how you – how you got the HIV rather than the HIV itself.

MARGARET: Yes, it's the route of transmission that is sort of critical as far as how the responses are, you've said.

INTERVIEWEE A: Yes.

MARGARET: Um, and you've said you don't know anybody with HIV apart from –

INTERVIEWEE A: No.

INTERVIEWEE B: Right. I don't know her directly, but I know XXXX –

MARGARET: Who is concerned that she may have, or this person may have HIV because of the needle stick injury.

INTERVIEWEE B: And my family were very sympathetic. You know, she was a young Muslim girl, and you know same ethnic origin as I. And they were very concerned about her. And it wasn't, "Oh my gosh, she's got HIV." It was "Ah!" You know, and I think if she was here in Leicester, I think my parents would give her family a lot of support. Um, so again that comes down to the route of it, yeah.

MARGARET: Um, what would, um – I think we've covered this really. The question is what would or do people affected by HIV receive from your faith community? Um, so I think what you've been saying is that, um, depending on the route of transmission, there would be support available. They could expect support. Um, but perhaps less so if it had been acquired sexually or, um, at least – that could apply also for instance to, uh, a woman who is a wife and who is a faithful wife to her husband, but whose husband perhaps has HIV and has infected his wife.

INTERVIEWEE A: Yeah.

MARGARET: Um, would it be assumed, do you think, if a woman in those circumstances has HIV that she has been, um, she has behaved wrongly or would she have to be explicit about how she had contracted HIV?

INTERVIEWEE A: I don't know. Would I question her? No. Would I question her? No. That's a very – I can't actually speak on behalf of the Muslim community. I think you'd get a very mixed response. Um, I mean I wouldn't – I mean that sort of thing that would come to mind like, "Oh, has she been playing away?" I would actually think, "Oh, okay, well it could be her husband." Um, you know I'd question it innocently. I wouldn't think one way or the other.

MARGARET: And it wouldn't necessarily influence the level of support, um, and the sort of compassion that people would feel for her?

INTERVIEWEE A: No, I mean if her husband contracted HIV and passed it onto his wife, not at all. I think she'd – you know, would get a lot of sympathy.

MARGARET: But it – but that man having HIV, people might feel a little bit more –

INTERVIEWEE B: Resentment.

MARGARET: Yes.

INTERVIEWEE B: Because he's passed it onto his wife and he's been uncaredful and the fact is you know, he's done – he's passed it on care – you know, really carelessly to his wife which is unjust so people may not be as sympathetic towards him.

INTERVIEWEE A: Though it would depend on how he contracted it in the first place. It could be accidentally *****

INTERVIEWEE B: But if he was aware of it – um, if he was aware of it and he knew he had HIV, I don't think he would get any sympathy. If he didn't know he had HIV, I think it's a different scenario.

MARGARET: Yes. And then if there is no sort of information available or if people think it's not our problem, it's somebody else's problem, how would anybody ever understand whether they had been exposed to HIV or not? I mean perhaps – perhaps a question. Um –

INTERVIEWEE B: In talking about spiritual leaders and Imams and so on and so forth, I said I'd probably wouldn't, but I do know an Imam who's 2X years old. Um, and I can go to him asking for, you know, on subjects. You know, taboo subjects, I'm able to talk to him. Because he's an open person within himself and he – you know, even though he's a male, um, I'm able to go to him and say, "Well, I've got – there's this problem and can you give me some guidance and what do you think?" Or you know, "I need – you know, how shall I go about it?" I would be able to go to him but only – as any – and I would go to him as an Imam but only because he was trusted and I think his age plays a factor. I mean to go to someone who's a fifty-year-old middle-aged man, I'd be less likely to because I felt – I think that's just – that's just due to generation gap more than anything.

MARGARET: And perhaps other young people would feel the same towards that person and they would sort of identify him as a person that they could perhaps approach if they were –

INTERVIEWEE B: Yeah, I mean I'm – yeah, I'm speaking from a personal perspective. I know some women who would say, "No, I would rather talk to another woman." So you know, you do get some women who say, "Okay, I'd just rather talk to another woman. He's a man. I don't want to talk to him." So I really do feel it depends on the person like N has already said.

MARGARET: Yes. Yes, of course. Yes. Um, can you suggest two messages that you might like to, you know, sort of put out there to help ensure that there would be support for people affected by HIV within the community?

INTERVIEWEE B: Two messages to show that there would be support available for them by their community?

MARGARET: Or to ensure that there is support?

INTERVIEWEE B: I don't - I don't know if I – we could do that on behalf of the community.

INTERVIEWEE A: That's right. Yeah.

INTERVIEWEE B: I don't know what the community thinks because I've never discussed it with them.

INTERVIEWEE A: There is support available but I'm not too sure if it's in that particular communities.

INTERVIEWEE B: I think when it comes to something like HIV, it's not – again, I mean someone who's a Muslim wouldn't see it as, "Oh, I need to go to someone of the same faith."

MARGARET: It would be about going to wherever there is sort of specialist help?

INTERVIEWEE A: Yeah, that's right.

INTERVIEWEE B: Or maybe talk to someone who's gone through the same thing. But regardless of – I don't think faith actually comes into it. I don't think the religion comes into something like this. I think it's really – I think that's like one of the reasons it hasn't come up.

MARGARET: That's interesting because one of my sort of – we're coming towards the end – questions is, do you think it matters what faith groups or faith leaders say about HIV?

INTERVIEWEE B: I think so, yes. I think it shows that. Now the reason that I wouldn't go to someone, a religious leader, is because I think that they're not clued up on the subject. If I had the confidence that they are clued up on the subject or they do understand, or you know, or they acknowledge, um, understood that HIV does exist and it can be contracted through various reasons, um, maybe I would – maybe I would reconsider if that person was open or that faith leader was open enough to talk about it, and showed support and it's like, yeah well why not. Um, I think it's important – I didn't think it was important before talking to you, but you said something when you mentioned the husband and wife thing, and well if he would – how would he know if he's contracted HIV? How would he know? Um, because again, it's that faith thing. But is that because they're just ignorant towards it, I don't know?

MARGARET: For instance, do you think it might be helpful if Imams or those who give the sermon in the mosque were able to talk in an informed way about HIV or – would that be a useful thing, do you think? Do you think people would listen and take that on board and the men would then sort of communicate that within the family setting or...?

INTERVIEWEE B: No, I think they'd get a – the Imam would get a mixed response of what he's doing the talk on. Again, when I say mixed, I think it would be like a 50/50 response. Um, I think some people may think this is not a concern of our community, why are you talking about it? It doesn't affect our community.

INTERVIEWEE A: Because ***** Islam *****

INTERVIEWEE B: Yeah, from that perspective. It depends what perspective you're talking about. I think unless they thought it was relevant as a community or if they knew a young Muslim who'd contracted it, then they would think differently. Again, because they don't know anyone, because they don't know any young people, then I – I don't think - ***** come out thinking, "Why would you – why did you talk to us about that for? We don't know anyone. It doesn't affect our community." Um, I think you'd get a mixed response. I think – do you think the younger people, like those who attend college and university, I don't think they'd take – they'd maybe *****

INTERVIEWEE A: I think they'd be more open to it.

INTERVIEWEE B: Those who've gone through education in this country –

INTERVIEWEE A: Especially this generation. I think they are more open to it. I think if somebody could just ask the question to a religious leader and I think it would depend on the

religious leader like, ***** said earlier, of what age they are. So maybe the religious leader might not be comfortable speaking about it *****

INTERVIEWEE B: Middle-aged forty-plus male, I don't think they'd be open to talk. I think – I don't think ***** go over and talk about it, whereas the younger generation might.

MARGARET: And what about sexual health education in schools? Is that something to be supported or not?

INTERVIEWEE A: I think in a way it is and it isn't. It is so it's making everybody aware what that can lead to, like STDs. But then in a way it isn't because you can get mixed messages. If they're like, um, talking about it everywhere you go, media, schools or even on posters, it's like they could be thinking that it's like actually encouraging it because it's talked about – talked about wherever you go. So it could be what perspective they're looking at it from.

INTERVIEWEE B: I think it comes down to age. And what I had – I was taught about it in school, about protection, um, and everything, and at that point, fifteen years old and in the same year before we actually had that lesson coincidentally one of my friend thought she may be pregnant, so it was happening amongst some of my friends who were fifteen, so at – at that point I thought, "Yes, this is really relevant." I didn't think it was relevant to me because I came from a practicing family and I was – I knew within myself that I would take that I would take that seriously. I don't think it was relevant to me but I did feel that it was relevant to the other students. I know that sounds a bit bad, but yeah I did. But I think age plays –

INTERVIEWEE A: Oh, I think age does play a big factor – a big factor of it. But I don't know about relevance. I think it's about awareness about having the knowledge even though it does not apply to you or it does. Maybe you do come – you might come across somebody, and if you have the right knowledge you can pass along your knowledge to them where they can access and where the support is available to them even though it might not apply to yourself.

INTERVIEWEE B: I mean N is right in the sense that, "Yes, it could encourage them about –" At the same time, it's quite scary when you see so many thirteen/fourteen year old girls get pregnant. Then you think, "Well, maybe they should have been taught it at a younger age." But then at the same time, that same class, you'll get other young girls and boys who are not at that stage yet and maybe, you know, don't need to know about it for another couple of years. It's a very – I – I don't know what. It's a very difficult – difficult to tackle.

MARGARET: So if you were – if you were asked to put out a message, um, about preventing transmission of HIV, what would it be?

INTERVIEWEE B: Oh definitely, uh – I mean – I think there needs to be more awareness, definitely. I think there definitely does. And I think there needs to be an awareness of how it's contracted.

INTERVIEWEE A: And what effects they can have as well.

INTERVIEWEE B: Yes, my education is literally through soaps. I know it sounds ridiculous, but that's how I learned about HIV. I've learned it through the media and non-fiction – you know, I'm talking about fictional, not - I'm not talking about documentaries on HIV or true-life stories, but simply through soaps. Um, on Home and Away a month ago, you know, Cassie got HIV through her boyfriend who'd contracted HIV but didn't know he had HIV. Um, and that was like "Oh, okay." And how she got the right support and there weren't that man prej – there was prejudices, but there was a couple of old people who did say within the community, um, who – there was a Christian person who looked down upon it saying, "Well, you know, it's sort of like your own fault." And gosh, you know, it's – I don't think it's – again I think that's very – led me to think that it's not really a faith thing. You will find people who have no faiths, maybe. I think it's a problem – it's a problem that concerns everyone but locally people don't think it's a problem at all.

MARGARET: We've – we've come to the end, really. If – unless there is anything else that you feel that is important to say that we haven't said or covered.

INTERVIEWEE B: No, I'd just like to reiterate that I do think it's important to understand how it is prevented because I may have learnt what I learnt from the soaps, but that may not be an accurate picture. I may not have the whole picture. And there may – I'm sure there's a lot at the minute I don't understand or I don't know. Um, and I think there needs to be general awareness because it may not, you know, in my - amongst my friends it may not have happened, amongst my parents, um, generation but there is a lot more unprotected sex and sex outside marriage within Muslims occurring more and more, you know. I think it's increasing rather than anything, you know.

MARGARET: And perhaps it's a sort of phenomenon within the community that is new and there isn't a sort of existing strategy, as it were, to deal with it.

INTERVIEWEE B: There isn't. And I think maybe it's with softly-softly approach. I think you know a softly-softly approach to it in educating specifically youngsters. As again, the older generation, parents, grandparents, I don't think they would particularly pay attention to it even if they did hear about it. But again, it's that *****I think young people, I think they're more aware of it. They are aware that it does concern them. So...

MARGARET: Thank you very much. Thank you.

APPENDIX E1c
TRANSCRIPTS – GROUPS
Group: JG10

MARGARET: So I'm just going to give the code for the recording XXXX. We'll need to speak up, I think because of the distance we are from the recording. That's the microphone for that bit and the microphone on the one nearest is there for that recorder. So, um, what in your opinions are the main reasons for HIV transmission around the world, in the UK and in Leicester? Do you know what the routes of transmission might be? Why do – why is – why do people get HIV?

INTERVIEWEE (F): ** do you just want to translate that first?

INTERVIEWEE (F): So basically through sexual relations, through going to the barber's with blades and stuff like that and through needles and injections with syringes.

MARGARET: And do you think that's the same around the world as it is in, say, Leicester?

INTERVIEWEE (F): I think so. And then – but in –

INTERVIEWEE (F): I think – I think it also depends on the culture and the religion as well because people have idea of religion. If you – you know, religion and bad things that you do have an effect on what you get so the perspectives of what it actually is is different around the world as well. Does that make any sense?

MARGARET: Mm hmm.

INTERVIEWEE (F): Um, but I think it's pretty much transmitted the same ways.

MARGARET: So the main sort of routes of transmission you think are the same globally as they are, perhaps, in Leicester?

INTERVIEWEE (F): Yeah, I would say the main one is through sex.

MARGARET: And do you think it's a concern for public health around the world and in the UK and in Leicester?

INTERVIEWEE (F): Um, yeah, definitely because there – I think especially in the Asian communities, a lot of it's hidden and it's controversial. If you've got-

INTERVIEWEE (F): ***** talk about it.

INTERVIEWEE (F): If you've got AIDS then perhaps you'll be branded as someone who's had sexual relations. If you're unmarried especially and you are found to have AIDS then people might question all sorts about your purity and your decency and your morals, and um, especially if you come from perhaps a religious background, a Hindu background or an Indian culture where it's not widely accepted to have sex before marriage. Um, in that case, it'd be frowned upon so it may be hidden. You can't hide it from your family for so long, but from the general public, you could say they've just got a general illness *****.

INTERVIEWEE (M): I think you've actually hit the nail on the head, basically. I agree with what she's saying and I also say that the younger generation, they understand ***** about HIV, but the older generation they won't – especially in India like in villages and places like that where they come from, HIV is like swept under the carpet. They don't want to know anything. There's no family planning or anything like that. They just, you know, um – just make as much children as you want basically and ***** people need to know – they need to - I think people should open up now and start talking about it because it's one of the most serious infections you can get at the moment, and it's life and death isn't it?

INTERVIEWEE (F): And yeah, with – England has the highest sort of under-age pregnancy in Europe. You know that no one's, you know, saving themselves for marriage, and um it's just got to be discussed more openly because if they're hiding it away and people aren't made aware of the types of risks that are associated with the fun they're having, then you're just – um, like heading for trouble, really, aren't you?

MARGARET: So do you think, um, it's a matter of concern within a Hindu faith community?

INTERVIEWEE (F): I'd say it's a matter of concern but it's also still today a very, very taboo subject. Um, because parents to a certain degree depending on, you know, their age and where they're from and when they moved to this country, they don't want their children to be educated in that area because children now are going to be educated from the age of 8 in that area. So in that sense, it's um – it's invading a parent's privacy as well because if they want to not express and explain to their children what the actual problem is and how it can have such an extreme effect on them and their entire life, but their – the schools and the government is saying that the children need to be taught from a young age. So it's an issue but it's how a parent thinks they're going to tell their child about things like that.

INTERVIEWEE (F): I think it's easier to discuss diabetes, high blood pressure and other –

INTERVIEWEE (F): Alcohol –

INTERVIEWEE (F): And other problems that are – or habits – that are present in the Indian community.

INTERVIEWEE (M): I think this ***** through the whole Asian community, not just the Hindus or the Sikhs. I think there's – I think everybody needs to learn about this HIV . Like you said, people will talk about diabetes and heart problems and this –

INTERVIEWEE (F): It's easy to talk about that.

INTERVIEWEE (M): Yeah, HIV *****not really talked about.

MARGARET: What would Hindu religion say about HIV and about people affected by HIV?

INTERVIEWEE (M): I think they're just left on their own devices to learn about it. I don't know. It's not really in the Hindu –

INTERVIEWEE (F): There's nothing in the script, not that I'm aware of.

INTERVIEWEE (M): - script or anything. There's nothing about it in the scripts or anything like that, HIV at all. You just learn from your own devices, really.

INTERVIEWEE (F): And it's based largely on Karma, so basically, you know you reap what you sow and you pay – you pay the price for your actions –

INTERVIEWEE (F): In your last life.

INTERVIEWEE (F): Yeah. Because we – because we believe a lot in reincarnation, that's the main basis actually of the religion, ***** maybe you're paying the price for whatever you did bad in your last life and that's why you've got AIDS now and, you know, that – a lot of people sort of do themselves down in any state because they think, "Ah, -"

INTERVIEWEE (F): No matter how large or small –

INTERVIEWEE (F): "I deserve it." A lot of people get into that mode don't they? I deserve it.

INTERVIEWEE (M): Yes.

INTERVIEWEE (F): You could also say with the Hindu – Hindu, um, ***** because a lot of them are African descendents. They came over when there was the divide, in their mind

the association is with the blacks of Africa of them having AIDS as opposed to – so it's sort of like the lower-class disease, um, because all the blacks in Africa were the servants around the house. So there's like – there's that definition as well, so that divide in their mind is – they associate it with the lower class so when it's here, they're going to still be quite, um, associated with the lower class as well.

MARGARET: I see.

(large Gujarati section not transcribed)

INTERVIEWEE (F): I just asked them why did they think it's not discussed in the house.

(Gujarati discussion)

INTERVIEWEE (M): Because of education in India.

INTERVIEWEE (M): You have to teach your children. You have to teach your children.

INTERVIEWEE (F): Can I just translate it for the tape? Okay, he said basically we can talk about anything but we're not exactly going to tell our parents if we've had sex with this girl or that girl. It's not something we'd do.

(Gujarati)

INTERVIEWEE (F): So because of our Indian culture and the respect for our parents, there are certain boundaries we don't cross and so he said like, okay if he's had sex with a girl and perhaps ***** AIDS, he just wouldn't discuss it.

INTERVIEWEE (F): But even if it wasn't with sex, it's usually directly associated with sex so for that humility factor –

INTERVIEWEE (M): I think we got to balance as well, then, people who came from Africa are more liberal, more tolerant about things like this, but in India they don't talk about this. But in Africa, those people who've been brought up there and been over here, you'll find them that they are more flexible in everything

INTERVIEWEE (F): They've seen it already in Africa.

INTERVIEWEE (M): They've seen it so they'll talk about it. They're more open. Where in India, the people there are more conservative in a sense.

INTERVIEWEE (M): In Africa *****

INTERVIEWEE (F): Also what are you saying is that in India there is none of this in the education system at all, so if they've never been educated from a young age up to you know when they're getting married, it's never a problem because they've never had – it's never been highlighted in their life. So it's always been covered up.

(woman speaking in Gujarati)

INTERVIEWEE (F): AIDS no.

INTERVIEWEE (M): ***** but in schools they discuss – boys they go a different class. Girls they go to a different class. Girls they go to a different class. They discuss about bodywise and everything. When AIDS and uh – if you get cuts tell somebody, it affects them.

MARGARET: And that was in Kenya?

INTERVIEWEE (F): Was it like open? Could you talk....?

INTERVIEWEE (M): Yeah, the teachers were ladies so they just talk openly.

INTERVIEWEE (F): ***** think because in Africa it's such a big issue over there as well as opposed to India, they're going to discuss it a whole lot more openly.

MARGARET: And that's generally the experience you think, of – of people in Leicester, Asians in Leicester who came from African countries, that they will have been exposed to it, to HIV, in a way that many people who are from India would not have been exposed to it and exposed to talking about it.

INTERVIEWEE (M): But I think what's happening in India at the moment is like the bigger cities like Bombay, Delhi, people are getting to know about it because –

INTERVIEWEE (M): Not in villages –

INTERVIEWEE (M): Not in villages, the problem is, in bigger cities, a lot of tourists go on these red light districts in Bombay and Delhi, and people tend to go there, and go around places and now because it – even in Bombay and places like that, HIV is such a high thing – risk at the moment and a lot of people are suffering with HIV and they're being educated now,

but you'll find that the villages and other place in India are not as open and not as, uh, you know like , as *** said, it's not, um – hiding it again I suppose. No, it's very difficult to –

INTERVIEWEE (F): Taboo.

INTERVIEWEE (M): Yeah.

MARGARET: Yes.

INTERVIEWEE (M): It's a bad influence. It's very difficult.

INTERVIEWEE (M): Mostly in the women. But men in cities now, they are very broadminded. They talk to daughters and openly and they make more education day by day and they try to transfer everybody in the village. And this is the thing *****, but yeah in village it really is a difficult. And they try to hide it as well.

MARGARET: But generally in the cities...

INTERVIEWEE (M): Oh they know very well, everybody.

MARGARET: ...people are – are used to talking about it now?

INTERVIEWEE (F): But I think in India – in India especially like your sort of promiscuity is linked to how affluent you are because then if you're richer, then you can sort of afford to go to clubs and drink and go to bars and meet other people and socialise, and um, whereas you know when you're less affluent, then you're sort of stuck in the mundane routine of life and can't do it.

INTERVIEWEE (F): But that's relevant everywhere as well, isn't it? That's relevant wherever you go.

MARGARET: You've said – you've said a little bit about this, but um, and it's implicit in a lot of the conversation, but if you could give a short outline of what Hindu beliefs say about intimate relationships, and I suppose by intimate relationships I mean sexual relationships. I mean I think that I've already heard you say is that the teaching would be, um, sexual relationships are to occur between a man and a woman but not before marriage. Is that – is that the teaching or is –

INTERVIEWEE (M): It's still there, but the young generation are changing now. Times are changing so people are changing. Um, the young generation I would say are like more into – it depends on –

INTERVIEWEE (F): I think they've become more Westernised and you – you become more Westernised when you grew up in a country which is nothing like your home country should I say, so the culture and the people that you're surrounded by are of so many diverse backgrounds and cultures that you're – should I say, you have a – you have a diverse view as well of how everything is and you have a merged view as opposed to just one narrow way of living because everyone around you is different. But if you were to look at like script-wise and look at the Holy Book it would say, yeah, sex should not happen before marriage.

INTERVIEWEE (F): It's okay between two consenting adults and when they're married. But that's related to – it's not just related to a man and woman. It's related to how it should be for their children as well.

INTERVIEWEE (F): I don't think there's any reference made to homosexuality –

(end of recording WS_10077)

(beginning of recording WS_10079)

INTERVIEWEE (M): It's like - I've got a few friends who are Christians and they say the same thing that even in the Bible it's very similar to what we say in the Hindu religion. Like no sex before marriage but then if you do, it's a sin. So it's very similar to –

INTERVIEWEE (F): Ours doesn't count as a sin though. Ours counts as Karma

(several murmurs of Karma and multiple people talking)

INTERVIEWEE (F): There's no reference though to homosexuality. It doesn't exist. Man and woman, not man and man.

(Gujarati section)

INTERVIEWEE (F): Shall I translate it? She said that basically that in our values as Hindus we don't condone it to have sex before marriage. It's never been condoned, however some

people still choose to go and do it and for those people who choose to go to the clubs and do whatever they want to do it's their choice and *****.

INTERVIEWEE (M): They're given a choice now...

INTERVIEWEE (F): It's adapting to the environment around you.

MARGARET: So I mean my other question would have been how far do you think people in your faith community conduct those intimate relationships according to their religion's teaching? So what you're saying is it's a very mixed picture? Some do, some don't and –

INTERVIEWEE (F): Well, *****.

INTERVIEWEE (F): Yeah, I think – I think first generation is a lot more prominent, first generation because you know, you were born here and you –

INTERVIEWEE (F): When our parents came from Africa or India, they tried so hard to hold onto our culture in England and so they were especially with the first child of the family, they were overprotective because if you see us deviating away from our culture they over-reacted to bring them back. It would also make them rebel whereas with the second and third child, everything is relaxed a little bit whereas that's in contradiction to India where a lot in the modern urban cities, Bombay and Delhi, they're now more open-minded than we are in some cases because they aren't trying so hard to hold on and to follow their culture whereas we were desperately trying not to lose it when we moved to this country. But it really depends ...

MARGARET: And do you think – do you think the traditional teaching, um, in so far as they have influenced, um, influence responses to people affected by HIV or to HIV in general? What would be a Hindu response to a person with HIV?

INTERVIEWEE (M): It depends.

INTERVIEWEE (F): It depends on the generation.

INTERVIEWEE (M): The generation and how liberal the family is.

MARGARET: So there's not a direct relationship to – to the religion?

(Conversation in Gujarati.)

INTERVIEWEE (M): I think what it is, like he's saying that – saying that you know after talking to everybody here and learning about it he feels a bit confident about talking to his Mum and Dad about HIV and if somebody had HIV, how you know. But he knows that if I had HIV by touching N or something like that, she won't get it unless it's intimate sex, you know. He understands that now, but if like you know he can talk to his parents about it now. It's good.

(someone speaking in background but can't make it out)

INTERVIEWEE (M): Yeah. ***** yes.

INTERVIEWEE (M): ***** If I'm a carer and come to you and do some shaving or something that blood can be contacted some other protection.....

(Several people talking over each other, then in Gujarati)

INTERVIEWEE (M): He's saying that when he goes to the barbers for a shave and stuff, the blade that they use, one thing if you've had a shave and there's blood on it they throw the blade away but they don't clean the blood on the actual thing so there's a risk of somebody catching something as well.

(can't make out new speaker's dialogue)

MARGARET: It's a very low risk but nevertheless, they should be careful.

INTERVIEWEE (F): Now when you go for an injection, now they throw away the syringe and the needle where before they just sterilised in boiling water. That was it. And they used the injection again.

MARGARET: They wouldn't do that now. Too risky.

INTERVIEWEE (F): *****

INTERVIEWEE (M): No, not *****

(Gujarati)

MARGARET: And you said something about that generally people are not talking or will not talk about HIV to one – talk to one another about HIV. The reasons why people won't or don't generally talk to one another about HIV, um, I think you're saying are not so much about – not

so much to do with the religion, the religious beliefs as to do with sort of cultural tradition. Am I right?

INTERVIEWEE (M): Yes.

INTERVIEWEE (F): And the notion of respect.

INTERVIEWEE (M): Respect as well. Mutual respect. How can I talk to them?

INTERVIEWEE (M): Sometimes you respect your elders and think how can I talk to them about stuff like this but sometimes it's like – it depends on which sort of family you come from because if you come from a more liberal family where you talk about things as a family

INTERVIEWEE (F): Anyway, he's my son, I'm his mother...

INTERVIEWEE (M): Sorry, *****.

(Several people talking)

INTERVIEWEE (F): A lot of kids, young adults they live two lives. You go out nine to five and you do whatever you're doing, but you still come home at five o'clock and then live your family life until bedtime and whatever you did between the hours of nine to five no-one needs to know, that's your life, right. And then you come back and just pretend you've been at school or at work and – because your parents are so strict and they're not going to allow you to go out in the evening because you did throughout the day and then because of that say you've caught AIDS how're you going to tell your parents because they will have assumed you were at school all that time or at uni or wherever and so there's that massive barrier..

MARGARET: And it's because it's sexually transmitted, because – it's because of that?

INTERVIEWEE (F): I would think – I would say that's the main thing. That's the thing that gets pointed at straight away. It's because you've, you know, had sex with somebody as opposed to you know you being in blood contact with somebody who has AIDS because you know –

INTERVIEWEE (M): The mentality *****

INTERVIEWEE (F): *****

INTERVIEWEE (M): Instant people assume is oh you've had sex, but they might not think that oh he's had a blood transfusion or something.

INTERVIEWEE (M): It's very different.

INTERVIEWEE (M): *****

INTERVIEWEE (F): Probably it would be the last thing on their mind.

INTERVIEWEE (F): The thing is with Asian parents, you've got the divide, you've got people who are desperately holding on to their roots and refuse to believe any... refuse to learn anything new to the point where they refuse speak English because that's where they're holding onto their roots so much and they've lived in this country for twenty-five years, and then you've got the people who adopt to new ways and are now exploring everything are willing to learn and accept everything that comes with living in a westernised country and educating themselves and therefore educating their children as well. So their children, if they ever did have AIDS – like if I had AIDS, I'd be able - I'd be open to talk to my mum and dad, um, as opposed to some of my friends who would never tell their parents about it.

MARGARET: Um, what about somebody going to the religious leader, um, the priest say or another leader, religious leader, somebody with a leadership role in the community? Would a person with HIV or concerned about HIV go to somebody like that to talk about it or get support or help?

INTERVIEWEE (F): I think it would depend on how closely related to your family, probably.

INTERVIEWEE (M): Definitely.

INTERVIEWEE (F): Probably it wouldn't be in confidence. I think there's a fear of leaking information. I think it's – I think it does depend though. I think it's very dependent because if you – let's say if you were a married person, you couldn't tell your family about it because you'd contracted it by a blood transfusion, you know, and you've got children. You've got a husband ***** , a young wed, a newly wed. You could not speak to a priest about it but then it depends how close they are, how far they are.

INTERVIEWEE (F): These things within Hindus, about certain communities, what caste you belong to, your priest will probably be the local priest for the whole community or for the whole caste group, and to go to him or her for advice, mainly him, might leak, you know and...

MARGARET: So they'd be worried about –

INTERVIEWEE (F): Yeah, and then –

MARGARET: - confidentiality.

INTERVIEWEE (F): -confidentiality.

INTERVIEWEE (F): Also depends on the priest. You need to feel confident and trust if you're going to share a very personal information but you know there's some things you know you can go to one priest and say Oh my God. I don't want to discuss. Or find another priest who is so modern, so westernised and so down to earth who can *** in a discussion who can give advice, support. It's all on individual, you know.

MARGARET: And um, would people normally go to the religious leader if they were concerned, if they have worries or anything?

INTERVIEWEE (M): No. No.

MARGARET: No, so it's not a common practice anyway?

INTERVIEWEE (M): People are afraid because there is no confidentiality. Sometimes there is no confidentiality. If I had HIV and I came to you and saw an Asian priest or someone from the community that I knew the next thing everybody would know. Straight away.

(Large section in Gujarati.)

INTERVIEWEE (F): He goes, basically he says if he tells anyone the whole community knows.

(Gujarati)

INTERVIEWEE (F): I can translate that by saying like about the gossip in the community and it's like it'll spread so fast if he doesn't die tomorrow from AIDS he'll die today from gossip. And then he said like because there's no channels of communication at all when somebody has AIDS, they would be a girl from there, a boy from there and when they get together. You don't know their sexual history. They don't know your sexual history. They could catch it from each other. So they have to respect each other enough to get tested. You could live a good future.

(Gujarati)

MARGARET: If people would be reluctant to go to the religious leader for those kinds of reasons. What about going to a health professional, to a GP or to a teacher in school? There's nothing about the religious understandings that would made a person reluctant to go to the GP or...?

(Gujarati)

INTERVIEWEE (F): He says here you would feel confident with the doctor. If there is something wrong with your body you've got to go to the doctor. He's seen people suffer from AIDS before, they deteriorate, and you melt like an ice cube ...

MARGARET: So, um, following on from that, do you know anyone with HIV?

INTERVIEWEE (F): He said he knew someone.

INTERVIEWEE (M): I also know there is two person died in my hands. Age 29, 28.

(Gujarati)

INTERVIEWEE (F): What he's – what he's saying is that now he is equipped with the tools, with the knowledge now most people are in India now as well to teach their children properly but it's still, it's not reached the villages. It's not reached the villages at all but, you know, hopefully in good time it does get there. Um, what else?

INTERVIEWEE (F): He'll tell his kids now.

INTERVIEWEE (F): Yes. When they grow up, what's right, what's wrong. Oh, how to deal with such things and they didn't have that education in the past.

INTERVIEWEE (F): But kids are getting married a lot younger then as well ... a long time ago ...it was more sort of... if your kids are at the time when they sort of ... if they're getting their period, they're old enough to get married. Um, you know, what is it, fourteen, fifteen years old, that's it, they're ready to go. But now as they're getting older, they're learning more themselves before they actually leave the parents house.

MARGARET: And is – is Leicester more like the village in India than the city? You know, do
– do - *****

INTERVIEWEE (M): It's so diverse.

MARGARET: But there – there will be then people who are happy or okay about talking about it and finding out about it, but there will be other people who are – who are less happy?

INTERVIEWEE (F): Need to understand also the Hindu community Leicester most of them are Gujarati. Gujarat's a massive state and even in Gujarat there's urban areas and rural areas. Cities in Gujarat that have more sex education than perhaps little villages so perhaps it's not reached down, hasn't filtered all the way down, but within Leicester, we've got a whole cross section of everyone from Gujarat. A bit of everything. But you've got also from Africa the growing Gujarati Africans. But you can't really generalise if it's the village or if it's an urban thing. It just comes, in any thing in any sort of opinion, it comes down to an individual themselves. Like I could speak to Mum – I could speak to my mum about something, but I couldn't speak to my aunt about the same subject. So it depends on that individual.

(Gujurati)

INTERVIEWEE (F): He's saying in India there was an advert for HIV and instead of um – instead of letting the children watch the advert on HIV, the parents sort of flipped the channels straight away to some other programme so the kids are sort of sheltered from what they actually need to know, but it's similar to watching like a film if it's, you know, a horror film that the children shouldn't be watching they'd flip channels then but then on the other hand the children will get the same sort of film and watch it by themselves, so it's –

INTERVIEWEE (F): Yeah, at least if the parents watch it with the children, the parents can educate the children, tell them what's right and what is wrong. However if the kids watch it on their own they make their own assumptions.

INTERVIEWEE (F): But also if they make up their own opinion if the parents have that communication with them, in the future if anything does happen, they can go to their parents as opposed to hiding it.

MARGARET: And how – if a person was known to have HIV in this community how would Hindu people respond to that Hindu person with HIV?

INTERVIEWEE (F): It's quite diverse. In a similar way I think.

INTERVIEWEE (M): It's difficult. If you're talking about the younger generation of people talking to that person about HIV then it's different, but –

INTERVIEWEE (F): I think everybody would question how did they catch it.

INTERVIEWEE (M): They'd want to know how he got it and *****

(several people talking, unable to transcribe)

(Gujarati)

0:27:17

INTERVIEWEE (M): What he's saying is if somebody had it he'd actually give that support to that person, he'd not just leave them and let them suffer. He'd help him as much as he can and give them that support they need.

INTERVIEWEE (F): You don't know what's going on in their mind.

INTERVIEWEE (F): He's saying if he had it - if his friend had it, if he had it himself, he would tell his friends but he's saying he wouldn't expect his friends to tell anybody else because you know then it just becomes a tale of Chinese whispers, then it becomes more gossip **** problem, but *****

INTERVIEWEE (F): But at the same time again, I also believe that you know when people find out it's HIV/AIDS, and uh, you know, once I share, that personal information with other people and I want to respond as a friend, it all depends on the individual person again. It depends like we are all educated people, we are aware of things, so we know how to provide support etcetera. However, but if there are older people who got no education about HIV/AIDS, etcetera, then their view will be completely different than this group.

INTERVIEWEE (F): Does that make sense?

INTERVIEWEE (F): In the Hindu culture, in Hindi culture, in some cultures. In some cultures, if a woman had her period – like first of all during your period you can't go into the temple.

INTERVIEWEE (F): You can't even be in XXXX.

INTERVIEWEE (F): Yeah. We wouldn't be allowed to be in XXXX. In some of my friends' houses, if a girl's on her period, she's not allowed in the kitchen. One of my friends has to eat out of paper plates, this is today, she was born in England. This is their belief that the woman is impure if she's on her period, right? And so that's a cultural belief. It's not a religious belief.

(cassette being turned over)

INTERVIEWEE (F): That's a cultural belief that the girl's ***** got HIV then an older person who's got that culture and those values will automatically assume to be impure, especially if they're like quite religious or something.

INTERVIEWEE (M): I think it's like everything, you know you've got to be educated. Like if somebody had a learning disability and you talk about it in the community they won't accept them, not everybody will accept them, but it's about education. It's same as HIV, people with learning disability, mental health problems. I think they've all got to be educated and, you know, if you're not educated then people are going to start thinking "Oh, HIV let's just throw that subject away"

INTERVIEWEE (F): That's the oldest thing though, isn't it? It's education – education v opinion and culture and you can't win either way. See the older you get, the harder it gets to change your opinion.

INTERVIEWEE (M): Like it's nice in this country because like you know like all these what people are saying at the age of eight or whatever when you start school, you've been taught about sex education and it goes through, yeah, and even when like people who come from Africa or India at the moment and their wives are expecting or whatever and you go to the family planning clinic, they're being taught there as well. So you know, it's – you know, being educated in this country and it's good like back at home not everybody was educated about it, so I think people are still afraid.

MARGARET: And would that be your sort of message really about helping people to understand more about HIV is more education about HIV?

INTERVIEWEE (M): I think so.

INTERVIEWEE (F): I think no I think –

INTERVIEWEE (M): In a way.

INTERVIEWEE (F): I think the older generation, um – I don't know whether it's relevant, whether they would just ignore it but I think they wouldn't be – they wouldn't say no. If it was marketed to them in a correct way, I don't think they would be – I don't think they would, um, ignore it. Turn their heads away.

INTERVIEWEE (F): Okay, a few weeks ago I read in the newspaper that they're giving some sex education at the age of five because – in schools because England has the highest underage pregnancy rate, right? And – they've – I mean I read that in regard to Africa they need more education but they 're already being taught at the age of seven, eight, or nine, and for me I think that's enough. I mean I think like it's more about the culture, the morals, OK that the British society faces perhaps you know. British families or there are certain areas in the UK don't have those strong family ties anymore, so the education regardless of how much they're getting, you know, it can work two ways, it can either be more informative to those who know how to sort of work the system or you know, or how to use condoms, but that's not going to fundamentally change their habits, is it?

INTERVIEWEE (F): Yeah, I agree with what she –

INTERVIEWEE (F): It's not going to change their own values. They'll learn okay I'll use condoms and I won't have sex with someone who's got HIV, but is it going to stop them having relations at a earlier age?

INTERVIEWEE (F): What you're saying is linked to like divorce rates as well because people are not married so much anymore and you see children see their parents, you know, going from partner to partner to partner until they themselves find the right one. As children, when they grow up, they don't see anything different. They just do the mirror behaviour of their parents. They think to themselves that okay, I should do pretty much the same thing until I find a partner. And then you've got peer pressure within schools as well. It's not – I think HIV is a thing that everyone least expects to catch and more so than Chlamydia, um, because it's you know, the most common one. It needs - yeah, it does need to start at home. The environment in the household needs to be right as well.

MARGARET: I mean the – the – one of the questions – one of the last questions is, "What are your views on sexual health education in schools?" So am I hearing that you perhaps think it's – it's okay but it, you know, we're perhaps going too far.

INTERVIEWEE (M): I think the age of five is too young. Eight – eight, I don't know. I think -
***** sex education when I was in secondary school so until secondary, until then. At the age twelve/thirteen, I think people should know because like you said, more and more teenage pregnancy, younger ones are having sex, schoolgirls pregnant.

INTERVIEWEE (F): It also has the reverse effect. If they're teaching too early then they think it's acceptable earlier.

INTERVIEWEE (F): Yeah they've got one of those blanket things as well haven't they. They can't – they can't just teach – they can't just divide and teach a certain amount of people who they think are more susceptible to something.

INTERVIEWEE (F): I would prefer after the age of twelve.

(People talking over each other, then in Gujarati.)

INTERVIEWEE (F): And I think what you're saying as well what everyone's view here relates back to the Hindu community itself because from a young age, children are sort of nurtured and taught other things. They've been taught a lot, the majority of kids in this area are taught a lot about religion. They come to the temple on, um, most occasions you know religion plays a big part in their lives, culture does, family does.

INTERVIEWEE (F): And girls – kids are always seen as the light of God, as of God's incarnation, especially girls until they sort of start their period.

INTERVIEWEE (F): Before we start our periods.

INTERVIEWEE (F): Then – then we are really pure in God's eyes, you know –

INTERVIEWEE (F): They're seen as the incarnation of God, all kids are.

INTERVIEWEE (F): And so I think to teach them too early is –

INTERVIEWEE (F): - taking away their purity.

INTERVIEWEE (F): Yeah.

INTERVIEWEE (F): Because it – it comes – in Hindi culture, it comes down to the way kids are brought up. We know that kids are going to learn this at some point, and most parents or a large proportion of will take that responsibility to themselves and teach their children step by step what they need to know, but for us five years old is too young because its invading childhood and purity and what they don't need to know they're not going to use it hopefully for fifteen years so why do they need to know at five?

MARGARET: But what you were saying earlier then, whilst parents may instruct their children in that sort of way when they're a little bit older, um, they're not necessarily going to

talk to them about HIV? Do you think there's a greater barrier in talking about HIV or again does it just depend on the individuals and the family concerned do you think?

INTERVIEWEE (F): I can relate my experience. Um, I pretty much was given a talk by both my mum and dad when I was about – just when I started my periods. Um, and they talked about, not really going into depth about things, but it was if you do this this is what can happen. If anyone touches you in a wrong way, this is what can happen. You know, just – as your parents, they teach you the very basics, HIV itself wasn't highlighted, it was just sexually transmitted disease as a whole.

MARGARET: And in Hindu families it would be regarded that that's the best way to provide education about sexual health rather than in school or is the school teaching acceptable but from say eleven or twelve. Is that what I'm hearing you say?

INTERVIEWEE (M): *****

INTERVIEWEE (F): At school, it's good but I think even – sometimes when they talk about it with their children, they – they 're happy that the school is taking that initiative to teach their children about it . But I think when it's done from the age of five years old when they've, you know, a couple of years before that they've just got out of nappies, parents thinking, "Well, you know, it's taking the innocence away from my child."

INTERVIEWEE (M): I think it would be nice like if my daughter went to school and she was *** it would be nice for her to come to me and us and talk to us about HIV as well. So she could say look, this is what we learnt at school this was about HIV. I don't understand, her Mum would understand, but there's other parents that go We won't talk about that. We don't want to know about that. What you learn at school is your business. But it's a shame. I think they learn from school they should come and talk to us about it as well.

INTERVIEWEE (F): The parents only go from their own experience, their own community, their own parents. It's not really the parents fault either.

INTERVIEWEE (F): I think the parents as well if they're going to start introducing it from five years old now, people who have got kids about three or four, the children are going - when a child like there's that idealistic line of a child saying Mummy and Daddy, where do babies come from? They're going to know about it before they even ask their parents that question. You know, that's going to be taken away from their parents as well.

(Gujarati)

0:40:35ish

INTERVIEWEE (F): What he's saying is that what he knows now, you know, he's – everybody here is not ideally going to go home and discuss what we've discussed in the last hour with their families and especially their parents, but he's going away with, you know with a lot of knowledge, and it's – you know, alternatively, he could come back here and, you know, teach his parents about these things.

(Gujarati)

41:20

INTERVIEWEE (F): I started like does he think that it's necessary for more of these meetings like this for the community and he said yes *****

INTERVIEWEE (F): The reason it works well is because the setting that we are in. We are in the Temple so people would not be afraid to come to the Temple. They know that people in here are devotees of the Temple, but although it's a taboo subject outside the Temple, within the Temple the doors have opened to discuss these issues. So although they wouldn't go to speak to a priest about it directly, but it's a safe house. It's a safe house.

MARGARET: Yes.

INTERVIEWEE (F): You're speaking to, you know, a professional that's going to educate you about something you don't know. It – it sort of makes it more formal in the Temple whereas in a community hall then it might be like ***.

INTERVIEWEE (F): It breaks a barrier, doesn't it?

INTERVIEWEE (F): ***** public, *****.

INTERVIEWEE (M): Like there are ten of us today, next time if we have some discussion like this there'd be about twenty and once the word spreads people will start coming in, especially younger generation will come in and chat about it and then they can go back and take leaflets and whatever, and then pass it on to the older generation. You know, a learning process.

(Gujarati)

0:42:44

INTERVIEWEE (M): He says that before immigration they would have a medical check up before you could come to this country, there's no such thing as that now. Before it was good. If you failed you wouldn't be allowed to come into this country, but then they'd give you a reason why you failed.

INTERVIEWEE (F): So are you saying you didn't have a medical check up before you came to this country?

(Gujarati)

0:43:42

INTERVIEWEE (F): He's saying – he's saying where he came from Africa, then he should have a medical test because that's where AIDS came from.

(Gujarati)

INTERVIEWEE (M): In our education when they gave it to us on the course they said don't blame only Africa or the monkey. Men always go for the business in his own way. Yeah, and he go India and Hong Kong and here and there and then he enjoys his life there. That's why they pass it to each other. But don't blame only Africa or the monkey or. Tourist people also go here and there.

(several people speaking)

INTERVIEWEE (M): What they're saying on the training courses is that, they actually said that the sailors at that time used to go to abroad like Africa and places, and you know they didn't have their wives with them so they had good times everywhere and that's how it spread.

INTERVIEWEE (F): *****.

INTERVIEWEE (M): It was a big trade.

INTERVIEWEE (F): To go back to what we were talking about a second ago is – to get in the Asian community, to get the older community involved, the older sort of like our grandparents or parents involved in teaching their kids, something like this would work well because they feel even if their kids was taking them by the hand here, they know that it's a good thing. They'd have somebody else teaching their children as opposed to them being there and them doing it they'll still be able to be in on it as well.

MARGARET: That's helpful, thank you. Um, we're nearly at the end. A message, if you can think of a message which would help ensure that there is support for people affected by HIV in this – in your community, this community, what would – what would be a single message that you would want to communicate?

(Gujarati)

0:46:28

INTERVIEWEE (F): I don't know if how suitable it is but knowledge is power, as simple as that. Knowledge is power, you know, to learn about it.

INTERVIEWEE (M): I think the message I'd give to people is do this sort of thing again and send leaflets out to people, on board, stuff out on the streets. We've got an HIV discussion meeting. What do you know about HIV? If you don't know anything about it please do come along to this centre then...

INTERVIEWEE (F): Increase engagement, community engagement.

INTERVIEWEE (F): Have it in the language that's spoken in the area so it's understandable to everybody.

INTERVIEWEE (M): It's like today. It's hats off to people who turned up today and had this discussion. I think that's what we need to do go out in the community and get more people involved and say to them look you know this is what we need to talk about. Are you open to discussions? Get them coming through.

MARGARET: And do you think, um – do you think the religious leaders can be involved in that? Do you think it matters what religious leaders say in relation to HIV?

INTERVIEWEE (F): I think it's perhaps good that they're aware that it's happening but they're not present in the room at the time because many people can be intimidated by religious leaders, by their presence.

INTERVIEWEE (M): I think the religious people, like me saying the priests, I think they need to be educated as well, and educated and I think they should come to these discussions and see what their views are.

INTERVIEWEE (F): Yeah.

INTERVIEWEE (M): It would be nice for them to come along and see what somebody who did have HIV, how supported would they be?

INTERVIEWEE (F): But they could also promote openness.

INTERVIEWEE (M): Exactly. It would be a good idea.

INTERVIEWEE (F): But then it's very dependent on the priests themselves because our society it's related to culture as well, and community is – you know, if you go to some place like XXXX it's society very much walking down the street where you know, families are all interlinked especially – and you know a family, one family is always linked to a place of worship, so it 's a kind of....

INTERVIEWEE (F): With a priest, he is usually quite old number one they're religious you know so you respect him on religious grounds then you respect them on the age grounds and they're so much older than and you respect them, then there's a respect boundary because you don't want to talk about certain things in front of them because you know there are certain expectations and you don't want for them to know about your personal life. There are so many boundaries between you and them. It's about losing face in front of them. It's a good thing that they accept it but you'd worry about whether it would have a direct impact on Hindu society as well, how people are perceiving things because then it could blow out of proportion, it could become a bit too open.

INTERVIEWEE (F): Because – I think there's a thing that if you make it too open – not too open, but if you not like overeducate people, but you don't want to make it so that promiscuity is sort of widely accepted as well. You know, there is that fine line between being open and liberating and educating and then also is it then acceptable for you to go and have sex with everybody and you know as long as ***** there is that compromising your values and your morals. And as a religious leader I guess they don't want us to do that either.

MARGARET: So you feel that there's a balance to be struck?

INTERVIEWEE (F): Yes, a very thin line.

MARGARET: But that the religious leaders do have some influence in terms of the kind of message about HIV that would be communicated to the wider community?

INTERVIEWEE (F): Yes.

MARGARET: We have finished this as far as my questions are concerned. Is there anything that you feel that you'd like to say that we haven't covered that, you know, hasn't been said? I'd be very – you know, I'd be very happy to –

(Gujarati)

INTERVIEWEE (F): What is the difference between HIV and AIDS?

MARGARET: Well we can have that conversation if we've finished the – is that it?

INTERVIEWEE (M): Yes, that should be it.

INTERVIEWEE (F): If you know anything about HIV, you can tell someone. When I was seven years old I knew about HIV when I was in India.

INTERVIEWEE (M): So you were taught in India about AIDS?

MARGARET: The one person knowing, they can pass it on to another person, and then gradually, gradually more and more people get to know. Yes, Yes, – that's helpful, thank you.

APPENDIX F1a
TRANSCRIPTS - INTERVIEWEES
Interviewee: AO1

MARGARET: Do you attend a place of worship; a church?

INTERVIEWEE: Yes, I attend a place of worship.

MARGARET: Where do you go?

INTERVIEWEE: XXXX

MARGARET: And is that XXXX?

INTERVIEWEE: Yeah, but we go – we do it in our own language, in XXXX language for Zimbabweans in the afternoon, yeah. We gather there in the afternoon at 2 o'clock, all Zimbabweans in our own language.

MARGARET: And so do you have a minister who comes?

INTERVIEWEE: Yeah.

MARGARET: A Zimbabwean minister?

INTERVIEWEE: Yeah, a Zimbabwean pastor.

INTERVIEWEE: And lay leaders, they will be there. Or sometimes the pastor will come like in two weeks' time but because the congregation is very big now. Congregations come from London, Oxford, Coventry, Northampton, even Scotland there are some.

MARGARET: And do they come each Sunday? They don't come from there to live in Leicester?

INTERVIEWEE: No, we just like – we are in Leicester. We also do our gathering in there, there in XXXX.

MARGARET: Oh, I see what you mean, yes.

INTERVIEWEE: But like yesterday we went with a bus to XXXX to have a service together. It was organised by the youth.

MARGARET: And did you attend a place of worship before you were diagnosed with HIV?

INTERVIEWEE: Um, before, I was just going to English mass, you know there are a lot of English mass but then thereafter, I heard that ah! There are people who are doing a gathering like the Zimbabwean XXXX in our language and I said ah, let me go there because they are doing it at the house in – in XXXX. So then when – so that people will be coming like more and more then we decided to find places like the church to do the service.

MARGARET: And how long have you been here in – in the UK?

INTERVIEWEE: Um, from 2001. I think it's almost five years?

MARGARET: Were you diagnosed before you came here or since you...?

INTERVIEWEE: No, after. After I came.

MARGARET: But you've been going to church? You've been attending church...

INTERVIEWEE: Yeah, I have been attending church....

MARGARET: ...before you were diagnosed and before you came here.

INTERVIEWEE: Yeah, before I came here.

MARGARET: And are you actively involved in your church? I know you go to the services, but do you have any other roles there? Are you involved with, say, teaching the children or music or saying the prayer?

INTERVIEWEE: No. I just go in there.

MARGARET: You're in the congregation, a member of the congregation?

INTERVIEWEE: Yeah. I go to worship.

MARGARET: Yes. And that was the same before your diagnosis?

INTERVIEWEE: Yeah. You know sometimes you feel to run around like you want to be – I want to like play with the kids. I want to do this, but you feel like you don't, like, make the

commitment that I can do it willingly. But you have to like take your time to think that, "Can I manage to lead the people?" or *****.

MARGARET: Yes.

INTERVIEWEE: But we can help if like maybe there is a – there is a all-night prayer, we can help by cooking, by just volunteer cooking or helping some of the things, not like I have to be, to have a role.

MARGARET: No. But you do sometimes do that, do you, help with the cooking through the night?

INTERVIEWEE: Yeah. Yeah, serving the food or something like that, yes.

MARGARET: Now some questions about the wider issues about HIV. In your view, what are the main factors contributing to HIV transmission around the world or in the UK or in Leicester? Shall I repeat that?

INTERVIEWEE: Yeah.

MARGARET: What do you think are the main factors contributing to HIV transmission around the world?

INTERVIEWEE: ***** like, um, to get support from the local authorities or to find it easier for you to – to live in the community and how to – you know, like, they don't even know that ***** but they don't even know that I'm HIV, but how do I cope with that *****?

MARGARET: So –

INTERVIEWEE: And how do they cope if they came to know that I'm HIV positive?

MARGARET: I suppose what I'm getting at is, what are the – what do you think are the kinds of things that make HIV transmission happen, that make infections with HIV happen?

INTERVIEWEE: But sometimes you don't even know that how will it happen. You know, sometimes when you get it like me, I didn't even know that I got it. I just think it came from my pants. But what makes me go to have a test is that my partner say, "Ah, you must go and get tested." But I wasn't even insistent or thinking of that. I was just like I came here to do my business. I have nothing to worry about. I'm not sick. I don't have any problem in my life, so

how can I just go and say I need to have a test whilst I'm not sick and I don't have any like something which is ***** into something that can – that like the kind of showing that I've got HIV. I didn't even know that kind of thing, so I just said, "Ah!" But my partner say, "Just go for the test." I said, "Ah! How can he tell me to go? I am not – Ah! positive" I refused it at first. I say, "Ah, what is the purpose of going there whilst I know that I am okay, I am all right?" ***** so I said I won't go. So he was trying to persuade me at the time but he himself, he didn't want to go. He said, "I had my test, and I had – I said let's go together then because you need to be tested right now so that I'll get – I'll make sure you are – " but then he refused, but then he say, "You go because me I've – I've already had my test and it's negative so you go because I don't know what the situation is."

MARGARET: And this was in this country?

INTERVIEWEE: Yes, in this country.

MARGARET: Do you think HIV is a concern as a public health issue in the world or in this country or in Leicester? What do you think from what you see, from what you understand?

INTERVIEWEE: I think it's a public health issue because it's not like there's – because it's in the whole world, so I think it's a public health issue because almost everyone now you don't know that the situation or most people now they've got HIV. Some, they are not even tested right now. There are so many are just saying that they don't want to go for – they don't want to show up or to go for the test.

MARGARET: And you think that's the case in Zimbabwe and also in Leicester?

INTERVIEWEE: Yeah. Even though in Zimbabwe, people they don't even go for test. I don't know right now if that they know if it's there, but they don't go for testing. Like me, because I had to be tested before I even ***** they don't – like they don't – if like some – some places like XXXX you just call yourself privately and you had your test and then – but unless they take your – even if they take your blood for a treatment, they don't test all that. They don't get all that information because they say no this is - we can't just like got that information they tell the person. They don't do that. They just like – like in that, they just treat you like you are sick with something. That's it. They don't go deep like and up to that extent. If you are sick, they just sit you and they tell you when you are sick, when you become ill, that's when they tell you that this is HIV. And it will be smooth. It will be serious that time and you don't get any medication or any treatment or ***** . You don't get any medication or any treatment. And you don't get any help from the society or from – yeah.

MARGARET: Do you think HIV is a concern in your faith community? In your faith group? In your church?

INTERVIEWEE: Ah, because you know it's – it's quite difficult to say like – to tell your members of the church or your – your leader. It's quite like you say this is private. This is like confidential. No, you can't even tell your partner but that when you really wholeheartedly that, "I must say it now." It's time for me to say but you can say it but then it's really very difficult because you don't know maybe that person he won't keep it private. You just like maybe talking about it, this and this, telling like other members that this when you see – you think, "Ah, why did I tell this one? No, he can't keep the – he can't keep the thing privately." So that's why you feel sometimes you doubt to tell the pastor or the leader that – that – for how that's – that is your condition. But it's almost worldwide that people know there's HIV in the first place, you know, but to tell him that you've got it is quite difficult.

MARGARET: What do you understand your religion is, that your church's teaching and beliefs say about HIV? Do you connect any of the teachings in your church with HIV?

INTERVIEWEE: You know what they do? Sometimes they'll be just praying like, you know if you are making prayers, in the middle of the prayers, the church leaders they will just be like, "People who are ill, who are not feeling well, including those with HIV," but it's just a normal prayer but they don't know who are the people in there in the society In the churches, who, we have got HIV, but they'll be just saying it as a normal prayer for everybody who is ill, different illnesses, some have got BP, sugar, *****. They've got different, different types of illnesses so they just include those with HIV, but they don't know. They don't know who are the members that who are really affected with it.

MARGARET: No.

INTERVIEWEE: And so it is quite difficult to pass around that information, that even you, you'll be thinking, if I tell this man, my pastor now, what does he think, the way he reacts – you know, it's – he's a human being. They are human beings but the way they react sometimes, they will be telling those people who are not even, and you can hear that – oh, the whole – all – everyone, they all seem to think, ah, she's got – she's got – do you see? That's why you're trying to avoid that. Because people will be pinpointing you behind your back. "Did you hear about the lady there that she's got AIDS because they say she's got AIDS," but you'll be confessing to your pastor that this is private, but himself is a human being. He can't keep it in his heart. He just like telling some – once he tells one person, ah, that person will tell another person until the whole society's found out your information. You get what I mean?

MARGARET: Does your Christian religion, beliefs, and teaching say anything about intimate relationships, those closest relationships?

INTERVIEWEE: They'll be just teaching about how to – how to – to like – how to – how to handle your family, how to – the difference between the husband and the wife or the, they don't talk about anything like – they don't talk about – mostly they don't teach anything about HIV, but they just talk about these feminists wife they know, because they don't know, really deep down what's happening in your family or in your relationship or partnership. They really don't know. They just know that these people are together and the way they must live like no arguing, no fighting, no violence, you know just try to sort out the marriage, or the relationships to work out. Or for you to have a good relationship, you must do this. That's what they always teach about.

MARGARET: So about –

INTERVIEWEE: Like me we have never contacted -

MARGARET: So the expectation would be that it would be marriage?

INTERVIEWEE: Yeah. Yeah, because we have never expected to get to teach anything about HIV since I was going to, but they don't even teach about HIV. I don't know to the youth section they will be talking about it that they don't even normally teach about HIV because there's no one, no one like who come up that saying, "I've got HIV," because – but maybe I think it's private so that's why they don't even want to enter that chapter again or –

MARGARET: So there is no real teaching about intimate relationships, sexual relationships or HIV, how a person might contract HIV or anything like that at all? It just doesn't – it just doesn't happen?

INTERVIEWEE: Yes.

MARGARET: And do you think – I don't know whether this question is pertinent in the light of what you've said, but how far do you think people in your church or your wider faith community conduct their intimate relationships according to their religion's teachings? So I think what I've heard you say is that the expectation is that intimate relationships, those closest relationships, sexual relationships are within marriage and – and so how far do you think, within your community, those people are conducting their intimate relationships within a marriage situation?

INTERVIEWEE: But even if you are like, you know, just considered their marriages like even if you – if you are not married, they can just support you by staying strong because maybe ***** but you are not married, like me now I have got the child with a partner, they just like give you – like just help, ideas to – to live your life and to – just help. You know, like if you are going to a gathering, some of the things you have got a problem with, can't even think what to do. You're confused. You say – if you go to them they just like help you, you tell them what's the problem you have and then they can make prayers for you, even to visit you as a member of the church, they can visit and say we have to go to offer, maybe you are just – you are sick or you are ill. Those are the people who can support you in prayer and all those things that go to.

MARGARET: And that happens?

INTERVIEWEE: Yeah. Yeah.

MARGARET: So people aren't being judgemental about a person's relationships or anything like that?

INTERVIEWEE: No.

MARGARET: They generally just want to be supportive?

INTERVIEWEE: Yeah. They just want to be supportive that you've got a problem with or you are having a problem with your husband, they'll support you but it's not that the whole – the whole congregation will know that, ah, this one is having problems with the husband. That too – That's – some people they can't keep some of the secrets. You know, if they had something, they would tell ***** and you end up knowing that ah, they are having a problem with their husband or whatever. You know, sometimes you – but you cannot do anything. People will be gossiping. People they can gossip, you see, but then it's not even good to gossip about something which is private like that because once you tell that, ah, I've got HIV, the person who you told will be shocked. That's why even to keep – trying to keep it in his heart or whatever without telling somebody else who is just like thinking that is a close person to him, but that person doesn't know what to think. They also tell the information to other people. You see what I'm saying, so like...

MARGARET: Yes, thank you. So do you think then that – that the sort of teachings and beliefs that there are about relationships and so on, do you think they influence how people in your church respond to HIV or do you think, um – suppose they knew that a person had HIV. Would they be supportive in the same way that they'd be supportive if someone was having trouble with their husband or something? Would they be as supportive or do you think they would behave differently?

INTERVIEWEE: Ah, they will be supportive because once you tell them that you've got HIV, they will be supportive because you need a lot of, like, a lot of guidance and prayer. Because it would be better for you to be able – like to help you with prayers and praying almost every time because God is the only person who can heal the person even – not like if you are – you are HIV, even if you are taking the medication, sometimes it – it doesn't work like – it doesn't work out - because you have got something different – different things in your blood or in your mind. Sometimes the medication can even fail to work for you because you've put a lot of – if – you need to be supported by prayers as well. God will need to heal you again, but not a hundred percent healing, but he's got the power to heal *****. So you have to – if you believe that God has got the power to heal me, I mean not – not the lay leader or the leader of the church, but you yourself you have to give permission that God will heal me.

MARGARET: Yes.

INTERVIEWEE: And to have the strength to walk or to do this, to walk around or run around like you are not even sick, it's God's power. You know what I mean? It's not like *****.

MARGARET: Is it different for people outside your church or faith community? Um, how do you think they respond to people affected by HIV? Um, do you think the religious teachings have any effect on how they respond too?

INTERVIEWEE: I was going to say the community as well. *****. Aha, they try their own way to help people with HIV. They act like if you are – let's say I'm just ***** they say to go out somewhere, find just a peace and quiet place, talking to you. They are really supportive for me out there.

MARGARET: You're painting quite a supportive picture. It seems in your view, people generally, if they know a person has HIV, if that's a religious person or not that they're going to be quite supportive.

INTERVIEWEE: Um, not from the religious side, but from just the community, the faith groups who are just being formed around this - in Leicester here. Those are the ones who really support more because – but even in the church, the members can support you but they – the point is that you didn't come open to them that you've got HIV, so they cannot just list the ***** , but they give enough support that they support you as a member of the church, but not that you've got HIV because they don't know and you didn't tell them that you have got HIV. It's not their fault that they don't sup – but they give you – the support that they give you, it's okay because they don't know the situations or your life history.

MARGARET: Yes.

INTERVIEWEE: ***** This is something which is deep down which is that which you cannot say. Even me right now, I can say my XXXX doesn't even know that, but I am just waiting for the time where I'm thinking, "Can I tell XXXX?" They are still like in the middle of anything *****. Now I can tell you now because I can't keep this thing from her. I feel like she's the one who's going to give me a lot of support. *****

MARGARET: Is XXXX in this country?

INTERVIEWEE: Yeah.

MARGARET: Is XXXX in Leicester?

INTERVIEWEE: Yeah. XXXX is the one who is always like, "Are you all right?" Calling me, this and this, even with the baby. Even though XXXX always, like, XXXX always caring about me but XXXX doesn't know that – I don't know. God, you know, sometimes it just like a click to say, "Ah, I need to help my XXXX in any of these things." Like we were had a baby shower – arranged for a baby shower, me I told XXXX I don't want even want – anyone to like a baby walker or baby shower or something like that, I don't want, and XXXX just decided to do it. Say, "Ah, I just need to do it for my XXXX. A baby shower you can get gifts." XXXX's trying to explain to me that you can get clothes. You can get this, this, a lot of things. People will come with presents. And I said, "No, I don't need that. You get what I mean, because it's different, like you say, "People were thinking maybe I can't manage to support my child." ***** "No, no, no, no. Let's just do it." A baby shower there. Because XXXX just – XXXX never – you know, like if you – if you say – my XXXX doesn't mind. XXXX just do it like it is a surprise, but me, XXXX knew that I need to tell XXXX, to ask XXXX do you want that because XXXX knows maybe, ah, XXXX doesn't want. As I say, I don't even want a baby shower at first when I was pregnant. I don't even arrange a baby shower. No. ***** The baby's there, "Can we arrange a baby welcome?" And I said, "Okay." *****.

MARGARET: We've covered –

INTERVIEWEE: ***** people will be gathering and will be wasting a lot of money, buying food, buying this. You just – you spend a lot of money on those things, other than like – people they just, like, no gathering. If anyone wants to bring presents, just bring presents or the money to me. Give the money to me because there's no need to buy these things, food, ***** . I think it's quite expensive to buy it. They say, "No, no, no, no.

It's not. Let me do it." There are people who are willing to help like making
***** somebody say, thirty pounds, thirty pounds, then they'll do the baby
shower, but me I always think and say, "Aha, why not give me that money and then I'll do
what I want with it?" I'd rather they give me the money that will pay my bills or pay this and
that and for a lot of things other than buying food and *****doesn't make sense to
me ***** I'll send money home to my XXXX who are back in Africa. That they
will enjoy the money but not to spend the ah blah, blah, ***** all the time.
Sometimes you get – You think, these people, "Why not give me that money?" There is
somebody coming *****.

MARGARET: Oh, I'm sorry. Shall I take this off you? Some of these questions we've
covered. The question is do people in your church talk to one another about HIV? What I
think what you've been saying is they probably don't talk to one another?

INTERVIEWEE: Yeah. The people don't even talk to one another about HIV because
sometimes, last time I just met other people in the GU clinic, you know, like those are church
members, I met them in GU but I was surprised, "Ah!" So you can't even – can't even ask
somebody that – are you - because you've just met in there and what the result. You know
the result and you can't really ask. No.

MARGARET: So you don't even talk about it to those people that you might have met in the
GU clinic?

INTERVIEWEE: No, I don't even – even them, they don't even come to approach me so
because we just like, ah, there's only a few who know of my condition or I don't know, people
they think that different way, but you just see each other, then you keep quiet. There's no
need to talk about it in the church. To ask her, "I saw you there." Oh, even though she's also
a - ah, I can't even ask her that. I saw you at the GU, what were you doing? Nothing. No.
XXXX. I think she's tired of sitting there.

MARGARET: I'll hurry. I'll hurry with mummy. And you don't talk to anybody in your faith
group?

INTERVIEWEE: No.

MARGARET: And the reasons why are because?

INTERVIEWEE: I only talk to the people I see like in the faith groups like at the hospital or
the LASS group or the Red Cross. That's the people I just meet and tell them because I know
they can give me support. I am not saying those church people –

MARGARET: But these aren't people – not people in your own community?

INTERVIEWEE: No.

MARGARET: These are – the others, yes?

INTERVIEWEE: Yes.

MARGARET: The staff at –

INTERVIEWEE: And even though I meet a lot of Africans there, but then they just know because *****because we will be the same ***** HIV people were there ***** HIV societies, HIV support groups, so they just know that anyone who has come here will be talking their stories about their tablets or medication today, but I don't take it out to the like, to the church and then ***** because they can give me support if I tell them but there's no – you know, sometimes you say, "Ah, how can I tell this church member that I've got HIV." Or some of them are like, they will be asking, "Why are you not breast feeding? Why not," but I didn't even tell them that this is the condition. But even if some of them, they research, they know that the person has got ***** because of this disease, maybe they know, because – but then they cannot approach you to ask you, "So are you HIV?" ***** they can't even do that. You get what I'm saying?

MARGARET: Yes. So what if you saw somebody from your church at LASS, would you?

INTERVIEWEE: Sorry?

MARGARET: If you saw somebody from your church...

INTERVIEWEE: Yeah?

MARGARET: At LASS?

INTERVIEWEE: Yeah.

MARGARET: Does that happen? Would you – would you speak to them then?

INTERVIEWEE: I can speak to them because definitely they just come to the LASS group, but I've never seen one go. Some people even though they don't even want to, like they know that ***** but they don't even go there or if – I don't know if they know about it

or they don't know, but they don't even go there. I've never met people from my church, but those people I meet, maybe they've got their relatives who are in my church. They will be saying, "Ah, this person *****" Like I saw a child there, the last time I saw the child, I said, ah, I know this child. The child just came with another lady. Then I was telling the mum that "Ah, I saw your child at this, this, this." But she didn't want to mention, to say ***** but she just say, "Ah yes." She was trying to say, "Ah, where did you see my child?" And then I'm thinking maybe – that's what I'm saying. People they think it's private. They don't want anyone to know, so they don't come to the LASS to see other people. They don't want to see – meet people that they – people definitely know that ah she's got HIV - or they just come and collect their food vouchers and go. They don't want to stay like, they chat they eat there because they are *****

MARGARET: They don't want to –

INTERVIEWEE: They drop in. They don't want to come for the drop in because they know that they will meet other people in there, and people will get to know that they've got HIV. They don't want people – so many people to know, so they just – know them, they come and collect their food vouchers they'll come and collect and go for their support for their food and all those things.

MARGARET: So it sounds as though quite a lot of people will not be accessing the support that is available because they are so anxious about meeting somebody that they know?

INTERVIEWEE: Yeah. Yeah. Exactly.

MARGARET: Do you think it's because of the religious teachings and beliefs that people – whether or not people talk to one another about HIV, or do you think it's something else? Do you think it's about the religious –

INTERVIEWEE: It's not – it's not about the religious. It's not about the person the way she takes it because she thinks maybe, if I – if I go to the public place and to the mass or the people that have died from AIDS, I don't want to. It's not – it's not about the religion. It's about the person watching, he or she. If I go there, then people will come to know that I've got HIV, you know. Once that time I say I come across another lady in the GU clinic. I was also surprised and she was also surprised that, "Ah!" and then no one said anything. No comment. Nothing. No questions. We just look at each other. "Hello." "Hello." Then she goes on her way, and she couldn't stay for long. I don't even know where she was going, but she couldn't even stay for long, but once you see the person there, you just know that it's not their first time to be there. And you know definitely I think she's got an infection or HIV. It could be anything, maybe she's got gonorrhoea or something like that, but you can't just ask

the person to ask, "I saw you that time..." you know? People they don't want anyone to know. Ah, it's just like we came across that day because they say, "ah." And she was also the way you react when you see each other. You look in your eyes. You'll be talking by your eyes only that there is no like language there.

MARGARET: So also your religion, your beliefs haven't influenced whether or not you talk to anybody. It's not to do with your religion?

INTERVIEWEE: No.

MARGARET: No, it's about –

INTERVIEWEE: It's nothing to do with me because I say ah, like now I'm saying I didn't tell my XXXX. It's only me that, "ah," shall I tell her? It's not according to - ***** because we go to the same church with my XXXX and the husband but that's 'can I tell you' or what?

MARGARET: So would you say it's a cultural thing or would you say it's just something that's difficult because it's talking, perhaps, about something where there is a big stigma?

INTERVIEWEE: No, it's like a cultural thing that, like, the XXXX if I tell you, maybe she won't even come to see me, or the way that she will look to you won't even be bothered. You say now if you – or if you are sick or if you are sick she can't even come to you but then you say, "ah," maybe ***** distance that your XXXX will be now distant away from you. But if she is a good person, she say, "Ah, I cannot just avoid my XXXX because of that. I need to help her." ***** but you don't know the way she understands about that. Yeah.

MARGARET: Simply because you've never talked to her about it?

INTERVIEWEE: Yeah. Because we have never talked about it.

MARGARET: Um –

INTERVIEWEE: Let's see now –

MARGARET: Do you want me to hold her or do you want to... shall we just stop that? Um, so we – we've said it's not religious teachings that affect whether or not people talk to anybody about HIV. It's more about cultural reluctance.

INTERVIEWEE: Cultural beliefs and...

MARGARET: Yes. And that would be the case whether or not people talk to health professionals or teachers or pastors about HIV? Just reluctance because it's not in the tradition/culture, the tradition of the culture to talk about those kinds of things. Is that what you're saying to me?

INTERVIEWEE: Yes.

MARGARET: And you've talked about your partner persuading you to go for a test.

INTERVIEWEE: Mm hmm.

MARGARET: That must have been very difficult for you then, with those cultural beliefs? Did they get in the way? Did they prevent you going to inquire about it?

INTERVIEWEE: It was very difficult for me because I just – he just wanted to know that what - ***** if I have HIV or not. But then he didn't even say that – he didn't even say that ***** I don't love you because you've got HIV. He's just like, "Go for testing, then from there we'll see what we can do," because I asked, "What if it comes positive? What will you do?" I was just asking that. ***** Let's say I've got AIDS, then what will you do then? Let's say I will be HIV positive. What *****He say no, he just want to know. But I don't want to like, say like, if I know it's okay then I know that ***** just go for the test, so if you don't go ***** because you don't want to be honest.

MARGARET: That sounds very caring of him.

INTERVIEWEE: Yes. Yes.

MARGARET: And he was saying that he wouldn't have left you if you had HIV but he might have left you if you didn't go for a test because he thought that was not being honest?

INTERVIEWEE: Yes. Yes.

MARGARET: So it was your partner helping to encourage you and persuade you that gave you courage to go and set aside your cultural beliefs and go to –

INTERVIEWEE: Also what was worrying me now me I go for the test and have HIV. He says me, I don't want to use a condom. I say you go for the test again ***** maybe you'll get the HIV or not so you go for the test. He was refusing. I don't get HIV from you. His

cultural beliefs. Because when I'm ready to go, I'll go but not now because *****. We have sex together without a condom. How can you say you don't get it?

MARGARET: Right.

INTERVIEWEE: So how can you say you don't get it from there? No, I know because of this because he comes from XXXX. He didn't want to come.

MARGARET: But I thought you said he had had a test?

INTERVIEWEE: Yeah, he had a test, but –

MARGARET: That was awhile ago?

INTERVIEWEE: That's like a while ago before he left.

MARGARET: Oh. So he wouldn't go for a test after he knew that you were positive?

INTERVIEWEE: Yes.

MARGARET: Right.

INTERVIEWEE: 'I am OK'.

MARGARET: So he convinced himself that he was OK even though he may not be?

INTERVIEWEE: Yeah, even though he may not be.

MARGARET: And you can't persuade him to –

INTERVIEWEE: Yeah, I can't even persuade him. I tried ***** and he didn't want to come.

MARGARET: I think we've covered some of these other questions. This question is - have you disclosed your HIV status to anyone in your faith group? Well, you've already said you haven't, have you? And the reasons are because of gossip and people –

INTERVIEWEE: Because ***** there's no, like, they didn't form any group like we need to talk to people but to form groups in the church. Because once you tell the person, they will like tell people you know like ***** they don't – they can't

keep things private. They don't, like what you are saying. They don't ***** confidential. They don't even know about that. They just like – they think ***** just say to people everyone knows that ***** you know like everyone even a person who is not even responsible for that, she mustn't know that. She cannot do anything about that rather than telling the whole place, the whole list that they knew that ah, these people have HIV, people they can't keep information – inside information like that.

MARGARET: Why is that? Why won't they do that?

INTERVIEWEE: I don't know. You know, it's like important to the culture as well
*****.

MARGARET: Everybody thinks they are to know everything about everybody.

INTERVIEWEE: Yes. Yes. To know everything about everybody, but I always just like this is like – you can go like to the hospital, that's it. To the LASS, to the Red Cross, those people they ***** You know that they don't even pass information. Even if they pass it, those people they don't ***** they don't know you but the people, if they who you are, it'll be a full story. ***** on the front page. They will be like marketing the story.
*****.

MARGARET: I think we've covered a bit of this. Do you know another person with HIV?

INTERVIEWEE: It's not like, you know they will be shocked. ***** shocked they maybe if they see you've got HIV, they think you are dying that day or that year or that day. *****"Be careful." They'll be just like ***** as if you are dying that day or as if it – you know, like they'll be saying there's no medication for it ***** disease, they think ah, the stuff like *****
Sometimes you see people discriminating ***** to sit next to you or to ***** Africans, they do that.

MARGARET: So even in the UK do people not realise that you can have medication and –

INTERVIEWEE: I don't know here, but I'm saying as African, even if they know you're getting the medication, people they just like, they don't even like to say ah. They can't even like sit next to you or talk to you. Some of them will react that way. It's not everybody, but some of them, most of them, they'll react. As Africans, they say ***** They can't even think that you're just the same, but some even to say to use this, to sit this or ah,
*****.

MARGARET: And do you think it would make a difference if the pastors of the churches spoke out about HIV and explained that, how HIV is transmitted and that it's important that people who have HIV feel supported and are not discriminated against.

INTERVIEWEE: Yeah, I think it's best that the pastor, if they find that a group can join together, find information that AIDS people are – people who are HIV, they need to be supported, not to be discriminated. You know, you can share – you can share everything with them, even like – it's just like, even this tea towel, dish towels, kitchen things, kitchen stuff, you can say even normal things, newspapers. This plate was used by this person. I cannot even use this plate again. You see, it's not like the – the AIDS, the HIV went to the cup or went to the plate or went to the spoon. It's not that, but it's transmitted through sexual or through those like, uh –

MARGARET: So you think if the pastors were giving information to the congregation, the people in the church, that that would make a difference?

INTERVIEWEE: Yeah, that would make a difference. Yeah. Yeah.

MARGARET: People would listen to them and...?

INTERVIEWEE: That would make a difference. People will listen to them then.

MARGARET: I've asked you about whether you know other people with HIV but not in your church? You don't know people in your church, other people in your church with HIV?

INTERVIEWEE: I don't know.

MARGARET: You've told me about what you receive from your faith community. They don't know that you have HIV, but what you receive is support and you feel comfort and the prayers are helpful and all of that.

INTERVIEWEE: Yeah. Even though they can ***** , they should say it because I need prayers to help. If there is something worrying me, they just come and do the prayers. Or they can pray if they are in their – their houses, that's okay, God will always listen. So it will relieve you from stresses and depression or even if you are sick, they just – they can't ***** is it part of HIV or is it just you are sick with something like, you know, a cold. Even though you'll be sick like, "I'm not feeling well," they can come and see you and just make a prayer. You feel strong after that. You feel if it relieved because you have got ***** some people, members of the church who are supposed to come in, cheer you

up making prayers, come and see you, "Are you feeling well now? Are you feeling all right? Let's have a look." You say –

MARGARET: And all of that is important to you?

INTERVIEWEE: Yes, that is important, yeah, to me because I know that I've got my friends and ***** there who can support me in that.

MARGARET: So you've never had an experience of how your faith group, your church or your pastor responds actually to a person with HIV because as far as you're aware, nobody speaks of it?

INTERVIEWEE: Yeah, nobody. *****

MARGARET: So we don't really know. It's just about being a little bit afraid of whether they would discriminate or whether they would exclude you or – or anybody with HIV. It's never actually happened, it's just that you fear it might happen?

INTERVIEWEE: Yeah, it might happen.

MARGARET: Um, yes so you – so you do get support from other agencies in Leicester and LASS is one of them, and the Red Cross.

INTERVIEWEE: Yes, the Red Cross.

MARGARET: Anybody anywhere else?

INTERVIEWEE: Um, *****

MARGARET: Are there ways that you think that services that are provided, the support services and so on could be improved in Leicester?

INTERVIEWEE: Hmm.

MARGARET: Do you find them, you know, adequate to your needs or do you think there could be something more, something better?

INTERVIEWEE: Um, *****there must be something more because once you get there, they – what they will – they don't do is that they can't give you, like, they give support

us, but you need something like you can just go to that, to that – to those shops that they give you the vouchers. Maybe you need to buy something extra with cash, you get what I mean?

MARGARET: Mm.

INTERVIEWEE: You can't even – like you need to buy meat somewhere else. That's what you do just buy this beef from the same place, the maize meal. Maybe you don't like that type of meat. You like something else different. You know like we – we like African food. I have to buy it maize meal. I can't get it from Sainsbury's. I want to buy meat to – that is, you know meat from Newton King? There is that meat from Newton King. It's like beef from Africa. You know what I mean? So you need to buy that type of thing, even there is sausages ***** , exactly that you say if you detest that like from Africa. So, or ***** so you need to find those food stuff off your – off your – African food.

MARGARET: Yes.

INTERVIEWEE: You need to buy it from those shops, those African shops. So you can't just do it because they give food vouchers for Sainsbury's so you can't do that.

MARGARET: Mm. And that's the only place that you can go, is it? Sainsbury's?

INTERVIEWEE: Yeah, that's the only place you can go with those vouchers. It's not for like, you can't even go any other shop. So maybe you need something like different foodstuffs even if you need your – there is quite a plenty of food, African food in this country now.

MARGARET: Yes.

INTERVIEWEE: And you can't go and buy that because you just to buy only those things from Sainsbury's. At the end of the day, the fruits are just the same, like bananas, oranges, but you need to buy the maize meal, you need to ***** , you know African food, so sometimes you need cash. You don't need those vouchers. You need cash. Just 50/50, if you get the ***** thirty pounds or you can get thirty pounds in cash, then you go and buy these things that you need because you had one ***** for them ***** they are not for that because they don't know what you really want to eat. They don't even ***** . There are some things it's good that they take that side that you need cash to buy the maize meal, the food that you want, the meat you want. You have to be free to buy what you want, to know what you want ***** because we have no choice now, we just say, ah, once they are giving me this, okay, that's okay I can't say – I can't say no. I can't say I want cash maybe because they are ***** there are policy is that they don't want to give cash to people. They just want to give you the vouchers and you go to shops or places or... You

can't get – otherwise you have to find your extra cash to buy the *****; to buy the food stuff, like African food, because you can't find those things in Sainsbury's. Even the vegetables you like like ***** , you know *****?

MARGARET: Yes.

INTERVIEWEE: You can't even get it from Sainsbury's. So you like something like that *****.

MARGARET: Are you able to tell them that it would be better if you could have part vouchers, part cash, say, because you have those particular dietary preferences –

INTERVIEWEE: No, we are not able to tell them because they just say we are only giving vouchers.

MARGARET: The only thing that they can do?

INTERVIEWEE: Yeah, that's the only thing that they can do, so some things ***** no choice. That's the only thing they can do. That's the only way they can help you. They cannot give you cash. You know some people they think that it's only that it's – it's not – it's like women – because they think maybe if you give these people cash ***** you can't even - ***** like thirty pounds. You can't even buy it. Like, you can't even go and buy like, say you want food and you start to go and buy a pair of shoes ***** . You have to buy that food stuff. Like I say, I want ***** . I want vegetables ***** . You know, they're quite different food, African food stuffs that I like.

MARGARET: Mm. Yes.

INTERVIEWEE: So, I'm ***** that the taste is good for me, and ***** the taste is good for me so I like those, like my African food, African food stuffs.

MARGARET: Yes. Yes.

INTERVIEWEE: You know what I mean?

MARGARET: Well, we all prefer that which we're used to, don't we?

INTERVIEWEE: Yeah. You know, even if you go like, if you buy the meat from – even though now there are boxes of those Johnston's chicken thighs and all those ***** , they sell the whole box for 10 pounds. So if you want to go and buy – you can't – you can't

go with the vouchers there and say, "I want this meat." And then – you know, and then they say, ah, because the meat is quite cheaper there. You can buy it for 10 pounds a whole box, I think maybe around 49 thighs and it makes you save. And like it's a way of saving because you can just like, you buy the whole box 10 pounds. It's worth it. ***** and if you go to Newton King, you can buy plenty of meat. Beef is very nice there. It's different. It depends what I like because I don't like this English beef because I find ***** it doesn't make a good taste to me. Something different.

MARGARET: Yes.

INTERVIEWEE: ***** the vouchers and then I will go and buy ***** the baby's milk, the baby's food stuff, ***** thirty pounds for her and thirty pounds for me. So what I am saying is that maybe sometimes ***** my XXXX like wants to do her shopping, then I say, can you use this voucher then you give me cash? And then I'll go and buy that maize meal, the meat I want to buy, then she'll go and buy it for me, you get what I mean? Sometimes she used to go to ***** , so we just ***** get the vouchers ***** she would get the cash, then she would go and buy that meat for me. So that I want to buy something else different *****.

MARGARET: But then of course, not everybody has got a XXXX who can help in that way.

INTERVIEWEE: Yeah, who can help in that way.

MARGARET: Yes. So that's one way that things could be improved. Can you think of any other ways?

INTERVIEWEE: Even though like, I don't know the way that like this ***** you know this like about the way we are staying here because sometimes you know it's like you come like the way you think maybe you just come as visitor here and it's difficult for you to get ***** . "This can help me. This can help me. This can help me." Even if you are – you know it's different situation. It's not everyone that will say, "Ah, if I go back to my country I fear something like political things or something like that." You are not even involved in that situation, but you can just start lying like I'm frightened ***** to my country. I'm facing this, this, that. It's – you have come here for something else. You come here to – you know our life is difficult maybe if you are in Africa you just compare that if I go to Africa, the life will not be good and the life will not work hard for me even though you are like me, you know, my husband passed away and now I am ***** to look after those kids, but what I am saying, ***** I mean African ***** I can't even get enough to look after both kids, to get support financially, even physically not financially, I can't even get

support through that. You get what I mean? So instead of like maybe you just come here for visiting and then like maybe your XXXX that time she just visited and then you decided to stay. Now I can't – I cannot go back to that – to those problems again. Once I am here, I just need to stay and do something. You get what I mean? But ***** it's difficult to find the way to do those things to just come out and do those things. You get what I mean?

MARGARET: Yes.

INTERVIEWEE: Because you need to support the family there because you know there is no one who is supporting them right now and they can't – they cannot get the support anyway. Or even if you say the relatives or your parent, they cannot manage to support your family. You need to be – to send for your family *****.

MARGARET: Yes. And there's no way as things are at the moment, there's no way that you can do anything....

INTERVIEWEE: Yeah, there's no way that you can do it here.

MARGARET: ... to help with their support?

INTERVIEWEE: Yeah, help with their support.

MARGARET: And it would be useful for you if you could have, if there was advice and opportunities to perhaps earn some money or –

INTERVIEWEE: Yeah. Yeah, to send some money, but you need to get something to do and then you send some money to support them because right now ***** one of the things is they are, even the time ***** things are just getting harder, harder and so you can't even get anything to support the family or to do something. You know, there is suffering all the time there is Zimbabwe so...

MARGARET: Mm. And also the sort of worries that you have about your family in Zimbabwe are not helping your own health?

INTERVIEWEE: Yeah, they are not helping my own health again. So even if I like – even if I go back there, there is nothing I am going to get there. In fact, it will be more worse than you – I will be suffering more – in more ways. It would be like worse now because once I go back there, I can't even get anything from there.

MARGARET: No. But the fact that you –

INTERVIEWEE: And I can't even support those family. You know sometimes you will be ah, it's just a little suffering. And it will be even worse because right now it's not even getting better.

MARGARET: No. And the worry affects you....

INTERVIEWEE: And then, yeah yeah, even if I – even if I found out that I was HIV whilst I was there, it's better for me to stay here and ***** manage to support the people who are back there because the – like the ***** I'm getting, even if you go for a cleaning job for people, that's it, you get a little bit, you get and then you can send your family in Zimbabwe *****.

MARGARET: Yes.

INTERVIEWEE: Like my first XXXX was even saying, "Oh, XXXX, even it's better for you to stay there so that you will be able to support us here because people the way they are here, don't even come back here. Things are quite hard here." She was just telling me all the *****.

MARGARET: Yes. Do you think –

INTERVIEWEE: They are missing me but you say, "Oh no, don't even" because I just think I am going to come back and they say "No, no, no, don't even come back. Better for you to stay there because things there are quite hard." But she is also missing that, "Ah, I wish my XXX was here," but then she had no choice. She doesn't have any choice. But ah, things the way they are, they are very hard, so you say, Ah, it is better for you to stay there because the letter you are sending, it is helping us a lot if you get what I mean.

MARGARET: Yes. Is there a way that the pastors in the churches can help? If they were to speak out more about the situation – in the UK, I mean, if they were to help you get the support and so on?

INTERVIEWEE: Yeah, to get some support and information about this, you know. I think it would be helpful if they can do that. Get a chance to speak out.

MARGARET: Mm.

INTERVIEWEE: Because sometimes even though those places are like that they don't know the procedures. You know, sometimes they can just ***** but they don't know.

They are not getting involved in those procedures, in those organisational societies. They are not finding the groups to go and, you know what I mean. They are not finding a way to do it, to just get those information to form those like – to form the supports and the help that they can – they're not getting the way to open up their minds or you know.

MARGARET: Oh, I see. Nearly at the end. What do you think could be the most important message is to prevent transmission of HIV? What should we be saying? What should the churches be saying, your church in particular to prevent transmission of HIV?

INTERVIEWEE: Just to encourage people to – to use condoms but the main point I look at it is that like, you know, people even if you like, if you are in the, or having a group meeting, people are telling them how to stop spreading of HIV. They say like ***** they say, "Ah, he's telling me to use a condom." You just agree whilst he is there. Once he goes out like he wants to use ***** his own business, you don't know. You can't just keep, you know, going to say to that, "Is he doing this? Is he following this instruction?" You know what I mean? It's ***** . He can't just go and follow up so the person is just like it's all up to him to make a decision that can I hurt myself in using this or using the condom with my partner? It's just like they love each other but they maybe there is a problem that you or your partner has got HIV so how can you prevent – you – you went for the test ***** You are positive and your partner is negative. So how can we prevent from our partner to get HIV? Or at the end of the day, they're going to say, "Ah, not me! Me, I want a child. If – how can I get a child with my partner because now my partner is HIV and how can he prevent that, you know? So this thing like ***** it depends with the person how to make his decision. The pastors may be discussing about that, talking about that, encouraging people to use condoms, ***** , but people they don't take it as a level that "Ah, ***** ." You know what I mean? And I want to enjoy it ***** but when I cannot use a condom, that's not – there's no – the person – it depends with what he thinks and what he wants.

MARGARET: Yes.

INTERVIEWEE: Because like the pastors and the leaders, they try their best to explain to people how to control – how to control that – the spread of HIV but people they don't take it.

MARGARET: Mm

INTERVIEWEE: People don't take it.

MARGARET: Right. So...

INTERVIEWEE: That's the main problem.

MARGARET: Right.

INTERVIEWEE: And the pastors and the other leaders, they can't just follow up to ever household, "Are they doing this? Are-" You know, it's like – it's not – it's not even worth it. It's up to the person who makes his or her own decision like, "I want to use a condom," or "I don't want to use the condoms," or "If I get infected with HIV or - "It depends with the religion what the person thinks now. It's not according to the religion, it's according to what he thinks. Well maybe there will be other beliefs rather than going to – to church or to believe in God, then he's got other beliefs that as for me if I have – I don't want to have sex because I know I will be okay. You know like I was saying that my partner just say, "Ah, I'm okay." I don't want any further whatever it is. You get what I mean?

MARGARET: Yes.

INTERVIEWEE: Even now – even telling me that I can give you, if you want, I can give you medicine from Africa. I don't know what sort of medicine is that so I thought maybe – I don't know if it's ***** they say no, don't worry. I'm okay. Because I don't want to buy – I don't know what is it for and you get what I mean? So because he's just telling that like African medicine, I don't know what medicine is that what he is taking there. So me and ***** . Since I don't come from XXXX – he's from XXXX and me from Zimbabwe. So I don't like to take any medicine that I don't understand what is it for.

MARGARET: No.

INTERVIEWEE: Unless if he is coming back ***** . ***** answer is I saw him eating also but then I will say ah, maybe I can take it but then he did not just listen to me and say, ah, I will throw it in the bin.

MARGARET: Do you think some other people would prefer to take the medicines from their own country rather than the medicines from – medications from the hospital?

INTERVIEWEE: Yeah, I think some people they just believe that their medicine from their African ***** cultural belief now. That's the cultural belief.

MARGARET: Yes.

INTERVIEWEE: They believe that their medicine, that African medicine from their country can help them ***** the disease but I don't know how far ***** because you know

our country Zimbabwe, we know there is such things because – some people might say that it doesn't help ***** so I don't believe that this African medicine they can cure HIV. I don't believe that because I don't have any experience about that. It depends the person who does it before, who takes that before and it's ***** it's helping him. Or maybe he take it before they are back home in Africa and when he came here they just tell you that, "You don't have – you are not HIV positive." So it's just because that his medicine is working. You see?

MARGARET: Yes.

INTERVIEWEE: You get what I mean?

MARGARET: Yes, of course. Yes.

INTERVIEWEE: Yeah. He just believe that this medicine is helping him so he believes that because he came here and had the test because he takes that medicine whilst he was in Africa and then ***** I'm really protected. Don't worry about that. So you get what I mean?

MARGARET: Yes.

INTERVIEWEE: *****.

MARGARET: Yes. Just to go back then, you think if the pastors could talk about using condoms and talk about other things in relation to safer sex and relationships and so on, that would help, but you think the –

INTERVIEWEE: The support *****.

MARGARET: *****.

INTERVIEWEE: ***** teach people how to have safer sex to protect themselves but people sometimes, they don't take it – they don't even listen to that *****. They think *****.

MARGARET: Yes, they're not necessarily thinking about what the pastor said *****.

INTERVIEWEE: Yeah, what the pastor say ***** yeah.

MARGARET: ***** But also what you were saying before is it's unlikely that the pastor would say anything like that anyway?

INTERVIEWEE: Yeah.

MARGARET: They're not likely to.

INTERVIEWEE: Yeah, because it's 50/50. Some people they take it. Some who they say, "Ah, what is this thing? No, me, I cannot take it." It depends now with the individual.

MARGARET: They might say it's not up to the pastor to *****.

INTERVIEWEE: Yeah, *****.

MARGARET: Right. ***** What do you think about young people in school having sexual health education and relationship education? In schools in the UK, there is some teaching, sex education teaching. Do you think that's a good thing for young people or not? What sort of view do you have?

INTERVIEWEE: It – it's a good thing to teach them about sex, at the end of the day, some of the kids know. They say, ah, I want to get *****. You get what I mean? They want to experience it, what will happen. Then they just go for it like this because they heard about it. That's what I'm saying it depends now with the ***** sometimes they just say *****. It's not every kid who'll listen to that.

MARGARET: Mm.

INTERVIEWEE: ***** He's not even interested. He or she is not even interested in that ***** that subject. He's not even got *****.

MARGARET: Like the people not listening really to the pastor ***** some of the young people wouldn't listen to the teacher or ...

INTERVIEWEE: *****.

MARGARET: What do you think would make them listen and take notice?

INTERVIEWEE: You know what it's some people they just – what will make them ***** sometimes they will just *****and you just like in the situation ***** start thinking back ***** information that teacher was teaching us that day. That day it was good, but me I didn't even listen. Now I'm just in the situation that this is how it is now. So how does he or she take advantage – you will take ***** ah, that was a good teacher *****

MARGARET: Mm. So it's better to have the information than not have the information?

INTERVIEWEE: Yeah, it's better to have to information.

MARGARET: Because there might be a chance that they would need to remember.

INTERVIEWEE: Yeah. Yeah they would remember it. Better to hear and use it. Even if they are ***** teacher always teach us about this, about this. Then they will come to like ***** he or she will ***** . And even if somebody is giving ***** the teacher always say this, this, this. We start thinking back ***** a good lesson for me to listen ***** .

MARGARET: Do you think it matters what our church leaders say about HIV and about, do you think it matters at all? Do you think if the church leaders said nothing about HIV things would be okay. We'd listen to the, doctors and the support people and so on. Or do you think they ought to be saying things about HIV and if they ought to be saying things about HIV, what sort of thing about HIV, the church leaders. Do you think it matters at all or do you think we just sort of carry on regardless of what they say.

INTERVIEWEE: You know, all – all – all I can say is that *****if they are just saying about HIV, the ***** they just think, "Ah there are kids who are just like they have no parents, who are orphans because of HIV, they'll be just the same to make like prayers for them. If – if they can help him any other way for those ***** suffering without kids without parents, they'll be just saying that. But they don't get it down to the fact how can they help those people, but they just like, "We pray for the kids who doesn't have parents. Their parents just like were just like taken away from with the HIV. They were just like – they died because of AIDS." They will just like thinking those kids in their prayers or they don't know that people – or they don't even talk about these people who are surviving right now with HI – who are HIV positive. They don't even talk about that or think about that. But I think once they are like in their – in that system that they have to teach people about it in the church or talk about it that as a group or to find a day that they can discuss about that in the church. Whoever interested to come can come because some people they say, "Ah, me I don't have HIV so ***** ." They just like – like what I'm saying like a ***** , those people

who are interested to go and get the advice, or to go and have a chat, those are the people who can come. But if you are not interested, then you just stay. You are not forced to come and join that group, but if you're interested ***** form a group that people who are interested to – let to ***** HIV, they can come and ***** such a day. Those who are interested can come. Those who are not, *****.

MARGARET: No.

INTERVIEWEE: They can find it at a different time or a different day so that *****people they don't like it.

MARGARET: But you think that that would be quite worthwhile, to do something like that for those people who would be interested.

INTERVIEWEE: Yeah, yeah. ***** to do something like that for those who are interested.

MARGARET: Mm. And it would be quite influential, do you think?

INTERVIEWEE: Yeah, it would be quite influential, yeah.

MARGARET: Although there would be a group of people who wouldn't be interested, nevertheless for those who were interested it would be helpful.

INTERVIEWEE: For those who are interested, they can come and join and then it would be helpful that way.

MARGARET: And is there anything else that we perhaps haven't covered that you feel is important to say about HIV and religion –

INTERVIEWEE: One of the problem that I am just like – because you don't know how to even talk of that problem, the first – in our culture like the African, there is a lot of discrimination that people say, "She is HIV positive." There is quite a lot of discrimination in our minds so ***** to solve that problem right now. That's the only problem which needs to be solved right now. Because there are a lot of discriminations, people they think it's dishonest, but some people know – they come to understand that "Ah, if the person you hurt is HIV, you have to help her or you have to help him." But most people mostly African they don't, they just tend to discriminate that, "Ah, this one got HIV" ***** How can we help you?

MARGARET: Do you see that as the biggest issue?

INTERVIEWEE: Yeah.

MARGARET: I would call it stigma. Do you understand stigma?

INTERVIEWEE: Yeah. Yeah. Yeah, because they still say, "Ah *****" They think that if she's got – he or she's got AIDS we can't even use the same toilet, use the same – we can't even sleep together. We can't even – you know what I mean? They just sort of – a lot of complication African culture. There are a lot of things. Like even my XXXX was just saying, "Ah, if anyone here has like has got AIDS, I don't even bother to look after him." It's your own business. You know she mentioned that at the end of the day, I don't know. ***** ah, everyone – obviously she's got her own life, anyone else who will say, "I've got AIDS. I'm not prepared for that, to look after that. I'm not prepared to take that."

MARGARET: And why is that? Is it because it's a sexually transmitted infection?

INTERVIEWEE: Because they say that this one is not – is not able to be cheated –

Door knocker sounds

INTERVIEWEE: Who is it? *****.

MARGARET: Perhaps it's somebody just going by.

The interview ended abruptly when a friend arrived and knocked on the door. The interviewee let her in and we had to finish.

Researcher's notes:

*The interview was conducted in the person's own home. Her baby is present throughout – at first sitting and gurgling happily while we conduct the interview. (These sounds are recorded and make transcription particularly difficult). Later the baby becomes fractious and the interview is interrupted while her mother feeds her. After her feed she sleeps in her mother's arms and we continue the interview. The mother's first language is XXXX. Many of the words are unclear on the recording. Several replays have been unable to identify a number of her words, sentences. These appear in the transcription as *****. The use of XXXX indicates a place or person or words where using them would risk identifying the interviewee. A further problem is created by louder background noises during one section of the tape. It is unclear whether this is due to tape or recorder malfunction or whether it was traffic and activity directly outside the house.*

The researcher experienced the interview as a difficult process. Discerning the interviewee's meaning required concentrated and sensitive listening, the occasional repeats and adaptations of the question.

The interviewee's situation is difficult. The researcher was concerned about her partner's refusal to have an HIV test in UK and the circumstances of her family in Zimbabwe.

APPENDIX F1b
TRANSCRIPTS - INTERVIEWEES
Interviewee: IO9

MARGARET:

Can you tell me a little bit then, about your – about your background? You said you were brought up a Catholic?

INTERVIEWEE: Yes, I was baptised Catholic. Made my first Holy Communion, confirmed, went to Catholic school, primary then Secondary Modern, got married in the Catholic church and confirmed, and my three children were baptised there as well.

MARGARET: So were you quite active in that church?

INTERVIEWEE: When I was very young, yes. I mean I – I should say that I was more made to do it more than voluntary if you know what I mean because it was a thing we all got, went to church on a Sunday morning.

MARGARET: And that was part of your family practice?

INTERVIEWEE: Yes. That was part of the family – yeah. Yeah.

MARGARET: Yes. Um, was that – was that before your diagnosis with HIV?

INTERVIEWEE: Yes. Yes.

MARGARET: Leaving your church or –

INTERVIEWEE: No, I'd actually – very dissatisfied with it before I became HIV anyway.

MARGARET: Right. So you decided – you stopped attending church.

INTERVIEWEE: Yes.

MARGARET: Can you – can you say something about the reasons why?

INTERVIEWEE: Well, I just thought it was – well, as I said it's hypocritical and, um, yeah I didn't believe what they were telling me to do and the Catholic church itself, you know, the power they had, the wealth they had and everything like that.

MARGARET: You found it, um, much more difficult as time went by to – to accept the teachings and beliefs that –

INTERVIEWEE: Yeah. Yeah. Yeah. Yeah. I mean I believe in Christianity and I believe in the Christian faith but the Catholic church, I don't believe in, if you understand that, yes?

MARGARET: But there was no association between your diagnosis with HIV and your beliefs –

INTERVIEWEE: No, no, no, no, no.

MARGARET: - and your attending the church or...?

INTERVIEWEE: Probably now I've been – since I was diagnosed, it's confirmed it even more especially some of the things the Vatican comes out with and you read about it and it just makes my blood boil. And then there's like places like South Africa, you know, where they have got Catholic populations and the Pope's condemning condoms and they say like uh, "Condoms are not safe anyway, HIV can pass through it." And I think, "What? That's so irresponsible." You know, poor country like South Africa and there's thousands still dying from it now, or millions. And I just can't believe it. I can't believe that they can just stand back and then not help when it's so simple. You know, well it as far as I'm thinking, it's so simple.

MARGARET: We'll probably be able to say more about that in a – a little later on.

INTERVIEWEE: Yeah.

MARGARET: Just a question or two about HIV as a health issue. Um, in your opinion, what are the main factors contributing to HIV transmission around the world and in the UK and in Leicester?

INTERVIEWEE: Well, as I said, like the Pope condemning condoms for a start, and then the government far too slow on the uptake of it. I mean I've been HIV for like, uh, 23 years/24 years, and there was hardly no – well, there was no education whatsoever then. It was something that happened in America and like basically when I was diagnosed, you was told to go away and that was it. Couldn't – couldn't – well, they couldn't do anything for you. So I mean they could have done more then to prevent it, but they just sat back and did nothing. I mean, that's the government and the Catholic church, I think they totally ignored it anyway.

MARGARET: And do you – do you see HIV as a cause for concern as a public health issue around the world?

INTERVIEWEE: Yeah, of course. Yes, yes, definitely. Well, when people are dying, yeah, of course they are.

MARGARET: And in the UK?

INTERVIEWEE: Yeah. I mean there's still people dying in this country now of it. I mean I had a friend who died last week. He had pneumonic – uh, pneumonia with complications and he was under forty. And that's with all the treatments you get now. And that just makes you wonder. In fact, I've had a few friends die over the years. And it's – you know, you get a bit cold. You get um, disheartened about what's going on. I mean I know they've got all these new drugs and your - uh, your CD count goes up and your viral load goes down and that but there's still people dying of it and you – you wonder why. And um, yeah I'm just a bit disillusioned.

MARGARET: Right.

INTERVIEWEE: I mean that's with uh – not – not with the National Health or anything like that, I think it's just general disillusionment. And I think it's almost – it's not forgotten, but people have it sort of put it at the back of their minds again. And especially with the younger generation, half of them don't even know anything about it really.

MARGARET: It's kind of slipped off the agenda?

INTERVIEWEE: I think so, yeah. Yeah.

MARGARET: Even though as a public health concern it remains a big issue?

INTERVIEWEE: Yeah.

MARGARET: And that's your – that's your point really, that it's a big issue, but it's not talked about enough?

INTERVIEWEE: No, I don't think it is. I mean, you know, I mean you don't want it on the TV all the while, but you hardly ever see anything about it. Now and again an odd program. Now there's a lot of younger people growing up that don't realise that, you know, how – how they catch it. There are still a lot of people still think you have to be gay, and I think it's more on the up in heterosexual couples and especially young people as well, very much so.

MARGARET: What do you think, um, your – the – the Catholic teachings would say about HIV? What – what does the Catholic –

INTERVIEWEE: Well, they totally ignore it. You're supposed to have a monogamous relationship whereas that never works. You're not supposed to use condoms because that's against their beliefs, and as I say their top doctors and Bishops or whatever say the HIV virus can pass through a condom and it's just a load of rubbish.

MARGARET: And do you think the Catholic – what about the Catholic response to people affected by HIV?

INTERVIEWEE: Well, I've not even come across it apart from being told not what to do. I don't think I've ever – well, I've said I've not been in a Catholic church for awhile, but if I did, I'd be very surprised to see a poster up about it in there. In fact, I'd be amazed because I don't think you'd get it.

MARGARET: And what in your view does the Catholic Church say about intimate relationships?

INTERVIEWEE: Well, it's just a one to one. You know, if you don't have a one-to-one relationship, you know, you're like – I don't know, it's like. But it isn't – it's not practical because I mean it's all right them saying, "Do this and do that," but people just don't do it. People are not monogamous. I mean some people are, and then it don't affect them but there's a lot of people who are not like that and especially gay people. You know, like sex as one of their main attractions for being gay, so you're not just – well, you will stay with one person, but they have a lot of partners as well.

MARGARET: You just said something about it, you know, not being the reality. How far do you think then that people do follow the teachings of the Catholic Church?

INTERVIEWEE: I don't think a lot of people do now, especially when it comes to contraception. But I think some countries might, but I think most intelligent people actually realise the Catholic Church is not going to support a massive family or anything like that. You have to do that yourself and people just can't afford it now. I mean you can't have ten children now, know what I mean? Where would you get the money from to support them?

MARGARET: And do you think those teachings and beliefs influence the responses of Catholics to HIV and to people affected by HIV?

INTERVIEWEE: Well, I think it makes them feel more guilty and basically that's it. But I think it would still – they'll still carry on. I mean you always feel – the Catholic Church always makes you feel guilty about everything. (Laughs)

MARGARET: And do you think that's the same – what about how those teachings influence how Catholics respond to people affected by HIV?

INTERVIEWEE: I – I – I actually think it does – it does have an effect on them because the look that I mean, you don't tell many people. You can imagine if you tell them they'll look at you like down on you like you've been wicked. You know, it's like the plague almost. You know, you've brought it on yourself type thing. I mean that's how Catholic Church works.

MARGARET: And do you think those teachings – do you think they influence how people outside the Catholic Church respond to HIV and people affected by it?

INTERVIEWEE: No, not really. No.

MARGARET: You don't think it has a wider influence?

INTERVIEWEE: No. No, because I think if you're not actually brought up a Catholic, I think you find it a bit strange religion anyway.

MARGARET: And you talked about, you know, being surprised if you were to see a poster in a Catholic Church about HIV, but do you think people in the Catholic community or churches talk to one another about HIV?

INTERVIEWEE: No, I wouldn't actually know that. I mean the only Catholics I know have usually dropped out, and we talk about it and one thing and another. And I talk about it in my family but it's like they don't talk about the Catholic, you know, their teachings on it. It's how they think about me and how we talk to each other. That's nothing to do with the Catholic Church, that. That's just how we are. And I'm sure the amount of people – most people are like that whether they're Catholics or not I should think but I think the religion does have an effect on people...initially – probably – probably not so much now, but I think it did at one time.

MARGARET: So you're saying your family who identify as Catholic talk about HIV with you, you know, you have those conversations, but that's because of your situation which they know about?

INTERVIEWEE: Yeah, and they actually know. Yeah, they know about it as well. Yeah. Yeah.

MARGARET: Yes. Yes.

INTERVIEWEE: Which is nothing to do with the church, that's not.

MARGARET: Yeah. And you've talked about what you think about the influencing, the sort of outside responses and you think – you think not. And also you're saying that those teachings haven't influenced whether or not you talk to anybody about HIV?

INTERVIEWEE: They haven't influenced me.

MARGARET: No. No. Can you sort of think back to – it's difficult I suppose to think back to before your diagnosis but –

INTERVIEWEE: Well –

MARGARET: Because that was the earliest days, wasn't it?

INTERVIEWEE: Yeah, it was just difficult to talk to anybody about it.

MARGARET: Yes. Yes.

INTERVIEWEE: Because I mean you couldn't talk to anybody because not many people knew about it.

MARGARET: No. No.

INTERVIEWEE: So there's nobody to talk – and then I went to my doctor. Well, I had to tell him and he just wrote on my – because you used to have the pages that he wrote on big letters HIV – no, it weren't called HIV, it was called something else, all in red pen, "Contagious" and that was just put in the files with everything else and basically he just said to me, "You are going to die." I mean it was put just as blunt as that. I can remember him saying that, so he didn't really understand much about it either. It was like – I think there was – there was no follow-up, no counselling. It wasn't until years later I found out that, down the GU clinic, they'd actually do a test to monitor, but that was a long while afterwards. But you had to go at 7 o'clock in the morning and – XXXX-

MARGARET: Oh yes.

INTERVIEWEE: He used to come in specially to do it because I know I don't suppose there were many people then, you know, to take your blood and just to see how it was going on but it's all totally different now. And it's like if you had a minor operation in the hospital, you used to have to wait 'til the very end one, the last opera – I think you still do, actually, because they have to make doubly sure everything's clean and everything like that so you've got to sit there all day and probably get counselled at the end of it and like you're there for ages.

MARGARET: It's not that long ago I can remember protesting about somebody who –

INTERVIEWEE: And he was always put – yeah, and he was put in an isolation ward, you know. I mean they didn't really know and basically everybody that come to visit you, they had to wear masks and things like that. I mean, that wasn't so long ago, probably about five – ten years ago, probably, might a bit longer.

MARGARET: You must have been one of the – one of the first people locally to be diagnosed here.

INTERVIEWEE: Well, I don't know because I was diagnosed down in XXXX.

MARGARET: Oh were you?

INTERVIEWEE: Yes. Yes. I was diagnosed in XXXX, then I moved back to Leicester and that I don't know why I went to the hospital. I don't – I don't – I can't remember now. But I remember a few years later when there was a – I was having an operation and they knew I was HIV. They said, "Do you want some support from LASS?" And I says, "Oh yeah." I don't know what it involved and that, but I says yes, and they says, "Well, we can't find any proof of you being HIV." And I thought, "What?" So they said they've got to have another test and I said, "Well, well okay then." And then they said, "Well, you've got to have counselling before you have the test." And I thought, "Well, I've lived with it for like ten years now and now I've got to have counselling," but then they found something. And I can remember it was – what was her name, nurse – Dr XXXX. She came in and said, "Some good news." She said, "Well, no, it's not really good, but we found your diagnosis." It happened quite comical, actually.

MARGARET: Yes, I can remember that was always one of the things, wasn't it, proof of diagnosis before you could access services.

INTERVIEWEE: I know. It was so strange. I used to go to the Body Positive when – do you remember XXXX?

MARGARET: Yes. Yes.

INTERVIEWEE: Because when he started it, I used to go to that and there was a few people and I found it that so depressing. People were just talking about themselves and there wasn't anything positive about it whatsoever apart from XXXX himself, he was the only positive person there. So I went a few times and I thought, "Oh no, it's not for me, this is not. It's just carrying others down." Just, you know, I've managed to get by some 23 years later so.

MARGARET: And have you always been with Dr. XXXX for –

INTERVIEWEE: Yeah, I think that – yeah, from when I actually –

MARGARET: From those early days-

INTERVIEWEE: Went under treatment, yeah. I mean basically it was like XXXX that used to look after me.

MARGARET: Yeah. Yeah.

INTERVIEWEE: Has he XXXX? Oh right, right, right, right, right. Yes.

MARGARET: Yes. Yes.

INTERVIEWEE: Yes. And then I had Dr. XXXX. Do you know XXXX?

MARGARET: Yes. Yes.

INTERVIEWEE: I had him as my doctor and he was brilliant, but I moved out the area and I've gone with this chap around the corner now because it was a bit far to go but I wish I hadn't now because he used to understand when you talk. You – you talk to him and he doesn't understand it. He's too – he's too medical. He doesn't understand the emotional side of it if you know what I mean.

MARGARET: Right. I see.

INTERVIEWEE: He understands all the, uh you know, what is wrong with you, blood counts, this and that but the emotional side of and things like, he don't quite understand that. He didn't realise how you feel in one thing or another sometime. If you go up to him and say why and then you start saying this and saying that and it seems you're saying the same things all the while. Now and again you do get a bit down with it, you know, after a long while with it.

XXXX like if you get a bad chest, you think, "Oh, is it something to do with that? Or is it just a cold?" or one thing or another.

MARGARET: Yes.

INTERVIEWEE: I mean you get – it's not hypochondriac, but you know what I mean you just actually think like that in the end.

MARGARET: Yes, of course. Yes. And do you go to – do you go to LASS or...?

INTERVIEWEE: No, not anymore.

MARGARET: No.

INTERVIEWEE: No. No. No. I used to – they used to send me the books out but there was – they used to send masses of stuff out, and you know, you'd look at it and there were a few articles you'd read, but it was all too heavy going. You know what I mean? I wasn't a doctor. I don't want to know everything that were going off. Important facts, I'd like to know but you – you get to know them anyway in the end. And I've not been to LASS or used them for years now.

MARGARET: Yes, I remember XXXX. He was -

INTERVIEWEE: He was a lovely guy, he was, very nice guy.

MARGARET: Yeah. Yes. Right. Um –

INTERVIEWEE: We sidetracked.

MARGARET: It's not difficult, is it? It's a long – you know, going back so many years. Um, so it – I think we have covered all of this really. So you can't – you can't imagine then a situation where you might have talked in a Catholic context to people about HIV?

INTERVIEWEE: No. No way whatsoever.

MARGARET: Or to the priest?

INTERVIEWEE: No. No, definitely not the priest. No. No, so I think probably even now they are a bit ignorant to it. I mean I don't know. I don't know even if they teach it in Catholic schools. I mean there was no time for sex education when I went and it was like never talked

about so I don't know if they talk about contracept – well, would you talk about contraception in a Catholic school? I actually wonder. I mean I don't know.

MARGARET: So it – you wouldn't because of not being confident that you'd get a supportive response?

INTERVIEWEE: No, no I don't – no, that's it is I wouldn't be confident at all talking to them. I think that'd be a waste of my time. It'd be the last place I'd approach. I – I just don't see any reason to approach it. I'd rather go out into the middle of the street and talk to them. I think I'd get more response off them.

MARGARET: And do you think that those beliefs and teachings would affect whether or not people went to talk to a health professional, to a GP or health advisor about HIV?

INTERVIEWEE: Well, it wouldn't stop me, no, because you know, that's a person I would talk to but I can't answer for other people.

MARGARET: So you think it's more likely that in the Catholic setting, a person who perhaps wanted some information about HIV would go to a health professional rather than to somebody in the church?

INTERVIEWEE: Well, I think so. I mean – yeah. Well, I mean could you imagine being sixteen and a Catholic and going up to your priest? It's one thing you say, "I'm gay and I'll need some information about this and that." I mean what would the priest say? I mean I don't know. I don't really know but I can't see them being very sympathetic and never have been. So I think, you know, I don't think anybody would go up to a priest and ask for church support and that. No way.

MARGARET: Do you think – do you think that has an impact on HIV prevention, information and so on? Do you think if people in church settings could feel confident about going to their clergy or somebody in their church for information, do you think that would help in terms of prevention?

INTERVIEWEE: Well, I think if I thought the priest was qualified and knew what he was talking about and I went up to him and asked him something instead of, you know, instead of like what the Catholic Church preaches 'condoms do not prevent HIV' and things like that, if I – you know, if there was a Catholic priest there who was up to date on all the facts and knew everything, yeah, I probably would feel confident. But I don't think – I don't think that's likely to happen. Well, I'm – I mean I don't know. It's been such a long while. Well, I did go to a baptism, a Catholic baptism, and the priest that done it was like the typical priest I remember

of like thirty years ago just waffling on about rubbish, you know, nothing important and this and that, and I thought, "Oh, it's not changed really, has it?"

MARGARET: But if you – but – but you think for yourself and perhaps other people, if you – if you thought that the clergy would respond sympathetically to your inquiries and you thought they had – they could give you accurate information, you would –

INTERVIEWEE: Yes. Yes, because I mean some people have got, uh you know uh, very firm beliefs in the Catholic Church and they probably do need that more than anything else. And I think it'd affect them people more if they went to a priest and they got sort of condemned or something. But if they went to a priest that was sympathetic and knew all the facts and everything else, I think they would talk to him and probably come away feeling a bit happier.

MARGARET: When you said it would affect them more if they were to be condemned, what – what would *****?

INTERVIEWEE: Well, I'm saying – I mean I'm saying if you were a young lad and you went to a Catholic priest and he just started spouting the evils of this and that, you wouldn't come away feeling too good, would you?

MARGARET: And that would be a barrier?

INTERVIEWEE: Yes. I think so, yes.

MARGARET: Um, you – you talked about having disclosed your HIV status to your family.

INTERVIEWEE: Mm hmm.

MARGARET: Have you disclosed to anybody else?

INTERVIEWEE: A few close friends, that's about it. And XXXX of course, Yeah.

MARGARET: But again I'm sort of asking you to think back to a previous time, I suppose. Can you think of disclosing your status within a church setting?

INTERVIEWEE: I wouldn't have done. I don't think I would now. I mean apart from talking to you, this and that in a convers – in just normal conversation, but there again I mean, uh, it really wouldn't come up in a normal conversation, really.

MARGARET: No. And knowing other people with HIV – you do know other people with HIV?

INTERVIEWEE: Oh, yes, yes. A lot.

MARGARET: Yes. And again a sort of difficult question really. I mean can you imagine a situation where Catholics with HIV might know other Catholics with HIV within their church?

INTERVIEWEE: Hmm, I don't really know about that.

MARGARET: No. No.

INTERVIEWEE: Because I think most of the ones I've met, I don't particularly ask people their religion any way for a start. I mean yeah they might say they're Christian so I wouldn't actually know. So, no, I wouldn't actually know that one.

MARGARET: No, that was unfair really because the question specifically relates to those people who are part of a church group or community or whatever.

INTERVIEWEE: Yes.

MARGARET: Yes. All things considered, what do you think a person with HIV might find helpful in their faith, in their church community in terms of support and so on? Do you think there are ways that churches could offer and provide support for people affected by HIV?

INTERVIEWEE: Well, yes, I mean um, years ago these two – I went – I had some friends in London. They belonged – I think it was something, not Salvation Army, a – a – a religious group like that. They had a drop-in centre and this was like ten years ago I think, and people used to go there. I mean that was like, uh, it was relaxed. It wasn't a religious thing, but it was like run by this religious organi – I can't remember who it was now. I don't think it was Salvation Army. It was something – something like that.

MARGARET: No, the Salvation Army did have something years ago.

INTERVIEWEE: It might have been – it might have been Salvation –

MARGARET: It was called Oasis.

INTERVIEWEE: That – that's it.

MARGARET: Oh is that it?

INTERVIEWEE: Yeah, that's it.

MARGARET: Oh right. Right.

INTERVIEWEE: Yeah. I mean that was good because that wasn't like going into a church. That was just a drop-in centre. And that actually worked. People used that. But that was a while ago.

MARGARET: There's also – there's also CARA in London and they – they were started by a Church of England priest who had a similar thing and then I started the same sort of thing here in Leicester, at The Lodge.

INTERVIEWEE: Yes. Yes, that's right, yeah.

MARGARET: But um – um – so – so what – what you're saying is that there are ways that churches can provide support?

INTERVIEWEE: Yeah. Yeah.

MARGARET: Um but perhaps it's the kind of support that has to be quite sort of open and relaxed and –

INTERVIEWEE: Yeah, well I think – I think it's more the practical support than the spiritual one, definitely.

MARGARET: Right.

INTERVIEWEE: You know, it's like you don't want church services and things like that. You want practical good – practical support.

MARGARET: And have you any – you've talked about some of this but you might have more to say - any thoughts about how Catholic churches are responding to HIV?

INTERVIEWEE: They're responding to it negatively. They want to take their head out the sand and see what's happening to the world, and that's all because of the Pope and the Bishops in Rome.

MARGARET: And this is particularly in relation to condom use?

INTERVIEWEE: Well, I think so, yeah.

MARGARET: Yeah.

INTERVIEWEE: I mean what – what more effective way is there – you know, preventing it being passed on than that? I mean that I think – it was totally disgusting. It's irresponsible of the Catholic Church and they should – at a time like this, they should be responsible for what's going on in the world.

MARGARET: You clearly feel very strongly about it.

INTERVIEWEE: I feel bitter about it, not strong words. I'm quite bitter about it. Every time I read something article in the paper like that I'm just seething. I think how can they say that because people do actually – this is it. People actually follow the Catholic Church. I mean, you know, what the Pope says what we do, God, that's terrible, absolutely terrible. It does make me mad, absolutely mad, and that's why I've really gone off the Catholic Church completely. For one thing, they've got too much money. I'm really bitter about it, really. I am, actually. I just don't agree with anything they say. I think they've left it far too late, you know, - well, it's never too late. But they should have been on – they should have been on the ball day one for this, not trying to prove ways that condoms don't work. They should have just changed – I mean sex – people are always going to have sex. I mean why is it in the Catholic Church you only have sex because you want to produce children? What rubbish that is. It's so outdated and all their ideas are so outdated and I mean I shouldn't be going on about this because it was totally different. XXXX was abused by a Catholic priest when he was eleven years old. And he's got a big chip on his shoulder and that's affected him mentally no end. And like that still goes on. What do they do? They send him off to the Vatican and hide him away. Totally disgusted. You know, the actual priest that abused him committed suicide. I mean if that isn't like, you know, admitting guilt, you don't know what is, do you? No, I am bitter about the Catholic Church. Very, very bitter.

MARGARET: Yes. So if you – if you could re-educate or educate the Catholic Church into what you feel are appropriate responses to HIV, what – what would be your message to them?

INTERVIEWEE: Be responsible for their actions. And they're not. You can't have one person telling millions what to do just because he thinks it's like against the Catholic religion. I mean these are intelligent people up there and there's people dying all over the world still because of what they say. That is not – that is not Christianity at all. It's not – not in my opinion. And until they turn around completely on condoms and things like that, I – I think they're doing more harm than good. Well, they're not doing any good at all. They're doing far more harm.

MARGARET: And that would be your sort of message generally for, um, - to the Catholic Church as far as the global situation is concerned and as far as the local situation?

INTERVIEWEE: Yeah. That's right. I mean if I ever had a chance to meet the Pope, that's one – the first thing that I'd – you know, if I could talk to him man to man, I'd ask him why. You know, and all his excuses, you know, wouldn't work on me. No, he could say what he wants, you know, get all the best brains of the Catholic Church explaining why HIV goes through a condom when everybody knows it doesn't, and how stupid.

MARGARET: Have you any thoughts about, um, sex education in schools?

INTERVIEWEE: Yeah. They should be taught everything. They should know everything about sexual education, you know, because it's all right saying they're going – you know, they say you're promoting homosexuality or you're promoting this. You're promo - but there must be at least some of the proportion of the kids who are going to be homosexual or are going to be this or are going to be that. And if they've got no idea about it, it must be a terrible time for them going through it. I mean it's probably easier now because a lot of the, you know, the straight friends have gay friends and they do understand but if you're on your own out in some school that's not like that, it must be terrifying. I mean it wasn't as bad when I was at school because it was like, uh – it was illegal anyway. So it wasn't talked about. So slightly more risqué I suppose. But no, I think they should be taught everything. Well, within reason anyway because these things do go on in the world.

MARGARET: And from an – what sort of age?

INTERVIEWEE: Now that's difficult, that is. I wouldn't like to say what age. I mean some kids are ready for it, some kids are not. You know – you know – well, I – I think there should be – if there was an open attitude towards sex, it wouldn't be a big issue. Instead of like you've reached thirteen as – I – I can remember like there's going to be a sex lesson. There a big buzz going around and when you got there were nothing. You come out no wiser than when you went in.

MARGARET: But by and large you are supportive of there being comprehensive sexual health education?

INTERVIEWEE: Oh yeah. Definitely. Definitely. Yeah, definitely.

MARGARET: Do you think it matters what religious leaders say about HIV?

INTERVIEWEE: Yeah, it does. It does to somebody who's got a firm belief in that religion, yeah. Of course it does. I mean it don't matter to me so much now because, you know, because I know they're talking rubbish but I mean if you were like a true Catholic and believed everything the Pope said, well, I mean for anybody like that, absolutely terrible. Yeah. Yeah, it does make a difference what they say. Because you've got a lot of naive people who – people that can't think for themselves just need somebody to lead them and they'll believe everything they're told. Mm hmm, yeah.

MARGARET: And are there any other things that you'd like to say that we haven't covered?

INTERVIEWEE: Most things. My little vent.

MARGARET: You feel there - there's nothing else?

INTERVIEWEE: I don't think so. No. No. **** Catholic Church ***. They have got to turn around. I know I said it's too late, but it's never too late. It might give them some more credibility as well. Don't think they've got a lot. It's like the Pope, he's only got to make a speech and you can't move in Vatican City. We had to ** Rome at the end of the month and XXXX 's XXXX's a big Catholic and Padre Pio. That's another thing – XXXX adores him and I was reading a little article in the paper that he's being exhumed and that he's going to be put on show and I thought, "Oh, how gross." XXXX says that's fantastic - (telephone rings) Oh, you'll have to excuse me, this'll be XXXX.

(telephone call not transcribed)

Yeah, XXX were fascinated when I told XXXX he was being exhumed and things like that. He was canonised weren't he. There was a big controversy over that because he had the stigmatas and that and I've read articles of him in like a – he did something to his hands to make them bleed and that, so I don't know. I don't know. I don't know at all. I mean I believe in good people but to be canonised you're a saint and I just don't believe in that at all. That's like almost supernatural. And I do believe in some supernatural things but I don't think Padre Pio was one of them. He was just a good, very good man.

MARGARET: So you're going to Rome to – to join in the celebration?

INTERVIEWEE: No, I'm not going to the Vatican. No, actually, I want to actually go and see him so I can tell his XXXX after XXXX. And that was the other thing. The conversation got bizarre then. I wonder if, you know, how well his body's been preserved and things like that and you think well I don't know. I don't know. Well, I don't know. I just wonder whether they buried him or not.

MARGARET: Shall I – shall I stop the recording?

INTERVIEWEE: Oh, yes. Yes. If you're quite happy with what you've got, yes.

APPENDIX F1c
TRANSCRIPTS - INTERVIEWEES
Interviewee: J10

MARGARET: The code, XXXX Do you attend a place of worship? Do you go to the temple as part of your religious practice?

INTERVIEWEE: Yes, I do go. Yes, I do go and I practice my religion.

MARGARET: And did you do that before you were diagnosed with HIV?

INTERVIEWEE: I was going and I was like, there are certain fasts and things like that I used to do but after infected, I became more involved in these things. I mean, like there are certain prayers, if I don't say those prayers, I won't eat my dinner or anything. I mean I have to go and pray it and then only I'll do it. And I feel relief at the back of my mind that, you know, I've done something at least to – build my strong willpower and things like that.

MARGARET: So it became more important to you, that practice, after your diagnosis?

INTERVIEWEE: Yes.

MARGARET: And you'd say that the reasons for that were your knowledge that you have HIV?

INTERVIEWEE: There is an XXXX knowledge of according to our Hindu culture, we say that if you pray this time, I mean, maybe your next birth, all your bad Karmas might be gone and then you might get a good life. Yes.

MARGARET: And are you actively involved in your faith group and your temple group? Are there things you do there other than go to worship? Are you involved in any of the social activities or food preparation or...?

INTERVIEWEE: Yes. I do go and there are lots of places where I go and we – I try to give as much as knowledge, not only on XXXX but any other sorts of problems or illness or anything. I mean I'll try and give them that knowledge and tell them like any XXXX problems or any things like that, because a number of people feel that, you know, like a vaginal thrush, they feel that oh by eating spicy food and everything, they are getting so they will try the home remedies and I try to explain to them that it's not that. It might be some bacterial or viral infection. They should go and see the doctors and everything. And I know that they feel shy if it is a male doctor. They would prefer a female doctor but I try to explain to them that,

"Look, they are the doctors. They are not interested in you for any other things. They are just interested what you are suffering from," and some people can get convinced with that but with some it's really tough for her, us.

MARGARET: So do you – does this happen sort of in the XXXX centre or does it happen – are you invited through your contacts at the temple or...?

INTERVIEWEE: It's – we do with the XXXX centre as well. Like I got involved with XXXX, XXXX, we try to target those areas and go to that and speak to the people. Okay in the starting first because we have three-day session. First day, I know that the people won't build that bonding between us. They will be a bit shy to speak up about their problems but after that once, they got into the confidential, they will start asking the questions and everything to me. And some people who know that my background, that I'm XXXXX and everything, they will try and call me up, and they'll try to say their problems or anything and I'll try to explain to them in the phone and everything that, "Look, this is the thing, or if you go to the doctor, speak like this and they will help you." So in that way, also, I do it. I try to help them.

MARGARET: But it's not – I'm interested in how – how your speaking to those groups, mainly of women, I assume, is that right?

INTERVIEWEE: Yes, mainly women.

MARGARET: Yes, how you make contact with them. Is it through the temple leaders or through your own...?

INTERVIEWEE: Not with the temple leaders because the temple leaders have never organised such a workshop at all. It is like different women groups and that we try to contact them, like XXXX Aid, XXXX XXXX different - different type of groups and we try to tell them that, "Look, we are doing with this – " Because when they see that name XXXX they think at least about AIDS, but when we say that not AIDS only, we are speaking about all sorts of things, all sexually transmitted disease and everything, and we try to speak them, but up until now, none of the male person has come out and spoke to us and said that, "Look, is it possible this way or this way?" They don't – I don't know if they feel still the barriers because if the women are there, the men doesn't want to go.

MARGARET: Yes.

INTERVIEWEE: It maybe their ego or something is going on, but they won't come out so now the second target we have tried to do is try to organise a male group, but I know it will be

MARGARET: And this is – when I was asking about your involvement in your faith group, in your community group, what about your involvement in your – in the temple group, among the people who attend the temple or the work of the temple? Do you have any – are you involved in any activities there? Do you help with any teaching of young people or any food preparation or music or anything like that? I mean that probably doesn't happen. It's probably that you just go to worship, say your prayers and just –

INTERVIEWEE: Yeah because there isn't any much things happening in the temple, and you know where these things are happening in XXXX centre, there the thing is they say that, you know, you have to be registered with city councils and things like that and I can't go there much so I go nearby the temple and if there is any sort of things, if they want they know me where I am and things like that but here it's just a worship and everything. That's it. There isn't any much things happening.

MARGARET: Yes. Yes. Which –

INTERVIEWEE: Because we tried to speak to the secretary XXXX and we have already told them that, "Look, we are here, and we don't charge or anything. We give free information free of charge and things like that," but up to now we haven't got any contacts yet that – or we wanted to organise something or anything because I think somehow they might have felt a fear because I'll tell you the truth that Asian people's minds are really narrow. They combine two things together. They combine HIV with AIDS. That's it. They don't see the difference. HIV is a virus and AIDS is a full-blown. They just think, "HIV – oh this person is gone completely. Within two or three years we'll hear something." So that is the main thing. And we are trying to get deep down to make them understand that, XX "Oh, we know. We know." But when you just try to find out and then you speak to them you know that, no, they don't understand or they don't know anything.

MARGARET: And your efforts to sort of make more contacts have not resulted in any new action.

INTERVIEWEE: No, not yet, no.

MARGARET: Just some questions about your thoughts about HIV transmission. In your opinion and from what you know, what are the main factors contributing to HIV transmission around the world and in the UK and in Leicester?

INTERVIEWEE: Main thing is, say, sexual and then it's injecting needles. Sometimes a woman is HIV and breastfeeding is the main thing and blood transfusion because – okay, in Western cultures they go through all the test and everything. Afterwards they do the blood transfusion, but – well, in Africa and Asia, they will just see the group matching and then straight away they won't go thoroughly through those all sorts of tests and everything and then they will do the transfusion. They won't do it at all.

MARGARET: Do you think that's still the case?

INTERVIEWEE: It is still the case. Yeah. And you have to force the doctors to tell them that, "No, you have to do certain tests on these ones and then only I will do the transfusion." Then it's okay, but if you don't say and you are not – like lack of education, some people are not that educated or they think that, "Oh, it's blood transfusion. Oh, you can get it from anybody and your blood group is matching. That's it." But they don't understand that there are so many different illnesses you can get through that.

MARGARET: And that's, you know, the sort of global picture really then you're referring to there. Do you think there are sort of particular factors regarding transmission in the UK and in Leicester? Do you think there –

INTERVIEWEE: There are –

MARGARET: You referred to sexual transmission, do you think –

INTERVIEWEE: They are. There are. They are in so many. And I know that there are many Asian people XXXX who are suffering from that, but they don't want to disclose. They want to live their normal life and I've spoke to a number of people and when I said that, "What do you use for the safety precaution?" I said that, "Do you use a condom?" And they say, "No, it's not a pleasure. We don't get the pleasure." Because I know once they reach 18 or something, they feel that they are enough, young enough to go outside and do things like that, and there are some people end up in drugs. Some people go in the college they think that they are young enough and one friend is doing so we should do it. And they start sharing the needles and everything.

MARGARET: And do you see HIV as a cause for concern as a public health issue in the world and in the UK and in Leicester?

INTERVIEWEE: It is. It is, I mean – It is. It is a big, big concern because if you see now cancer. Cancer was a first cause people were thinking, "Oh, cancer, cancer, cancer." But cancer has become common and people started knowing about the cancer effects and

everything, but if you ask about HIV, nobody wants to know. Nobody – I mean, they don't even know the full meaning of HIV or AIDS if you tell them
XXXXXXXXXXXXXXXXXXXXXXXXXXXX, "Do you know this illness?" And they were combining with this bird flu things.

MARGARET: Oh.

INTERVIEWEE: They were combining with this bird flu thing and I was in shock and then I used to tell them that, "No, bird flu is different. This is different." And they didn't know what it is.

MARGARET: What do you understand your religion's teachings and beliefs say about HIV?

INTERVIEWEE: They don't say anything. They don't say anything. I've never seen that in publically where even spoke about any sex education or anything. They won't say it because still there is a bonding between your mother and child or elder people. They won't speak anything about the sexual education or anything. They don't speak at all because I think they're full up with shy and they said that, "Oh, children are a bit small. You shouldn't speak to them. They'll get a bad influence in the mind. They'll start going outside and things like that. They don't speak." But in a way, if they go through a long way, it's better if you tell them that since they are 18, coming into their teens, if you try to tell them everything because I've seen that even when you are watching the TV or something, if there is a kissing scene going on, "Oh, can you change the channel? It's not good for them to see these things."

MARGARET: So those who are responsible for teaching about the religion, the religious leaders teaching the young people about their religion and the beliefs and so on, they would say it is not right to talk about sex or to talk about HIV or to talk about sexuality or they would say that's not to be done as far as our religion is concerned?

INTERVIEWEE: Yes. Yes, they wouldn't talk anything like this. I mean, if say – if you talk about it, they'll say, "Oh, she's a bad person. She's a bad person. She's talking openly like these things." They won't understand that why that person is trying to teach or tell the truth. They will just tell you that, "Oh, she is a really rough character person," and things like that.

MARGARET: So what would the religion teach about intimate relationships? I mean, there must be an understanding and acceptance that sex does go on between married couples at least, so where does it get spoken of or referred to?

INTERVIEWEE: They – they only teach – no, they only teach you is you shouldn't have any sexual relationship before the marriage. After marriage, your husband has only the rights and

you should just obey your husband. I mean, they won't say that, "Oh, you can have a relationship without marriage," or anything like that. They don't teach you anything at all, even for the hygienic for the woman, they won't say anything that look the woman should say hygiene and things like that. They won't say it except when you are – when the four-day's periods time, you are not supposed to attend the temple they're told. They said that those four days you are not clean. You are unpure. That's it. That is what we will have been told, but we have never been told that these things are – or how to build the relationship with the husband or anything.

MARGARET: And do you think that people in your faith community, Hindu people, conduct their relationships, their intimate relationships, according to those teachings or not?

INTERVIEWEE: Well, they are now the time is change and still you can see that some people are going out and some people fall pregnant because I know that there was a time that abortion was not allowed in our community because we say that once you abort a child, then for seven birth, you have to repay that things, but now it's common.

MARGARET: So once if a person had an abortion, the saying is once you abort a child you have to repay with seven births.

INTERVIEWEE: You have to repay seven births. Yeah. But now it's common. Things are common. Sometimes, you know, if a young girl without a marriage she became pregnant and just put the name of their parents and everything in the society, they do go for it but it's still, you know, still we are backwards in that ways. We are not that forward that, "Oh, we should accept that person who has been a victim." Sometimes you might be a rape victim or some things like that. They don't understand that. Even if you have been raped or things like that, they would say that it was your fault. "You wore this kind of clothes and you – why did you go night time or some certain times?" They won't see that she was just a victim, but they would just say that, "Oh, it's your fault."

MARGARET: And so, I mean it sounds from what you've been saying that those teachings, those beliefs, influence how people in the community respond to HIV and people affected by HIV, that by and large there is a silence around all of that?

INTERVIEWEE: Yeah, there is a silence and they won't speak at all. They won't speak at all. Today, if I go in my community and in my temple and if I say that, "Can anybody come out with the fact they are with HIV?" I know that nobody will come out. And over there only I can count there are certain people that are affected but they won't come out because they feel that, "Oh, if we'll say that we are HIV, our children – nobody will marry our children. Nobody will call. We'll be out of the community." There are a number of things. Your social life will

be ruined, everything. Because people feel that if you are HIV and if you go to that person's house, if you shake hands or if you drink at that person's house or things like that, you might get infected with it.

MARGARET: And do you think that has any influence at all on whether or not people outside – or how people outside that particular community respond to HIV or do you think it's just within the Hindu community that that's the issue?

INTERVIEWEE: It's not only Hindu. There are Asians, I can say. Asians, including you can say Bangladeshi, Muslims, all sorts of things they are. Because according if you see that we still count we are Asians and we are not supposed to speak to our children in friendly terms about any sexual things or HIV or anything because we feel that, "Oh, we might have done something bad. That is the reason we got this illness. We might have been – in a prebirth, we might have done so many bad things that we are the victims of these things." So it is that still going on in our mind. I mean they don't say on the medical terms that we are being infected by some thing, other things, not just by our bad Karmas or anything like that.

MARGARET: But that is a Hindu thing rather than a Muslim thing or do you think it cuts across all Asians?

INTERVIEWEE: No, it comes all Asians. All Asians it comes the same thing.

MARGARET: Even for Muslims, that sort of belief?

INTERVIEWEE: It is. Yes, it is belief. It feels that God is punishing us. Yeah.

MARGARET: Right. So it is more a cultural issue than a religious issue in your view?

INTERVIEWEE: Yeah. Yeah, it is a culture issue because as I told you that, still our Asian culture is backwards. Still, still they are really backwards. They have not gone that further or – as I told you that when we are watching a TV, and if certain things come out on the TV, we'll just tell the children, "Oh, can- " or either the parents or anybody elder will just stand up and go away from there because if they say their children won't listen to them because they see that, oh, it's a bit shy to see these things openly in front of the children or the family members.

MARGARET: I see. Just to stay with that point a moment, you referred to the sort of pre-birth kind of thinking, belief, and I was sort of making the distinction between Hindu and Muslim thinking that a Muslim would not have that same idea about the Karma, but you think that culturally, that might influence the religious belief

INTERVIEWEE: Actually, actually if you see – I have a research and I can take out the printout for you because all the Asians, Muslims, some Muslims, different Muslims, they have come out from Hinduism. Before the Jesus Christ 750 years ago, we were all Hinduism only and from that some people did try to divert their religion into Christianity. Some people have gone into Muslims, Shias, Kojas, Memons, everybody and still we continue with this pre-birth of things. Yeah, we go through that pre-birth issues we are going still and there are a number of things we are having a similarity. Like they have the fastings, we have the fastings things, everything. They worship, we worship. Except we worship the picture they don't worship. They say that it's invisible and they are doing the prayers, things like that. But it's the same thing. Like before marriage, the relationship, it's the same way in the Muslims. They won't have the relationship. We don't have the relationships.

MARGARET: Yes, that's very helpful, thank you. So people in your faith group and in your community don't talk to anyone about HIV?

INTERVIEWEE: No, they don't.

MARGARET: XXX?

INTERVIEWEE: Yeah. Yeah, XXXX XXXX because if I start speaking in my community, I know that they will think that either I am loose character or either I'm just a bit cracked or something, why I am speaking all these things about HIV and nobody is interested in knowing. They are interested in other things, about the TV drama, things like that or the family conflicts and things like that, but they are not interested in these things.

MARGARET: So it's a mixture of culture and religion that influences whether or not people talk about HIV in your community you would say?

INTERVIEWEE: Influence is there plus I think real thinking, the way people are thinking because still we are so narrowminded that we are not accepting the fact that we have to learn these things. We have to know everything. It's not – they don't want to know anything. As I told you, they are not interested in these things. I mean, they can come out. They can speak. But they don't want to know because they know that this illness is connected with sexual things. They don't want to know that thing at all.

MARGARET: Even though it may be a serious health issue?

INTERVIEWEE: They don't want to know because I told you, you know, that what they think is that if they will speak about – if they will know that today I am a victim of HIV or AIDS, they will think that I have gone somewhere because they think that, "Today you slept and

tomorrow you have been diagnosed.” They don’t know that the virus can be in your body for years and years without even showing any sign and that some person can die even with that virus, they won’t know because I was just going through some books and everything. I know that early ‘50s, I mean from ‘30s and everything, people were dying from TB because that time the medication was not out. With a number of other illnesses, I was looking at it. That time this research didn’t come out about HIV. It came out in ‘80 when one person was being diagnosed in Uganda, Kenya and after that they gave this name to this virus, HIV and things like that. But if you go in research about that person who was in ‘30s died of TB or anything, you might have find the traces of HIV in that body because at that time also the same equipment will have been used, the same things would have been used, but that time it was not the major issue because now it’s the major issue come out and people came to know and they know that this is HIV, but I can 100% say that that person might had that virus in their body but because at that time it wasn’t – or they were saying, “Oh, it’s TB? TB. That person did die? That person did die.”

MARGARET: Yes. So what do you think is the answer? How is it going to be possible to enable people to understand and to know more about HIV? How is it going to – how is that barrier going to be broken down?

INTERVIEWEE: I think the main thing is that the Hindu or any other Asian people, the priest has to get involved in that, and we should start speaking openly, and we should try to give the knowledge as much as we can to the people and to the young generation that, “Look, you have to use your safety first.” I mean, there are things like, say, there are so many people involved with these drugs things and everything. They are injecting everything, and there is lots of awareness going about it. Why not give the awareness about HIV? I mean, you can give it if you will. I mean, you don’t have to use those slangy language. You can use a really good language and try and make them understand that, “Look, you have to understand what is HIV, what is AIDS.” First you have to teach them that these two things are different and how it has been effected because still there are people who feel that some poor mothers, they are not being able to feed their babies. I mean, that lady might know that she’s infected with HIV, but due to the family pressure, “Oh, breastfeeding is good. You should feed your baby this, this thing.” For that person might be trying so hard to try to explain that, “Look, I don’t get enough milk,” or things like that because I know that things are happening like that also.

MARGARET: So it needs a much greater effort on the part of the health services to bring information to groups in the Hindu communities?

INTERVIEWEE: Yes.

MARGARET: But also you're suggesting that the leaders of communities, including the priests of the communities, should also take a role in bringing that information and helping people to understand?

INTERVIEWEE: I think, you know, they should organise every month or something like that, a seminar. We should call all the people – it should be open for the public and first the priest should be told that, "No, this is not an issue where your bad Karmas or whatever you have done in your prebirth is coming up." The priest should understand and he should try and educate the people because I know that a priest's voice will be listened – it's a direct one, because if I will be standing up and speaking, they won't listen. But because priest is – we worship next to the God and we say that, "Oh, he's a high rank person," and if he starts understanding things, I mean, I know that things can go really in the right way.

MARGARET: And – we've covered an awful lot of ground. Not much more to go.

INTERVIEWEE: No problem.

MARGARET: Do you think then that because of that silence and that reluctance to speak about HIV and perhaps think about HIV it affects whether or not people go to seek advice about HIV, go to a health professional, go to a GP and ask questions or go to a practice nurse?

INTERVIEWEE: They won't go. They won't go until they are infected, they won't go.

MARGARET: So when you say infected, until they fell ill?

INTERVIEWEE: Yeah, they felt ill, they have been diagnosed, then only they will go. Because XXXXXXXXXXXXXXXX you can go to direct GP. You can go to GU. You can go direct to the hospital if you feel the symptoms or anything like that. You should go and you have the rights to go and say because everything will be in that room only but still people won't go until they are too worry and they find that, oh, their health is going down and down thereby, then they will go but without that, they won't go. They feel that, "Oh, I'm healthy. I'm fine. I don't want to go and speak."

MARGARET: So the main concern then becomes prevention and because people are not engaging because of the silence and the reluctance and so on, prevention becomes a big issue?

INTERVIEWEE: Yes, prevention becomes a big issue and they feel that, "Oh, I've not done anything wrong so I won't get infected with it." But as I told you that that virus can stay in your

body for ages and ages without even waking up. And once it's woke up, your immune system starts falling down and then everything comes out, but why don't you just go before – like there's a saying that, "Why don't you build a bridge before the floods come up? It's better that you built the bridge and you should do." I mean, today when I was been diagnosed, straight away I took my children because I didn't want them that when their health is completely down and then to treat. I know it is really from the scrap that you have to start and then when I took them, everybody was shocked and they said that, "Why did you bring your children to be tested and everything?" Okay. They told me but they told me to take my time and I took them and until that one week, the results were not out. I mean my mind was just going round and round that if they come out positive, what will I do? What will I do? What sort of life I will be living? But back of my mind, I was thinking one thing that, "Okay, if they have been turned out positive, then the good thing will be that they will have start the treatment before they really felt poorly," but touch wood, they were all negative.

MARGARET: So you haven't disclosed your HIV status to anyone in your faith community?

INTERVIEWEE: No, I haven't disclosed because the thing is I know that it will affect my children's life. It will affect my social life and things like that. I mean, as I told you, there's no knowledge about it. They think that after XXXXX XXXXX death, they might think that I have gone outside and slept with someone because it affected me after three years. They won't think that that virus was in my body from long back, and I know that people will start pointing my children that, "Look, the mother was really a rough character and she was going out and these children are not in a good family people."

MARGARET: So you've just – your XXXX knows?

INTERVIEWEE: My family knows. My children, my XXXX knows, and they understood very well about it because, okay, I kept ready the people to speak for me. I mean XXXX social worker knows about it. The XXXX people know about it, but I did keep ready two or three people that if anything they go down, they are there to understand and they can make them understand but I didn't have that much to go because I explained to them and they understood very well.

MARGARET: Do you know another person with HIV?

INTERVIEWEE: Yes, I do. Not only one, so many people I know.

MARGARET: Yes. In your – in Hindu community?

INTERVIEWEE: Yes.

MARGARET: Asian community?

INTERVIEWEE: Asian community ***.

MARGARET: As well as wider?

INTERVIEWEE: Even from different groups, also, I know. And I know really one of – one is my XXXX and I know that he is HIV. And, uh, first in the starting as I told you that it was difficult for my XXXX to understand and things like that, but when I sat with her and explained to her everything, these things are and how it effects and everything. I mean she started taking XXXX, things like that, so I know they are but even my XXXX cannot go to anybody and tell that, "Look, I'm HIV." Even in a workplace, he wouldn't say – there is in a form written that "Are you HIV positive?" He wouldn't write it.

MARGARET: You talked at the beginning about going more to the temple and the prayers are important to you since your diagnosis and that you receive a sort of strength through that. Is that right?

INTERVIEWEE: Strength and I think I find peace of mind. I mean by saying the prayers and things like that, I feel that my willpower is getting stronger and I feel peace of mind is that when I'm involved with my prayers and everything, I don't think about my illness or anything. I just think that, "Oh, God is there to protect me from everything."

MARGARET: Yes. So because of the silence, it's impossible to say how the faith community would respond to somebody with HIV. You know, we haven't actually seen that in practice.

INTERVIEWEE: Well, when – last – two years ago when I was on radio and when I spoke that – one of the RJ was asking me the question that, "Why you are scared to speak to the community?" And when I told them that it will attack my children and my family and my social life, the Hindu XXXX XXXX said that, "We are aware and we will really be helpful to help that person." But I know that when they will come face to face to me, I know that XXXX XXXX XXXX XXXX. He will accept me but the rest of the community won't accept me. So it is difficult for me that to tell them that, "Oh, I should go and tell that I'm suffering from this illness.

MARGARET: You've mentioned LASS and the support you get from LASS and other agencies you feel that the support that you receive is adequate to your needs. Are there other ways that you would like to see support available?

INTERVIEWEE: I think LASS is there, but I think the Asian people should form certain groups. Okay, we are trying our level best from – through the LASS only, but I think more Asians should be getting involved in this, but I know that if there will be an Asian group doing like this for HIV and things like that, you know, we can't just keep our things in ourself. I know that they will start speaking to somebody when that is the main problem. And I know that being an Asian, the person won't go in an Asian group. They feel that they will speak out their illness in outside, but in a way LASS is doing a really fantastic job. They – whenever you go there, you try to explain your problem and they will make you understand. If they are stranded, they will try to get either a health visitor or somebody and make you understand. That person will be sitting with you. I mean if you want to speak in the group, they can speak in the group. If you want on your own, they can speak with you on your own. But in that way, plus they are providing us, say, with a lack of funding nowadays we are going every two months to the cinema, but there was a really good time that we used to go every month. And we should feel proud that oh at least somebody is there to take care for us and they are taking us outside. Like last week when I had an XXXX on the XXXX and they made sure that everything was well organised for me and they were really ringing me up. At least I know that they are there. And today when my son was not willing to accept these things and I was feeling that I should tell him. I should tell him, the younger one, and I was really getting confused day by day and I wasn't myself and one day I went to LASS and I spoke to XXXX. I said to XXXX, "Things are not going the right way. I'm really worried because he's using my personal things like Bonjella," because I used to get mouth ulcers and things like that. And I told that, "What should I do?" And she told me that, "Take your time. Speak to that person." Because there was a time that my chart was going up and down, up and down and he used to think that why she used to be an active person and most of the time whenever I'm telling her, she's sleeping. She's not herself. Then finally I found the courage and I told him that, "Look, I'm suffering from this illness." And then, next time when I took him to LASS, XXXX was there. She did explain to him and he understood very well and today is doing fine. I mean he can understand my issues and he cannot force me things like that.

MARGARET: So if you had to provide two messages or one message, important messages which could help ensure support and care for people affected by HIV in your faith community, in your Hindu community, what would they be?

INTERVIEWEE: Live with dignity. Why should you feel bad that you have been infected? You should be proud that at least you are in this country. You get all sorts of help. You should be proud and you should live with the dignity.

MARGARET: And what would you say to those people who are not affected by HIV? Well, who we think are not affected by HIV, but in the wider Hindu community, what would you say to them to ensure that there is proper support for people affected by HIV?

INTERVIEWEE: I would say that, "Don't neglect your health. Health is wealth. And try to accept those people who are infected. I mean, they are just like you, ordinary human being. Try to accept them."

MARGARET: And that was about ensuring support in the wider community. What about a message to prevent transmission of HIV?

INTERVIEWEE: I would say use condoms and don't try to use – I mean, if you are using drugs, try to use a different syringe. Don't use the same syringes. I would say that only and before going for a blood transfusion or things like that and make sure that you explain to your doctors that I hope it has been tested for HIV or Hepatitis C or B or whatever. I mean, you should – first you should be peace of your mind, you should think that, "Oh, these things have been already tested." Then only you should go ahead.

MARGARET: And what do you think about sex education in schools?

INTERVIEWEE: It should be compulsory. I think it should be compulsory from, say, once the child is in year 8, slowly, slowly from year 8, we should try and educate them. We should try and target those community – I mean college, schools, at least, you know, when they are in certain age before going for an intercourse or anything, they're aware that they should use the safety first. I mean, the schools, the health visitor is there. She's providing the pills and everything but she should also provide the information regarding this STI, all the sexual transmission disease and everything. She should provide that also.

MARGARET: And we're almost at the end. Do you think – we've talked a little bit about this and what you think about the role of the faith group leaders in relation to HIV, but my specific question is do you think it matters what faith groups and faith leaders have to say about HIV?

INTERVIEWEE: Faith leaders I don't think because I don't know – they have not been got involved in all these things still. It is – I think we have to start from the scrap. They should understand everything first and if they understand, I think one day maybe, I don't know about ten/twenty years, they might start accepting those people who are HIV, but first they should understand as I told you in the beginning that we are the victims. We have not done any bad things. Not in my prebirth – I don't know about my prebirth or anything, but we are just the victims, ordinary victims. And they should understand these things.

MARGARET: So you're saying that it's better that they don't say anything about HIV until they know much more about HIV, until they speak as an informed person?

INTERVIEWEE: I think because the thing is they combine two things together as I told you in the beginning. They think HIV is AIDS. They don't know HIV is the virus name, AIDS is once you are full blown. They combine two things together and it becomes a big issue then. They just – if I tell that, "Okay, I'm HIV positive." I know that they won't say HIV positive, "Oh, she's suffering from AIDS." Now, that is the main thing. They should understand first that what is HIV, what is AIDS and what sort of things does it affect and how it affects. Then I think they will understand the things. And they can after that start accepting the people that not by shaking hands or by using the toilets or drinking in the same glass or anything can infect you.

MARGARET: And is there anything else that you'd like to say or comment on that we haven't covered during this time?

INTERVIEWEE: Well, there isn't any – much things but I think now the Asian community should wake up because this is a major crisis going on and people should start understanding these things.

MARGARET: Is that it?

INTERVIEWEE: Yes.

MARGARET: Thank you so much.

INTERVIEWEE: Yes, it's all right.

APPENDIX F1d
TRANSCRIPTS - INTERVIEWEES
Interviewee: K11

MARGARET: The code XXXX. Do you attend a place of worship?

INTERVIEWEE: Yeah, yeah, we belong to the XXXX church in XXXX. I'm a XXXX now, for my sins. My parents are XXXX so I have sort of grown up, sort of , from going to Sunday school, reached the mid teens and then sort of fell out and then obviously went back when I was about 21, I think I started going again. So yeah, we're regular goers.

MARGARET: So you attended a church before you were diagnosed with HIV?

INTERVIEWEE: Yes. Oh, yeah, yeah.

(beginning of recording WS_10065)

MARGARET: There hasn't been any change there. The diagnosis hasn't made a difference to your attending or not attending?

INTERVIEWEE: No. No.

MARGARET: I was going ask are you actively involved but clearly you are XXXX.

INTERVIEWEE: Yes. Yeah. I think you take on sort of roles because everybody in the church is getting older and because I'm younger, um, they sort of actively encourage you to do something and I don't think XXXX is a completely difficult job. I mean we have coffee mornings once a fortnight and try and arrange jumble sales and things like that, but yeah no. I'm quite actively involved with the church and the XXXX and we've got a crèche as well and so on and XXXXXXXXXXXX.

MARGARET: Do XXXX go?

INTERVIEWEE: Yes. Yes. XXXXXXXXXXXXXXXX.

MARGARET: And you were active before your diagnosis?

INTERVIEWEE: Yes. Yeah. Well, I thought about as much as I could. I mean because I was away XXXX it was difficult. Every time I came home we obviously went. And because of the XXXX I did tend to go on a Sunday morning. XXXX XXXXXXXXXXXXXXXXXXXX. But no, I've always enjoyed wherever we've been I've, you know, yeah been quite active, yeah.

MARGARET: And just some questions about HIV. In your opinion, what are the main factors contributing to HIV transmission around the world, in the UK, in Leicester?

INTERVIEWEE: In what? The sort of contributing factors?

MARGARET: Mm hmm.

INTERVIEWEE: I think it's bad luck. I really do. I mean I got mine sexually and I think it was just one of those things that we just – you know, my ex-partner didn't know. He passed it on and, you know, we didn't know. Around the world, I think there's still a lot of ignorance and, you know, I think it's still in Africa they don't believe that it's passed through sex. They don't believe that it's active, do they, or something? But yeah..

MARGARET: And do you think it's a cause for concern as a public health issue?

INTERVIEWEE: I think so. I mean when I was 14 and 15, we had all the adverts on television that, you know, "AIDS is going to kill you. Sort of thing" and I think even at that point we were sort of, "It's going to happen to somebody else. It's not going to happen to us. We're-" Even when I got my diagnosis, my friend came with me to get the diagnosis and she said, "It doesn't happen to people like us." And, you know, I think that's got to change. I think a lot, you know, a lot more – I think we need to be more publicly, you know, outspoken. I mean we need to talk about it but it's older people now who are going into second relationships where their marriage has broken down. They don't think they're at risk. They don't think, you know, they've not been tested. And, you know, when I speak to people, I speak to friends and, you know, disclose my – my status, they're sort of like, "Oh my goodness," and they don't – I think they don't think that they could be, you know, affected or infected, and it's quite scary the people that just don't think that it's going to affect them. They just think that, you know, I don't know if it was going to be some.. by looking at you they're going to be able to tell. And obviously I'm just a normal person doing normal things and you can't tell, and that's – that's the whole thing. So yeah, I think we, yeah, definitely need to be more going on.

MARGARET: How long ago were you diagnosed?

INTERVIEWEE: Um, diagnosed XXXX years, been positive for just over XXXX now so quite awhile.

MARGARET: And do you think HIV is a health concern in your church?

INTERVIEWEE: It's a – yeah, it's scary. I do a lot of, you know, charity work. We tend to do a lot of money for XXXX research XXXXXXXXXXXXXXXXXXXX A friend of mine said to me – “Do you know anybody who's personally been, you know, affected?” And I said, “Oh yeah, I've got a friend.” And she went, “Is it a man?” And it was like – and part of me wanted to say, “No, it's me. No, it's me.” But I knew she'd just – the pity in her eyes was just too much and I thought, “I can't-“ you know, “I'm quite happy. You know, I'm okay, but I don't need anybody's, you know, pity.” We want to get on and try and move on with this. – yeah, and I think it'd take quite a lot for the older people, with that. I mean for some of the people now it's not an issue at all. When I was first diagnosed, I came home, um, there was a gentleman who's known me all my life and he wrote me a letter and it said, “Something's wrong,” he said, “I can tell, but you're not ready to tell me but I can see sadness in your eyes.” And it was – quite moved me at the time, but yeah, and he knows now, but it took me a long time to sort of tell him and disclose to him, but yeah, different people have different understandings and yeah.

MARGARET: And what do you think your church's teachings and beliefs say about HIV and people affected by HIV?

INTERVIEWEE: I still think they tend to believe that it doesn't – it's not affecting our country. I think that's – there's still a lot of talk about, you know, when people do sermons its AIDS in Africa, and it's not about how it's affecting us in this country, and I still don't, you know – I mean, XXXXXXXXXXXXXXXXXXXX she did a lot of work for HIV in the local community. XXXXXXXXXXXXXXXXXXXX, I don't think there's any sort of prejudice, I suppose. I still think they believe that it's, you know, it's not a problem in this country at the moment. I think they still think it's a, you know, a problem elsewhere.

MARGARET: So where there's an interest at all, it connects with something far away over in Africa or somewhere else?

INTERVIEWEE: Yeah, it's not – yeah – not here.

MARGARET: What would your church say – what would it teach, what does it believe about intimate relationships?

INTERVIEWEE: Um, I don't know! It's strange really because XXXXXXXXXXXXX a divorce and she's got a new relationship and a new man and she's obviously quite open. We haven't got – I don't there's any problem with our religion about intimacy and, you know and discussing that, that's not, you know.

MARGARET: There's an openness?

INTERVIEWEE: Yes. Yeah, I mean "living in sin" is not huge. It's not, you know, you wouldn't be condemned for living in sin or having, you know, been sexually active or anything like that. That's not, you know, we're quite liberal.

MARGARET: Yeah, so there isn't – there isn't a sort of particularly conservative approach to those relationships?

INTERVIEWEE: No. There's not at all.

MARGARET: Do you think that's sort of the case throughout XXXX in particular or do you think it's a sort of Christian thing or do you think it's a XXXX thing?

INTERVIEWEE: I don't know. No, I don't think it's a particularly XXXX thing. I think – I think, you know, the XXXX at the moment kind of thing. I've got XXXX who lives in XXXX who I thought was very liberal and very – XXXXXXXX preacher – XXXXXXXXXXXXXXXXXXXX and she wouldn't allow them to sleep in the same room even though they lived together, and it was – do you know, it was this very strange when you think people are very liberal and very, you know – and they've got married and they're quite happy and thingy but at the time it was very sort of quite shocking XXXX.

MARGARET: So do you think then that those beliefs about HIV and people affected by it, those beliefs about intimate relationships affect how your church responds to people with HIV?

INTERVIEWEE: Um, I don't know because I don't think it's ever been raised in sort of that sort of an issue or that sort of context so I don't think – I don't think it's ever been talked about in that sort of extent. I think it's, you know, one of those things where it's, you know, it doesn't matter because it's not happening here. It's happening there and so it's not really –

MARGARET: The connection isn't really being made?

INTERVIEWEE: Yeah. No, or they associate it with gay men and I don't think there are many gay people in our church but I – I don't know. I don't think we have but, you know, maybe – I don't know how they'd be accepted to be honest. So, XXXX lady I was talking to was like, it must have been men, and it was like mmm, XXXX.

MARGARET: Yeah. So would there be a less accepting attitude do you think towards a same sex relationship?

INTERVIEWEE: I don't know. I don't think because I think we've never had one, I think it might be quite sort of, not tutted about, but I think there'd be a lot of – sort of you know, discussion about it and that sort of thing, but I don't think anybody would be particularly against it, but I think there'd be a lot of, sort of you know, because they don't understand I think, that would be – yeah.

MARGARET: Yes, so you don't think there's any sort of real connection, or do you, between what your church thinks about HIV and the wider community?

INTERVIEWEE: No, I don't know.

MARGARET: You've mentioned this a little bit, do people in your church talk to one another about HIV though that would be in the context of HIV in Africa perhaps or...?

INTERVIEWEE: Probably, yeah, more – yes, more in that sort of context. Obviously they'll talk about when XXXXXXXXXXXXXXXXXXXX we're raising money, you know, for the local community XXXXXXXXXXXXXXXXXXXX They don't read or they don't associate it with a local sort of project to be honest though.

MARGARET: So it's not the case that the sort of church's teachings influence whether or not people talk about HIV?

INTERVIEWEE: Not – no, not really, no.

MARGARET: It's more about the individuals themselves, whether or not they have an interest –

INTERVIEWEE: Or they're aware of it– yeah, I think the awareness is probably there but I think because our congregation is slightly older, I don't, just don't think it affects them so they don't sort of, you know...

MARGARET: Doesn't really register.

INTERVIEWEE: No. No.

MARGARET: Did, again if you could perhaps say a little bit with the recording, talking about how you felt telling your church leader about your own diagnosis.

INTERVIEWEE: I've not.

MARGARET: Oh, I beg your pardon. Sorry, I thought you were talking about – I thought you were saying XXXX.

INTERVIEWEE: XXXX knows, but XXXXXXXXXXXX not XXXXXXXXXXXX anymore.

MARGARET: I've got you.

INTERVIEWEE: Our XXXXXXXX at the moment, it's – I haven't – it's a bit – it's a very sort of grey area whether you tell people or you don't tell people. And you, you know, I don't think it would do either of us any favours if I told. I think I, you know, I could quite easily tell XXXXXXXXXXXX, and I don't think XXXXXXXX a problem at all with it but I don't feel that I need to tell XXXX, and XXXX obviously found out through XXXXXXXXXXXXXXXXXXXX and I haven't got any problems at all with that and you know, our relationship's grown, you know, a lot since I've told XXX.

MARGARET: Sorry, I misunderstood then, so XXXXXXXX–

INTERVIEWEE: XXXX used to be XXXX.

MARGARET: Right. Right.

INTERVIEWEE: Yeah, XXX.

MARGARET: XXXXXXXXXXXXXXXX Yeah.

INTERVIEWEE: XXXX XXXXXXXXXXXX XXXX.

MARGARET: XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX?

INTERVIEWEE: No. XXXXXXXXXXXX.

MARGARET: Right. XXXXXXXX I see.

INTERVIEWEE: XXXX.

MARGARET: And so you haven't disclosed to this XXXXXXXX?

INTERVIEWEE: No, no.

MARGARET: Um –

INTERVIEWEE: Now, it's not that I don't think that XXXX be able to accept it. It's not. It's just one of those things that, um, I think the HIV is a part of my life, but it's not a massive part of my life. It's there and we deal with it and as sort of a family we deal with it, but we don't talk about it every single day. So if I'm – and if I have bad times that's really, you know, it's just if something's changing or something's happened and we happen to talk about it but it's not something that's at the forefront of my life all the time and so we've moved on from that and get on with everything, so...

MARGARET: And it's nothing to do with religious teachings or beliefs?

INTERVIEWEE: No. No. No, I think XXXX quite, you know, acceptable and that wouldn't be an issue at all.

MARGARET: Do you think people in your church, if they did have a concern about HIV, do you think they'd feel able to, given their church background and their XXXX context, do you think they would feel able to talk to their XXXX and look to talk to a health professional?

INTERVIEWEE: Yeah, I think I don't think there'd be any issue at all talking to the XXXX . We have – I mean, there is XXXX XXXXXXXXXXXX if anybody's got any concerns. You know, and it's probably a lot of people have got a little twinkling that they've, you know, that I've got some connection with it, but I don't think anybody's actually put, sort of, two and two together and think that. I just think they think that we're a quite normal, happy family, and that's – you know, that's it and if I was HIV positive, then there'd be something they could tell, that they'd see me getting poorly or something like that, but no, I don't think there'd be any issue at all to be able to speak to a XXXX.

MARGARET: And nothing to do with your church background or that context affected whether you talked to XXXX or talked to a health professional or went to seek advice or anything like that?

INTERVIEWEE: No.

MARGARET: And have you disclosed your status to anyone in your faith group?

INTERVIEWEE: A couple of people, two people. I didn't, um – my XXXX felt the need to tell people. I think, you know, you do your own sort of coming to terms with it, and whereas XXXX been able to talk to me about it, talk to my family about it, I think XXX needed other people as a support network as well so XXXX sort of told a few sort of friends that XXXX –

yeah, so yeah, there are a few people within the church that do know about my status and we all XX Yeah, so...

MARGARET: And did XXXXXXXXXXXXXXXX you know who XXXX had told?

INTERVIEWEE: Not until afterwards. And XXX said, "And I've told," "And I've told," it's sort of like, "Okay, that's fine." My XXXXXXXXXXXXXXXXXXXX, after XXXX XXXXXXXXXXXXXXXX, XXXX said, you know – I think XXXX spoke to my XXXX about it. XXXX didn't actually speak to me. I think I'll have to tell XXXX and have a chat XXXX XXXX and sort of see what XXXX, you know – and the next weekend XX gave me a really big cuddle and I thought, "Okay, it's getting strange," that kind of thing and I said to XXXX, "I'm a bit worried because XXXX's just given me a really big hug," and XXXX went, "I think XXXX's told XXXX, "Oh that's OK, but yeah no, I'm really lucky in the respect that I've never had a bad reaction. Everybody I've told has been supportive, and wanted to ask questions, wanted to know what they could do and I had a friend when I was first diagnosed, when I'd just been told, and she phoned up Terrence Higgins Trust and said, "My friend's just been diagnosed. What can I do to help her?" And it was – that sort of threw me completely because it was like, you know, and it's – I've been very, very lucky, I know that, so...

MARGARET: And you know other people with HIV and you – that's through the support groups that you're connected with?

INTERVIEWEE: Yeah. Yeah.

MARGARET: And you don't know, or do you know, anyone else with HIV in your church?

INTERVIEWEE: I don't know if there's anybody else. I don't think there is, but I don't – no, I don't know.

MARGARET: What is it that you receive from your church in terms of – in terms of, Oh I suppose, why do you go to church? What is it that keeps you involved?

INTERVIEWEE: Um, I think you get a sort of – I mean I – you know, teenage years, I think you think you know everything and everything. You know, you think – you know, you don't believe in anything and thing – um, and then when I actually got into my early 20s, my XXXX died, and at that point, I did, you know, question my faith quite a lot, but I still found comfort in it. I still, you know, that's why I went. I felt safe and I felt secure and you feel like you belonged to, you know, a particular group. And I like that feeling. I like that feeling that we are a family, that we – I think that's why I can go as well because obviously the XXXX go, I

go, my XXXXXXXXXXXXXXXX go when they're XXXXXXXXXXXXXXXX, so we do go to church as a family. I think it's something we all do together, and I – yeah, I just – I enjoy going, so...

MARGARET: So it does give you considerable support but it's not that. .. from the way you've described it would be the same whether or not you have HIV?

INTERVIEWEE: Yes. No, I've always found, you know, the comfort and guidance and yeah.

MARGARET: Do you think it would be the same whether or not you were known to have HIV?

INTERVIEWEE: I think there would be a considerable backlash for a time. I think there'd be meetings and discussions. I think that, you know, half the congregation would be like, "That's fine. Let's, you know, let's find out about it. Let's deal with this." And I think the other half would, you know, would sort of sit on one side of the church while we sat on the other. I think there's still, you know, a lot of skepticism around the whole thing. And I don't think that's anything – you know, I don't think it'd be me in particular. I think it could've been anybody. You know, they just don't understand, you know. Or people might be hurt that I've not said anything. You know, I've not come out and disclosed straight away and not, you know. That's, you know, all theory and hypothetical and Yeah.

MARGARET: Would it make a difference to you if there was greater interest and greater awareness and so on around HIV?

INTERVIEWEE: To me, probably not. The – no, I mean my life, you know, I've got a very nice life at the moment, there's nothing, you know. Um, I think to other people, I think there needs to be a lot more – I don't think it's specifically to do with the church. I think it's to do with the whole community. There needs to be a lot more awareness. Um, but yeah.

(Unidentifiable voice in background)

INTERVIEWEE: It's one of those – yeah, I think we all need to stand up and say I'm positive. When I went to the, um, World AIDS Prayer meeting at the Friendship House and there was a fantastic man who said, "We need to stand up and we need to tell people." And I came out of that meeting saying that's it. I'm going to work and we're going to tell everybody at work and thingy. And then when you get like 24 hours down the line, you're thinking, "Maybe I'm not going," or "Maybe I'm not quite that brave." But I understand what he means. I think we all need to stand up and say, "I'm positive. It's not affecting my life as, you know, as much. I'm not going to, you know, contaminate you just by touching you. We are, you know, but there are a lot more of us out there than you realise and I think there needs to be a lot more

awareness and a lot more people need to get tested to sort of stop, stop the spread at the moment because it's getting a bit rife. So yeah.

MARGARET: And you've – you also get support from LASS...

INTERVIEWEE: Yeah.

MARGARET: ...and FAITH...

INTERVIEWEE: Yes.

MARGARET: Is that – do you find that – all that is adequate to your needs or is there – are there gaps at all that you feel need to be filled or would help you if they were filled?

INTERVIEWEE: I don't know. I don't think – I'm in a quite strange situation because I'm on my own with XXXX and I work. I, um, struggle sometimes to get to the meetings to get to the support group and that sort of thing because I work, but I am quite, you know, happy. I know where the support is if I've got a particular problem and I know that I can go to LASS. I know that I can go to FAITH and that's fine. When I can attend the meetings, I do attend the meetings. I don't feel as if, you know, I'm not lacking anything. You know, I think the women's group is a fantastic idea. We had one when I was in Nottingham. I think you need to be with other women and it's quite nice to sort of talk about things with other women and talking about disclosing to the children at the last meeting I went to. And that was – it's quite interesting to sort of hear other people's theories and, yeah, some people have got children who are like fourteen years old and they've not told them and I thought, you know, my XXXX are coming up to XXXX and they're aware. They know that I've got poorly blood. They know that I go to the hospital, and they know there's something. They're not, you know, I think at the minute they're too young to understand the complete picture, but they've got an understanding. I think as long as you sort of teach them that, and that was quite, you know, and these women have got like fourteen year olds, and it's like, they see it on television all the time. And they're going to- you know. I want my XXXX to know that I've not hidden it from them. I don't want to burden with it because that's not – but I need them to understand that this is something. I think hopefully it'll give them a greater awareness when they're older, when they become obviously sexually active so that they're much more responsible. I think it's important. But no, I don't – I think, you know, the groups that we've got are good. You know, the FAITH group's brilliant when we go on the day trips and things. They're fantastic, XXXX really enjoy it. I'm able to take either XXXX XXXX with me just to help me with the XXXX which is, you know, and I'm really lucky that I've got that support network as well, but no, I don't think – I think, you know, we've got quite a lot in Leicester. I think if you go to other

parts of the country, Nottingham, you know have lost quite a lot of support and things. I think in Leicester we're quite lucky.

MARGARET: And you find it okay and – it's a long way to travel to XXXX isn't it?

INTERVIEWEE: Yeah. No, I'd much – I found going to the Royal just, it's a nasty place. And when you go the XXXX, it's – they've got like a separate wing which I know they've got, because you know when you go to the Royal, people are looking at you. And because you've got an appointment and it's not like a drop-in clinic, it's – you know, people looked at you, "Why have you got an appointment and we've not got an appointment?" There's a lot of, you know –

MARGARET: Yes. So the fact of the distance isn't an issue?

INTERVIEWEE: No. No, not at all. I'm, you know, quite happy.

MARGARET: You've found somewhere where you're content, you're satisfied with the care that you receive and ...?

INTERVIEWEE: Yeah. Yeah, I mean I get my XXXX by email. Everything's done, the numbers you can tap in you know. Yeah, my results are done by email. I go every three months. You know, I'm quite healthy and quite well. And the Royal wanted to see me every couple of weeks. And it's – you know, if you're trying to lead a normal life, you can't do it. You know, having to explain.

MARGARET: No, its very intrusive isn't it.

INTERVIEWEE: Yeah, Work know that there's something wrong with me. The occupational health know and were very, very understanding, very good. When I filled in the questionnaire I expected a phone call back up. I expected them to go into medical or something, but the girl who spoke to me said, "We haven't got a problem at all with it." She said, "When you start having difficulties in your working environment, let us know. We will see what we can do to help you." And it's been fantastic. And I have regular medical appointments and my boss wouldn't dream of asking what it was about. I just say, "I've got a medical appointment. I'm going." And that's it. That's as much as he needs to know.

MARGARET: That sounds like really good practice.

INTERVIEWEE: Very good. Yeah. If I've got any problems and need extra time off, then I say, "I need time off because of this," and that's fine. So yes.

MARGARET: If you were asked to give two clear messages to prevent transmission, what would they be in your church, say, and in Leicester wider community?

INTERVIEWEE: Um, free condoms for ever. You know, it's just... And children are more active sexually, again at a younger age, but I think we need to go in and probably do more in sexual education because I think, you know, we've got teenage pregnancies. It's horrendous. HIV – children catch it, and that's the awful thing. Um, I think just more awareness. I mean, definitely more, probably more on the television. I mean we had that Stephen Fry programme which was nice but it was quite negative. A lot of the aspects were quite negative about – I mean there's lots of us out there living and doing and I think, you know, we're all quite well luckily at the moment. But I think within church, um, more openness. I think there needs to be more – I mean I'd could quite happily stand up and say I'm HIV positive. Let's talk about this. That wouldn't be an issue at all, but I think it's just – I'd worry about XXXX. I think my disclosing wouldn't be an issue, but I've got XXXX to worry about and think about and, yeah, that sort of thing. So, I think more openness and free condoms.

MARGARET: Perhaps more initiatives being taken by church leaders to sort of raise the issues – do you think that might help?

INTERVIEWEE: Yes. Yeah, not just pretend, you know, that this is just in Africa because it's here and we need to be doing something about that here, not just you know, we had a chosen charity for the year this year and that was XXXX. Um, so we had to, you know, we were asked to put XXXX suggestions for this year, and we've gone for another sort of African charity but I think sometimes it's, you know, we need to do some work in this country. That's – you know, where – but I know they need – I know they're desperate for – you know, but let's – let's put the money – let's put some in this country. Let's put some in that country, and let's – you know, so...

MARGARET: You've just sort of touched on sexual health education in schools, what – can you say anymore about that? What are your views about that?

INTERVIEWEE: Oh, well I think the earlier the better to be honest. I think, you know, then it's – you know, instil a little bit from an early age. I mean, it sounds really silly, XXXX know that to have a baby you need a mummy and daddy who love each other very much. I mean I know they're only XXXX, but there's going to come a stage where they are, you know, they're going to get – I don't know what's the age they go, nine or ten now, I think it's quite early, and I think you know you've got to introduce it and be open. I think parents have got to be open. I didn't – my parents were never – we could talk about lots of things but my mum never did sort of have the sex talk with me. It was what you found out on the playground and I don't think

children need to find out like that. I don't think it should be left to the school completely, but I think, you know – I think it should be a, you know, gradual thing to do with parents and the school and the school should keep the parents up to date with what they're doing so that you can talk about it when they come home. We did sexual disease as well about fourteen and my Mum was reading through the leaflets. I don't think she had any sexual education at all and you know I think it's quite advanced, but yeah, definitely I really, you know, because they need somewhere to go. I know we've been talking about not giving the pill to girls when they're under sixteen and that sort of thing, and I think we need to – I'd like to hope that parents are more understanding. You know, I like to hope that when XXXX get to fourteen, they'll feel able to come to me and talk to stuff like that, you know, huge.

MARGARET: Again, you've said a little bit about it, but do you think it matters what church leaders say, what they believe and what they say about HIV?

INTERVIEWEE: Um, I think so. I mean, we're um, the children at our Sunday School obviously are not old enough to be sexually active, but I think that, you know, if the church leaders sort of sat down and spoke to them about it, I think the children would, you know, sit up and take notice because they are, sort of you know, well respected. Um, they've got a youth club in XXXX with older children and younger children and it'd be quite nice if they, sort of – I don't know what they do yet because XXXX are not old enough, but if they sort of took a lead or had somebody in to do a talk, then that'd be quite sort of useful. I think you can, you know, interact it, it doesn't need to be *** and awful and you'll catch awful diseases. I think if you explain it to them and, you know, help them protect themselves, then that's fine.

MARGARET: That's lovely. Is there anything that we haven't covered that you feel you'd like to say?

INTERVIEWEE: Oh no. No, I mean, you know I'm – I just – there's such a – I think the main thing was that people don't think it's going to happen to them. I think that's still huge out there and still thingy. I'm quite a strong believer in fate and I think that God's done this to me for a reason. I don't think it's – you know, he's not punishing me. He's not doing anything like that, but I think somewhere along the line, this is going to be useful for something. You know, going to be thingy, while my XXXX, you know, thinks it's a completely bad thing and that God is punishing us and, you know, I'm like – he doesn't believe at all. He thinks that God doesn't, is nothing and I'm like, it's not all, you know. So I think it's happened for a purpose and, you know, I'm quite happy in the knowledge that, you know, some point down the line that it's going to be useful for me in some respect.

MARGARET: Thank you very much.

INTERVIEWEE: No problem.

APPENDIX G1
TREE NODES

| TREE NODES | |
|---|---|
| Appropriations of beliefs and teachings | |
| | Appropriations of teachings and beliefs Beliefs about disease progression Beliefs about transmission Coherent believing Compassion Condemnation Dissonance Healing power of faith Individual agency, social freedoms Moral, sexual rectitude Religio-cultural authority |
| Disclosure | |
| | Anxiety about confidentiality Knowing others with HIV Talking to health professionals etc Talking to religious leader Telling someone you have HIV Who knows |
| Experiencing support of faith group | |
| | Appropriate response of faith community Appropriate support by faith group Involvement in worship Responding to person with HIV Support from faith group - HIV disclosed Support from faith group – HIV not disclosed Support in faith group |
| Experiencing support of other agencies and wider community | |
| | Response outside faith group Support from other agencies, sources |
| Knowing people with HIV | |
| | Knowing of someone with HIV Knowing others with HIV Knows person with HIV Knows person with HIV in faith group Support from faith group - HIV disclosed Talking to religious leader Telling someone you have HIV Who knows |
| Knowledge about HIV | |
| | Beliefs about transmission HIV as public health issue Prevention and care messages |

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|---|--|
| | <p>Prevention message for faith community Prevention message for local community Routes of transmission Routes of transmission - UK - questionnaire Routes of transmission - Leicester - questionnaire Routes of transmission - world – questionnaire Sources of information</p> |
| Living with HIV | |
| | <p>Experience in Africa, Asia, etc Getting tested Leaders encouraging HIV test Life changing Participant(s) talking about HIV Participants' stories Teachings influencing talk about testing Treatments Worship and diagnosis Worshipping community</p> |
| Making meaning | |
| | <p>Appropriations of teaching and beliefs Discrimination, prejudice Gender issues Healing power of faith Identity, belonging and HIV transmission Influence of diversity Involvement in worship Life changing</p> |
| Religious teachings | |
| | <p>(Hetero) sexual rectitude, traditional morality Authority of religion Beliefs challenged Condemnation, judgment Individual agency, freedom, choice Non-judgmental, compassion and care Religion's teachings and beliefs re HIV Social justice Teaching re intimate relationships Teachings about HIV Teachings not known, silence</p> |
| Sexual Health Education for children and yp; about sex education | |
| | <p>Conducting intimate relationships Sex ed: age appropriate Sex ed: cultural and moral issues Sex ed: don't know Sex ed: emotions and relationships Sex ed: forget or do not listen Sex ed: in family context Sex ed: inadequate Sex ed. Learn about it – do it Teaching re intimate relationships</p> |

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|--------------------------|---|
| | Yes to sex ed |
| Stigmatising | |
| | Anxiety about confidentiality Avoidance Discrimination, prejudice Gender issues Getting tested Influence of diversity Judgment re behaviour Not an issue Stigma Teaching re intimate relationships |
| Talking about HIV | |
| | Faith group talking about HIV Faith leaders talking about HIV Initiating discussion Talking to health professional etc Talking to religious leader |