

## Exploring the support needs of HIV positive mothers with uninfected children

An account of speaking with ten local women  
about life, motherhood and HIV



# Exploring the support needs of HIV positive mothers with uninfected children

An account of speaking with ten local women about life, motherhood and HIV

Study undertaken and authored by Raksha Pandya (BSc)  
(Family Support and Research Worker: Faith in people with HIV)

November 2006



In partnership with



"Faith in people with HIV" is a registered charity offering spiritual and pastoral support and affirmation to people affected by HIV in Leicester, Leicestershire and Rutland.

Working with people of all faiths and with those who have no formal religious affiliation, the term "spiritual" is understood to mean the wider aspects of emotional and physical wellbeing.

The project is managed by the Bishop of Leicester's Chaplain for people affected by HIV. Its services are available to anyone living with HIV or affected by it (e.g. partner, family or carer) irrespective of background, culture, beliefs, ethnicity, sexuality, age or disability. The service is confidential and respects the rights of people affected by HIV.

"Faith in people with HIV" helps to raise awareness of HIV in faith communities and other groups and, working in close partnership with other voluntary and statutory agencies, seeks to promote good sexual health, foster understanding and break down barriers of stigma and discrimination.

## Published by Faith in people with HIV

The Lodge, Margaret Road  
Leicester LE5 5FW

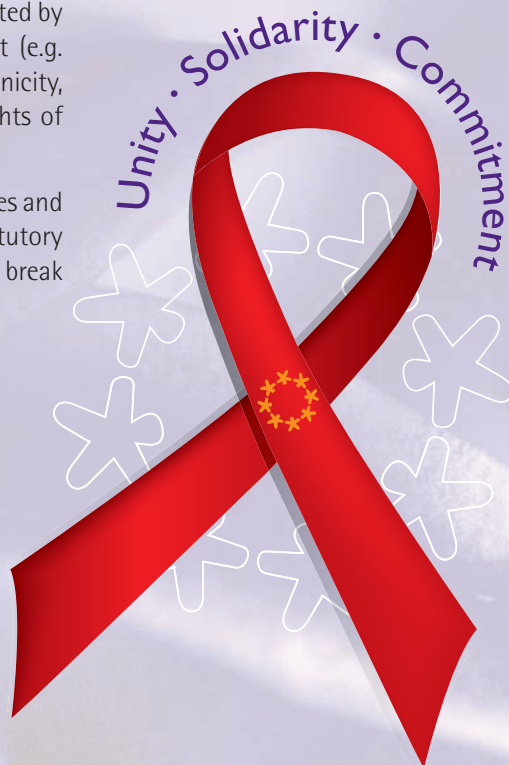
Tel/Fax: 0116 273 3377

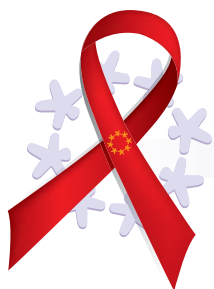
Email: [trevor.thurst@btconnect.com](mailto:trevor.thurst@btconnect.com)

© Faith in people with HIV 2006

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system or transmitted in any form by any person without the written permission of the publisher.

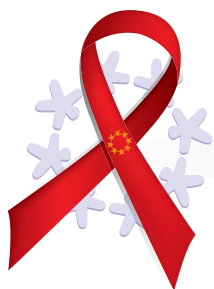
Registered Charity Number: 1102534 - Faith in people with HIV is registered in England and Wales as a company limited by guarantee number: 3318773. Registered office: The Lodge, Margaret Road, Leicester, LE5 5FW





# Contents

|   | Page number |
|---|-------------|
| Preface .....   | 4           |
| Acknowledgments .....                                 | 5           |
| Executive summary .....                               | 6-11        |
| Exploring the support needs .....                     | 12-45       |
| Introduction .....                                    | 12-14       |
| Ethics .....  | 15          |
| Sampling .....  | 15          |
| Fieldwork .....                                       | 15          |
| Findings .....  | 16-45       |
| Analysis .....  | 46-54       |
| Recommendations .....                                 | 55          |
| Conclusion .....                                      | 56          |
| Reflections from the mothers about the research ..... | 57          |
| References .....                                      | 58          |
| Useful telephone numbers .....                        | 59          |



## Preface

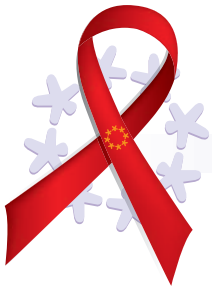
This study was commissioned by Leicester Cathedral from August 2005 to August 2006. It was managed by a Leicester charity called 'Faith in people with HIV'<sup>1</sup>.

The researcher and author of this report Raksha Pandya whilst also working as Families Support Worker (funded by Leicester City Council) was employed by 'Faith in people with HIV' for one year to carry out and deliver this study. During the time of this research Raksha was also undertaking her final year of her Masters Degree in Health and Community Development. She is currently writing her dissertation on the impact of charging failed asylum seekers for HIV treatment and the implications this may have on public health, human rights and cost-effectiveness.

Raksha Pandya is a British Indian woman, who grew up in Leicester and has a work history linked to social care and health in the fields of homelessness, learning disabilities, mental health and drug and alcohol treatment.

Raksha has published a piece of research through Turning Point (a substance misuse service in Loughborough) called "Exploring drug and alcohol related needs of refugee and asylum seeker communities living in the Northwest of Leicestershire". Raksha has also written a chapter for a book called 'Working with Black Young People' through De Montfort University. This is due to be published in Spring 2007. The chapter is based on developing participatory action research techniques in health promotion settings.

1. 'Faith in people with HIV' is a registered charity based in Leicester covering Leicester City, County and Rutland, offering spiritual and pastoral support to people infected and affected with HIV. Working with people of all religions and with those who have no formal religious beliefs. The term spiritual to 'Faith in people with HIV' means the wider aspects of emotional and physical well-being. The Project is managed by the Bishop of Leicester's Chaplain for people affected by HIV. The service is open to anyone who is living with HIV or is affected by it (e.g. partner, family or carer) irrespective of background, culture, beliefs, ethnicity, sexuality, age or disability. The service is confidential and respects the rights of people affected by HIV. 'Faith in people with HIV' also helps to raise awareness of HIV in faith communities and other groups, it seeks to foster understanding and break down barriers of stigma and discrimination.



# Acknowledgments

This research would not have been possible without the mothers who participated and gave their views and opinions therefore we wish to thank them first.

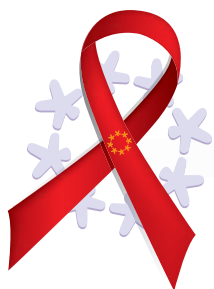
Since August 2005, a team of professionals including:-

- Dr Pratima Patel (MA), Adult Planning and Service Development Officer - Adult and Community Services Department, Leicester City Council.
- Juliet Houghton (RGN; RSCN; MSC), Children's HIV Specialist Nurse – University Hospitals of Leicester – National Health Service (NHS) Trust
- The Rev. Canon Michael Wilson (MA, MBA). Leicester Cathedral
- Rev. Trevor Thurston-Smith, Director of 'Faith in people with HIV' and the Bishop of Leicester's Chaplain for people affected by HIV

have strategically guided and steered this work through meetings, emails, telephone advice and general willingness to help, so Raksha would like to take this opportunity thank them sincerely.

Finally on behalf of the steering group for this research, we thank the following services for their help and support

- Leicestershire AIDS Support Services (LASS)
- University Hospitals of Leicester NHS Trust
- Leicester Social Services Adult Team
- Leicester City Council
- Positively Women (London)
- African HIV Policy Network (London)



# Executive Summary

...In the UK approx  
58,300 people are  
living with HIV...

Exploring the support needs of HIV positive mothers with uninfected children: An account from speaking with ten local women about HIV and motherhood

## Background

Globally 40.3 million people are living with HIV (UNAIDS Epidemic Update 2005). In the UK, approximately 58,300 people are living with HIV (London Health Protection Agency Centre for Infections 2005).

Locally, it appears infection rates in Leicester, Leicestershire and Rutland (LLR) are also increasing. (Choosing Health In Leicester 2005 :13).

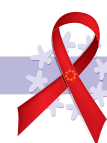
In August 2004 the Leicester Health Protection Agency recorded the following data:

- 605 cases of HIV were diagnosed through statutory health across the 6 Primary Care Trusts in LLR.
- 301 were females.
- 44 were white females and 257 were women who classed themselves as having a Black or Minority Ethnic (BME) background. (Leicester Health Protection Agency 2004)

This research was required because local anecdotal information suggested uptake of medical, social and welfare support services by HIV positive women (most often, although not exclusively from BME origins) in LLR appeared to correlate with significant HIV related events (i.e. at the time of HIV diagnosis or during pregnancy), but it was thought that access of support services may not continue in the longer-term. Given the limited knowledge around the type of formal and informal support networks that positive mothers and uninfected children may have been accessing or requiring, this study aimed to identify the:

- services they were currently accessing
- services they would welcome
- barriers that they experienced in accessing support services
- issues to consider to inform future service provision

AIDS = Acquired Immuno Deficiency Syndrome  
HIV = Human Immunodeficiency Virus



## Method and Sampling

Cluster and purposeful sampling<sup>2</sup> procedures (see Denscombe 2003 :14, 15, 16) were used. Ten semi-structured interviews were carried out; nine in Leicester City and one in the County. (We did not have any participants from Rutland).

## Key findings

### Participant Profile

...Two women were widowed by their husbands dying of AIDS related illness...

| AGES | RELIGION  | ETHNICITY          | IMMIGRATION STATUS |
|------|-----------|--------------------|--------------------|
| 24   | Pagan     | Mixed Race British | British Citizen    |
| 25   | Christian | Black African      | Asylum Seeker      |
| 28   | Christian | Black British      | British Citizen    |
| 29   | Christian | White British      | British Citizen    |
| 29   | Christian | Black African      | Asylum Seeker      |
| 30   | Christian | Black African      | Refugee            |
| 33   | Christian | Black African      | Asylum Seeker      |
| 36   | Christian | White British      | British Citizen    |
| 42   | Christian | Black African      | Refugee            |
| 46   | Hindu     | British Indian     | British Citizen    |

### Women's lifestyle

- Three women were born in Leicester; one migrated to Leicester in 1968, one in 1993, one in 2001, two in 2002, one in 2003 and one in 2004.
- Two women were the owners and the occupiers of their houses. Two lived in rented accommodation. Six lived in council housing or housing provided through National Asylum Support Service (NASS).
- Five women lived in one postal area of Leicester. Eight women felt a sense of belonging in the area in which they lived. Two mentioned they would feel more content if there was a safe place for their children to play.
- Four owned a car.
- Four had part time jobs, two were full-time students and one was a part-time student.
- Two women were widowed by their husbands dying of AIDS related illness. Three women were living with their partners of whom two of the partners were HIV positive. One was going through a divorce. Another was separated and two were looking for long-term relationships.

2. Purposeful sampling selects information rich cases for the purpose of the study and Cluster sampling is when the researcher would approach existing groups and services to find possible participants.

...Seven mothers thought HIV affected their life in many ways including; appetite, sleep, libido, relationships and the future...

- Various sources of income funded household running costs including, paid work, benefits, loans and child maintenance paid by the fathers (where applicable).
- Seven mothers were single parents. Six said that they would like to attend college to fulfil their potential but were unable to do so until their children commenced school. Therefore they recognised that their choice was limited.
- All ten mothers walked 15 minutes or more daily. Two smoked regularly and drank occasionally.
- Eight women ate healthy food. One woman (who is a refugee and a single mother of four children, three of which are living with her) experienced hunger due to impoverishment and lack of food for her family to share.
- Four used a local library.

### Language

- Whilst all ten women spoke English, three African women felt that the accent of the indigenous population in the UK was not easily understood by them.
- Six different mother tongues (first languages) were spoken between the women. These were; English, Shona, Ndebelé, Swahili, Chichewa (Nyanja) and Gujarati.

### HIV

- Five were on anti-retroviral therapy (ART).
- Six mothers believed that despite their HIV status they were generally in good health. Four women said that they regularly felt unwell.
- Seven mothers thought HIV affected their life in many ways including; appetite, sleep, libido, relationships and the future. These seven women said they experienced difficulties of living with HIV and being a single parent as being tiring and / or hard work.
- Regarding HIV tests: Four women were diagnosed in 2004, three in 2003, two 1998 and one in 1992. Four mothers were tested for HIV during anti-natal screening. Two women said their infection was a result of being raped in Africa.

### Support

- Three mothers used a local Surestart scheme.
- All ten women appeared to have very little knowledge of what Leicester City Council and Social Services provided or offered.
- Nine women used Leicester Royal Infirmary (LRI). Eight said that Genitourinary Medicine (GUM) clinic was too busy and took too long for them to be seen, although most of these women said that staff at GUM clinic were caring and friendly. All the mothers and their children were registered with a general practitioner (GP). Mixed comments were made



...general public continue to stigmatise HIV positive people and this is often harder to live with than the HIV infection itself...

- about GP's. Some said that their GP did not understand their condition and others were confident that they did.
- Four women who were diagnosed during pregnancy felt they were fully supported and encouraging and positive comments were made about the level of support provided by a specialist paediatric nurse.
  - Two mothers diagnosed at blood donor centres said no support was offered. Four women who were diagnosed at Leicester GUM clinic saw a health advisor who provided minimal pre-and post test support/counselling.
  - Six women said their families were offered no formal help or support.
  - Four used Leicestershire AIDS Support Services (LASS) and one also used 'Faith in people with HIV' for enquiries concerning their HIV. Two women used GUM for enquiries.
  - Two women suggested professional guidance on diet was lacking.
  - All ten mothers were the main carers for their children. Whenever the mothers became ill, the children's fathers would help with childcare (in the cases where the fathers still kept in regular contact with the mother for the child (ren). One mother was confident that her eldest daughter who is in her late teens would look after her other younger siblings.
  - Nine mothers received domestic help from family. One mother who was on her own in the UK received support from new friends.
  - Four mothers received help from their children in and around the household, including help from older children looking after their younger siblings.

### Disclosure

- Six mothers had disclosed their HIV status to a partner / member(s) of their family. Most of the women who have not yet disclosed their HIV status said that they believed their families would be supportive.
- Nine mothers had not disclosed to their child (ren). The ages of the children varied. Four mothers had one or more pre-school aged children, four had children who were school-aged and one had adolescent children.
- The mother who had disclosed her HIV status to her children said that they were in their adolescence when she told them and since then they have been very supportive.

### HIV and the future

- All the women said that further campaigning is required to promote positive messages of living with HIV.
- Most of the comments on perceptions and how to change society suggested that the general public continue to stigmatise HIV positive people and this is often harder to live with than the HIV infection itself.
- Seven women said that after disclosing their HIV status to their children they would like to be able to access a mother and children group for social

...the best practice in disclosure to children should be identified...

and emotional support. They said that mothers and or their children can meet others in a similar situation to theirs. Additionally two women said it would be useful for somebody on the same premises to look after their children at this social group so that mothers could meet other mothers and their children can meet other children.

- One mother (who was seeking asylum in the UK and who was a single mother) said assistance with childcare should be offered for when mothers have to attend important appointment's e.g. at GUM or the Solicitors.
- Three mothers would like a "one-stop shop" or resource centre where all contraceptives, informal support and free immigration advice can be offered.

## Recommendations

In light of the key findings the following is suggested to improve the quality of life of HIV positive mothers with uninfected children:-

### Children and Young people affected by HIV

Further research needs to be carried out to explore the impact of children and young people having responsibility to provide domestic help and care for HIV positive parent(s), in line with other young people affected by chronic illness within a family. Additionally HIV services should ensure a link with existing mainstream youth services available so that children and young people affected by HIV are supported.

### Co-ordinated Services

Specialist HIV services should work closely together to provide a more co-ordinated package and to liaise with mainstream services so that they are aware of issues around HIV (including stigma and discrimination). Liaison could take place between specialist HIV and mainstream services in the Leicester area which will help provide more accessible facilities to people living with / affected by HIV.

### Support with Disclosure

Existing HIV services should consider avenues such as self help/training courses/workshops to enable HIV positive women to consider ways in which to disclose their HIV status to family members including children and friends etc, so that disclosure can become an easier process. With regards to children, the best practice in disclosure to children should be identified so that HIV positive mothers could be supported to disclose to their children at the right time using the most appropriate approach for them. Support regarding disclosure should also include access to other support services that are available such as family therapy if required. Information about support that is available



...After disclosing their HIV to their children, mothers said it may be useful to access support and help from specialist services together as a family...

regarding disclosure should be promoted widely so that HIV positive mothers are aware of this.

## Information

HIV services and information about a range of issues regarding HIV needs to be promoted widely across all routes of HIV testing, so that people infected or affected by HIV (including HIV positive mothers with uninfected children) can know where to get help and support. This information could cover for example:

- How to access pre and post test counselling
- Healthy eating and access to a dietician, if required
- Advice on future sexual health for people infected or affected by HIV

## Stigma

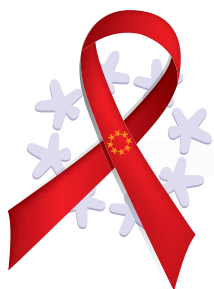
It is recommended that some of the mothers who took part in this research should be given an opportunity to share their experiences (should they wish) in the form of an activity through poetry/drama or art on or around World AIDS Day 2006 which would represent their views on the stigma of living with HIV.

## Conclusion

This study provided a snapshot of the experiences of ten HIV positive mothers living with HIV, and therefore it can not be generalised to a wider population of HIV positive women. The mothers in this study were participating in daily activities that included employment and education. Additionally the mothers were supported informally by family and friends. The mothers identified difficulties that included access to information and support services/areas in which their lives can be improved such as: More social/friendship-type of support after they disclose their HIV status to their children and consistency in information/advice that was being offered regarding sexual health (e.g. oral sex) as well as the need for consistency in counselling (pre and post HIV test).

After disclosing their HIV to their children, mothers have said that it may be useful to access support and help from specialist services together as a family.

It is anticipated that this study will inform future partnership working in HIV services and mainstream services in Leicester and surrounding areas. The report will be disseminated widely for information sharing and expand knowledge base about this particular service user group (HIV positive mothers with uninfected children).



# Exploring the support needs

...In the UK approx  
58,300 people are  
living with HIV...

## Introduction

Globally 40.3 million people are living with HIV. To indicate a breakdown from this estimated figure, 38.0 million cases appear to be adults; 17.5 million of these seem to be women and 2.3 million cases are showing to be in children less than 15 years of age. (UNAIDS Epidemic Update 2005 in NAT 2005). Here in the UK, approximately 58,300 people are living with HIV (London Health Protection Agency Centre for Infections 2005), over a third of whom are unaware of their condition (NAT 2005). NAT argue that although the epidemic continues to climb among men who have sex with men, the main increase is among heterosexual couples, with the majority of cases possibly acquiring the virus in Africa, making African communities 59% of diagnosed cases in the United Kingdom (UK) in 2004 (ibid).

Leicester has been an historic meeting place and preferred choice for settlers of economic and political migration since the 1960s. Migration to Leicester continues today mainly through Home Office dispersals of Refugees and Asylum seekers (RAS). Leicester has a higher percentage of Black and Minority Ethnic (BME) groups, in comparison to the 13% in England (Buckner et al 2004). Migration to Leicester has helped the city to become more vibrant and multicultural. The diverse population of Leicester City numbers 280,000 (Invest Leicestershire 2006). The city has a younger population in proportion to the national average. The general health and well-being of people living in the city is comparatively lower to than national average. The standard life expectancy is lower than the national average too (ibid).

BME groups and in particular RAS from certain parts of Africa and Bosnia or Serbia are a high risk group in relation to HIV infection (Department of Health 2003). Ample evidence suggests RAS and BME groups continue to remain disadvantaged in health (Naidoo and Wills 2000 :38).

The UK Government has cited on numerous research papers and strategies that there is a clear link between 'sexual ill health, poverty and social exclusion' (eg. see The National Strategy for Sexual Health and HIV 2001).

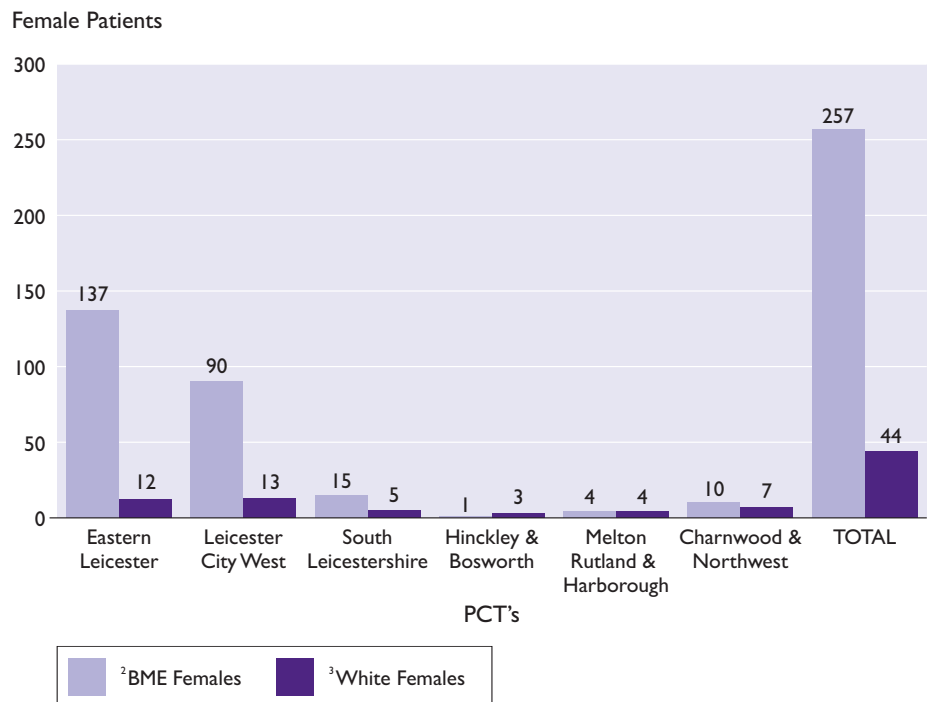
At a local level, it appears infection rates in Leicester, Leicestershire and Rutland (LLR) are also growing (Choosing Health In Leicester 2005 :13). In August 2004 the Leicester Health Protection Agency recorded the following data; 605 cases of HIV were diagnosed through statutory health across the 6 Primary Care Trusts (PCT's) which then existed in LLR. Figure 1 on page 13 shows a total of 152 HIV infections diagnosed in the white population (108 cases were white males and 44 white females) in comparison to the 257 cases in BME women (as shown in figure 2) and 196 cases in BME men (as shown in figure 3).



**Figure 1:**  
HIV+ White patients  
seen for statutory  
medical care in 2004



**Figure 2:**  
HIV+ Women patients  
seen for statutory  
medical care in 2004



It also appears through local data surveillance that HIV infection rates in BME women is higher than infection rates in BME men (see figure 3). This could be because women are more likely to be diagnosed earlier than men due to the introduction of HIV testing of expectant mothers in 1992.

**Figure 3:**  
HIV + BME patients  
seen for statutory  
medical care in 2004



This research was required because local anecdotal information suggested uptake of medical, social and welfare support services by HIV positive women (most often, although not exclusively from BME origins) in LLR appeared to correlate with significant HIV related events (i.e. at the time of HIV diagnosis or during pregnancy), but it was thought that access of support services may not continue in the longer-term. Given the limited knowledge around the type of formal and informal support networks that positive mothers and uninfected children may have been accessing or requiring, this study aimed to identify the:

- services they were currently accessing
- services they would welcome
- barriers that they experienced in accessing support services
- issues to consider for future service planning

<sup>1</sup>White = anyone who regarded themselves as White during their diagnosis

<sup>2</sup>BME = any women who regarded herself as Black or Minority Ethnic during her diagnosis

<sup>3</sup>White = any women who regarded herself as White during her diagnosis

<sup>4</sup>BME = anyone who regarded themselves as Black or Minority Ethnic during their diagnosis



...All the mothers agreed to co-operate fully in this study and to contribute meaningful dialogue to ascertain the necessary information...

## Ethics

Respect for confidentiality, privacy and rights to anonymity were vital in this study, as were safety and security of the mothers and their families. The research was carried out with honesty and integrity and the ethical code of conduct was guided directly by the parallel standards to that of De Montfort University research protocols (2005). Raksha Pandya had received clearance from the Criminal Records Bureau (CRB) in August 2005, which is a requirement when working with children, families and vulnerable people in the UK. All mothers who participated in the research were reminded that they could withdraw from the research interview or decline to answer any question. A monthly project steering group provided scrutiny on ethical issues throughout the timescale of the project. Members were:

- Dr Pratima Patel (MA), Adult Planning and Service Development Officer - Adult and Community Services Department, Leicester City Council.
- Juliet Houghton (RGN; RSCN; MSC), Children's HIV Specialist Nurse - University Hospitals of Leicester - National Health Service (NHS) Trust
- Rev. Trevor Thurston-Smith, Director of 'Faith in people with HIV' and the Bishop of Leicester's Chaplain for people affected by HIV
- The Rev. Canon Michael Wilson (MBA). Leicester Cathedral

## Sampling techniques

Two types of sampling procedures were used, these were; Cluster and Purposeful. For the cluster sampling, seven existing service users from 'Faith in people with HIV' and LASS were approached, who were happy to be contacted and who would fit the research criteria (positive mothers who have uninfected children). For the purposeful sampling, a specialist nurse contacted recently discharged HIV positive mothers and asked if they wanted to take part in this study, these mothers were interested and completed the capacity of the ten participants.

## Fieldwork

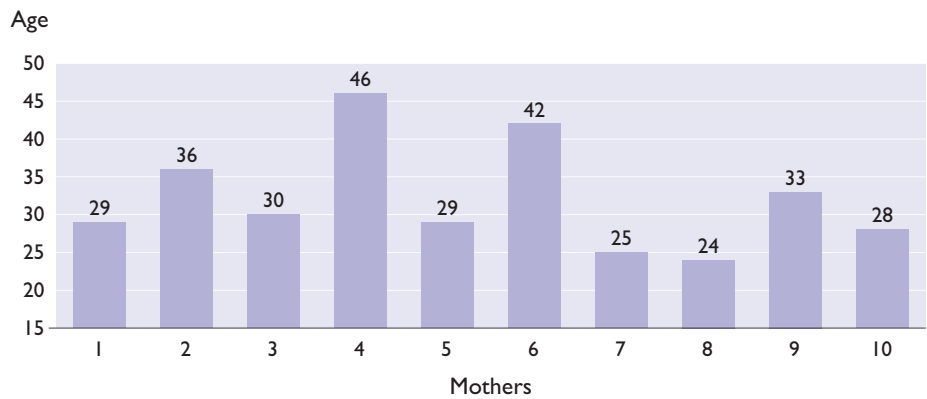
Initially, the researcher met the mothers individually or spoke frequently over the phone to help establish a relationship and to clearly explain why this research was needed. From the ten interviews that took place, eight interviews were in the women's own homes and two were carried out at HIV interagency premises in Leicester. Some of the interviews took over two hours.

All the mothers were briefed on the ethical information regarding this type of social research. All the mothers agreed to co-operate fully in this study and to contribute meaningful dialogue to ascertain the necessary information.

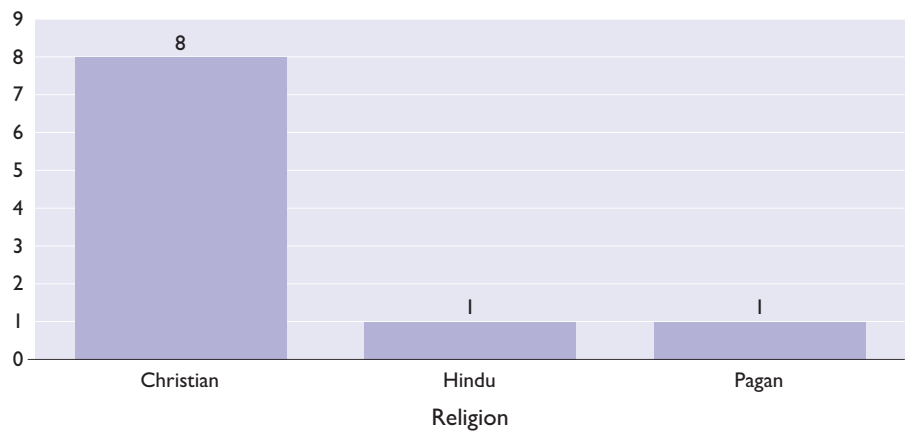
## Findings

### Background

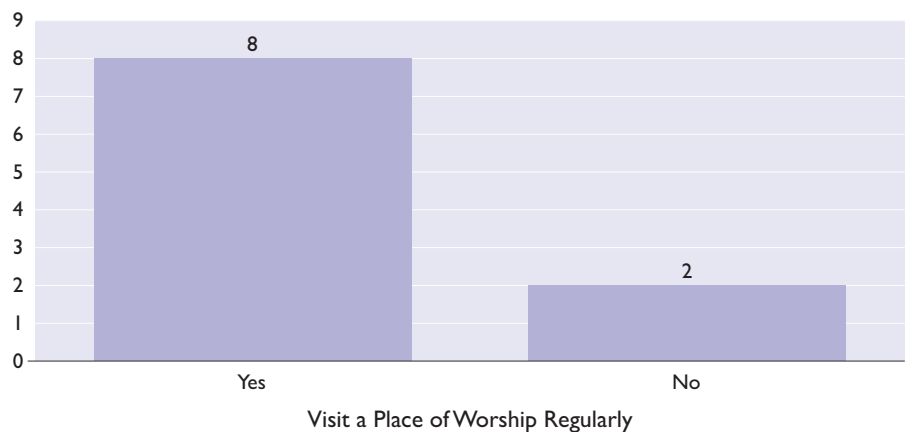
1. What is your age?



2a. If applicable, what is your religion?

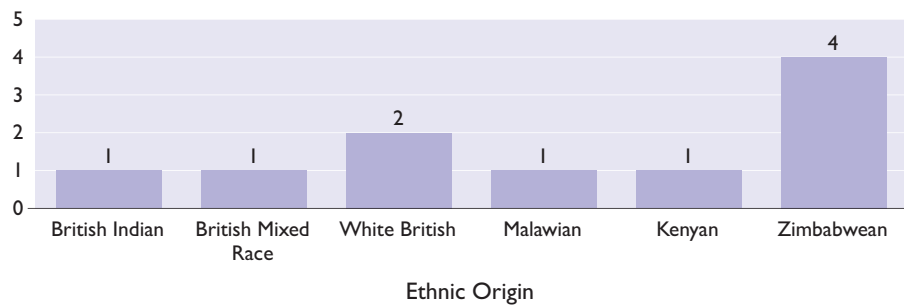


2b. Do you go to a place of worship regularly?

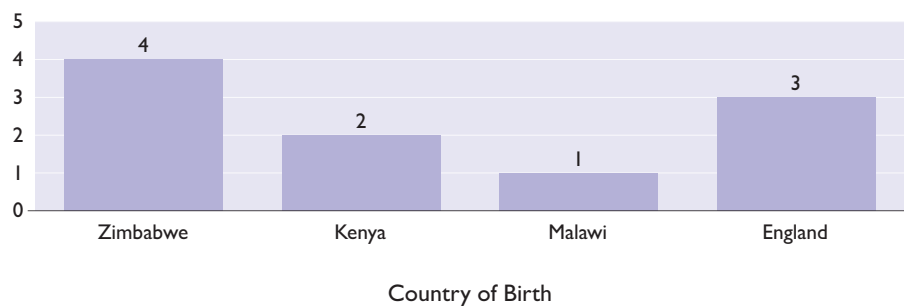




3a. What is your ethnic origin?

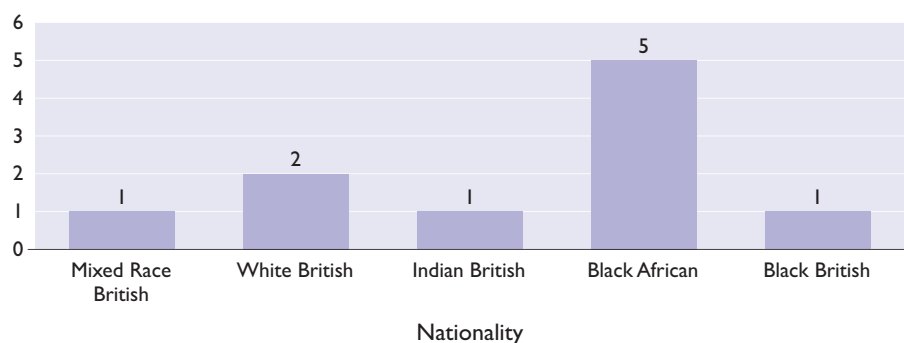


3b. In which country were you born?



3c. What is your current nationality?

This question is referring to what the mothers identified themselves as during the research interviews e.g. the mothers who are refugees or asylum seekers (see question 4.) class themselves as being black women from Africa whereas the mother who was born in Kenya who is also black, but since she granted British citizenship, she identified herself as Black British.

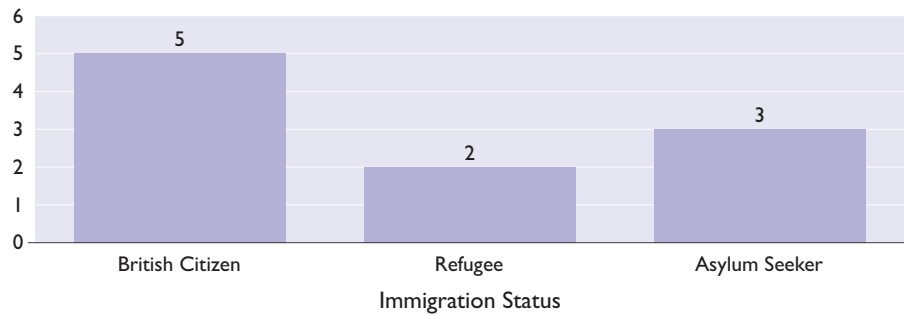


...All ten participants could speak, read and write in English, however Shona and Ndebelé was the mother tongue amongst the Zimbabwean women...

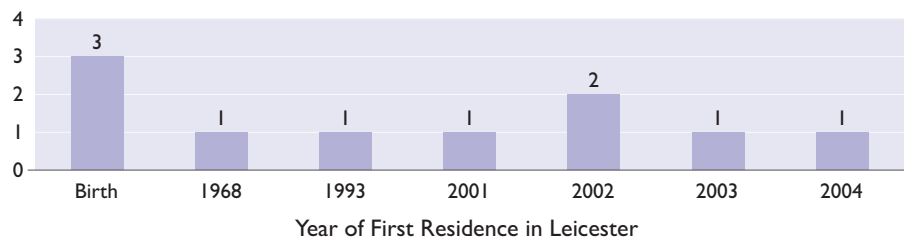
EXPLORING THE SUPPORT NEEDS

## Immigration

4. What is your immigration status?



5. How long have you lived in Leicester?



6. What is the biggest difference for you living here in the UK and living in your country of origin?

Applicable to seven women

“

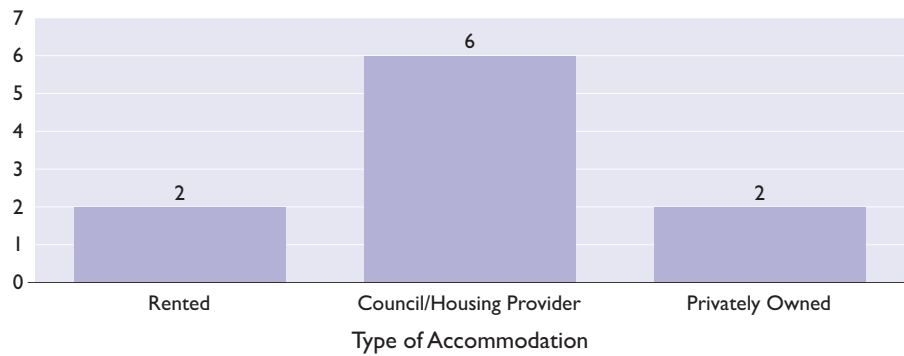
- “Better schooling and medical facilities”
- “Cultural differences – food, social life, weather, cultural diversity”
- “As I have lived here most of my life I don't remember what it is like living there”
- “Lots of wars going on over there, I have found peace here”
- “Our country is getting poorer – many political problems over there”
- “Weather is much better in Kenya because it is warmer. The education system is much easier here than back home”
- “Here I am not in fear after repeatedly being raped. I fled from Africa, I used to disguise myself over there, here I don't need to do that. Over here I have made some real friends”

”

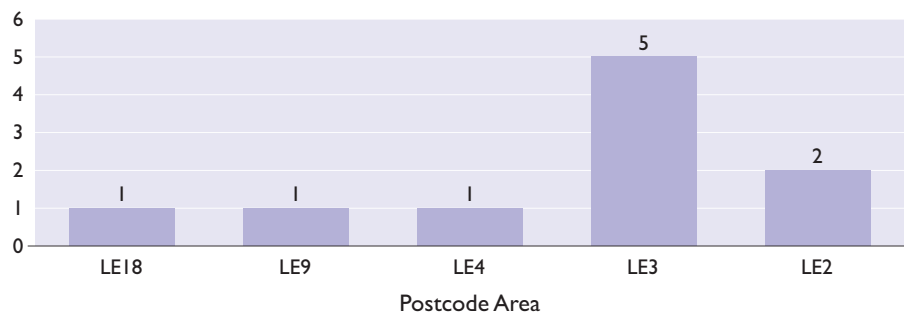


## Housing

7. What type of accommodation do you live in?



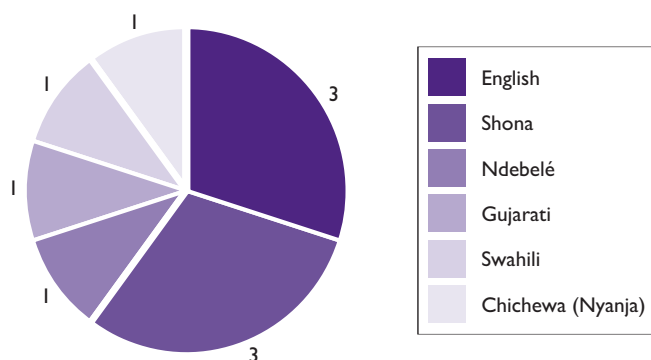
8. What is the first half of your post code?



## Language

9a. What is your preferred first language (or mother tongue)?

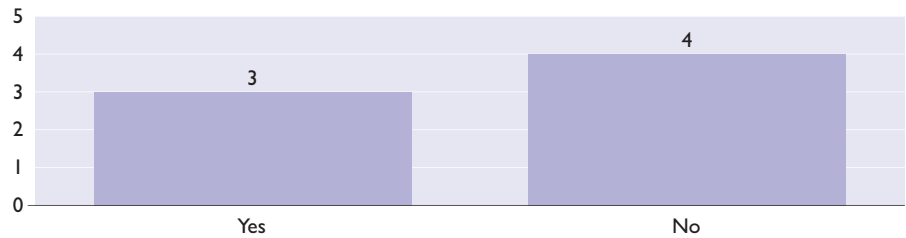
Preferred Language



EXPLORING THE SUPPORT NEEDS

9b. Do you experience language barriers?

Applicable to seven women



COMMENTS ABOUT LANGUAGE BARRIERS

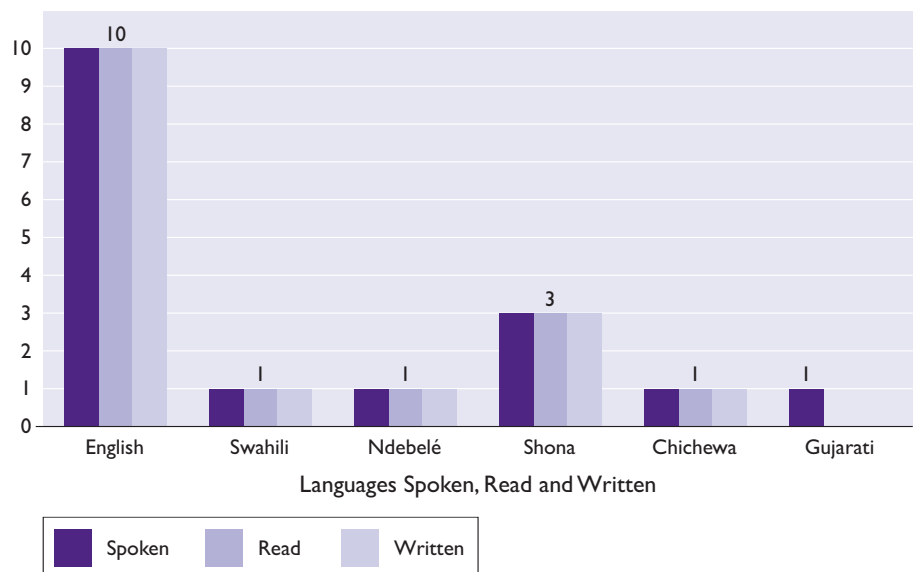
*"I don't think it's 'language barriers' but I struggle to understand the accent. Accent is a barrier if that counts"*

*"Because I am quite new here in this country, I find it difficult to understand when people talk too fast. But I am learning English at college"*

*"In my country we learn English in school so I do understand but here everybody speaks very different, I think maybe my accent is different"*



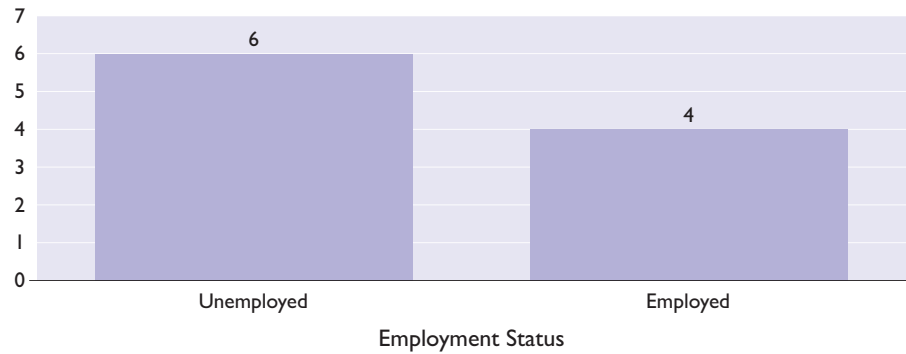
9c. What languages do you speak, read and write?





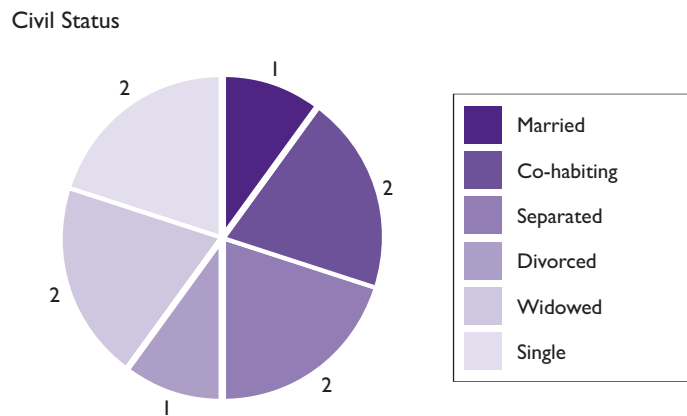
## Employment

10. Are you employed?



## Civil Status

11. What is your civil status?



## Partners Employment

12. What do they do?  
Applicable to three women

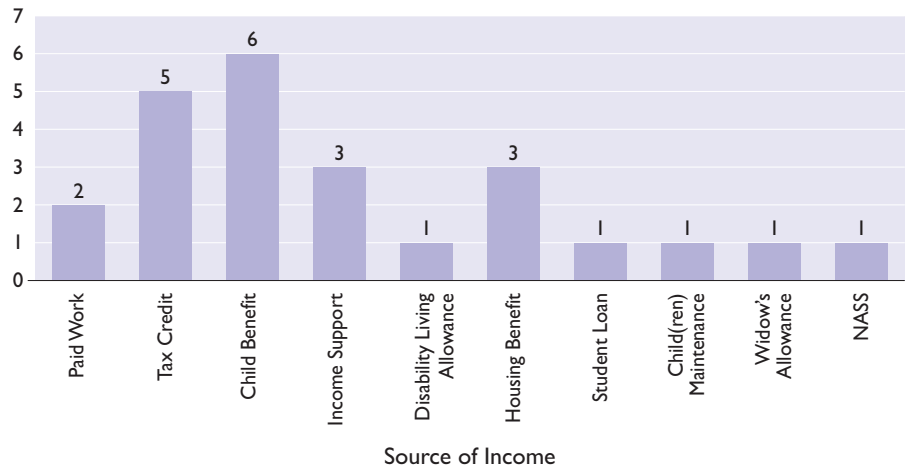
“  
 “Lorry Driver”  
 “Education Department (council)”  
 “Warehouse Operator”  
 ”

EXPLORING THE SUPPORT NEEDS

Income

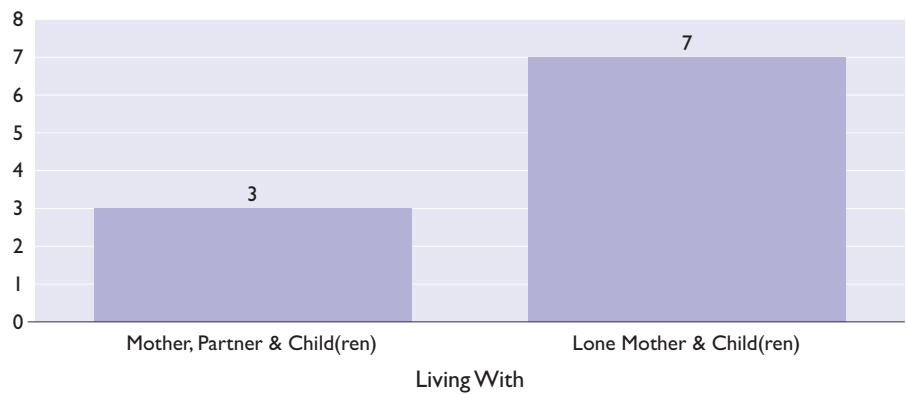
13. Where does money to support the family come from?

Please note mothers gave multiple answers to this question

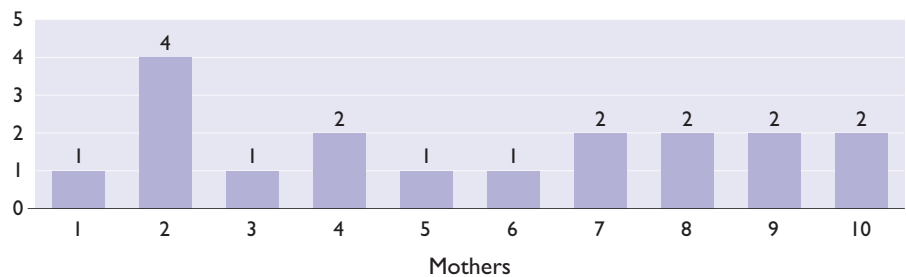


Family

14. Who lives in your house?



15a. How many children do you have?





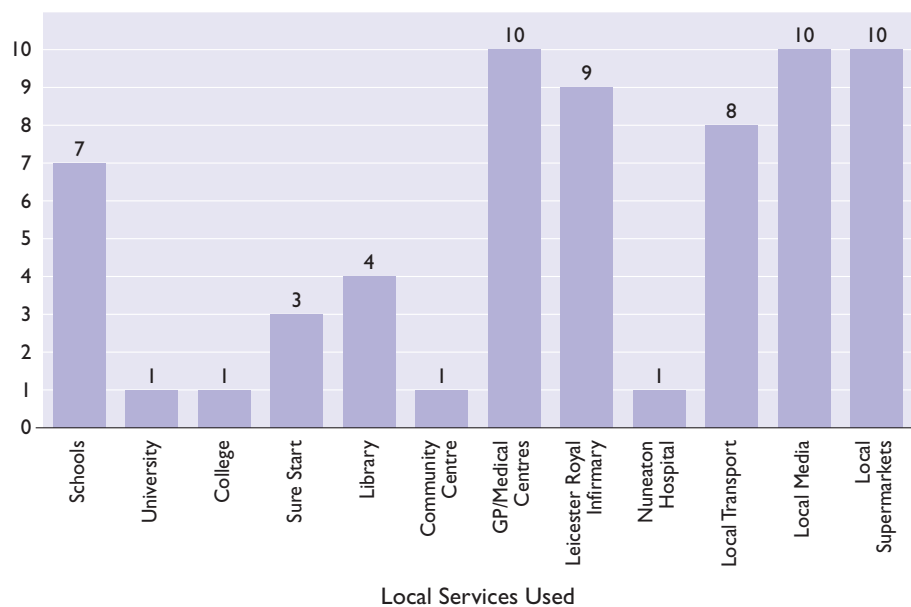
15b. If your children do not live with you, where do they live?

Out of the 18 children, 16 lived with their mothers except for two, in which one was over 21 years old and living in Zimbabwe alone. The other family's child lives with grandparents here in the UK who is still at a dependant age.

### Local Services

16. What local services do you and your family use?

Number of Families



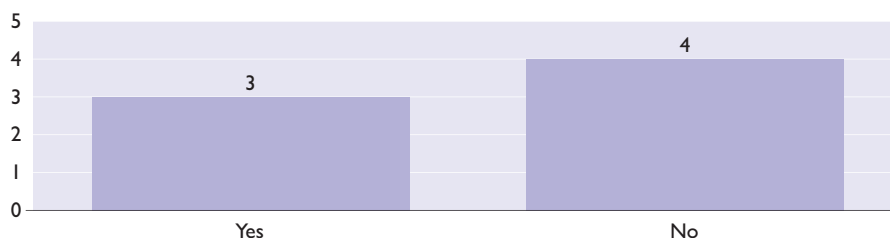
17. What do you like/dislike about these local services?

“*Library opening hours are not suitable*”  
*“Library does not stock enough books”*  
*“Council do not clean our area well”*  
*“GP receptionists do not give appointments”*  
*“GP receptionist has lack of knowledge of HIV”*  
*“GUM waiting times are too long”*  
*“Buses are too expensive and impractical with children”*  
*“Buses are dirty”*  
*“Local media creates more stigma”*”

EXPLORING THE SUPPORT NEEDS

**18. Are there any barriers to accessing these services?**

Applicable to seven women



**19. Which services do you think are missing in your local area in your opinion?**

Please note answers came from seven women, some of whom gave multiple answers

“

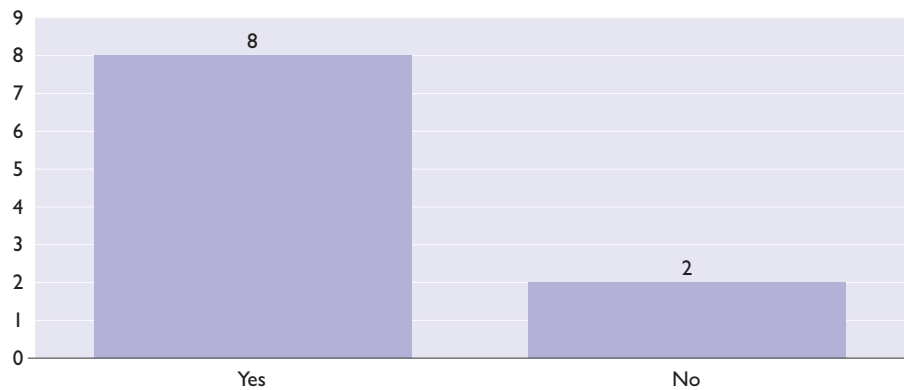
- “African Mother and Baby Group in Braunstone”*
- “Better pushchair friendly, cheap bus transport”*
- “Free child care so that I can go to college and my baby can meet other children, at the moment she only sees me”*
- “A children’s club to help single (positive) parents”*
- “Mother and baby group”*
- “Heterosexual women’s group – Offer advice/support to other single mothers”*
- “Children’s grievance group – to offer support and emotional help to children”*
- “Homework help for children from single parent families. When my children come home from school I have to do everything for them and most evenings I simply don’t have the energy to do their homework with them. I would love to have some time for myself and my children will learn more too”*
- “Specialist childcare service for single positive mothers so that mothers can have time for GUM/doctors appointments”*
- “Immigration and living with HIV support service”*
- “Mothers Group”*
- “Free childcare for asylum seekers so that we can attend solicitors/medical appointments and we can rest assured that our children are in safe hands”*
- “Children’s groups”*
- “African women’s group where I can meet more women and talk about my cultural foods, hair and anything else”*

”

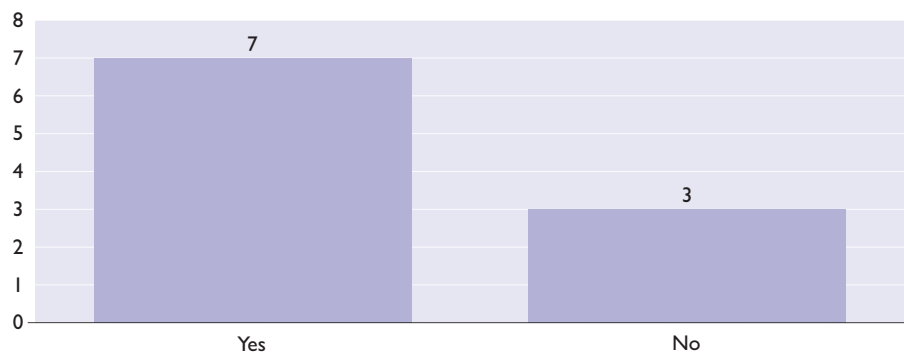


## Community

20. Do you feel a part of the community that you live in?



21. Have you met your neighbours?

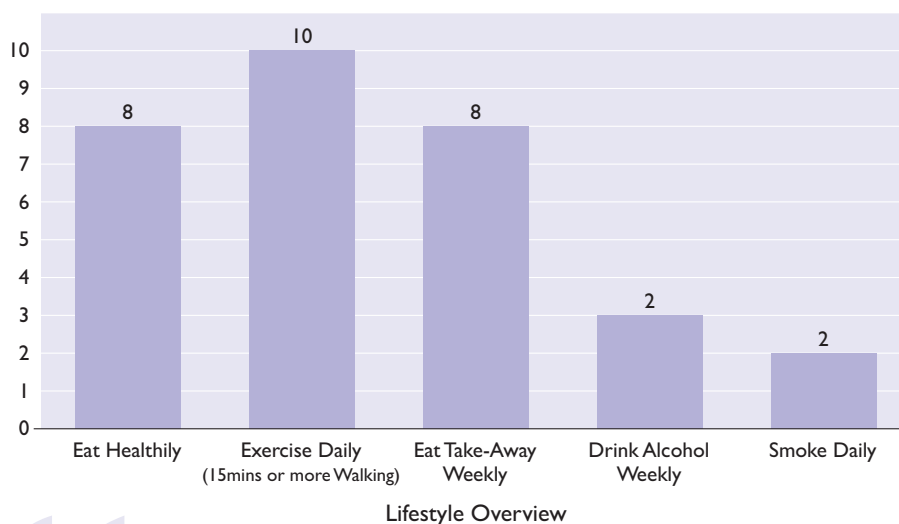


*SOME COMMENTS ABOUT NEIGHBOURS...*

- "Only moved here recently"*
- "They drink too much and fight"*
- "They are noisy; they slash tyres and throw stones at our back door"*
- "My neighbours complained about my family to the Council when we had my daughter's birthday party, even though we had invited them."*
- "Fine we say Hi to each other"*
- "They are good to us and supportive; if I don't see them for a while they would come round and ask 'how are you?'"*
- "If my neighbour doesn't see me for a while they will telephone"*
- "They are fantastic"*
- "I just keep myself to myself"*

## Lifestyle

### 22. What is your lifestyle like?



#### COMMENTS ABOUT LIFESTYLE AND FOOD...

*"Yes we eat healthy - although if I am tired I will make freezer food"*

*"I eat everything but it depends on whether I have money to buy food - sometimes I'll be hungry but I won't have food to eat. I try to sort the children's food out first because of their school. Sometimes my cupboards are empty when they come back from school and they will eat just apples."*

*"2 to 3 portions of fruit/veg/salad daily, fish and meat weekly cereal and bread daily"*

*"We try to eat balanced diet - food is expensive"*

*"Yes I eat properly - 5 pieces of fruit and veg. 2 or 3 portions of meat, and a bar of chocolate daily!"*

*"I eat salad, seasoned fruits, 5 pieces of fruit and veg a day, liver, potatoes, cereal, oats and porridge"*

*"Average day would be, Fruit and Fibre cereal, tea and toast, Nutrigrain bars and cob for lunch, then for dinner, 2 chapatti's, rice and curry, throughout the day apples, bananas and grapes"*

*"It depends if I have time I will eat fruit, if not then fruit"*

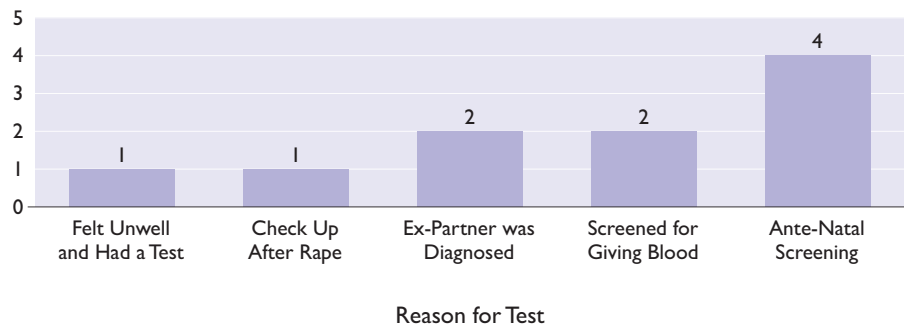
*"I only eat a little bit of fish and meat"*

*"It is balanced, oats/cereal in the morning, steamed veg with fish or chicken at lunch and then pasta or something in the evening"*

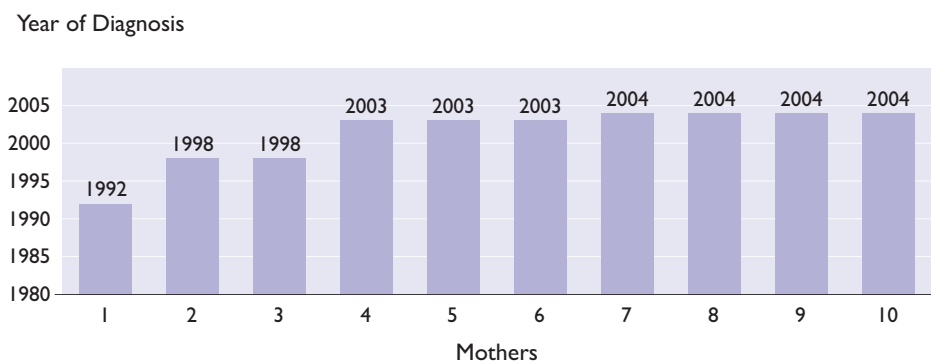


## Diagnosis

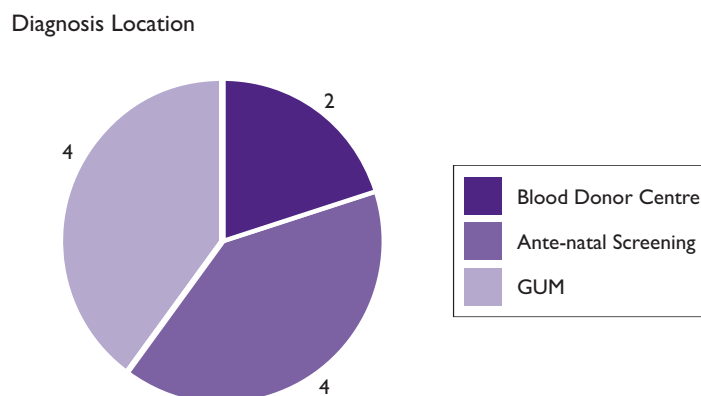
**23a.** How did you find out you were positive?



**23b.** What year was this?



**23c.** Where were you diagnosed?



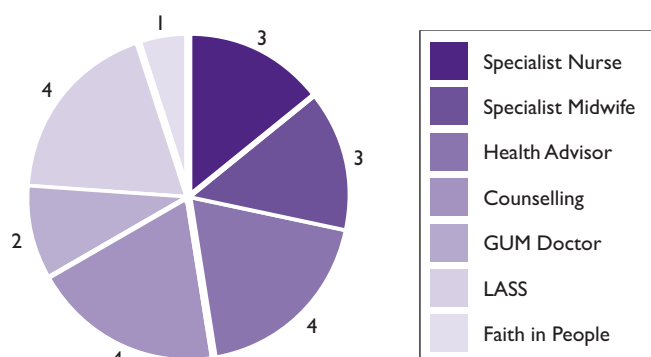
...Another woman noticed lumps on her legs and her GP recommended an HIV test at GUM...

EXPLORING THE SUPPORT NEEDS

24. What kind of support were you offered?

The answers in the pie chart below are the mothers initial responses to the question. However it is worth noting that the four mothers diagnosed during ante-natal screening would have all received help from a children's specialist nurse, a specialist midwife and a GUM doctor. Similarly the four mothers diagnosed through GUM all would have received clinical help from a GUM doctor as part of the clinical guidelines that NHS staff adhere to at the point of diagnosis.

Diagnosis Support



25. How do you think your needs were met during the time of diagnosis?

Please note one mother gave more than one answer

*"Sexual health advice was poor – no consistent explanations between professionals"*

*"I was offered nothing"*

*"There was no pre or post-test counselling. I slipped into depression. It wasn't easy to pick up the pieces"*

*"I was glad to be offered LASS and Faith in people"*

*"Only the nurse on the ward spoke to me"*

*"I was offered lots of help but I just did not want any"*

*"Would have liked to have learned more about HIV"*

*"Needs were all met but at the time I was going through denial"*

*"Somebody was always there"*

*"My baby was monitored throughout the pregnancy"*

*"My health advisor was really good, she asked me to apply for a visa"*



26. How do you think your family's needs were met?



*"My daughter was too young"*  
*"Not told my children"*  
*"My mother works at the LRI so she knew where to ask for help"*  
*"We were left to deal with it"*  
*"My husband was tested straightaway"*  
*"My mum went to LASS"*  
*"My partner got tested"*  
*"As I was pregnant they really looked after me, my appointments were on time and there was always someone to talk to"*  
*"The paediatric team was lovely, very helpful"*  
*"Both children's needs met well."*



27a. Once the tests came back negative for your child, what kind of help and support were you receiving from personal and professional networks?

Four mothers had not had their children tested, but they appeared to be healthy, said the mothers. Please note these are the comments from seven mothers



*"Paediatric specialist nurse kept ringing me/texting me during birthdays/Christmas. She was my strength. My friends and family and partner were very supportive"*  
*"The paediatric worker was great, she put us in the picture about our daughter's tests"*  
*"Me and my partner were helping each other"*  
*"At Nottingham City Hospital I used a drop-in facility for support"*  
*"I was offered excellent support from the specialist nurse/midwife"*  
*"No counselling was offered but family friends were helpful - but they didn't really understand"*  
*"My children are not tested but they are fit and healthy"*



EXPLORING THE SUPPORT NEEDS

**27b.** What was missing that you may have wanted?

Please note one mother gave two answers to this question

*"I am different I think because I just got on with it. I had my partner to help me with my problems, although a proper dietician would have been good"*

*"More counselling type of support, a dietician maybe too"*

*"I would have liked a post-natal HIV counselling service together with a health advisor to talk to"*

*"It was enough - nothing was missing"*

*"Nothing - it was hard, but I wanted to be alone"*

*"It was enough, I was confident my daughter's tests were negative though, I did want to talk about it just in case. A special health advisor was missing I think"*

*"Pre and post-test counselling was missing. I had to go to work on the day I got my results. I was in floods of tears. I was told I couldn't have children. Maybe it could be a routine thing where during pre-test counselling the counsellor can prepare/suggest that on the day of your results you may want an afternoon/morning off"*

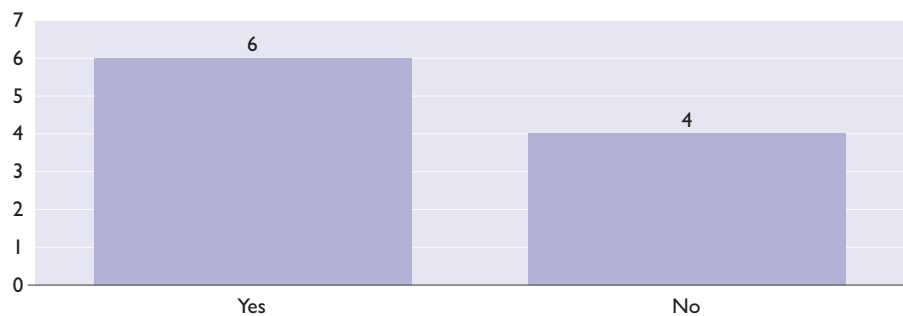
*"My daughter was delivered by c-section and I could not walk much. I was lucky my friend looked after me, but I had no professional help"*

*"Nothing - I would have liked some time alone to reflect"*

*"More sexual health support - as some professionals tell me I am allowed to have oral sex without a dental dam whereas others tell me different"*

**Disclosure**

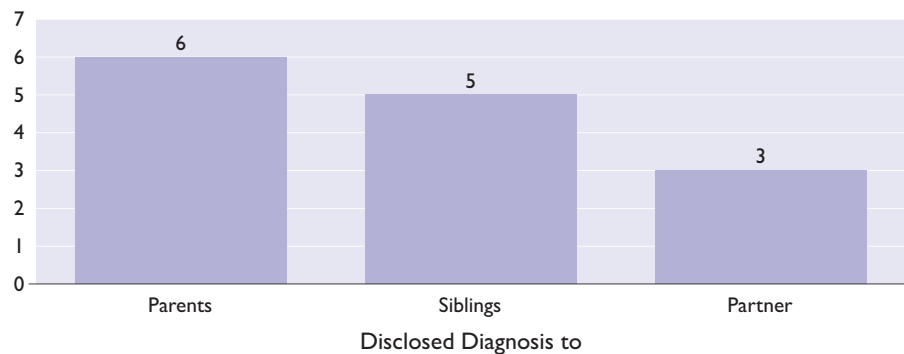
**28a.** Does anyone in your immediate family know about your HIV status?





**28b. Who have you disclosed to?**

Please note some mothers gave multiple answers to this question



**28c. Reasons for disclosing:**

Please note some mothers gave multiple answers to this question



*"I wanted to be happy"*  
*"I wanted them to believe that I was repeatedly raped and that this is what he did to me"*  
*"My family are highly supportive"*  
*"Have a nurse in the family"*  
*"We are a very close family"*  
*"It was too major to keep to myself"*  
*"My partner as he needed to get tested"*  
*"I did not know what was to happen to my baby if I died."*

**Reasons for not disclosing:**

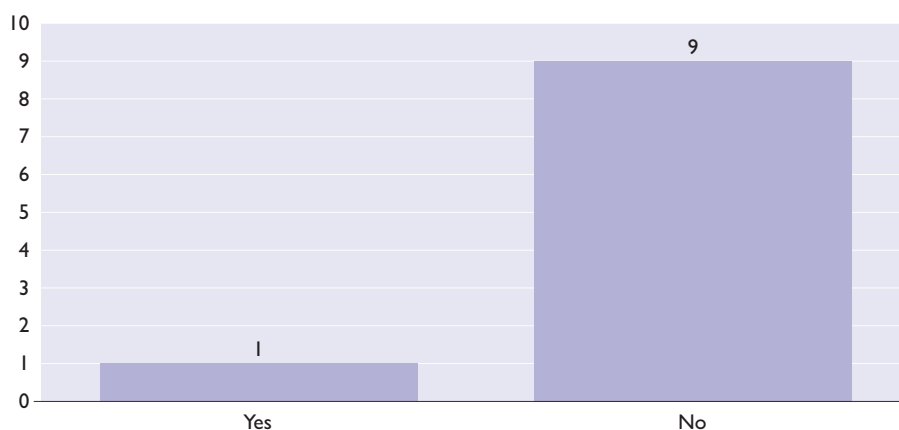
Please note some mothers gave multiple answers to this question

*"Mother has high blood pressure"*  
*"Grandparents are old"*  
*"My instinct tells me who I can and cannot tell"*  
*"I don't want anyone else to know"*  
*"I don't want to worry them"*  
*"I have not told my parents as I want to prepare them first. I am trying to see if they stigmatise other people with HIV - see what are their reactions to HIV is when I mention it (when things have come on the TV about HIV)"*



EXPLORING THE SUPPORT NEEDS

29. Do your children know about your HIV status?



SOME COMMENTS ABOUT DISCLOSING TO CHILDREN

*"They had to know as I was getting tired and stressed about 3 years ago. They now come to Candlelight gatherings and other functions with me"*

*"They are too young - I will tell them when they are older"*

*"My children will think 'My mummy is going to die! It would affect their school, it would affect their minds. Even if we are struggling to buy food I do not tell them. They worry me"*

*"I want to find their reactions to HIV first from the media to prepare them. Once their reactions improve I will tell them"*

*"She's too young - I will tell her when she grows up"*

*"She's too young, I will tell her when she is 15-16 years old"*

*"She's still too young to understand - she cries even if I'm poorly. If she sees me taking the medication I tell her it is a pill so I don't have any more children"*

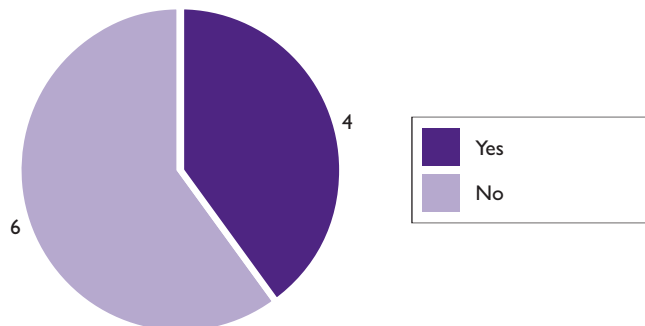
*"They know I go to hospital, I take tablets and that I have poorly blood - but I will tell them properly one day"*

*"It is not easy telling children - she is very sensitive - she is young"*

*"When she is older I will tell her - but disclosing is different for everyone"*



30. Does your wider family know about your HIV?



*REASONS FOR NOT DISCLOSING TO WIDER FAMILY:*

*"It would place a burden on them"*

*"If I told my sister she would tell our mum, if my mum knew she would tell others in the family. They think somebody with HIV would die tomorrow"*

*"I don't know how they would react. I had my younger sister die of AIDS my family were very supportive of her but if they found out about me they will worry"*

*"My mother thought it best if we keep it to ourselves - rumours can kill a person"*

*"My uncle's wife knows as she knew I was abused by him - we are both infected by him but he is dead"*

*"My ex-husband was a haemophiliac. I got it off him so I don't have many secrets from my family - they are all very supportive"*

*"My mum told her friend for her own support"*

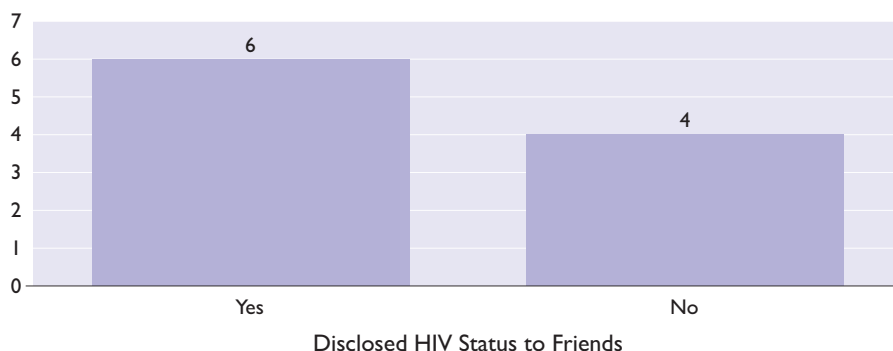
*"They won't accept - won't understand, they will think I am dying"*

*"Too much stigma, I don't want my family worrying"*



EXPLORING THE SUPPORT NEEDS

**31a.** Do you have any close friends who know about your HIV?



**31b.** If yes, how are they involved in your life?



- "The girls I socialise with"*
- "Friends at LASS who I would speak to more if I had credit"*
- "Close friend at LASS but she never spoke of her status so we drifted apart"*
- "She calls me every day, buys me and my daughter clothes, she comes to see me"*
- "My best friend took a keen interest, attended appointments with me at hospital"*
- "When I was diagnosed I instinctively knew who I could and could not tell"*

If not, then why?

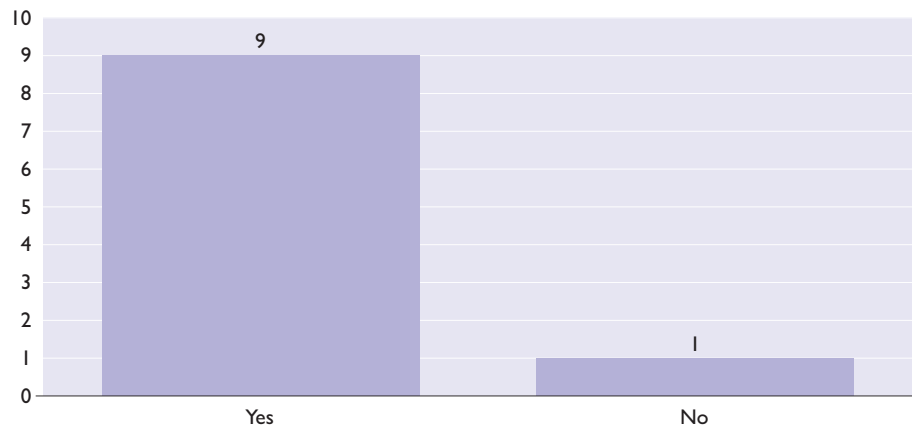
- "If my family do not know, I am not going to tell my friends"*
- "Can't tell my friend - she once came to see my baby and said why don't you breastfeed her, she's hungry. I felt so bad I wanted to tell her but I didn't, I lied and said I feed her at night"*
- "Not sure what their reactions would be"*





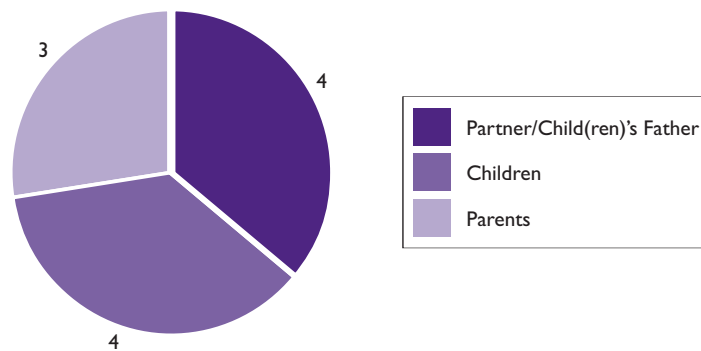
## Household

**32a.** Do you get any help and support from your family at home?

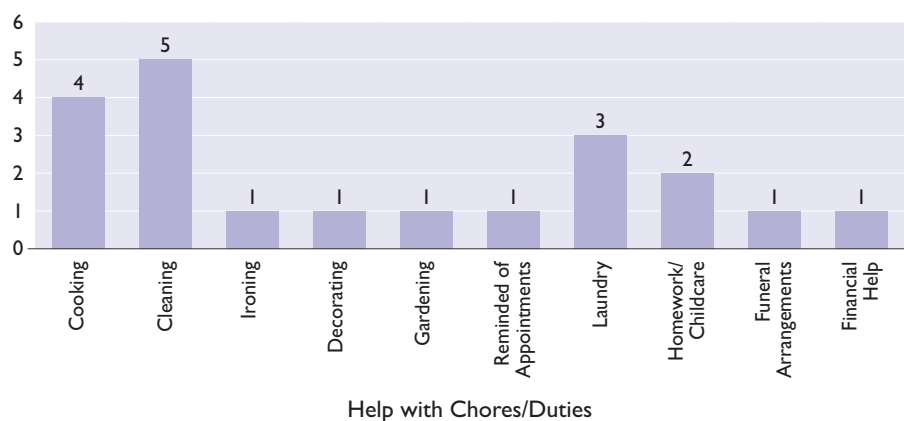


**32b.** Who helps?

Help & Assistance



**32c.** What chores do you receive help with?



Help with Chores/Duties



COMMENTS REGARDING HOUSEHOLD HELP...

*"I would like someone to look after my daughter when I go to college"*

*"I wish my mother could live a bit nearer to look after the girls more sometimes"*

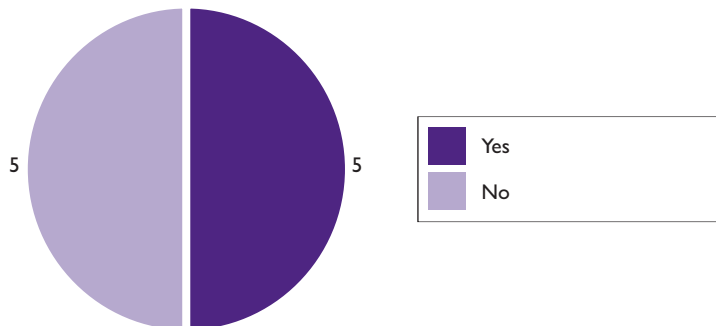
*"Me and the children have bonded really well"*

*"They [two children] are used to looking after themselves"*



## Medication

33. Are you taking medication for your HIV?

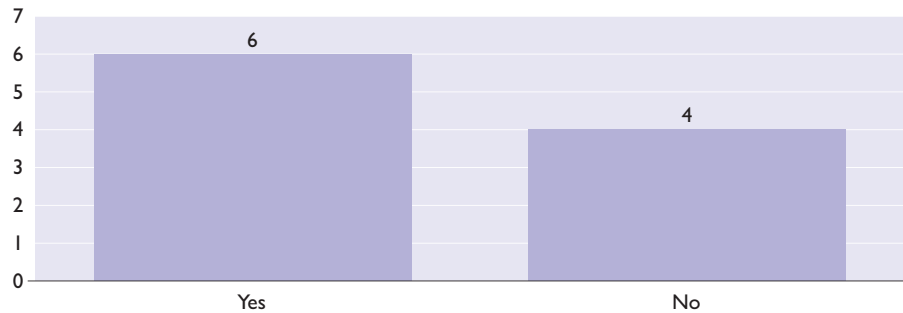


The antiretroviral drugs taken by the five women were:

- Nevirapine,
- Combivir (Lamivudine/Zidovudine),
- Efavirenz,
- Didanosine,
- Zidovudine,
- Truvada (Emtricitabine/ Tenofovir Disoproxil)
- Atazanavir.



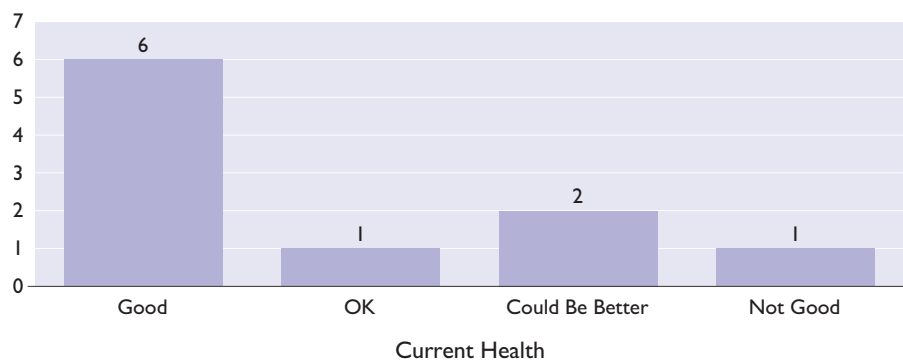
34. Are you taking any other medication?



Other daily medications that were taken by the 6 women were:

|                    |   |
|--------------------|---|
| Anti-depressants   | 2 |
| Vitamins/Omega 3   | 2 |
| Contraceptive Pill | 2 |

35. How do you think your current health is?



36. How healthy do you think the rest of the family that you live with are?



- "Both active/healthy"*
- "Very healthy sons"*
- "They are OK"*
- "My daughter is very healthy"*
- "My children are very healthy"*
- "Me and my daughter are very healthy but my partner is not healthy"*
- "My son is healthy - he likes to eat a lot"*
- "All healthy - my daughter recently had her MMR vaccination"*
- "Very healthy"*
- "Yes, everyone is healthy"*

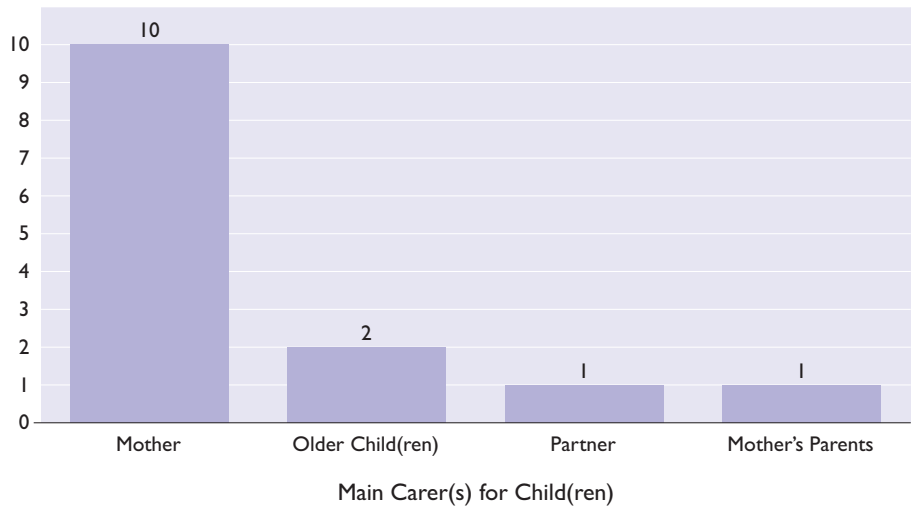


EXPLORING THE SUPPORT NEEDS

Childcare

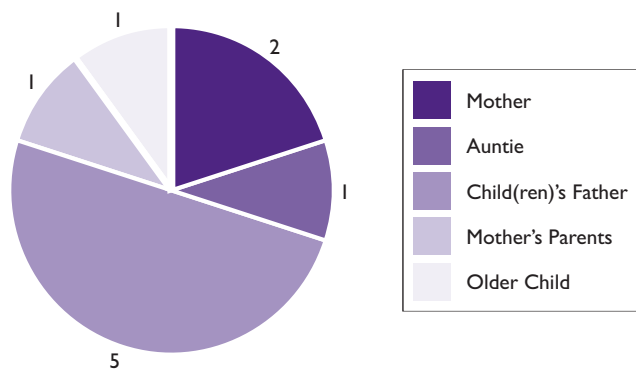
**37. Who is the main carer(s) for your child(ren)?**

Please note four of the mothers gave multiple answers to this question



**38. Who looks after your children if you are unwell?**

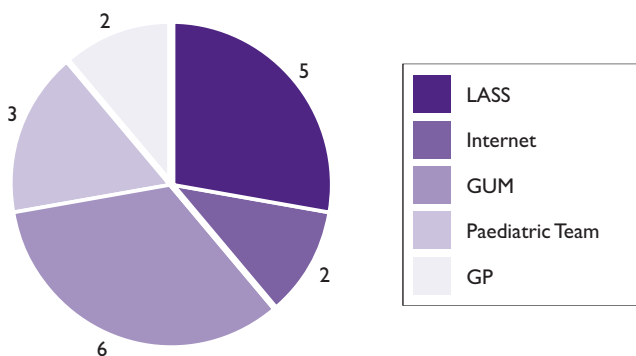
Who Looks After Child(ren) if Unwell



**39. If you have any queries about your HIV, where do you go to enquire?**

Please note mothers gave multiple answers to this question

Source of Information





40. How do you think your HIV status has an affect on your lifestyle?



*"I don't let it - I do not let it rule me"*

*"It causes me to worry more, I experience trauma more, I sleepwalk and get nightmares"*

*"I don't let it, I'm hoping next year to get a mortgage that's when I'll feel the nitty gritty I think"*

*"My tablets take priority over my life. I also have to hide my tablets in case some one finds out about my HIV. In medical forms I don't tick I'm positive"*

*"My medication makes me feel sick, all the other things are now dealt with. Before I had confidence problems, problems in meeting men, I abused drugs and alcohol - medication versus the party lifestyle. Arranging childcare in case I die and of course funeral arrangements"*

*"As I worked in the field of HIV work in Zimbabwe, I am familiar with how HIV affects people so it did not affect me that much"*

*"I cannot breastfeed my baby and friends and family could not understand why (they do not know I am HIV)"*

*"I try to eat/sleep better, live healthier and try not to catch colds or get stressed."*

*"It does not affect me too much, I will not let it"*

*"It changes everything. I can't take drugs (illicit), sleep with someone without a condom, always have to have HIV conversation with new partners, be careful around blood spillages etc"*



...*"I cannot breastfeed my baby and friends and family could not understand why (they do not know I am HIV)"*...

## Perceptions

41. How do you think your HIV status affects the way your family perceive you?

*"Family think that you are not allowed to go and date anyone and that I need to be extra careful when dating"*

*"I don't want them to pity me. I think she (mum) feels sorry for me. She thinks I may die at any time"*

*"They would be very concerned, they would not be judgemental"*

*"I don't know"*

*"If they knew they would be very supportive"*

*"It does not affect them but they worry, they don't let me get stressed"*

*"Maybe they would be disgusted by me. People would think I am near to death. My children and sister would be worried"*

*"I am sure it's always at the back of their head but it does not show"*

*"When I was abused they did not believe me - them knowing that my uncle had done this to me. I think they would be understanding now"*

*"My brothers are very supportive of me. If I'm a bit quiet or not well they will ask me 'what is the matter?'"*

...*"When I was abused they did not believe me - them knowing that my uncle had done this to me. "*...



42a. How do you think society perceives your HIV status in relation to employment/housing/education or in relation to any other areas of your life?

...“ I’ve been fired because of HIV. People think you sleep around, people have silly stupid reactions”...



*“They all think I’m normal but HIV is something deadly. It’s the stigma that’s the most painful. I would not be accepted in my community if they knew”*

*“People in my culture see it as a curse – a bad thing. When I went for my nursing interview I was told that I couldn’t do it”*

*“Issue of stigma is getting better I think”*

*“Some people may see you as promiscuous. Society needs to learn that even if you only have one sexual partner all your life you can still have it”*

*“People would treat you totally differently through lack of knowledge”*

*“It’s seen as a shame in my culture. I would get treated so differently. They would badly discriminate me. Even if you don’t dress good/smart people will judge you as not clean/untidy. If you tell them you are HIV they will think you are dirty”*

*“I’ve been fired because of HIV. People think you sleep around, people have silly stupid reactions”*

*“People discriminate. You are further stigmatised for being black African HIV+. Many people will think you are promiscuous and sleeping around. People can label you ‘prostitute’”*

*“Education is needed; I think people are confused with messages/information about HIV. The wrong information is more stigmatising (positive information could change this I think)”*

*“People think you sleep around or not had a good start in life, that can be coupled with people thinking you are dirty and should not be having children. People also think it’s touch contagious”*



EXPLORING THE SUPPORT NEEDS

42b. Please explain how you think this can be changed/ addressed in your opinion?



*"Adverts are bad - you are only told negative things. Some optimistic information about HIV could reduce stigma. Posters are 'catchy'"*

*"People need to talk about it more and be brave in disclosing - only this could raise awareness"*

*"People need to be taught through the media and magazines and clear simple messages like 'You can't catch HIV through sharing a drink/cutlery with someone or through public toilets'"*

*"People have told me 'it does not happen to people like you' It is up to us to tell these people and others that 'It can happen to any of us'"*

*"Educating people on living positively. Positive messages need to be heard. People need to tolerate people"*

*"More education lessons on simple things like 'it can't spread through kissing'"*

*"People need to be explained on TV, radio, newspapers and magazines so people can learn what HIV is. Message needs to be clear 'HIV can get anybody, anybody can be infected or affected'. It can even get the people that discriminate, they may think they are not and they could be - just like us"*

*"NHS media campaigns, anonymous stories of people's lives. More celebrities could create awareness in the press to highlight issues here in the UK"*

*"Changing society could take a very long time. Education/information needs to be made readily available. People should willingly want to change and not be forced to change"*

*"It would be a part of the National Curriculum. It could be an eye-opener and reduce stigma"*





## Help and Support

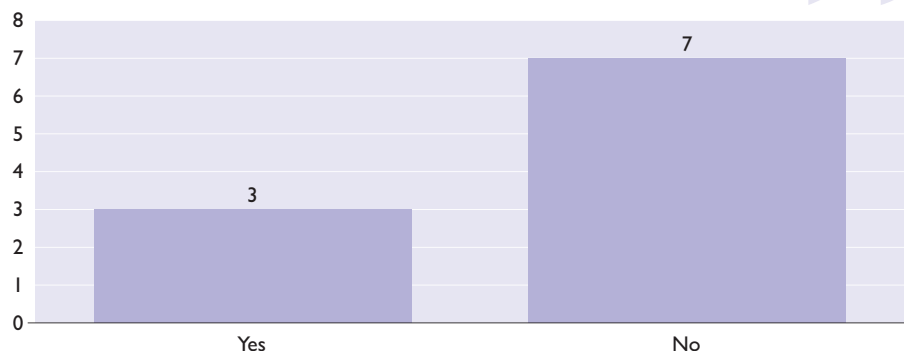
43. What kind of support for your HIV may you find useful if it was offered?

“

- “Information advice on HIV and immigration issues so that I can be clear of what I am entitled to. Also that my daughter can be better supported”*
- “A service that makes a database of resources for people living with HIV living locally and nationally”*
- “Once my children know my status a children’s youth group or something would be useful”*
- “A women’s group or Saturday group”*
- “Quiet day trips with other families, positive mothers/negative children. It’s refreshing to talk with others and you can relax.”*
- “Nothing - I want my privacy”*
- “Once I have disclosed to my daughter it would be good to get some help for the both of us”*
- “Mother and children’s group looking at training/development on living with HIV, learning to cook, IT lessons for self help”*
- “I’m OK at the moment”*
- “I would like a service to be easily accessible, a ‘one stop’ shop where you can get condoms for free, dental dams, informal support and meet other women in a similar situation”*

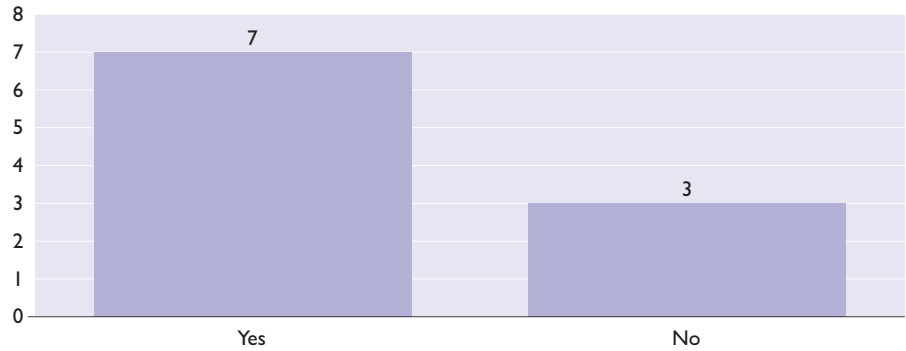
”

44. Do you know any other women/men in a similar situation to yours?



EXPLORING THE SUPPORT NEEDS

45a. Would you like to meet other people (men/women/mothers) living with HIV?



45b. What would be your reasons for this?

*"Others to talk to - nice to hear different stories"*

*"Company to talk and have a laugh"*

*"To hear their opinions, if I met someone with HIV I can be myself"*

*"It's interesting to listen to others views"*

*"I live a full life at the moment so it's not the right time"*

*"I want my privacy"*

*"It's relaxing, you can learn from others"*

*"Not men, just other women"*

*"It makes me feel like I am not alone"*

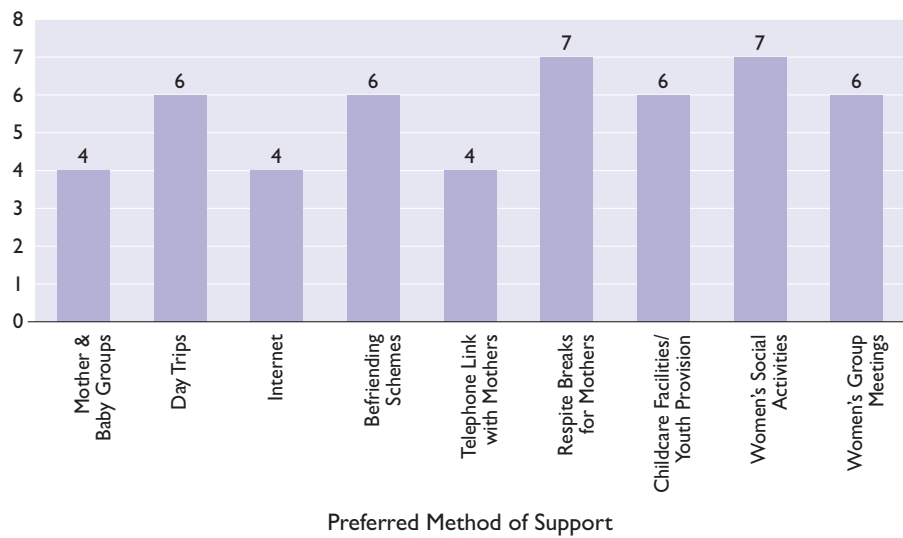
*"Not ready at the moment"*

...“If I met someone with HIV I can be myself.”...



**45c.** What would be your preferred method of doing this?

Please note mothers gave multiple answers to this question



**45d.** Why do you prefer these methods?



*"I would like my daughter to make friends"*

*"Making friends, sharing knowledge, being part of society, relaxing together"*

*"As a straight woman/single parent there just isn't enough support"*

*"More interactive"*

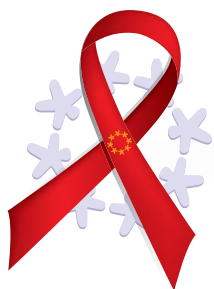
*"Get to meet other women in my kind of situation"*

*"Meet other women and refresh, get peace of mind"*

*"For research purposes, helping others"*



...*"As a straight woman/single parent there just isn't enough support."*...



# Analysis

...The participants who had moved to the UK for political reasons appeared to feel safer, since moving here...

## Ages

The participant's ages ranged from twenty-four to forty-six years old.

## Religion

When the participants were asked about their religious/spiritual beliefs, they all identified themselves as belonging to a religion. Eight out of ten were Christians. Seven of the Christians went to church. Several strands of Christianity were present; four went to Pentecostal Churches, one went to a Methodist Church, one to a Roman Catholic Church and one was a Methodist who went to the Jehovah's Witness Kingdom Hall. One participant regarded herself as 'Pagan being earthly balanced' but did not go to worship. Finally one participant was Hindu, who went to a Temple to worship.

## Ethnic Origins

One woman was born in Malawi (Black-African) who is currently also an asylum seeker. Seven women were born in three different parts of Africa; four in Zimbabwe (all of Black-African origin of whom two are currently asylum seekers and are two refugees). Two women were born in Kenya (one was of black African origin and the other was of Indian origin). Both these women migrated to the UK and were granted British citizenship, these two women now identify themselves as being 'black British' and 'British Indian'. Finally the other three participants were born in the UK (two white British indigenous women and one mixed White British and Black Caribbean woman).

Three women had lived in Leicester since birth, one moved to Leicester from Africa in 1968, one in 1993, one in 2001, two in 2002, one in 2003 and one in 2004.

## Immigration

The participants who had moved to the UK for political reasons appeared to feel safer, since moving here. However it was mentioned on several occasions that the British climate was colder and more generally, schooling and medical facilities seemed to be fairer and better equipped here in the UK in comparison to Africa.

## Accommodation

Two women were the owners and occupiers of the homes, another two women lived in privately rented houses. Six of the women lived in council housing or NASS provided housing. Nine of the participants lived in the city of Leicester. One participant came from Leicestershire.

## Languages

All ten participants could speak, read and write in English, however Shona and Ndebelé was the mother tongue amongst the Zimbabwean women. It may be



...Seven of the mothers were single parents...

worth noting, three participants who had most recently arrived in the UK said they experienced 'accent barriers' rather than language barriers. Lengthy conversations took place between the researcher and participants about how in Africa, English is spoken and taught in schools but here in the UK, there was a major difference in the accent which therefore often appeared to hinder understanding 'heard' words.

### Social Status

Four of the participants had part time jobs in clerical work or cleaning. Three women were seeking asylum here in the UK and did not have work permits, however these mothers were at college learning health care, computers and English ESOL. Another woman was studying for her degree at the local university. One was a full-time mother to a fourteen month old baby. Finally one mother was researching to set up a charity for bereaved children with positive parents.

It would appear that all of the participants led reasonably full lives most days of the week.

### Civil Status

Civil status varied across the women. Two women were widowed by their husbands dying of an AIDS related illness. Two were single and looking for relationships, one was divorced, two were separated, two were co-habiting and one was married - from these, two felt comfortable to mention that their partners were HIV positive. The three women who had partners, said that their partners had full-time jobs.

### Household Income

Household and family running costs were paid by various means of income, including benefits, loans, paid work, and children's fathers paying maintenance costs.

### Single Mothers

Seven of the mothers were single parents.

Six of the mothers had children in the age range of one to five years and therefore the children were the full-time responsibility of the mother. Three of the mothers had children aged between six and eight years old. And three mothers had older children aged thirteen to twenty-one years old. This suggests a potentially large difference in the children's ability and level of dependency on the mother by the child.

One mother of four children aged thirteen, fifteen, eighteen and twenty one, said that her eldest son is living in Zimbabwe alone.

Another mother of two children had a one and two year old, the eldest was living with her grand-parents in Leicester.

...the knowledge of what amenities the Leicester City Council and Social Services offered was limited...

## Local Services Used

The women only mentioned services they and their child(ren) use, not the services used by the fathers (where it was applicable).

## Schooling

Six of the mothers had children that went to a local primary school and or college. One mother's adolescent children went to a local college and were fairly independent, whereas three had children that were not old enough to go to school, these mothers said that once their children attended school, they would also go to college and study for qualifications.

## Personal Education

Six of the women said they had (for their own needs) recently enquired about a course at college, if not already attending they will enrol for the new term beginning September 2006.

## Library

Four of the women regularly used their local library to borrow reading books for themselves and/or for their children or for using the Internet.

## Sure Start

Three women regularly used local Sure Start schemes. The benefits included the opportunity to socialise and change their environment.

## Leisure

Two women took their children to the local Leisure centre where they all enjoyed swimming. Another woman who is also a single parent said that her daughters went to Rainbows once a week, which gave her the opportunity to pursue interests of her own.

## City Council and Social Services

Overall the knowledge of what amenities the Leicester City Council and Social Services offered was limited. Although housing issues were mentioned as was the waste collection services, there appeared to be a lack of understanding on housing support and general information about the Council. One woman who has a Social Worker spoke highly of her saying that she had been instrumental in her settling process and arranging for her to talk to a counsellor.

## General Practice

All the women and their children were registered at their local Health Centre. Views on the services of the General Practice they used varied. Some said that they had no problem in making or getting appointments promptly whereas others said that their surgery's rules made it very difficult to make an



...General Practitioners appeared to have a very vague understanding of what living with HIV entailed...

appointment on the same day. It was also mentioned that their General Practitioners (GP's) appeared to have a very vague understanding of what living with HIV entailed. One had moved house but had remained registered with the same GP as she found she had established an understanding relationship with him. Another said that her GP was also a doctor at Genitor-Urinary Medicine (GUM) clinic and therefore felt comfortable around him in any of the two settings. One woman said that her doctor was from Zimbabwe and therefore she felt he understood both her HIV status and her country's political situation.

### Hospitals

Nine women used the Leicester Royal Infirmary (LRI) and one used a hospital in Nuneaton as it was nearer. Seven women who used the LRI said that the GUM clinic was 'far too busy'. Three also mentioned that it takes a lot of time to be seen and that they struggle to find the appropriate home/child care arrangements. Despite these points most of the women said that staff at GUM were friendly and caring.

### Transport

Four women had their own car. Eight used the local buses/trains. Some said that bus routes were often difficult to get to with a baby and pushchair; others said that buses were dirty and not kept clean and found alternative transport.

### Local media

Six women said that they regularly bought the Leicester Mercury newspaper. Four said that instead of buying the paper they preferred to watch or hear the local news.

### Local supermarket

All ten women used large supermarkets such as Tesco, Asda, Morrison's or Sainsburys to buy food. The main reasons for using these were 'more variety', 'cheaper' 'special offers', 'convenience' and 'good quality foods'.

### Barriers to services

Only two women said they had no problems in accessing or using any services. From these two, one was born in the UK and the other had moved to the UK eighteen years ago and therefore both appeared well-adjusted and aware of local amenities.

One woman of the eight that did experience barriers commented 'I think I just don't know what is actually out there'. One wanted to know more about local African places and shops whereas another said she was limited in what she could and could not do due to her immigration status. Many of the women commented that their children were too young for them to fulfil personal goals for example, going to college. Others commented that support or respite care

...Others suggestions included 'homework help' and help with 'childcare assistance' when having to attend important appointments...

was very restricted due to the ages of their dependant children. The women that were refugee or seeking asylum were even further disadvantaged as many of them were single parents with very little support from friends or family.

### Services that are missing

Only three women were fully satisfied and could not suggest any improvements. It is worth noting that two out of these women had a partner living with them. The rest of the women gave ideas of what they thought would help their 'current lifestyle'. The general consensus was that living with HIV and being a single parent to one or more children was very hard work. Therefore most suggested ideas linked to a social group where single women /mothers can go to relax where childcare is provided on the same premises or having a separate social group for children and young people. Others suggestions included 'homework help' and help with 'childcare assistance' when having to attend important appointments

### Sense of community

Eight women felt a sense of belonging in the area where they lived, as they had neighbours/friends/family and local facilities that they used e.g. buses, shops, health centres and hospitals all nearby. When asked what would make their lives easier, two women said they would feel more content if there was a safe area for their children to play. One mother said she would like friendlier neighbours she also said that her current neighbours seem racist towards her. Seven women had integrated into their community and their local area. These women appeared to be close to their neighbours too.

### Lifestyle

All the women walked for 15 minutes or more daily.

Eight women ate healthily; for breakfast many ate cereal, oats and bran. For lunch fish/chicken, salads, steamed vegetables, boiled potatoes/rice or low fat curry. An average of five pieces of fruit/vegetables were consumed throughout the day in a juice form or freshly eaten. Nine out of ten mothers bought take away food at least once a fortnight. One mother however did mention financial hardship. She often bought the cheapest food for herself and three children but she was often left hungry as there was insufficient to share. Two mothers consumed alcohol regularly. One consumed thirty-six units of alcohol a week and smoked two or three cigarettes daily. Another consumed a maximum of twenty-five units in one night once a month and smoked fifteen cigarettes daily. It is noteworthy that these women were both born in the UK.

### How diagnosed

Four were diagnosed in 2004, three in 2003, two in 1998 and one in 1992.

Eight women were diagnosed in Leicester, one in another city in England and one in another region of Great Britain.



...One mother often bought the cheapest food for herself and three children but she was often left hungry as there was insufficient to share...

...A woman who was working in the Armed Forces... was told not to mention her HIV status to her colleagues, if asked she was to say had she had "acute leukaemia"...

The woman diagnosed whilst on duty in the Armed forces was screened for donating blood. Similarly in the out of Leicester city case, the mother was first diagnosed through blood she had donated.

One woman went to see her GP (in the UK) after she was repeatedly raped in Zimbabwe, the GP advised her to go to the GUM clinic.

Another woman noticed lumps on her legs and her GP recommended an HIV test at GUM.

Two women were prompted to have tests after their long-term partners were diagnosed. The other four had been diagnosed during pregnancy.

### Support

The mothers gave multiple answers to this question.

Four women said that they used LASS for support. One woman also used 'Faith in people with HIV' for support. Four women saw a health advisor upon diagnosis and subsequently counselling was offered. Three women were supported through their pregnancies and afterwards through the specialist paediatric nurse and specialist midwife. Two women used GUM for support.

Most women diagnosed through pregnancy said there appeared to be lots of medical and social support during pregnancy, both through the maternity team and the paediatric team. However these women are not currently engaging in any type of formal support.

A woman who was working in the Armed Forces says that she was advised to take sick leave for ten days to help her come to terms with her HIV. She said she was told not to mention her HIV status to her colleagues, if asked she was to say had she had "acute leukaemia".

Four women said that pre- and post-test counselling was not offered to them. One woman said that the denial of accepting the HIV was overpowering and made her choose not to have any support. One woman believed sexual health advice from GUM was inconsistent. Another four said they would have liked a dietician to talk to. Two women thought that they wanted re-assurance that they can live a healthy life despite being HIV positive.

Mothers diagnosed through ante-natal screening explained that their children were well-cared for by the paediatric team and partners were tested through GUM.

Four of the women have not had their children tested as they appear to be fit and healthy. However three women were professionally supported by the paediatric specialist nurse whilst their children were getting tested. One woman used a drop-in facility at Nottingham City Hospital. Another felt she did not require any professional help.

### Disclosure

Six of the women had disclosed their HIV status to some family members and

...HIV services should consider planning to help the mothers during the time of disclosing to their children...

close friends. The four that had not disclosed to anyone appeared to all come from black African backgrounds and their reasons for not telling were mainly stigma - related.

Nine of mothers chose not tell their child(ren) about their HIV status and seven of these said their children are too young. It seems reasonable to comment that whilst these mothers had not disclosed to their child (ren), many will disclose as their child (ren) grow older and HIV services should consider planning for this period to help the mothers during the time of disclosing to their children.

### Domestic help

Nine women received some type of domestic support from their family. And four said support came from their children. The help that the children offered ranged from the following; washing up, cooking, cleaning, help other siblings with homework, vacuuming, tidying up and providing moral support when their mother is unwell.

Most of the women said that they would like some help with childcare and homework help and others said that they are satisfied with the current arrangement of household help, be it through family or their own children.

### Medication

Five of the women had started antiretroviral therapy. The lists of antiretroviral agents used by the five women were as follows: Nevirapine, Combivir (Lamivudine/Zidovudine), Efavirenz, Didanosine, Zidovudine, Truvada (Emtricitabine/Tenofovir Disoproxil) and Atazanavir. Two women also took multi-vitamin tablets and Omega 3. Two were on the contraceptive pill. And two were on anti-depressants.

Six women felt that they were generally in good health, however two women on antiretroviral therapy were experiencing some problems, one said she was losing too much weight and the other said that she has quite a low CD4 count and her viral load was high due to forgetting to take medication a few times and was on her third combination of drugs as the other combinations were no longer effective.

All ten stated confidently said that their children were fit and well.

### Childcare

Six mothers were the only carers for their children and four of these had one or more children under the age of two years old. Two mothers had one or more children aged five or six years old.

Four mothers said that although they were the main carers for their children, they did receive help. Three received help in childcare from older children in looking after younger siblings. Two mothers had own parents to help with childcare, if and when it was needed.



...protecting her children from her own blood-spillages when they have minor cuts from accidents was crucial...

## HIV and Life

All of the women had somewhere they could enquire about their HIV, whether that was a local service, the Internet or a friend.

Only three women confidently said that their HIV does not restrict them. In one woman's own words she said "I don't let it affect me". It is worth noting that from these three women, two were UK citizens and the third was a woman seeking asylum who had her partner living with her. She was looking forward to starting college once her daughter was older. She said that 'life goes on with HIV'.

The other seven women said everything in their life had changed, love, relationships, their future, loss of, sleep, appetite, libido and enthusiasm. Those women on medication said that the side-effects of medication and remembering to take medication had taken control over their life. One African woman said that not being allowed to breastfeed her baby in front of her sister was a very difficult time when her baby was born and culturally this was viewed as 'shameful'. Two who used recreational drugs previous to their diagnosis said they were swiftly prompted by their own instincts to stop using to help preserve their life for their children. Another mother said protecting her children from her own blood-spillages when they have minor cuts from accidents was crucial. One mother went through a stage of severe depression and said that was her time to come to terms that she was dying. Although since then she has been taking anti-depressants and her outlook on life has significantly changed for the better.

## Perceptions of HIV

Four of the women had not disclosed their HIV to their family; they all tried to guess what their family's perceptions would be like about their HIV. Their answers varied, one said "they [family] would be supportive", another said her family would be "disgusted" and think that she was going to die. One, whose uncle had repeatedly raped and infected her, said if her parents were not dead they would have believed her about the sexual abuse she went through. Another woman said she thinks that they would pity her. One believed her parents would be very supportive and not have judgemental views.

The women that did disclose their HIV status, all said that their families/ partners or child(ren) were thoughtful, helpful and caring to their needs and therefore their perceptions of living with HIV seemed optimistic.

All women said that the stigma of HIV is more powerful and soul-destroying than HIV itself. Many women said that stigma linked to disclosing an HIV status in employment, education, social support and personal life would probably feel like disclosing 'I am 'cursed', 'dirty', 'promiscuous', 'uneducated', 'easy', 'a prostitute', 'had a bad start to life' and 'contagious'.

Four women said, people still think you can catch HIV through sharing cups, cutlery and toilet seats. One African woman said, being black, a single parent,



...the stigma of HIV is more powerful and soul-destroying than HIV itself...

a refugee and HIV positive, reinforces stereotype imagery of the current media portrayal of HIV.

The women were asked how current perceptions could be challenged and they gave various ideas and opinions. Most of them said more positive media messages need to be aired about living with HIV. Others said that celebrities can play an instrumental role in raising awareness and changing attitudes. Soap operas for example, Eastenders (Mark's role of living with HIV) are also good sources of information and awareness raising in the British and global fight against HIV and stigma. One woman said it should be incorporated into the National Curriculum. Others said it needs to be talked about more between friends and family. Another woman said her friend said the classic line, "it doesn't happen to people like you!" but the message should be "it happens to anyone". One woman said 'we all as a united community need to be braver about our lives'

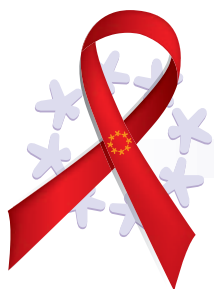
### Further help

Two women said currently they did not require any help but said in the future they envisage themselves using a service of some type after disclosure.

The majority said a single mothers group would be useful to establish. Two women said that once their children will be aware of their status they would like some support for both themselves and for their children.

Only three mothers knew of other positive people. The other seven said that they would like to meet other men or women who are parents living with HIV for company and friendship. The majority of the women said that their preferred method of meeting others was through women's groups, social events, day trips and respite breaks.

Others said that they would like a childcare service so that they could pursue their own interests whilst their children were in safe hands.



# Recommendations

...best practice in disclosure to children should be identified so that HIV positive mothers could be supported to disclose to their children at the right time using the most appropriate approach for them...

In light of the key findings the following is suggested to improve the quality of life of HIV positive mothers with uninfected children:-

## Children and young people affected by HIV

Further research needs to be carried out to explore the impact of children and young people having responsibility to provide domestic help and care for HIV positive parent(s), in line with other young people affected by chronic illness within a family. Additionally HIV services should ensure a link with existing mainstream youth services available so that children and young people affected by HIV are supported.

## Co-ordinated Services

Specialist HIV services should work closely together to provide a more co-ordinated package and to liaise with mainstream services so that they are aware of issues around HIV (including stigma and discrimination). Liaison could take place between specialist HIV and mainstream services in the Leicester area which will help provide more accessible facilities to people living with/affected by HIV.

## Support with Disclosure

Existing HIV services should consider avenues such as self help/training courses/workshops to enable HIV positive women to consider ways in which to disclose their HIV status to family members including children and friends etc, so that disclosure can become an easier process. With regards to children, the best practice in disclosure to children should be identified so that HIV positive mothers could be supported to disclose to their children at the right time using the most appropriate approach for them. Support regarding disclosure should also include access to other support services that are available such as family therapy if required. Information about support that is available regarding disclosure should be promoted widely so that HIV positive mothers are aware of this.

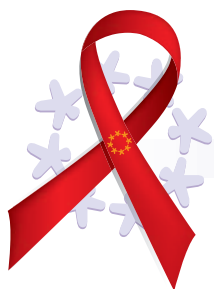
## Information

HIV services and information about a range of issues regarding HIV needs to be promoted widely including across all routes of HIV testing, so that people infected or affected by HIV (including HIV positive mothers with uninfected children) can know where to get help and support. This information could cover for example:

- How to access pre and post-test counselling
- Healthy eating and access to a dietician, if required
- Advice on future sexual health for people infected or affected by HIV

## Stigma

It is recommended that some of the mothers who took part in this research should be given an opportunity to share their experiences (should they wish) in the form of an activity through poetry/drama or art on or around World AIDS Day 2006 which would represent their views on the stigma of living with HIV.



## Conclusion

This study provided a snapshot of the experiences of ten HIV positive mothers living with HIV, and therefore it can not be generalised to a wider population of HIV positive women. The mothers in this study were participating in daily activities that included employment and education. Additionally the mothers were supported informally by family and friends. The mothers identified difficulties that included access to information and support services and areas in which their lives can be improved such as: more social/friendship-type of support after they disclose their HIV status to their children and consistency in information/advice that was being offered regarding sexual health (e.g. oral sex) as well as the need for consistency in counselling (pre and post-HIV test).

After disclosing their HIV to their children, mothers have said that it may be useful to access support and help from specialist services together as a family.

It is anticipated that this study will inform future partnership working in HIV services and mainstream services in Leicester and surrounding areas. The report will be disseminated widely for information sharing and expand knowledge base about this particular service user group (HIV positive mothers with uninfected children).



## Reflection from the mothers about the research findings

After showing the findings to the women who participated in this work various comments were made:

*"I didn't realise there were so many other single mothers living with HIV. I will be more at ease in participating in any other research... anything that helps."*

*"It's nice to know that I am not the only one who experiences difficulties in understanding the English accent [a comment was made by another mother about understanding the accent in Leicester]. Plus if this research didn't happen I wouldn't have had such a lovely day to Lincoln Cathedral" [This mother become a service user at 'Faith in people with HIV' after participating in the research. Faith... held a trip to Lincoln Cathedral in August - which this mother came along to]."*

*"I'm not surprised about the numbers of women who had to wait so long for appointments at GUM. The recommendations seem spot on."*

*"I can't believe that in this day and age people in Leicester experience hunger - it's very sad that this happens." [A comment made by a participant saying she experiences hunger]."*

*"It's nice to see my experience counts in your report. I would love to see some changes around improving the pre and post-test counselling especially in the blood donor centres across the country."*

*"It's good to show me what the other women said, as it helps me to learn from other people's life. Through sharing experience we will one day not stand alone in the fight against HIV/AIDS."*

*"I would really like to meet the other women. I will do my bit for World AIDS Day. Well done for completing this." [Comment made about one of the recommendations in the report]."*

*"It was interesting to read about the other woman's experience over disclosing to her children. That's really brave of her, its making me think about how I will do it with my kids. Maybe I can contact you [Faith] when I decide to disclose to my kids. The recommendation about helping us learn the skills around disclosure is a good one, it sounds like exactly what might just help us feel like we can have help if we need."*

*"It's positive to hear we are all strong, intelligent women keeping busy with work and education and bringing up the little ones."*

*"Who knows, your next research should be a follow up study in 5 years time to see what we are up to and whether the other 9 of us have disclosed to our grown up kids!"*



## References

Buckner L et al (2004) Gender Profile of Leicester's Labour Markets, Centre for Social Inclusion, Sheffield Hallam University, Leicester City Council and European Union – European Social Fund.

Choosing Health in Leicester (2005 :13), Annual Report of the Director of Public Health, Eastern Leicester and Leicester City West Primary Care Trusts, accessed online at: [www.phleicester.org.uk/Documents/AR05Web.pdf](http://www.phleicester.org.uk/Documents/AR05Web.pdf) on: 10-1-06, website update not given.

Communicable Disease Report (2001) AIDS and HIV Infection in the UK: Monthly Report, 26th April 2001, Vol.11 No17.

Denscombe M (2003 :14,15,16) The Good Research Guide: for small scale research projects, 2nd Edition, Part 1 - strategies for social research - Surveys and Sampling, Open University Press, Glasgow.

Invest Leicestershire (2006) Area and Population and Workforce, accessed online at: [www.investleicestershire.com/template\\_01.asp?pageid=547](http://www.investleicestershire.com/template_01.asp?pageid=547) on: 10-1-06, website updated in 2005.

Leicester Health Protection Agency (2004) SOPHID Data Leicester.

London Health Protection Agency Centre for Infections (2005) cited in National AIDS Trust (2005) Fact Sheet 2 UK Statistics (Last updated in November 2005) National AIDS Trust publication, London.

Naidoo J and Wills J (2000 :38) Health Promotion: Foundations for Practice, 2nd Edition, Royal College of Nursing, Baillière Tindall, China.

National AIDS Trust (2005) Fact Sheet 2 UK Statistics (Last updated in November 2005) National AIDS Trust publication, London.

The National Strategy for Sexual Health and HIV (2001) Better Prevention, Better Services, Better Sexual Health: The National Strategy for Sexual Health and HIV, Department of Health, London, accessed online at: [www.dh.gov.uk/assetRoot/04/05/89/45/04058945pdf](http://www.dh.gov.uk/assetRoot/04/05/89/45/04058945pdf) on: 10-1-06, website updated in 2006.

Statement of Ethical Principles in the Conduct of Research Practice (2006) De Montfort University (DMU), School of Applied Social Sciences, MA Health and Community Development, Post Graduate Dissertation Guide, Printed at DMU Leicester.

United Nations AIDS Epidemic Update (2005) cited in National AIDS Trust (2005) Fact Sheet 2 UK Statistics (last updated in November 2005) National AIDS Trust publication, London



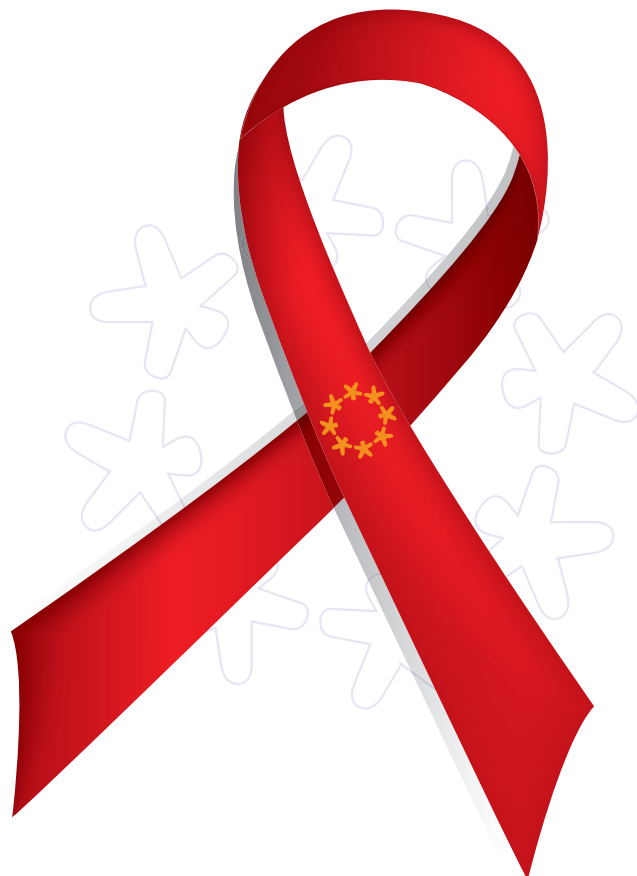
## Useful telephone numbers

### Leicester City, County and Rutland

|   |                |
|---|----------------|
| Faith in people with HIV:                     | 0116 273 33 77 |
| Leicestershire AIDS Support Service (LASS)    | 0116 255 999 5 |
| TRADE   | 0116 254 1 747 |
| Specialist Dietician                          | 0116 258 67 35 |
| Department of G.U Medicine (Leicester)        | 0116 258 52 08 |
| Department of G.U Medicine (Loughborough)     | 01509 56 88 88 |
| Midwife Specialist                            | 0116 258 599 0 |
| Drug Advice Centre                            | 0116 222 5 999 |
| Turning Point (Substance Misuse) Loughborough | 01509 611 111  |
| Rape Crisis                                   | 0116 255 88 52 |
| New Futures                                   | 0116 255 96 96 |
| Refugee Action                                | 0116 261 6 200 |
| Social Services (Leicester)                   | 0116 258 51 41 |
| Social Services (Leicestershire)              | 0116 258 69 86 |

### National

|                           |                |
|---------------------------|----------------|
| National AIDS Helpline    | 0800 567 123   |
| Positively Women (London) | 020 7713 0222  |
| Terrance Higgins Trust    | 0845 12 21 200 |



**Published by Faith in people with HIV**

The Lodge, Margaret Road  
Leicester LE5 5FW

Tel/Fax: 0116 273 3377

Email: [trevor.thurst@btconnect.com](mailto:trevor.thurst@btconnect.com)

Registered Charity Number: 1102534 - Faith in people with HIV is registered in England and Wales as a company limited by guarantee number: 3318773. Registered office: The Lodge, Margaret Road, Leicester, LE5 5FW