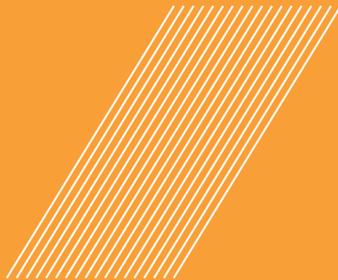
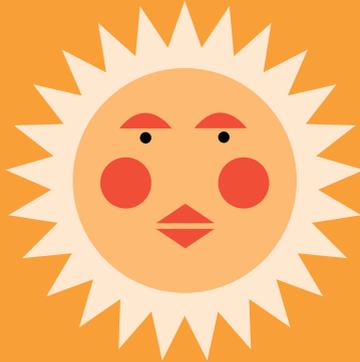
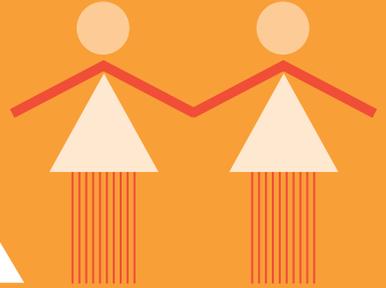




PRIME

# Menopause in women living with HIV in England: findings from the PRIME Study

Shema Tariq on behalf of the PRIME Study Group



MAY 2018

# Contents

Key messages	3
Background to the PRIME Study	4
Design of the PRIME Study	5
Findings	
Description of PRIME Study participants	6
Menopausal symptoms in women living with HIV	8
Managing menopausal symptoms	11
Recommendations	14



## Key messages

In 2016, 10,350 women living with HIV aged between 45 and 56 (potentially menopausal age) attended for HIV care in the UK; a five-fold increase over ten years.

---

Addressing the needs of women living with HIV in their midlife and beyond is of increasing importance in HIV practice and policy.

---

The PRIME Study is one of the largest studies globally looking at the impact of the menopause on the health and well-being of women living with HIV, with data on nearly 900 women aged 45-60.

---

The menopause transition can have multi-dimensional impacts on the health and well-being of women living with HIV.

---

We found a high prevalence of somatic (including hot flushes, muscle and joint pains and sleep disturbance; 89%), urogenital (including vaginal dryness and sexual problems; 68%), and psychological (including anxiety and depression; 78%) symptoms in women living with HIV aged 45-60.

---

Women with menopausal symptoms were more likely to be psychologically distressed (having depression and/or anxiety on screening) than those without symptoms.

---

Women living with HIV aged 45-60 were more likely than women without HIV to report sexual problems, although these were common (over 50%) in both groups.

---

Nearly half of all PRIME Study participants stated they did not have enough information about the menopause, leaving many feeling under-prepared.

---

Use of menopausal hormone therapy to improve menopausal symptoms was strikingly low in this population.

---

Women living with HIV described particular challenges during the menopause as a result of living with HIV. These included difficulties distinguishing menopausal symptoms from HIV-related symptoms, difficulties accessing appropriate menopause care, and the impact of menopausal symptoms on HIV management e.g. adherence to antiretroviral therapy.

---

Participants identified access to menopause-related information and peer-support as important ways of supporting women through the menopause transition.

---

We recommend that HIV clinical services, GPs and HIV support services be aware of the potential impact of the menopause transition on the health and well-being of women living with HIV, and ensure that services are able to support women during this time.

---

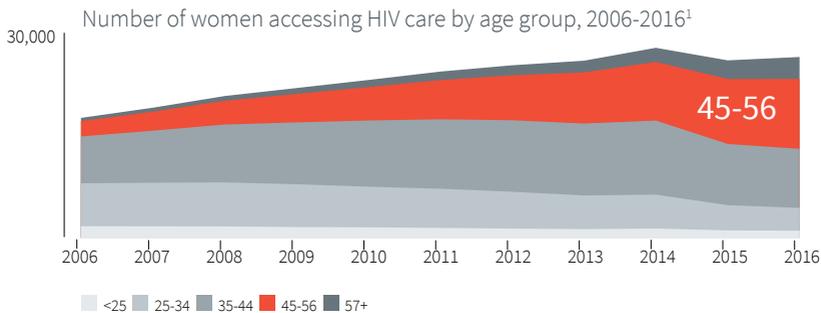


## Background to the PRIME study

Over the past two decades, HIV medication (known as antiretroviral therapy, or ART) has transformed HIV into a long-term condition with normal life-expectancy for people stable on treatment. This means that more people living with HIV in the UK than ever before are reaching their 40s, 50s and beyond, which is something to celebrate.

As people get older, they experience changes to their body and their health. For women, an important change is the menopause. The menopause is the point at which women's periods stop as their ovaries stop working, and usually happens in their early 50s. It is a gradual process and is linked to a range of symptoms that can affect women's quality of life, work and relationships. Menopause can also be brought on by surgery to remove the ovaries, and by certain types of medical treatment such as some medicines used to treat cancer.

In 2016, 10,350 women living with HIV aged 45-56 (the age when women usually go through the menopause) attended HIV clinics in the UK. This is nearly half of all women attending for HIV care in the UK and is five times the number in 2006. However, up until recently we have known very little about the menopause in women living with HIV, with almost no data on women in the UK.



We designed the PRIME Study (**P**ositive **T**ransitions Through the **M**enopause) to address these gaps in our knowledge. We wanted to find out how the menopause impacted the health and well-being of women living with HIV. Nearly 900 women living with HIV aged 45-60 across England have taken part, completing questionnaires and interviews. This makes PRIME one of the largest studies of HIV and menopause globally. In this report, we present findings from key analyses of PRIME Study data.

1. Zheng Yin, Public Health England, personal communication, 05/10/17.



## Design of the PRIME Study

The PRIME Study is a mixed-methods study, combining quantitative and qualitative methods to try and answer our research questions more completely. We carried out our research between June 2015 and April 2018 in three phases:

### Phase 1

Working with the HIV peer support charity Positively UK, we conducted three focus group discussions with women living with aged 45 and over. A total of 24 women attended one of the focus groups in June-August 2015. The aim was to gain some initial understanding of how menopause affects women living with HIV so we could better design the rest of our work. In Phase 1 we also conducted a survey of menopause management in HIV among GPs.



### Phase 3

We conducted interviews with 20 women who completed questionnaires in Phase 2. These qualitative interviews have allowed us to explore how women living with HIV experience the menopause, in more depth. They also gave women the opportunity to tell us if there was anything we had missed out in our research.



### Phase 2

We recruited women living with HIV aged between 45 and 60 from 21 HIV clinics across England (including six outside London). Women did not have to have gone through the menopause to take part.



They were invited to complete a confidential paper questionnaire with questions about their general health, HIV history, menstrual cycle, menopausal symptoms, management of menopausal symptoms, and sexual function.

We approached **1,999** women of whom 1,312 (66%) were eligible to take part. Of these 1,312 women, 1,059 (81%) agreed to take part in the study. We have completed questionnaires on **869** women.

## Meaningful inclusion of women living with HIV in the research

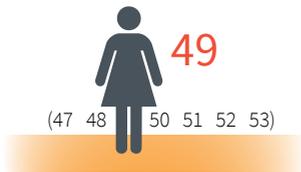
We are committed to including women living with HIV at all stages of the research process. The study proposal was discussed and reviewed by women living with HIV. We recruited three community representatives (all women living with HIV aged 45 or over) to sit on our Expert Advisory Group via the UK-CAB (the UK's HIV treatment advocacy network). These three women have provided insight and expertise into the design, conduct and dissemination of the study. Two of PRIME's community representatives also worked as peer researchers in Phase 1, providing invaluable expertise in recruitment, facilitation of focus groups and analysis of data.



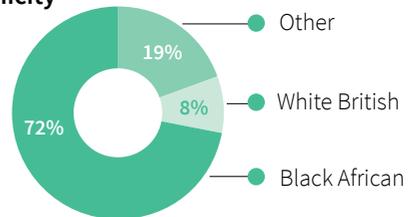
## Findings: Description of PRIME Study participants

### Characteristics of 869 PRIME Study participants

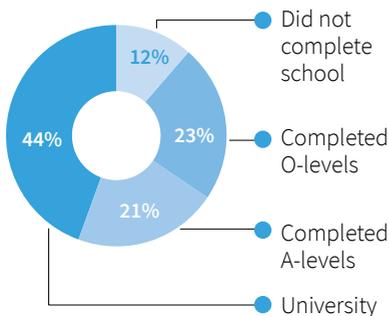
#### Median age (interquartile range)



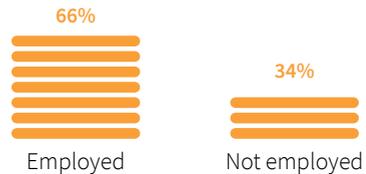
#### Ethnicity



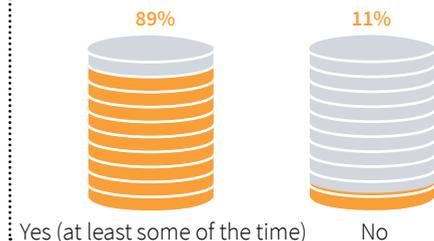
#### Completed education



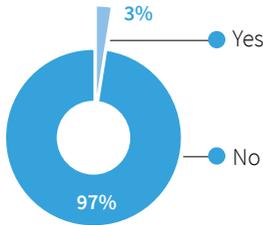
#### Employment



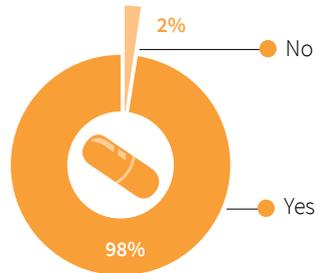
#### Enough money to cover basic needs



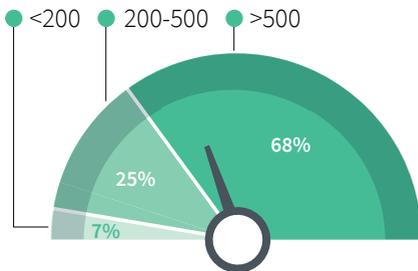
### Recreational drug use in past 3 months



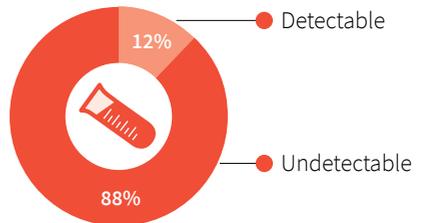
### On antiretroviral therapy



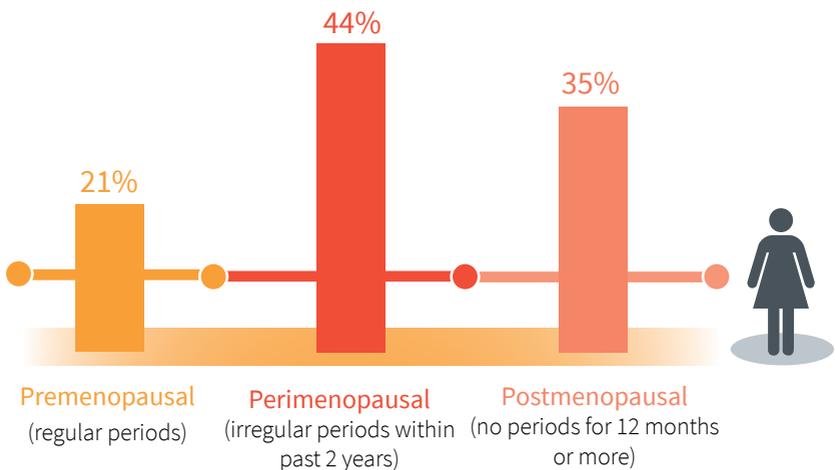
### Last CD4 count (cells/mm3)



### Last HIV viral load



The majority of PRIME Study participants were either peri- or postmenopausal, as you would expect of women in this age group.



# Findings: Menopausal symptoms in women living with HIV

## Prevalence of menopausal symptoms

In the PRIME questionnaire, we asked about 11 symptoms that are often related to menopause. We divided these symptoms into three domains:



**Somatic:** hot flushes, palpitations, joint and muscle discomfort, sleep disturbance

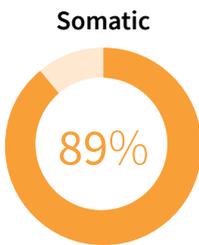


**Urogenital:** vaginal dryness, urinary tract symptoms, sexual problems



**Psychological:** depression, anxiety, irritability, exhaustion

Symptoms in all three domains were common in all PRIME study participants, but were more likely to be reported by peri- and post-menopausal women. The most commonly reported symptoms were somatic, with nearly 90% of all participants reporting these.<sup>2</sup>



Women faced particular challenges in recognising symptoms as a result of also living with HIV, describing difficulties in distinguishing menopausal symptoms from HIV-related symptoms or side-effects of ART.<sup>3</sup>



*It leaves you feeling 'what is going on here'? Is it HIV? Is it the menopause?*

2. Tariq S, Rolland A, Burns F, Sabin CA, Gilson R. Menopausal status and symptoms in women living with HIV in the UK: results from the PRIME Study. 9th IAS Conference on HIV Science; 23-26 July; Paris 2017.

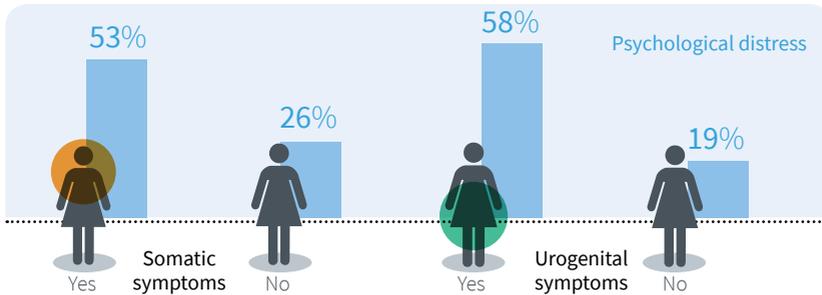
3. McGregor-Read J, Pettitt F, Petretti S, Burns F, Gilson C, Sabin C, Tariq S. "You're suffering all these things and you keep going backwards and forwards": experiences of the menopause among women living with HIV in the United Kingdom. 21st International AIDS Conference (AIDS 2016); Durban, South Africa 2016.

Furthermore, some described the difficulties of having to manage menopausal symptoms in the context of living with a long-term condition:<sup>4</sup>

**“** *If I wasn't coping with HIV and I was dealing with menopause alone, maybe it would be easier. I've got to cope with the two at the same time. If you haven't slept for the whole night and you need to take medication... it just gets so annoying.*

## Psychological distress and menopausal symptoms

Nearly half of all PRIME Study participants (46%) were categorised as having psychological distress<sup>5</sup>; 29% screened positive for anxiety and 25% screened positive for depression. A greater proportion of women with either somatic or urogenital menopausal symptoms had psychological distress, compared to those without symptoms.<sup>6</sup>



**“** *My menopause is now interrupting my life quite seriously. I think I have gone into a depression. My sleeping pattern is so horrendous and so chaotic that I feel very emotional.*

## Sexual function

The sexual health and well-being of women living with HIV, especially as they get older, is often overlooked. We know that the menopause can lead to vaginal dryness, changes in body shape, and can impact how women see themselves. These things can all lead to declines in sexual function including sexual desire.

**“** *I've got no sex drive at all, and that's impacted on my relationships, and for whatever reason people don't seem to care about women's sex drive. They only care about men's sex drive.*

4. Ibid.

5. Scoring  $\geq 3$  in the validated brief Patient Health Questionnaire-4 (PHQ-4).

6. Tariq S, Burns F, Rolland A, Sabin C, Sherr L, Gilson R. Menopausal symptoms are associated with psychological distress in HIV+ women. 8th International Workshop on HIV & Women; 2-3 March; Boston, USA 2018.

We compared data on sexual function from sexually active PRIME Study participants<sup>7</sup> with data from similarly aged HIV-negative women who took part in Britain's 3rd National Survey of Sexual Attitudes and Lifestyles (Natsal-3).<sup>8</sup>

Sexual problems were common in both groups of women aged between 45 and 60, but more common in those living with HIV.<sup>9</sup>



**69%** **Women living with HIV** reported  $\geq 1$  sexual problem lasting  $\geq 3$  months in the past year

**54%** **Women without HIV** reported  $\geq 1$  sexual problem lasting  $\geq 3$  months in the past year

The most commonly reported sexual problem in women living with HIV was a lack of interest in sex (52%). Just over a quarter (28%) of PRIME Study participants described having vaginal dryness. Women living with HIV were significantly more likely to have overall low sexual function than HIV-negative women. However, they were also more likely to seek help for sexual problems than women without HIV, likely a result of their more frequent contact with healthcare providers and sexual health services.

**Commonly reported sexual problems**

**lack of interest in sex**      **vaginal dryness**

**30%**

**Women living with HIV** had sought help from  $\geq 1$  source for sexual problems

**17%**

**Women without HIV** had sought help from  $\geq 1$  source for sexual problems

7. The tool we used to measure sexual function is only validated in sexually active women.  
8. <http://www.natsal.ac.uk/about.aspx>  
9. Toorabally N, Mercer CH, Mitchell KR, Burns F, Gilson R, Sabin C, Tariq S. Association of HIV status with sexual function in women aged 45-60. Conference on Retroviruses and Opportunistic Infections (CROI); March 4-7; Boston, USA 2018.

## Findings: Managing menopausal symptoms



*Mostly in our culture, we don't talk about these things [periods], so we sometimes experience things without knowing exactly what's going on.*

Women in the PRIME study reported being under-prepared for menopause. This was especially the case for women from sub-Saharan African communities, where the subject of periods and menopause were often seen as taboo.<sup>10</sup>



47%

of women said they did not have sufficient information about the menopause

### Accessing care for menopausal symptoms

Participants described difficulties accessing appropriate advice and care for their menopausal symptoms, partly as a result of living with HIV. Many described being caught between their HIV doctors and their GPs.



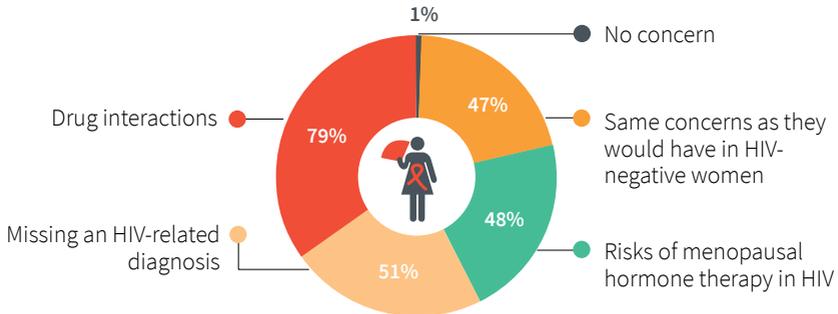
*[The HIV doctors] are telling us to take everything to the GP... the GP then tells you to take it back to your HIV consultant. It's very frustrating if you're suffering all these things, and you keep going backwards and forwards.*

We conducted a survey of 88 GPs to explore their management of menopause in women living with HIV.<sup>11</sup> We found that over 95% of GPs reported being confident in managing menopause in general, but that less than half (46%) reported confidence managing menopause in women living with HIV. The overwhelming majority (96%) felt that menopause in women without HIV should be routinely managed in primary care, whereas just over half thought that menopause in women living with HIV should be managed in primary care.

10. McGregor-Read J, Pettitt F, Petretti S, Burns F, Gilson C, Sabin C, Tariq S. "You're suffering all these things and you keep going backwards and forwards": experiences of the menopause among women living with HIV in the United Kingdom. 21st International AIDS Conference (AIDS 2016); Durban, South Africa 2016.

11. Chirwa M, Ma R, Guallar C, Tariq S. Managing menopause in women living with HIV: A survey of primary care practitioners. *Post Reprod Health.* 2017;23(3):111-5.

## GP concerns about managing menopause in women living with HIV



## Treatment of menopausal symptoms

Although the menopause is a natural transition, some women find that their symptoms are improved with medical treatment. This includes systemic menopausal hormone therapy (MHT, previously known as hormone replacement therapy or HRT) for hot flushes and mood changes, and vaginal oestrogen cream or tablets for urogenital symptoms.

### Common approaches for managing menopausal symptoms

---

#### Menopausal hormone therapy

- Oral hormonal tablets, skin patches or skin gel for hot flushes or menopause-related mood changes
- Vaginal oestrogen creams, tablets or rings for vaginal symptoms

#### Non-hormonal medication

- Antidepressants for hot flushes
- Topical vaginal lubricants and moisturisers for vaginal symptoms

#### Behavioural and lifestyle measures

- Exercise including yoga
- Reducing alcohol intake
- Stopping smoking
- Cold packs, fans and dressing in layers

#### Psychological

- Cognitive behavioural therapy (CBT)
-

We found that the use of MHT and vaginal oestrogens were low in women we surveyed.<sup>12</sup>



8%

Women with somatic symptoms who reported currently using MHT



3%

Women with urogenital symptoms who reported currently using vaginal oestrogen

However, it is important to note that not all women living with HIV wanted to take these treatments, with some describing the importance of avoiding further medication in addition to their ART.



*I don't want to take anything else [menopausal hormone therapy]. I don't want to be a slave to something else.*

### What do women want?

As previously discussed, many women felt they did not have enough information about the menopause, leaving them unprepared for the changes they experienced. It is therefore unsurprising that women highlighted the importance of accessing menopause-related information, many feeling this was best accessed within HIV services.



*It would be good to hear about [menopause] earlier, then we would start noticing it in our bodies. It would be a thing that we know. Not a kind of shock. You don't know what is happening to you. Come and teach us. Tell us more.*

Another key insight from PRIME Study participants is the potentially important role of peer-support during the menopause transition. Many women had experienced the benefits of peer-support at previous points in their HIV journey, and could now see that other women living with HIV who had experienced menopause could provide invaluable support.<sup>13</sup>



*Now that we're together [in the focus group] we understand we are all going through the same thing. We really need to talk about this and learn from each other.*

12. Tariq S, Rolland A, Burns F, Sabin CA, Gilson R. Menopausal status and symptoms in women living with HIV in the UK: results from the PRIME Study. 9th IAS Conference on HIV Science; 23-26 July, Paris 2017.

13. McGregor-Read J, Pettitt F, Petretti S, Burns F, Gilson C, Sabin C, Tariq S. "You're suffering all these things and you keep going backwards and forwards": experiences of the menopause among women living with HIV in the United Kingdom. 21st International AIDS Conference (AIDS 2016); Durban, South Africa 2016.



## Recommendations

HIV clinical services, GPs and HIV support services should be aware of the potential impact of the menopause transition on the health and well-being of women living with HIV.

---

High-quality and accessible information about the menopause should be available to all women living with HIV attending HIV clinics. The AIDSMap factsheet on HIV and menopause is an example of one such patient resource: [www.aidsmap.com/Menopause-and-HIV/page/3117291/](http://www.aidsmap.com/Menopause-and-HIV/page/3117291/)

---

HIV clinical services are well-placed to assess the need for further menopause-related care and support among their female patients.

---

We endorse forthcoming British HIV Association (BHIVA)/British Association of Sexual Health and HIV (BASHH)/Faculty of Sexual and Reproductive Healthcare (FSRH) guidelines that recommend annual assessment of women's menstrual cycle within HIV clinical services and proactive assessment of menopausal symptoms in those aged over 45.

---

We welcome the statement in forthcoming BHIVA Standards of Care for People Living with HIV that HIV clinical services should establish care pathways addressing the needs of women living with HIV transitioning through the menopause.

---

If women with menopausal symptoms require further treatment or support, we recommend management within primary care, supported by close liaison with HIV specialists.

---

Providing training on management of menopause in women living with HIV (either through e-learning or lectures within existing training packages) is key in developing confidence and skills among primary care staff.

---

Peer-support for women living with HIV transitioning through the menopause is likely to have an important role in building self-efficacy and resilience.

---

Research priorities include the development and testing of behavioural interventions (including peer-support) for women living with HIV transitioning through the menopause; the impact of menopausal hormone therapy (MHT) on mental health, clinical outcomes, and quality of life in women living with HIV; and characterisation of drug-drug interactions between MHT and antiretroviral therapy.

---

Commissioners of care for women living with HIV need to recognise the impact of menopause on women's well-being. Given the number of commissioning bodies with responsibilities across the HIV pathway, appropriate needs assessments and joined up approaches to commissioning are required to ensure best outcomes.

---



[The questionnaire] brings to light issues I have not been able to think through despite the effect they have had on me. Very poignant and helpful.

### **Further information and support**

Positively UK: <http://positivelyuk.org>

AIDSMap: Factsheet on HIV and menopause:  
[www.aidsmap.com/Menopause-and-HIV/page/3117291/](http://www.aidsmap.com/Menopause-and-HIV/page/3117291/)

BHIVA/BASHH/FSRH guidelines for the sexual and reproductive health of people living with HIV:  
[www.bhiva.org/SRH-guidelines-consultation.aspx](http://www.bhiva.org/SRH-guidelines-consultation.aspx)

## Acknowledgements

This work was funded by the National Institute of Health Research (NIHR) in the form of a postdoctoral fellowship awarded to Shema Tariq (PDF-2014-07-071).

**The PRIME Study Core Team:** Fiona Burns, Richard Gilson, Alexandra Rolland, Caroline Sabin and Shema Tariq. We also thank the PRIME research assistants Tuhina Bhattacharyya and Saliha Abbassi.

**The PRIME Study Expert Advisory Group:** Comfort Adams, Jane Anderson, Mwenza Blell, Jonathan Elford (Chair), Janine McGregor-Read, Fiona Pettitt, Janice Rymer, Jane Shepherd, Lorraine Sherr, Emily Wandolo.

This study would not have been possible without the following clinic staff:

*Barking Community Hospital* (Rageshri Dhairyawan, Emma Macfarlane, Sharmin Obeyesekera, Cecelia Theodore); *Brighton and Sussex University Hospital* (Yvonne Gilleece, Alyson Knott, Celia Richardson); *Chelsea and Westminster Hospital* (Mimi Chirwa, Ann Sullivan, Mini Thankachen, Sathya Visvendra); *City of Coventry Health Centre* (Sris Allen, Kerry Flahive); *Guy's and St Thomas' Hospital* (Julie Fox, Julianne Iwanga, Annemiek DeRuiter, Mark Taylor); *10 Hammersmith Broadway* (Sophie Hobday, Rachael Jones, Clare Turvey); *Homerton University Hospital* (Monica James, Sambasivarao Pelluri, Iain Reeves); *Kings College Hospital* (Sarah Barber, Priya Bhagwandin, Lucy Campbell, Leigh McQueen, Frank Post, Selin Yurdakul, Beverley White); *Lewisham and Greenwich NHS Trust* (Tarik Moussaoui, Melanie Rosenvinge, Judith Russell); *Mortimer Market Centre* (Tuhina Bhattacharya, Alexandra Rolland, Shema Tariq); *New Cross Hospital Wolverhampton* (Sarah Milgate, Anjum Tariq); *North Manchester General Hospital* (Claire Fox, Gabriella Lindergard, Andrew Ustianowski); *Royal Free Hospital NHS Trust* (Fiona Burns, Nargis Hemat, Nnenna Ngwu, Rimi Shah); *Southend Hospital* (Sabri Abubakar, John Day, Laura Hilton, Henna Jaleel, Tina Penn); *St Mary's Hospital* (Angela Bailey, Nicola Mackie); *University Hospital Birmingham* (Reka Drotosne-Szatmari, Jan Harding, Satwant Kaur, Tessa Lawrence, Monika Oriak, Jonathan Ross); *West Middlesex Hospital* (Kimberley Forbes, Ursula Kirwan, Shamela De Silva, Marie-Louise Svensson, Rebecca Wilkins).

We are also grateful for support from Positively UK and the UK-CAB.

Most importantly, we thank all our participants for sharing their time and experiences so generously with us. You are the reason this report exists. Thank you.

This report presents independent research funded by the NIHR. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

**Contact:** [s.tariq@ucl.ac.uk](mailto:s.tariq@ucl.ac.uk)

**Twitter:** [@Prime\\_UCL](https://twitter.com/Prime_UCL)

[www.ucl.ac.uk/prime-study](http://www.ucl.ac.uk/prime-study)



PRIME

