



empowering

WOMEN KNOW BEST:

What are the best practices in effective, high-quality HIV support for women in the UK?

We want change. We are positive.



POSITIVELY UK

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1. Foreword

By Joyce Gould, Baroness Gould of Potternewton

This Report is the first to set out so distinctly and clearly key factors that affect women living with HIV. I am therefore pleased to support and publicise this report by writing this foreword. It interweaves the personal with the political by women living with HIV and the fact that women's access to services, particularly in the field of HIV, is now seriously limited by funding cuts and the government's austerity obsessions.

It does so by outlining the work done by people working in this field both in statutory and non-statutory bodies and by drawing on the outcome of the 'Women Know Best' conference of 2014.

The main issues set out in this Report, of mental health; gender based violence, pregnancy and motherhood; accessing health care services and social and political engagement and advocacy are thoroughly and concisely documented and the relevant research services are given by those of us galvanised to follow up this research.

A very important strategic point is made that women are consistently underrepresented in HIV advocacy. This report should go some way in altering this situation.

It is believed that this is due to the lack of women only support groups because women often find it difficult to discuss these personal matters in mixed groups due to personal, social or religious beliefs.

Following on from this well documented observation the report notes at least eight gaps in the services currently provided for women living with HIV. All worth noting in this brief foreword. They range from Lesbian and Bisexual women; Trans women; women who do sex work; incarcerated women; women ageing with HIV, clinical support and gender based violence.

After setting out most thoroughly the wide range of the problems the Report goes on to make recommendations for further identifying the needs of women and how they can be improved. With its five key recommendations it identifies how the lives of women living with HIV can be improved. It calls for improvements in the mental health of women living with HIV, by improving the level of services provided by Health and Social Services Departments; the training of Health and Social Care personnel in recognising signs of violence and for the commissioning of new innovative projects to involve women living with HIV in the design and outcome of policy and programmes at local and national level. It also looks at the role of the Community Groups, and Healthcare Providers.

Although the problems outlined in this well documented Report are huge the portrayal of the work being carried out by many committed professionals and women's organisations is heartening. The author deserves the plaudits of everyone connected with this problem. The Report written by a woman drawing widely the experiences of women and women's groups will go a long way to raising the profile of women as it gives us the ammunition to improve the policy and service for all.

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2. About This Report

By Silvia Petretti, Positively UK, Deputy Chief Executive

It is with a profound sense of achievement that I introduce the Women Know Best Report, and thank the many people who made it possible.

This report addresses the wide range of issues which specifically affect women living with HIV and looks at some of the best way to address them. You may notice that we have not identified the general notion of stigma as an issue, but we have tried to shed light on how discrimination and negative attitude specifically affect women, especially in the form of gender based violence, which disproportionately affects women living with HIV.

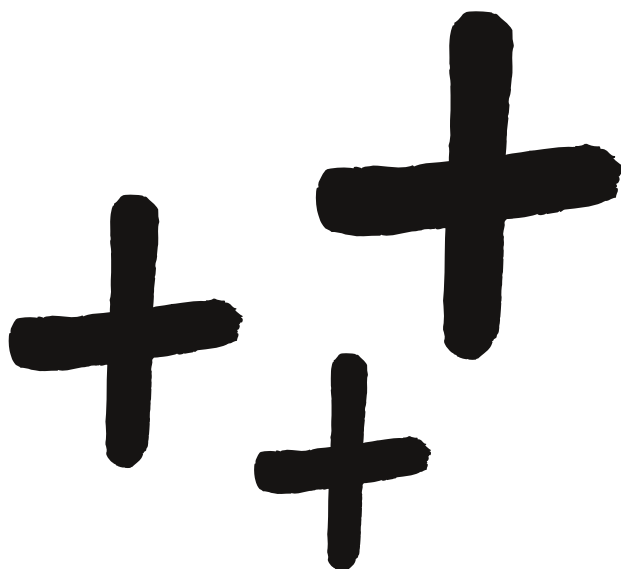
The report is the result of the meaningful involvement and collective work of women with HIV: together we planned the conference and delivered the workshops. This work would have not been possible without the contributions of many positive women who came to the conference and travelled from different parts of England, Scotland and Wales to contribute their experiences and knowledge.

I would like to thank the steering group members: Kath Charters, Virginia Cucchi, Angelina Namiba, Janine Read and Alice Welbourn.

A special thanks goes to Kate Thomson, who was among the founders of Positively Women, Positively UK's mother organisation. Kate gave us an inspiring plenary speech on the history of women living with HIV activism in the UK and globally.

Thanks also to Prof Jane Anderson and Dr Rageshri Dhairyawan for speaking at the plenary about specific medical, social and policy issues women living with HIV presently face in the UK. Collaboration between doctors, researchers and women living with HIV is essential to improve the health and lives of women living with HIV.

Last but definitely not least a huge thank you to Hayley Gleeson, who did the literary review to identify good practices and wrote this report. Alliance between community activists and academics is an essential ingredient in making the advocacy of women living with HIV fruitful, so that together we can create a world where women living with HIV are healthy, safe, and respected.



3. Executive Summary

Background

Women living with HIV face a higher risk of poverty, mental ill health, and gender-based violence than the general population, and are more likely than men who have sex with men to be undiagnosed or diagnosed late. HIV services and women's services are threatened by austerity measures and funding cuts, despite the fact that research has highlighted the importance of women's services as a way of improving physical, mental and social wellbeing.

This guide has been produced in conjunction with women living with HIV, and provides a helpful evidence base for support organisations and commissioners to improve and expand their support services for women living with HIV. We first outline the key issues facing women living with HIV in the UK today. We showcase examples of best practice from throughout the UK across a range of sectors that have been successful in tackling these issues and improving women's health and wellbeing. Finally we end with recommendations for commissioners, voluntary and community groups, medical and social researchers, and healthcare providers to improve policy and programmes.

Method

In December 2014, Positively UK hosted the "Women Know Best" conference in London, which brought together 47 women living with HIV from across the UK. Women discussed the key issues that affected their lives, shared experiences, and developed recommendations to improve services. Workshops on motherhood, gender-based violence, mental health, ageing, and healthcare services were delivered, all facilitated by positive women. We then built on the ideas from the conference, and findings from a literature review, to produce a bottom-up report which is grounded in the real-life experiences of women living with HIV.

Results

Evidence from the conference and literature review highlighted a number of key issues for women living with HIV. These included mental ill health, gender-based violence (GBV), romantic and sexual relationships, pregnancy and motherhood, ageing with HIV, poverty and financial instability, accessing healthcare services, engaging with social and political advocacy, and participating in clinical trial research. There were several areas in which we could not identify current best practice, and that deserve special attention to develop and establish support. These include services for lesbian and bisexual women, trans women, sex workers, and women within faith communities.

3. Executive Summary

Key Recommendations

- Improve the mental health of women living with HIV by providing well integrated health and social care services, including peer support, which address holistically the specific needs of women.
- Commission innovative projects that promote the active and meaningful engagement of women living with HIV in the design and delivery of policy and programmes at community and national levels.
- Train frontline health and social care staff in recognising signs of violence and introduce screening and referral to effective support for GBV in clinical and community settings.
- Address the lack of gender specific data, and underrepresentation of women in clinical trials: increase positive women's treatment literacy and ability to work collaboratively with researchers in designing, implementing and evaluating research.
- Provide sustained support to networks of women living with HIV to increase their strategic influence and advocate for change that will improve women's wellbeing and quality of life.

4. Introduction

There are approximately 107,800 people living with HIV in the UK (Public Health England, 2014). This includes more than 35,000 women, of whom 29% are undiagnosed and unaware of their positive status. Women are the second largest group affected by HIV after men who have sex with men (MSM), yet women are more likely than MSM to be undiagnosed or to be diagnosed late, which leads to poorer health outcomes. Black African women have a particularly high prevalence of HIV: of all Black African women in the UK, about 7.1% are living with HIV, almost four times higher than the general population of women (Public Health England, 2014).

Women living with HIV face unique challenges. Their increased biological vulnerability to HIV entwines with social injustices and inequalities. Women's gender identity, personal and environmental factors, and perceptions of their social role all colour their experiences of living with HIV (WHEC, 2014). Women's experiences living with HIV are different from men's, and there continues to be a need for women-specific HIV support services that focus on improving physical, mental and social wellbeing. However, HIV services and women's support services are threatened by austerity measures and funding cuts. Additionally, the underrepresentation of women in HIV research means that their voices are often silenced and their opinions not heard (d'Arminio Montforte et al, 2010).

5. This Report

At Positively UK we have over 28 years' experience of providing peer-led support for people living with HIV. Women we work with have expressed a variety of unique needs that are not currently being met by existing services. In December 2014, we hosted a conference that brought together almost 50 women living with HIV from across the country (map). The aim of the conference was to promote open and honest conversation about the key issues women face, to discuss how the needs of women living with HIV can effectively be addressed to improve health and wellbeing, and to identify best practice within support services for women. Women discussed a broad range of topics, from pregnancy to ageing to incarceration to empowerment, and participated in workshops facilitated by HIV-positive women. The aim of the day was to produce specific recommendations for improving policy and programming for women living with HIV in the UK.

We have built upon the conversations from the conference to produce this best practice guide as a tool for commissioners and community organisations. We first highlight the key issues identified through the conference workshops and literature review. We then showcase several examples of current good practice from around the UK that are successfully tackling these issues. We highlight gaps in current research and service

delivery, and finally conclude with a number of policy and programme recommendations to improve women's health and wellbeing. Women living with HIV have a wealth of experiences and knowledge, and we believe that they are central to transforming and improving HIV support services. With this in mind, this report is grounded in the real-world experiences of women living with HIV in the UK today.

Attendee Map

**Women
Know Best
Conference**



6. Key Issues

Mental Health

It is well established that people living with HIV are at higher risk of mental ill health, including depression, anxiety, and low self-esteem, than the general population (National AIDS Trust, 2010). 70% of women living with HIV who participated in a 2013 survey at Positively UK had experienced mental health issues in the past year, compared to 50% of positive men, suggesting that women living with HIV are at particular risk of mental ill health (Positively UK, 2013). Feelings of instability, stigma, and discrimination all contribute to poor mental health for women. Barriers to accessing support for women include distance from appropriate services, unclear pathways into psychological care, feeling stigma or shame about HIV or their mental health, or feeling that their needs were not understood by health care providers (Maternity Action and Women's Health and Equality Consortium, 2014). Mental health support is vital, as unaddressed mental ill health can lead to deteriorating physical health through reduced adherence to HIV medication and reduced ability to self-manage HIV symptoms (Positively UK, 2013).

Gender-based violence (GBV)

Women are at particular risk of gender-based violence, including physical, emotional and sexual violence. Violence may be a cause or consequence of HIV status. Power imbalances in relationships may mean that women are coerced into sex or are unable to negotiate safer sex, increasing their risk of HIV transmission. Additionally, women who live with HIV may be increasingly vulnerable to violence due to the stigma associated with the virus. A small study in London found that half of women living with HIV had experienced violence at the hands of their partner (Dhairyawar et al, 2013). Women may be discouraged from seeking help due to financial dependence on a violent partner, concerns about immigration status, or the feeling that they will be judged or treated unfairly (Petretti et al, 2013). Poor understanding of the links between GBV and HIV means that there are currently no

integrated specialist services for women living with HIV who are survivors of violence.

Romantic and sexual relationships

Fear of rejection or violence following disclosure of HIV status is a significant barrier to women finding romantic and sexual relationships. Women report low self-esteem and low libido as they age, which leads to avoidance of relationships and increased loneliness and isolation. Women report that in clinical settings, there is little focus on their right to enjoy a safe and pleasurable sex life (Jelliman, 2013). Women report that sexual and reproductive healthcare is often inadequate, and that they are not given enough information about STI testing and cervical screening. Also, many women are not being informed about hormonal and intrauterine methods of contraception, and their potential interactions with ARVs. (Sophia Forum, 2014).

Pregnancy and motherhood

All women have the right to decide whether and how to start a family. However, women living with HIV must consider many issues that could affect their health, or the health of their child. For example, women living with HIV are often unclear about the impact that HIV or its medications might have on their fertility, or on their children. Women who are diagnosed in pregnancy also face concerns about disclosing to partners or other children. Breastfeeding is a particular issue: although BHIVA guidelines recommend that women living with HIV should not breastfeed, many women are unable to afford formula milk, and feel stigma around not breastfeeding (for example, they may fear that relatives or friends will assume that they are HIV-positive based on the fact that they are not breastfeeding).

Ageing with HIV and concurrent health conditions

HIV today is experienced as a lifelong chronic condition, and 1 in 4 people living with HIV in the UK is over 50 (Public Health England, 2014). As women age, they may develop concurrent

6. Key Issues

health conditions, including cardiovascular disease, osteoporosis, cancers including breast, cervical and ovarian cancer, and symptoms of early menopause (UNAIDS, 2013; Women for Positive Action *undated*). Women tell us that they are worried about drug interactions between ARVs and other medications, including cancer treatment, hormonal contraceptives, hormone replacement therapy, and high blood pressure treatment. Some women have also shared their experiences of stigma and discrimination by carers who have a limited understanding of HIV and HIV transmission.

Poverty and financial instability

Changes in welfare and benefits eligibility over the last few years have negatively impacted the majority of people living with HIV, in particular black and minority ethnic women. In 2014 Counterpoint Policy Alliance reported 78% of BME women had experienced decline in their mental health since welfare changes, while 69% had experienced a decline in their physical health. Black African mothers are more likely than any other group to apply for financial assistance from Terrence Higgins Trust's Hardship Fund (THT, 2014). Immigration status also has a huge impact on financial standing – women who have no recourse to public funds are unable to claim benefits, and these women are hit especially hard. Poverty can increase the risk of depression and anxiety, and can reduce adherence to medication because of issues with housing, income, nutrition, and limited access to care.

Accessing healthcare services

HIV care in the UK is amongst the best in the world. The huge majority of people diagnosed with HIV begin accessing care very soon after diagnosis, and 90% of people diagnosed with HIV who need treatment are taking it. Adherence is high, and most people who are taking ARVs have undetectable viral loads. This is consistent for both men and women (Public Health England, 2014).

However, negative experiences with health care

services are common among women living with HIV. Women at Positively UK's Women Know Best Conference shared a number of negative experiences, including GPs sharing their HIV status with other health care providers, receptionists discussing HIV loudly in front of other patients, and paperwork being conspicuously and inappropriately labelled. Women have been inappropriately questioned about how they acquired HIV, and often face various assumptions about their lifestyle, for example around drug use and sexual practices. In a 2014 study, a majority of women reported that their GPs were not very knowledgeable about HIV, and that they had concerns around confidentiality within the healthcare system (Maternity Action and WHEC, 2014).

Social and political engagement and advocacy

Women experience a number of barriers to social participation, including mental ill health, stigma and discrimination, fear of disclosure, partner violence, and family or caring responsibilities (Solomon & Wilkins, 2008; THT, 2014). Women are more likely to experience poverty and financial instability, which inhibits their ability to engage socially; asylum seekers and other women with no recourse to public funds are especially disadvantaged (THT, 2014). These factors all contribute to women having a higher burden of social isolation than men (UNAIDS, 2007).

The GIPA Principles (Greater Involvement of People living with HIV) emphasise that active participation of people living with HIV in the development and implementation of support services will improve the effectiveness of these services (UNAIDS, 2007). BHIVA guidelines state that people living with HIV should be "partners in care rather than passive recipients of it", and that meaningful involvement of people living with HIV in service design and delivery will improve quality of care and health outcomes (BHIVA, 2012). However, despite the strong case for involvement laid out in these documents, women are consistently underrepresented in

6. Key Issues

HIV advocacy and engagement. Aside from the previously mentioned barriers to social engagement, women may also lack the confidence to speak up. A lack of women-specific support may exacerbate this, as some women will find it even more difficult to discuss certain issues in mixed forums, due to personal, social or religious beliefs.

Clinical trial research

Since 2000, women have comprised only 20% of research participants in randomised clinical trials on antiretrovirals, despite making up half of the global population living with HIV. Researchers often exclude women because of uncertainties around pregnancy and how drugs will impact unborn foetuses, and trials that do include women participants do not analyse gender differences. Additionally, women often find it difficult to participate in clinical trial research because of caring responsibilities, lack of information, and concerns about confidentiality. This means that we may be unaware of how ART efficacy is affected by body size, metabolism, pregnancy, hormone replacement therapy, and hormonal contraception; and that our knowledge of women's specific needs around treatment, care and support is limited (d'Arminio Monforte et al, 2010).

“involvement can improve self-esteem and boost morale, decrease isolation and depression, and improve health through access to better information about care and prevention... public involvement of people living with HIV can break down fear and prejudice” – from BHIVA Standards of Care



7. Case Studies of Best Practice

7.1 Community Based Peer Led Programmes

LASS Women's Project

The Leicester AIDS Support Services (LASS) Women's Programme aims to improve positive women's quality of life by:

- increasing knowledge and understanding of HIV and its treatments
- providing peer support and reducing social isolation
- boosting women's confidence
- offering qualifications and skills-building to empower women to move into education or the workplace

It also aims to shape local services by building relationships with care providers to influence the way that women living with HIV are supported in clinical settings. Women have the programme tailored to their specific support needs. They are asked about the areas of their life that they find difficult or that they need help with through the use of a spider diagram, where women rank on a scale of 1-10 their confidence around 8 areas.

Topics of the workshops are identified by positive women and are often facilitated by women in the programme. LASS ensures the sustainability of the programme by training participants to become trainers themselves, and by working with local clinicians to help steer the project and influence commissioners.

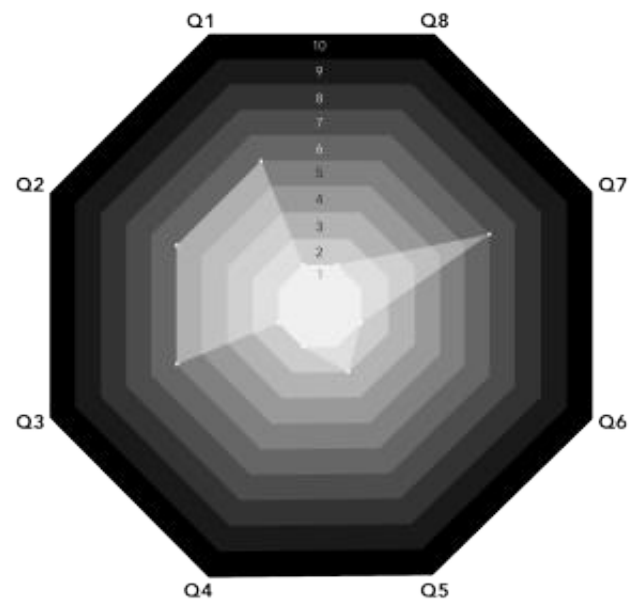
The programme has received very positive feedback. LASS has been successful in helping several women move into employment and apply for college. Women report that their increased knowledge around HIV and the emotional impacts of peer support make them more confident to advocate on their own behalf. More and more women are being trained to lead various elements of the programme. The programme has also led to concrete policy change: the formation of strong relationships with local health care professionals

has led to a change in psychological care pathways, meaning that women are now referred into psychological care more effectively.

Leicester AIDS Support Services. 2014.

Sample of individual's spiderdiagram

1= not confident and 10 = most confident



How positive do you feel about:

- | | |
|------------------------|--|
| Q1. Disclosure | Q5. Family & friends |
| Q2. Relationships | Q6. Dentist |
| Q3. College or studies | Q7. Medication management |
| Q4. Work | Q8. Being settled (in relation to immigration) |

Positively UK Peer Support

Positively UK provides peer-led support, advocacy and information to women, men and young people living with HIV to manage all aspect of their diagnosis, care and life with HIV. Working in partnership with the NHS, peer support is integrated at clinics across London. All frontline staff live with HIV themselves, and Positively UK provides intensive and certified training to staff and volunteers, helping them to develop the skills necessary to effectively support service users. The organisation runs a range of peer-led support groups, including specific groups for women, and a programme of workshops to support people with a new HIV diagnosis, those managing pregnancy or planning a family, and those who wish to get involved with advocacy and activism. Outreach

is provided in prisons across London reaching some of the most vulnerable women affected by HIV. Every year Positively UK support over 1,000 people living with HIV.

In 2013, an external evaluation of Positively UK's peer support service was conducted on 137 service users, 71% of whom were women. This evaluation revealed overwhelmingly positive experiences, with 95% reporting that peer support had improved their overall wellbeing; 88% reporting that it helped them better understand and manage their HIV; and 77% stating that it helped them talk to others about their HIV (Positively UK, 2014). Positively UK's peer support programme won the "Personalisation of Care" and "Best Third Sector Project" awards at the 2014 Patient Experience Network awards. The Peer Navigators Programme, which trains people living with HIV to provide peer support in HIV clinics, won the Community-Led Research Prize at the 2015 BHIVA Conference.

Positively UK. 2014.

SHE

The SHE to SHE programme is a women-specific peer support toolkit developed in the UK by HIV physicians and women living with HIV. The toolkit is composed of nine sections, covering topics including HIV diagnosis and treatment, disclosure, mental health, contraception and fertility, sex and relationships, and how to integrate peer support with clinical care. It aims to enable positive women to lead peer support sessions with other women, share experiences, and access up to date information about HIV. The SHE toolkit has since been rolled out across Europe and has been translated into 10 languages.

SHE Programme, 2014.

7.2 Sexual Health and Relationships

Between the Sheets

Between the Sheets is a collaboration between Liverpool-based HIV support organisation Sahir House and Liverpool Community Health. It is an annual, women-only event, which provides a safe, inclusive forum for women living with HIV to explore issues around sexuality. Past events have included presentations and workshops around contraception, sex and pleasure, HIV transmission, pregnancy, disclosure, and sexually transmitted infections. Women have also shared personal stories from their own lives.

Evaluation has been overwhelmingly positive each year since the initial event in 2012. Women report increased knowledge about sexual and reproductive health, as well as increased feelings of empowerment and self-esteem. Women appreciate the uniqueness of the event, and value the chance to discuss sensitive information in a women-only setting. Women still reported that they wanted further support with disclosing their HIV status to a partner; practical information about sex including how to use internal condoms and dental dams; advice on pleasurable and safe activities to do with a partner, and getting pregnant, among other topics. Women reported that this support needed to be done in women-only settings, through peer support or through professional counsellors or sex therapists.

"The themes that came out were a sense of wonder that being on ART, undetectable, and adherent might well mean I am no longer infectious!! No longer infectious!! No longer do I need then to be intimidated or bullied for my HIV status and no longer does it need to be brought up in every argument. I have a right to contraception but was never told of different methods and their pros and cons."

"I cannot think of an event like this that has

7. Case Studies of Best Practice

been held particularly for women and I've been HIV positive for 20 years! It is pioneering and I hope is the first of many around the country" – participant.

Jelliman, 2013.

7.3 Pregnancy

From Pregnancy to Baby and Beyond

From Pregnancy to Baby and Beyond is Positively UK's unique and innovative peer support programme for women who are diagnosed with HIV while pregnant, or who are planning on starting a family after HIV diagnosis. At the core of the programme are "Mentor Mothers": women living with HIV who have had children themselves. Through training, and drawing on their own personal experiences, they are able to work within multi-disciplinary teams to offer practical and emotional support to women who are pregnant or planning on starting a family. This includes support and guidance around complex issues including coping with new diagnoses, disclosing to partners or other children, testing other children for HIV, concerns around breastfeeding, immigration status and poverty, and the importance of ART adherence during pregnancy. As well as the one-to-one tailored peer support, women can also access workshops on the HIV and Pregnancy Journey, delivered within HIV charities settings and co-facilitated by Mentor Mothers. This programme is the first of its kind in the UK which is led and delivered by women living with HIV.

The programme has seen very positive outcomes, with both Mentor Mothers and mentees benefitting. All mentees (10/10) reported a better understanding of transmission routes and breastfeeding, 9/10 reported improved engagement with health and social care, and 8/10 reported reduced social isolation. Mentees in the programme benefitted from practical support (e.g. baby clothes donations, signposting to food banks); accurate information about pregnancy and HIV; improved self-confidence and ability to self-

manage HIV; and a new sense of empowerment and optimism. The programme has built strong relationships with healthcare services including antenatal clinics, HIV clinics, and midwives, and these healthcare providers have reported better treatment adherence and emotional wellbeing among their clients who participated in the programme. Many clients have remained with the programme and been trained to become Mentor Mothers themselves.

7.4 Gender Based Violence

Homerton Hospital HARK Questionnaire

The HARK Questionnaire was developed as a way of quickly asking women about intimate partner violence in an effective and sensitive way. There are four questions:

H HUMILIATION

Within the last year, have you been humiliated or emotionally abused in other ways by your partner or your ex-partner?

A AFRAID

Within the last year, have you been afraid of your partner or ex-partner?

R RAPE

Within the last year, have you been raped or forced to have any kind of sexual activity by your partner or ex-partner?

K KICK

Within the last year, have you been kicked, hit, slapped or otherwise physically hurt by your partner or ex-partner?

Sohal et al, 2007

If a woman answers "yes" to one or more of these questions, there is a high likelihood that she has experienced intimate partner violence. This test identifies about 81% of survivors of violence.

This HARK Questionnaire was not specifically developed for use in HIV settings, but has been

tested at specialist HIV clinics in London with a high success rate at identifying women who have experienced violence. A small study on 191 women living with HIV attending an East London clinic revealed that the lifetime prevalence of intimate partner violence among these women was 52%, with 14% experiencing it in the past year and 14% experiencing it while pregnant. Younger women, and Black non-African women are more likely to experience violence. Intimate partner violence was associated with mental ill health, but the direction of causality is unclear (Dhairyawar et al, 2013). This short questionnaire is easy to integrate into consultations and support sessions and has shown very promising results at identifying women living with HIV who are experiencing gender-based violence. However, this study was the first study to explore partner violence among women living with HIV in the UK, and we cannot generalise the prevalence and experience of violence in London to the rates in other parts of the country.

Power and Control Wheels

Power and Control Wheels offer a useful way for HIV support organisations to initiate discussion with clients around gender-based violence. Creating a wheel in a group setting is a good way to explore how violence and abuse is linked to power and control, and the factors that influence power and control. A wheel has power and control at the centre. Radiating out are the forms of violence and abuse that someone might experience: emotional, physical, sexual, isolation, financial, institutional, and more. This serves as a way to talk about topics such as unequal power, gender inequality, sexism, et cetera. At Sophia Forum and Positively UK's WISE UP+ advocacy conference in 2014 (see section 6.5), a facilitator from Imkaan* used a Power and Control Wheel to promote conversation around women's rights, GBV, and resilience. 91% of women in the session rated it as excellent or good.

See a larger version of the Power and Control Wheel above at <http://www.theduluthmodel.org/pdf/PowerandControl.pdf>



<http://www.theduluthmodel.org/pdf/PowerandControl.pdf> - but they can easily be customised and adapted to suit the needs of clients.

*Imkaan is a London-based black feminist organisation that belongs to the Women's Health and Equality Consortium. Read more about Imkaan's work here: <http://imkaan.org.uk/>

7.5 Advocacy and Participation

WISE UP+

Women Inspire, Support and Empower to Unleash Positive Potential (WISE UP+) is an advocacy training specifically designed for women living with HIV, developed by the Sophia Forum in collaboration with Positively UK. WISE UP+ aims to address the lack of women's presence and voice in decision making around HIV, by providing women with the skills and tools to become advocates. WISE UP+ 2014 took place over three days in Manchester, with 24 women living with HIV in attendance.

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Over the weekend, women attended workshops on human rights, women's power and control, the importance of meaningful involvement of women with HIV, advocacy skills, and understanding NHS structures for participation, as well as sessions on sex and pleasure, gender-based violence, poetry for activism, and yoga. The feedback and evaluation from women who attended WISE UP+ were overwhelmingly positive. 95% of women rated the sessions as excellent or good, and women reported learning more about their rights, feeling empowered and confident to advocate for their rights, and that the workshop was a great social opportunity to engage with other women living with HIV and share experiences. Women who participated in WISE UP+ have also gone on to speak and present at major national conferences as well as smaller workshops and events.

Participation Tree

The Participation Tree (see opposite) was developed by the International Community of Women living with HIV (ICW), and is a visual representation of the importance of women's meaningful involvement in policy and advocacy. The premise of the tree is simple: there are 6 levels of involvement in decision-making ranging from 1 (very little involvement) to 6 (very significant involvement). Level 1 is down at the roots of the tree, and is often manipulative and tokenistic use of positive women who are put on show but are not included in the important decisions about policy or programmes. Further up the tree, decisions are made mostly by others but with some input from women living with HIV. Level 6 is at the top of the tree, where fruits are flourishing, and signifies that organisations are working in partnership with women living with HIV.

The tree illustrates that a programme will only flourish and grow when women's voices and experiences are truly listened to and integrated into policy decisions. This is another useful tool that HIV organisations can use in group settings with women, to discuss barriers to participation

and help women to identify the support or services they need to get them up to level 6.

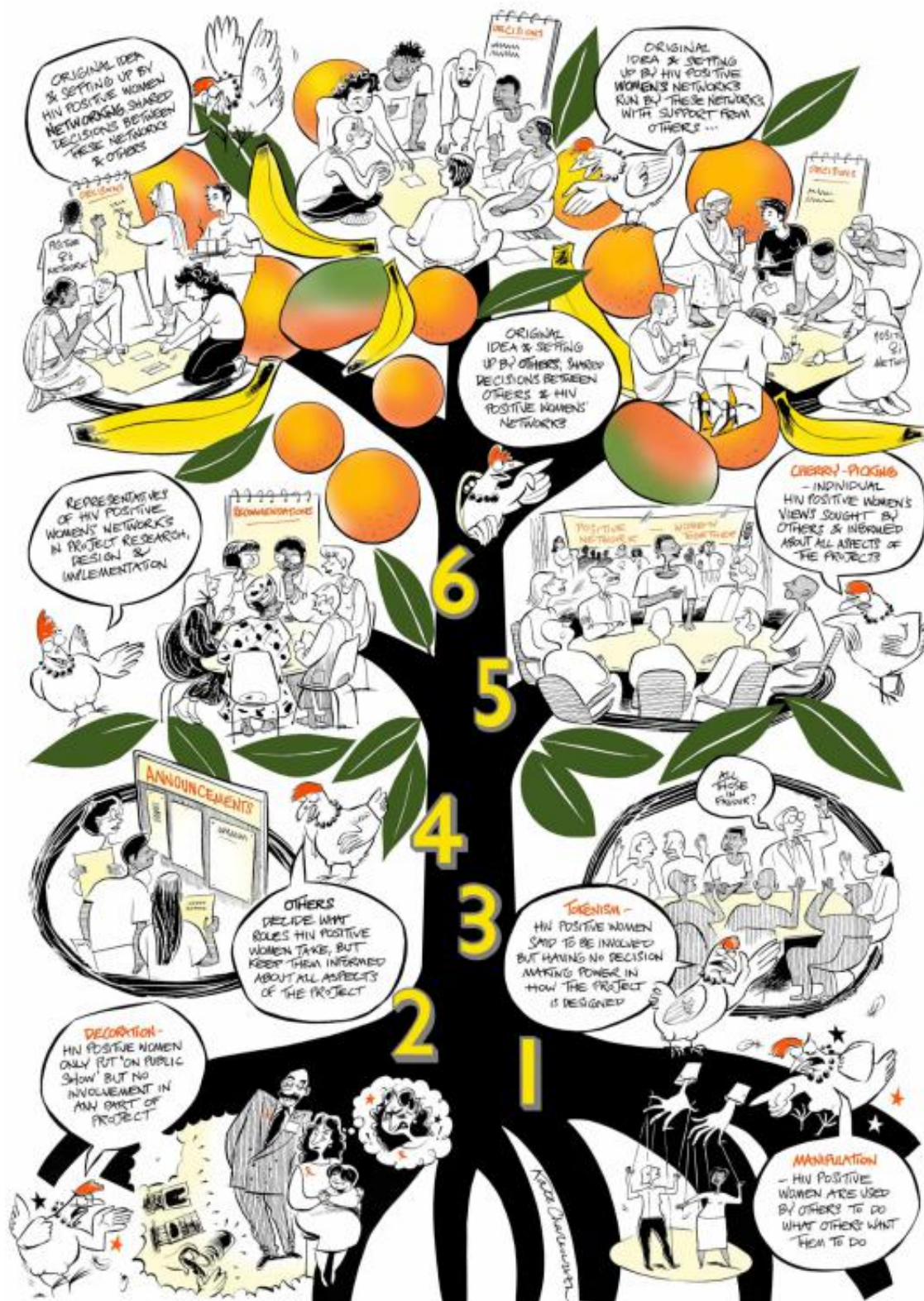
Women Know Best

Positively UK's first "Women Know Best" conference was held in December 2014 and was instrumental in the development of this best practice guide. This conference was unique because women living with HIV were involved at all stages of planning, development, and delivery. The content and structure of the day was designed by a steering committee of women living with HIV, who used their experiences working and volunteering with community organisations to highlight the key needs of their women peers. Aside from two clinical speakers, all of the presenters and workshop facilitators were women living with HIV. Finally, all conference delegates were women living with HIV who came from all over the UK and were selected using an online recruitment process. The selection criteria included geographical representation, ability to contribute on key issues, linkages to positive women groups, and commitment to disseminating information and feeding back to other women.

Women heard presentations on a variety of programmes currently in place addressing pregnancy, incarceration, growing up with HIV, empowerment, sexuality, and more. Women then participated in participatory workshops designed and led by positive women, around gender-based violence, pregnancy and motherhood, healthcare services, ageing with HIV, and mental health.

The feedback received through evaluation forms was excellent. Every workshop was rated by every woman as "excellent" or "good", and every woman agreed that her contributions were heard and valued. All women reported that the conference was relevant to their life and experience.

IS YOUR ORGANISATION BEARING FRUIT?



INTERNATIONAL COMMUNITY OF
WOMEN LIVING WITH HIV

iamicw.org

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7.6 Clinical Trials

Women in Clinical Trial Research

In 2010, Women for Positive Action published an article called “Better mind the gap: addressing the shortage of HIV-positive women in clinical trials”. This article outlined the major barriers to women’s participation in clinical trial research, and provided some concrete guidelines for improving the proportion of women represented in trials.

Barrier	Strategies to facilitate participation
Family/childcare commitments	Support with childcare or parenting responsibilities during study visits
Inaccessible clinic hours	After-hours clinics to fit in with women’s lifestyles
Trial inclusion criteria which exclude women	More flexible recruitment criteria where appropriate
Risk of pregnancy leading to exclusion	Clearly defined procedures for women who fall pregnant during the study, to determine whether unplanned pregnancy is reason for discontinuation; options and support for pregnant women to continue in trials where appropriate
Trials often require the use of multiple forms of contraception	Advice and support around contraception; flexible requirements; financial support for any additional contraception costs
Possible lower adherence among women	Information on the importance of adherence; one-to-one support in a style that takes into account the emotional and social needs of women; understanding of the reasons behind lower adherence (depression, isolation, intravenous drug use)
Cultural factors e.g. resistance from husbands	Information and support for women and partners in a style that takes into account their emotional and social needs and allows them to make a fully informed decision
Language barriers or long and complex consent forms	Provide consent forms in a range of languages or offer support/translation so that women can make a fully informed decision to participate
Fears over trial confidentiality, particularly for women who have not disclosed their status	Information and support to reassure women about confidentiality; understanding of the reasons women fear disclosure (e.g. violence from partner)

Adapted from d’Arminio Monforte et al, 2010.

8. Gaps in Service Provision and Research

There were several areas in which we could not identify current best practice, and that deserve special attention to develop and establish support. These include services for:

Lesbian and bisexual women

There is a common misconception that lesbian or bisexual women cannot have HIV. However, this is not the case: 23% of women living with HIV who attended Between the Sheets in 2012 identified themselves as bisexual. Inclusive, non-heteronormative programmes for women are needed to ensure that the needs of bisexual and lesbian women are being met.

Trans women

Trans women globally are 49 times more likely to acquire HIV, and there is an urgent need for specialised support services for trans women living with HIV (Baral, Poteat et al, 2012).

Women who do sex work

Globally, women who do sex work are 14 times more likely to acquire HIV. These women also face additional barriers to accessing HIV support services including stigma around sex work and fear of disclosure to clients (Baral, Beyrer et al, 2012). In the UK some research showed declining rates of STI among women who do sex work (Ward H, Day S, Weber JN. 1999); however, more HIV & sex work specific research is needed alongside better collaboration between women advocacy around HIV and sex work.

Incarcerated women

The prevalence of HIV among incarcerated women is 13 times higher than the prevalence in the general population (Positively UK, 2013). However, incarcerated women often face substandard healthcare, concerns about confidentiality, and fear of violence if their status is disclosed. This affects mental and physical health, which in turn may exacerbate HIV.

Faith communities

A 2010 report by the African Health Policy Network found that after contacting 392 Muslim faith organisations, only 43 responded, half of whom were reluctant to offer HIV-related support, and 14% of whom reported that they had never heard of HIV (AHPN, 2010). There is urgent need to begin breaking down the stigma around HIV and sexuality in order to provide effective and holistic support to women within faith communities.

Women ageing with HIV

While services exist for supporting people ageing with HIV, specific women-focussed ageing services are scarce. There is also a lack of understanding about the effects of living with HIV on menopause. This was a particular area for development identified by women at the 2014 conference and is now being investigated by the PRIME (Positive Transitions through the Menopause) Study at UCL.

Clinical support

Women living with HIV still report that their GPs and HIV consultants are not placing enough emphasis on women's health, including safer sex and fertility advice, mammography and colposcopy. There is also a need for better integration between primary care and psychological services and increased awareness of the prevalence of mental ill health in women living with HIV.

Gender-Based Violence

While the HARK Questionnaire is a useful and effective way of identifying survivors of violence, the links between HIV care and violence support services are not yet established, and there is not yet any specific integrated support for women living with HIV who have experienced violence.

9. Recommendations

For Commissioners of Healthcare and HIV Services

- Commission peer support that complements clinical care, improves treatment literacy, promotes the importance of adherence to treatment, and signposts to other health and social care services
- Improve engagement and inclusion opportunities for women living with HIV ranging from women-only consultations to events to develop skills around activism and public speaking to ensure the needs of women are effectively represented
- Provide specific funding for comprehensive and long-term monitoring and evaluation of new women's programmes, using a range of quantitative and qualitative methods, in order to build up the evidence base around women's support and improve effective commissioning in the future
- Prioritise commissioning innovative projects that address under-resourced areas such as GBV, women's engagement in policy, treatment literacy and faith involvement, while supporting the sustainability of successful existing initiatives
- Promote and encourage the active and meaningful involvement of women living with HIV in the development and delivery of new and existing programmes
- Commission women-only mental health services in collaboration with a variety of voluntary and community groups, including specialist organisations for women living with HIV, GBV survivors, trans women, and women of various faiths

For Voluntary and Community Groups

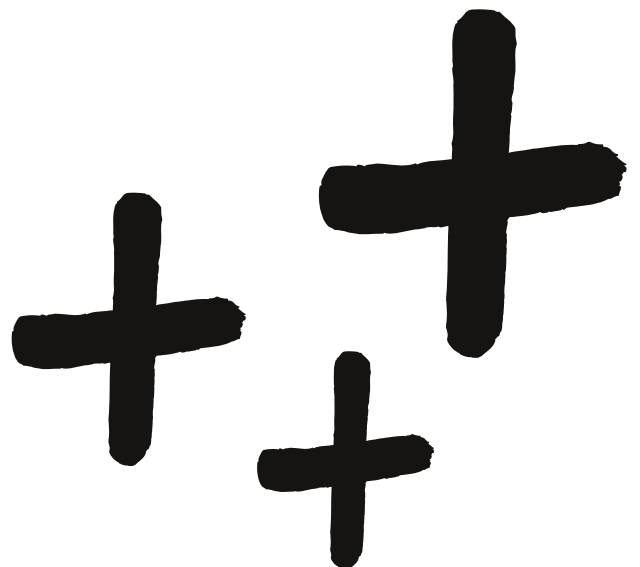
- Improve awareness and understanding of women's support needs and mental health, and develop ways to discuss mental health issues with women to reduce internalised stigma and shame
- Introduce screening for gender based violence, such as the HARK questionnaire, and work to develop strong referral and support pathways to both local domestic violence or GBV support organisations as well as psychosocial support including networks of women living with HIV
- Partner with local clinics or health services to integrate peer support into regular clinical care for women living with HIV
- Improve engagement and inclusion opportunities for women at local and national levels and source funding to cover women's participation in these events, including travel and childcare support
- Provide opportunities for women to develop and improve treatment literacy and treatment advocacy skills, and emphasise the benefits of participating in medical and social research

For Medical and Social Researchers

- Undertake further studies into the links between HIV and GBV, so as to better estimate the rates of violence within the HIV community and support the development of strong, integrated support models, including more in-depth research on the use of the HARK questionnaire among women living with HIV
- Integrate an intersectional approach within research, recognising how gender inequality compounds with other characteristics like race, ethnicity, sexual orientation and poverty to influence health and wellbeing
- Conduct research on how women understand and use various prevention techniques, including pre- and post-exposure prophylaxis and treatment-as-prevention
- Design studies which are sufficiently powered to disaggregate data by gender, and analyse gender differences in programme or treatment outcomes
- Ensure that research projects, particularly randomised controlled trials, have proactive strategies to enrol greater numbers of women
- Create opportunities for women living with HIV to engage in designing, conducting and evaluating research, and build partnerships with women's organisations

For Healthcare Providers

- Train frontline staff in recognising signs of violence, and introduce screening for GBV
- Partner with HIV voluntary and community groups to integrate peer support into clinical care for women living with HIV
- Improve sexual and reproductive healthcare for women living with HIV, including giving advice on dual contraception, healthy relationships and fertility, as well as discussing the importance of regular cervical smears
- Develop relationships with psychological care providers and refer women into counselling or psychosocial support where necessary, and improve awareness of the high prevalence of mental ill health among women living with HIV
- Explain confidentiality policies clearly and transparently with women, and ensure that all clinical staff are respecting and maintaining women's confidentiality



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Positively UK

345 City Road
London
EC1V 1LR

info@positivelyuk.org.uk
+44207 713 0444

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