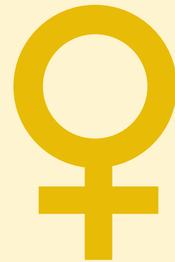
GBV+HIV

VIOLENCE AS A CAUSE OR CONSEQUENCE OF HIV FOR WOMEN IN ENGLAND



A FEASIBILITY STUDY REGARDING A POTENTIAL NATIONAL INVESTIGATION

> "Violence against positive women is any act, structure or process in which power is exerted in such a way as to cause physical, sexual, psychological, financial or legal harm to women living with HIV."
>
> Hale and Vazquez 2011

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Designed by Jane Shepherd

ABOUT SOPHIA FORUM

The Sophia Forum is a small charity that aims to raise awareness of issues facing women living with HIV in the UK and globally. For more information about us and/or to join our mailing list please visit: www.sophiaforum.net

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ACRONYMS

AHPN	African Health Policy Network
AIDS	Acquired immune deficiency syndrome
BASHH	British Association for Sexual Health and HIV
BHIVA	British HIV Association
GBV	Gender-based violence
HIV	Human immunodeficiency virus
IPV	Intimate partner violence
MARAC	Multi Agency Risk Assessment Conference
MSM	Men who have sex with men
NAM	National AIDS Manual
NAT	National AIDS Trust
NICE	National Institute for Clinical Excellence
SARC	Sexual Assault Referral Centre
SPOC	Special Point of Contact
THT	Terrence Higgins Trust

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EXECUTIVE SUMMARY

There are estimated to be 91,500 people living with HIV in the UK, of which nearly one third are women, and the vast majority live in England. Ensuring good health is not the only challenge for these women; they frequently face issues of gender inequality that may manifest as physical, sexual or emotional abuse.

International research has identified significant correlations between being a woman living with HIV and experiencing gender-based violence (GBV). However, in England and across the UK the link between HIV and GBV remains under-researched and relatively unacknowledged. At present, specialist HIV and GBV services tend to act independently of one another which may lead to missed opportunities for identifying and/or adequately supporting women affected by both issues.

This study, exploring the potential for a national investigation into violence as a cause or a consequence of HIV for women in England, was carried out between February and June 2012. Using the Hale and Vazquez[1] definition of violence against women living with HIV as a basis,organisations accessed by women living with HIV and by women who have experienced GBV were surveyed, in-depth interviews were conducted with staff from HIV support organisations and relevant stakeholders were consulted.

The surveys showed that of the HIV support organisations who responded, many are not routinely collecting data about women's experiences of GBV and many GBV support organisations are not routinely collecting data about whether women are living with HIV. For those HIV support organisations that were able to provide data, the prevalence of GBV was lower than the 52% found in a recent study into intimate partner violence (IPV) conducted at Homerton University Hospital.[2]

Survey results from this study showed that when GBV is disclosed within HIV support organisations or HIV clinics, appropriate support is usually offered in the form of one-to-one support within the organisation itself or referral to a violence against women organisation. Several HIV organisations and clinics reported having policies or protocols for managing such disclosures. In some cases these were based on adult safeguarding procedures.

Findings from the interviews demonstrated the broad range of experiences of GBV amongst women living with HIV. These include threatening a woman with prosecution for reckless transmission of HIV, physical violence and institutional abuse such as failure to acknowledge discrimination against women living with HIV and to recognise service access needs. For migrant women, GBV may have taken place in their home country or en route to this country and may be on-going in this country.

The difficulties of providing appropriate support to migrant women in England who have experienced various forms of GBV over a lengthy period of time, in a variety of settings under different political and personal circumstances and from one or more individuals was a theme raised by support services. Migrant women living with HIV who reside on a spousal visa can face financial and social dependence on those who perpetrate GBV. Women may be reliant on their abusers for travel to obtain health care, language interpretation to negotiate English systems, food and shelter for themselves and their children and access to a wider cultural and faith-based community.

Support services and institutional stakeholders described women living with HIV who also experience GBV having to deal with multiple and complex health and personal issues simultaneously whilst, as a consequence of the abuse, they may be prevented from seeking services that can offer them assistance.

The concept of 'layers of stigma' was described whereby women living with HIV and experiencing GBV may be doubly stigmatised and fear disclosing one or both issues.

Respondents also discussed the need for developing work that engenders a better understanding of the perpetrators of GBV.

1. 'Violence against positive women is any act, structure or process in which power is exerted in such a way as to cause physical, sexual, psychological, financial or legal harm to women living with HIV.' Hale F. and Vazquez M. *Violence Against Women Living with HIV/AIDS: A Background Paper*, 2011. Washington: Development Connections.

2. Dhairyawan R., Tariq S., Scourse R., Coyne K. 'Intimate partner violence in women living with HIV attending an inner city clinic in the UK: prevalence and associated factors'. Poster presentation at BHIVA conference, Birmingham, April 2012.

Several issues arose related to identifying women living with HIV who have experienced GBV. This is important because they may face significant challenges to their mental and physical health as well as be prevented from seeking services that can offer them assistance. In order to ensure that they are able to access appropriate support it is necessary to determine who is best placed to identify them and what the best way is to do this. Should there be pro-active screening with an appropriate screening tool or should services await self-disclosure? There is a need for staff training in how to ask GBV screening questions and to ensure that effective care pathways are in place when GBV is disclosed.

It is important to maintain up-to-date knowledge of issues pertaining to HIV. Non-HIV professionals may be unaware of the changing bio-medical and social aspects of living with HIV and as a result are not updating their practice accordingly, which may perpetuate forms of institutional abuse. It was also recognised that HIV support professionals may need training in identifying and supporting women with GBV (including training in how to ask about women's experiences of GBV and the use of appropriate care pathways).

Finite resources and issues around institutional identity mean that there is sometimes a reluctance to develop partnership working between HIV and GBV organisations. However, it was acknowledged that both sectors could benefit from reciprocal professional training, as well as broader dialogue to understand the reasons for the reluctance to collaborate.

The findings from this study demonstrate that it is both feasible and desirable to continue to investigate the intersection between HIV and GBV in this country. Of those who responded to the surveys, 74% indicated an interest in being involved in further research. In addition, a number of developments, including the stated intention by the Chair of BHIVA,[4] to highlight women's issues while she is in post, increasing interest among voluntary sector HIV organisations in GBV and the development by the National Institute for Clinical Excellence (NICE) of public health guidance on Domestic Violence due in February 2014,[5] mean that the current climate is increasingly receptive to continuing to investigate the intersection between HIV and GBV.

RECOMMENDATIONS

- In the short to medium term, there should be a more thorough mapping of HIV support services, enabling Sophia Forum to understand the recurrent GBV issues that are common to women living with HIV in England. There should also be the proactive development of partnerships with sectors that are already involved in elements of this work (i.e. human rights and international development sectors).
- A good practice guidance toolkit should be developed in order to recognise the variety of challenges faced and ensuing excellent practice developed by some HIV support services around the HIV/GBV intersection.
- Training packages that challenge cultural norms of acceptability of GBV against women living with HIV should be developed. aimed at:
  - Women who have experienced GBV in order to enable them to recognise and address the various forms of GBV and increase knowledge of their rights and support available to them
  - Men who perpetrate GBV in order to challenge belief systems about and cultural norms of the acceptability of GBV, and to understand how the law will act against them if they perpetrate GBV[3]
  - Individuals and organisations involved in providing support for women, to increase skills and knowledge amongst professionals who will inevitably work with women affected by both issues.
- In the long-term, mixed-method research is needed to delineate the true extent of the HIV/GBV intersection and to understand the impact of GBV at both the individual and societal level. Individual level includes physical and mental health issues, such as adherence to anti-retroviral medication; attendance at clinic; and child protection issues.

3. Sophia Forum recognizes that perpetrators may also be victims of trauma or affected by cultural norms around masculinity but this was not the focus of this work and should be explored in depth elsewhere.

4. Professor Jane Anderson, personal communication, 23 May 2012.

5. Preventing and reducing domestic violence: how social care, health services and those they work with can identify, prevent and reduce domestic violence. http://guidance.nice.org.uk (accessed 20 July 2012).

6. The current cross-governmental definition of domestic violence is: 'any incident of threatening behaviour, violence or abuse (psychological, physical, sexual, financial or emotional) between adults who are or have been intimate partners or family members, regardless of gender or sexuality'. (Home Office 2005). Final scope available at: http://guidance.nice.org.uk/PHG/44 (accessed 3 August 2012).

INTRODUCTION

Globally, the connections between gender-based violence (GBV) and HIV are now recognised but the international evidence has had a limited impact on policy or practice in England. In recognition of this, a feasibility study was commissioned by the Sophia Forum (using a grant awarded from the Big Lottery Fund's Awards for All programme) to explore the potential for a national investigation into violence as a cause and/or a consequence of HIV for women in England.

The aim of this study was to determine if there is interest in and evidence for the need to pursue a national investigation into the connections between GBV and HIV and, if so, to make recommendations on how to take this forward.

The work plan for the study can be found in Appendix 1.

The study involved:

- Surveying organisations accessed by women living with HIV and by women who have experienced GBV to try to: quantify the number of women affected by both issues; identify referral pathways used by these organisations to support women affected by both issues; and to ascertain levels of interest in participating in a larger study
- In-depth interviews with staff from HIV support organisations, providing services for women living with HIV, to explore the above issues in more depth
- Consulting with relevant stakeholders about evidence gaps at the intersection of HIV and GBV
- Running a stakeholders' event.

The original terms of reference included interviewing women living with HIV who had experienced GBV. After taking advice it was concluded that to do this required an ethics structure, which it was not possible to put in place within the short timescale of the study. This part of the study was replaced with interviews with those working in HIV support organisations, as described above.

This report describes the methodology and findings from the feasibility study. It concludes with recommendations for future work at the intersection of HIV and GBV.

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METHODS

1. Briefing paper

Based on a review of the literature carried out by a Sophia Forum intern, a short briefing paper was written to introduce the study and state its wider aims and objectives for those invited to participate (see Appendix 2).

2. Advisory Board

An advisory board of experts in the field of HIV and GBV was set up by Sophia Forum to inform and support the study (see Appendix 3 for a list of members of the Advisory Board).

3. Surveys

Identifying organisations and individuals to participate in surveys

Five distinct types of organisations/individuals were identified, contacted and asked to complete an online questionnaire.

- **HIV-focused support organisations.** These were identified from the AVERT website.[6] AVERT is 'an international HIV and AIDS charity, based in the UK, working to avert HIV and AIDS worldwide, through education, treatment and care'.
- **GBV-focused support organisations.** These were identified by web searching for Sexual Assault Referral Centres operating in England[7] and domestic violence services in the same areas[8].
- **Refugee-focused support organisations.**These were identified using the websites of five key organisations: Refugee Council,[9] The Testimony Project,[10] Red Cross[11] and Hope Projects,[12] as well as 1Big Database[13].
- **Physicians specialising in HIV who work in geographically dispersed HIV-specific clinics.** Genito-Urinary Medicine (GUM) and HIV clinics in England were identified using a search facility on the National AIDS Map (NAM) website.[14] Names and email addresses of lead physicians specialising in HIV were identified in a geographically dispersed selection of these clinics, using personal knowledge and contacts and by web searching.
- **Doctors working in women's prisons.** The names and email addresses of doctors providing sexual health and HIV clinics to women in prison in England were obtained from the Chair of the prison's sub-group[15] of the Clinical Governance Committee of the British Association for Sexual Health and HIV (BASHH).

6. www.avert.org
7. www.rapecrisis.org.uk/Referralcentres2.php
8. www.womensaid.org.uk/regional_map.asp?section=00010001000800060003
9. www.refugeecouncil.org.uk
10. www.testimonyproject.org/testimonyprojectuk/article/signposting/community-organisations-london
11. www.redcross.org.uk
12. www.hope-projects.org.uk/node/11
13. www.1bigdatabase.org.uk
14. www.aidsmap.com
15. Dr Alan Tang

Only organisations and individuals in England were contacted, because of the constraints of the grant award.

Most of the HIV-focused support organisations were contacted by phone to check that contact details were up-to-date, ascertain if they were doing work with women where the issue of GBV might arise and obtain the name and email address of a relevant individual to email with a survey, to try to increase the response rate.

A large number of organisations working on issues related to GBV and to refugees were identified. Owing to time constraints, it was initially decided not to make phone contact as had been done for the HIV-related organisations.

Survey questionnaires

Using the Survey Monkey website,[16] separate questionnaires were designed for each of the above five professional groups, asking about the work they do with women living with HIV who have also experienced GBV. The Hale and Vazquez[17] definition of violence against women living with HIV (see Box 1) was used to define GBV for the purposes of the questionnaires. Respondents were asked to consider this definition when answering the questionnaire.

BOX 1: DEFINITION OF VIOLENCE AGAINST WOMEN LIVING WITH HIV

Violence against positive women is any act, structure or process in which power is exerted in such a way as to cause physical, sexual, psychological, financial or legal harm to women living with HIV

The main issues addressed in each of the questionnaires were the same and are summarised in Table 1. The full surveys are available in Appendix 4.

Contacting organisations and individuals to complete the survey

Potential respondents were sent a copy of the briefing paper and an explanatory email, inviting them to complete the survey. This email contained either a direct link to the survey (for the HIV-related organisations only, as they had already been contacted by phone, informed about the study and the intention to send them a survey) or a link to a specific page (one per group) on the Sophia Forum website for the four other groups of organisations/individuals. On these pages were links to the appropriate survey. This was in order to comply with the anti-spamming policy of the Survey Monkey website.

After an initial poor response and in order to enhance the response rate from the GBV organisations, up to five organisations were selected, from the original list of GBV

16. www.suverymonkey.co.uk
17. Hale F. and Vazquez M. 'Violence Against Women Living with HIV/AIDS: A Background Paper'. 2011. Washington: Development Connections.

TABLE1: KEY ISSUES ADDRESSED IN QUESTIONNAIRES AND INTERVIEWS	
All questionnaires	• Data collection in relation to women disclosing either experiences of GBV or that they are living with HIV • Women disclosing either experiences of GBV or that they are living with HIV. • Ways in which women who have experienced GBV or are living with HIV are identified. • Existence of policies or protocols to follow if a woman discloses GBV or that she is living with HIV. • Responses to disclosures of GBV or HIV. • Follow-up of onward referrals. • Interest in being interviewed or involved in further research.
Interviews with HIV support organisations	• What is the impact of GBV on health/ability to access health care of women living with HIV? • What training is given to staff to identify women who have experienced GBV? • What specific support services do you provide for women who have experienced GBV? • What are the other organisations women are referred to following a disclosure of GBV? • What are your experiences of referring to other organisations? • Feedback from service users. • What are the barriers to accessing other services? • What needs to change and what resources are needed?
Interviews with institutional stakeholders	• Do you have policies at the intersection of HIV and GBV? • Are you collecting data at this intersection? • Are you developing or delivering work at this intersection? • International literature shows the gendered nature of the HIV epidemic and reciprocal links between HIV and GBV – why is this not the case in England? • Is it feasible to develop mandatory targets around: recording incidences of women who are living with HIV and have also experienced GBV? What about a) recording incidences etc; and b) support offered etc? • Do you know of examples of good practice in relation to joined-up working around HIV and GBV?
Interviews with academics	• What research are you doing at the intersection of HIV and GBV? • What are your conclusions and recommendations for future research? • International literature shows the gendered nature of the HIV epidemic and reciprocal links between HIV and GBV – why is this not the case in England? • Does your work suggest it is feasible to develop national mandatory targets around: recording incidences of women who are living with HIV and have also experienced GBV? What about a) recording incidences etc; and b) support offered etc? • Do you know of examples of good practice in relation to joined up working around HIV and GBV?

organisations, in seven geographically dispersed conurbations (Birmingham, Bristol, Leeds, Liverpool, London, Manchester, Newcastle). They were phoned to check if they had received the survey, to prompt them to respond and to attempt to obtain the email address of a key individual to whom it could be re-sent. Emails were sent to those on this revised list with a link to the survey. In addition, members of the Advisory Board were asked to send out links to the HIV and GBV surveys via their networks. Reminder emails were also sent to the HIV support organisations and the HIV physicians.

4. In-depth interviews

Based on the responses to the surveys, a selection of respondents from the HIV support organisations were invited to be interviewed to provide more narrative detail about their experiences of supporting women living with HIV who have also experienced GBV. Interviews were carried out face-to-face or by telephone. Key institutional stakeholders were also identified and invited for interview. Interviews were carried out face-to-face or by telephone with those who were available. Finally, four academics working in this area were interviewed. The areas covered in these interviews are shown in Table 1.

5. Analysis of the interviews

Most of the interviews were digitally recorded and then transcribed. The remainder were written up from contemporaneous notes. One of the institutional stakeholders provided an email response to the questions. Recurring themes and concepts were identified from the transcripts and email.

6. Stakeholders' Event

A stakeholder' event was held on 14 June 2012 at the Diana Princess of Wales Memorial Fund offices in Central London, to which the Advisory Board members and all those who had responded to the survey and had been interviewed were invited (see Appendix 5 for programme). Others were invited who were identified during the course of the study as being involved in relevant work and through the networks of the Advisory Board. A preview document was sent in advance of the meeting (see Appendix 6), summarising the methodology and the themes that had arisen. At the event, the findings were presented in more detail (see Appendix 7 for presentation) and break out groups were invited to discuss the following questions and then feedback: a) Do you have any comments? b) Are there any surprises? and c) Have we left anything out?

Short-to-medium term and long term recommendations for further work were then presented and break out groups asked to discuss the same questions. Feedback from the day, that was congruent with themes derived from the interviews, is included in the relevant 'themes' section of the results. Any new points that arose during the Stakeholders' Event are listed at the end of the results section.

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RESULTS

This study took place between February and June 2012.

1. Surveys

Number of organisations contacted

Emails containing links to the appropriate survey were initially sent to:

- 45 HIV support organisations
- 161 GBV support organisations
- 86 Refugee support organisations
- 50 HIV physicians
- 9 doctors running clinics in women's prisons.

However, it is not possible to state exactly how many HIV-, GBV- and refugee-focused organisations had received an email (requesting them to complete a survey) by the end of the study.

There was a high rate of bounce-back of emails or 'undeliverable' messages, particularly from the GBV- and refugee-support organisations. In some instances this seemed to be due to the organisations' security firewalls. In an attempt to mitigate this, email addresses for some of these were checked and the request re-sent. In addition, there was wider unquantifiable dissemination of the surveys to HIV- and GBV-specific support organisations via networks available to the advisory board members. As a result, the final number of recipients is not known.

It is not possible to guarantee that all the responses to the surveys intended for HIV-, GBV- and refugee-focused support organisations were completed by the intended type of organisation. Not all respondents identified themselves; however, it is known that individuals from some HIV organisations completed the survey intended for GBV organisations and vice versa. There were a number of reasons for this. One email that was sent to several HIV-focused organisations mistakenly contained the link to the survey intended for GBV-focused organisations. By cross checking those who gave their contact details with the type of survey completed, it became clear that a couple of HIV-focused organisations had used this link to respond to the survey and so completed the wrong one. In addition a link to the survey intended only for HIV-focused organisations was disseminated more widely via Twitter and Facebook, without clear guidance about who should be completing it.

Number of survey responses

Table 2 shows the numbers of organisations/individuals who started and completed each type of survey questionnaire. It is worth noting that small organisations often receive many surveys and questionnaires but do not have the capacity to respond to all of them. This does not necessarily indicate a lack of interest but of time constraints.

TABLE 2: RESPONSE RATES BY TYPE OF ORGANISATION/ INDIVIDUAL FOR WHICH SURVEY INTENDED

Survey intended for	Number who started survey	Number who completed survey
HIV support organisations	27	20 (74%)
GBV support organisations	32	22 (69%)
Refugee support organisations	3	2 (67%)
Specialist HIV physicians	15	9 (60%)
Prison doctors	0	0
Total	**77**	**53 (69%)**

Analysis of survey responses

HIV support organisations

Although 18 of 27 organisations (67%) said they would be aware if a woman accessing their service had experienced GBV, only 7 (of 12 who answered the question; 58%) said they routinely collected this information. The main route of identifying women who have experienced GBV was by self-disclosure.

The most common responses to a disclosure of GBV were to offer one-to-one support within the HIV-focused organisation itself (80%, 16/20) or to refer to a violence against women organisation (85%, 17/20). 60% of respondents followed up on referrals (12/20).

Of 11 HIV-focused organisations that provided data, all but one reported a lower prevalence of GBV than a recent study carried out in the HIV clinic at Homerton University Hospital suggests (see Box 2).

Few organisations (14%, 3/21 who answered the question) had written policies on GBV although 62% (13/21) had protocols that staff would be expected to follow if a woman disclosed GBV. It was clear from comments made in response to this question that several organisations would use protocols to safeguard vulnerable adults to deal with this issue, as appropriate.

GBV support organisations

Eleven out of 30 organisations (37%) said they would be aware if a woman accessing their service was living with HIV but only six (of 11 who answered the question; 55%) said they routinely collected this information. The main route of identifying women who were living with HIV was by self-disclosure.

Eight (of 27 who answered the question) had written policies about HIV and 12 (of 28) had protocols that staff would be expected to follow if a woman disclosed that she was living with HIV.

BOX 2: SUMMARY OF HOMERTON HOSPITAL STUDY

Intimate partner violence in women living with HIV attending an inner city clinic in the UK: prevalence and associated factors

Authors: Rageshri Dhairyawan*, Shema Tariq†, Rosalind Scourse†, Katherine Coyne*

* Homerton University Hospital, † City University

Methods
191 women living with HIV (70% Black African) completed an anonymous questionnaire to determine exposure to intimate partner violence (IPV).

Results
52% reported experiencing IPV ever.
14% reported IPV in the last year.
14% during pregnancy.

Associations
Being of black or other ethnicity and being younger.
Having a mental health problem.

The most common response to a disclosure of living with HIV was referral to a medical organisation (79%, 22/28). It was also common to offer one-to-one support within the organisation (64%, 18/28) and referral to an HIV-focused organisation (64%, 18/28) and 48% (13/27) of respondents followed up on referrals.

Under half (44%, 12/27) had protocols that staff should follow if a woman was worried that she had contracted HIV. The most common response to such a disclosure was to refer to a medical organisation (100%, 28/28).

HIV-specific physicians

Although nine of 14 (64%) said they would be aware if a woman accessing their clinic had experienced GBV, only one (17%, 1/6) said they routinely collected this information. The main routes of identifying women who have experienced GBV was by self-disclosure or because the women they were looking after had been referred by other services (100% and 70% respectively, 10/10 and 7/10). None of the respondents provided data on the numbers of women accessing their clinics who had experienced GBV.

The most common responses to a disclosure of GBV were: referral to a violence against women organisation (90%, 9/10), referral to a health advisor in the clinic (90%, 9/10) and assessing the situation with respect to child protection issues (90%, 9/10). It was also common to offer one-to-one support within the clinic (70%, 7/10) and to refer to police, Social Services or a Sexual Assault Referral Centre (all 60%, 6/10). Few respondents followed up on referrals (22%, 2/9).

One (of 10 who answered the question) had written polices on GBV and seven (of nine who answered the question) had protocols that staff would be expected to follow if a woman disclosed GBV. Two respondents mentioned guidelines on safeguarding vulnerable adults in response to this question about protocols.

Refugee organisations

There were too few responses, from the refugee organisations to be able to draw any conclusions.

Conclusions from survey responses

Many HIV-focused support organisations and clinics are not routinely collecting data about women's experiences of GBV and many GBV-focused support organisations are not routinely collecting data about whether women are living with HIV. For those HIV-focused support organisations that were able to provide data, the prevalence of GBV was lower than found in the recent Homerton study (see below). Protocols for managing women with HIV who disclose GBV are often based on the safeguarding procedures for vulnerable adults and, in the main, appropriate referrals are being made.

Interest in being involved in future research into links between HIV and GBV was high among those who responded to the surveys (74%, 39/53).

2. In-depth interviews

Eight individuals from HIV support organisations were interviewed as well as one individual from an immigration organisation who had completed the survey intended for HIV organisations. The organisations represented were geographically dispersed and are listed below:

- Cornwall (Kernow Positive Support)
- Coventry (Terrence Higgins Trust)
- Huddersfield (The Brunswick Centre)
- London (Body & Soul, Positive East, Positively UK)
- Manchester (George House Trust, Greater Manchester Immigration Aid Unit)
- Slough (Thames Valley Positive Support)

One representative from each of the following institutional stakeholders was interviewed: African Health Policy Network (AHPN), British HIV Association (BHIVA), Rape Crisis and Terrence Higgins Trust (THT).

Four academics were interviewed:

- Dr Rageshri Dhairyawan (Barts Health NHS Trust, London)
- Professor Charlotte Watts (London School of Hygiene & Tropical Medicine, London)
- Dr Shema Tariq (City University, London)
- Professor Gene Feder (Bristol University, Bristol)

A written response to the questions was collated and emailed by the BASHH Sexual Violence group.

In response to a request to be interviewed, the National AIDS Trust (NAT) sent an email describing some signposting to the issue of GBV on their website and information about a planned roundtable seminar on women and HIV, in which GBV was to be discussed (held 15 June 2012).

Lastly, the following institutional stakeholders were approached but interviews were not carried out due to insufficient lead-time to obtain the necessary clearance required by the police and prisons, and resource issues (largely in relation to the availability of personnel to talk) from the other stakeholders.

- London Metropolitan Police
- Prisons via Clinks (an organisation that supports the Voluntary and Community Sector working with offenders in England and Wales)
- Department of Health
- Home Office
- Health Protection Agency

3. Themes that emerged from HIV support organisations and institutional stakeholders

This section of the report identifies themes that emerged from telephone and face-to-face interviews with HIV support organisations, overlapping themes from interviews with institutional stakeholder representatives as well as related themes that arose during the Stakeholders' Event.

The scope of GBV

Respondents discussed the need to understand and support women experiencing GBV and gave examples of a variety of different types of GBV that span both personal and institutional environments. Examples of this were:

- HIV status can be used by partners or acquaintances to establish both financial and emotional power within relationships.
- Partners may make threats to abandon the family and to disclose sero-status to friends, family and in the workplace (in some cases via social media websites).
- Threats of prosecution for reckless transmission of HIV were used to exert power and control.
- Reference was made to institutional abuse. For example poor practice within statutory housing services that failed to understand discrimination perpetrated against female clients living with HIV by staff and/or residents or accommodate the access needs of women living with HIV.
- For migrant women, GBV in all its forms may have taken place in their home country or en route to the UK. In addition, it may be ongoing in this country.

Migration and GBV

The difficulties of providing appropriate support to migrant women in England who have experienced various forms of GBV over a lengthy period of time, in a variety of settings under different political and personal circumstances and from one or more individuals was a theme raised by support services.

There is a significant relationship between immigration status and GBV. Women living with HIV who have no recourse to public funds are often unable to access refuge space and housing that would enable them to leave violent and abusive relationships/ environments. It is clear therefore that if the state does not support women with no recourse to public funds, it effectively does not recognise the violence that they face.

There are public health implications of inadequate support for women with no recourse to public funds if they are unable to remove themselves from the cycle of violence they experience. One service described a series of repeat hospital attendances following physical GBV for a woman they were supporting who was not able to access refuge accommodation.

Migrant women living with HIV who reside on a spousal visa can face financial and social dependence on those who perpetrate GBV. Women may be reliant on their abusers for:

- Travel to obtain health care
- Language interpretation to negotiate English systems
- Food and shelter for themselves and their children
- Access to a wider cultural and faith-based community.

Challenging their abuser/s would put them at risk of extreme personal isolation as well as threatening their own and their children's safety.

Understanding the experiences of women with HIV who have experienced GBV

Support services and institutional stakeholders described women living with HIV who also experience GBV having to deal simultaneously with multiple issues which can overwhelm them. For example, women who are first diagnosed with HIV through antenatal testing have to come to terms with a new diagnosis and the associated health implications, as well as considering the health needs of their unborn child, alongside the reality of living in a violent, abusive or controlling partnership. For some women this means that they are unable to prioritise the GBV they experience.

It was stated that women living with HIV who experience GBV may prefer to build a relationship with one service (usually a specialist HIV support organisation) and thus, if seeking support for GBV means going to another organisation, they may be unwilling to do this as it may result in their HIV status becoming more widely known.

Women living with HIV who experience GBV face significant challenges to their mental and physical health and may be prevented from seeking services that can offer them assistance. Participants describe forms of GBV where the perpetrator instils a fear of social stigma and prevents access to clinical services or withholds medication. Perpetrators may use a number of strategies to exert control, ranging from accusations that the woman's status will bring shame to the family, through to assertions that belief in God will cure them of HIV to justify preventing them from taking medication. Services described women who had been threatened by perpetrators that their children would be removed by Social Services if their HIV status became known. Women may distrust statutory services (which in their home country may have been the perpetrators of abuse) and so may be unwilling to seek support from institutions here that could assist them.

Impact of stigma

The concept of 'layers of stigma' (both internalised and public) was described during interviews. Women living with HIV and who have also experienced GBV may be doubly stigmatised and fear disclosing one or both issues. Circumstances were described where women living with HIV face destitution unless they engage in transactional sex either for basic subsistence, such as accommodation and food, or for cash. If they experience violence within this situation, they are unlikely to seek help as they are fearful of the moral and social opprobrium they may face.

Working with perpetrators

Respondents discussed the benefits of developing work that engenders a better understanding of the perpetrators of GBV. It is clear that violence can be perpetrated by both men and women, and may be perpetrated by a partner, spouse or a family member. In most reported forms of violence however, the male is the perpetrator and the woman is the victim.

There may be benefits of understanding more about issues of male disempowerment and emasculation, particularly amongst the migrant communities with whom they work. Migrants arriving in England may have to deal with a significant shift from more patriarchal cultural norms to ones where the gender equality movement has promoted legal and human rights for women in society. This was described eloquently by one of the interviewees:

"We really need to engage with the African men too … I did a focus group with some of our African men and it was so illuminating. They were saying things like 'our women get off

the plane here and they think they have the same rights as British women' (I could barely make eye contact with some of these guys who were saying these things, because I was like – yeah – guess what? They do.) … But I was really pleased that I was in a group where these men were saying these things because then we knew where they were coming from."

During the stakeholder event it was agreed that increasing understanding of perpetrator motivation in order to challenge and modify behaviour would be useful. However concern was expressed that this might take valuable resources away from work with women living with HIV and that this was therefore not the desired first priority.

Identifying and responding to the needs of women affected by GBV

Respondents considered where and to whom women living with HIV and experiencing GBV were most likely to disclose. Medical professionals (General Practitioners, HIV specialists etc.) are a group with whom most women will have contact and it was suggested therefore that they could be potentially pivotal in identifying women who have experienced GBV. However, it was recognised that there are other medical and non-medical services ranging from psychology through to specialist services for people who use drugs, sex workers and refugee and asylum groups who could also carry out such identification. For all of these services and personnel the following four key issues need to be addressed in relation to identifying GBV:

1. What is the best way to find out about GBV? Should there be pro-active 'screening' with an appropriate screening tool or should services await self-disclosure?
2. Need to train staff across clinical and support sectors to ask about GBV.
3. How to ensure that effective care pathways are in place when GBV is disclosed.
4. How to ensure that asking about GBV is ongoing without being intrusive.

There were numerous ideas that emerged regarding the best way to respond effectively to GBV. Effective needs assessment and case management were seen as crucial. Women's reluctance to 'bounce' around numerous services requiring them to repeat their stories to many different individuals was discussed. It was suggested that there should be a special point of contact (SPOC) role identified in all services to lead on the response to GBV. In addition, an example of excellent practice in this area was given from an East London teaching hospital, where specialist HIV liaison midwives identify women who have experienced GBV and work with them closely to act as their first tier case managers, ensuring that women who experience domestic violence remain supported to engage in antenatal care and to explore with them options for further support via other borough based services.

HIV support organisations described some of the work that they currently do with women who disclose GBV. This includes counselling, legal advice, case management and workshops on relationships. In addition, some HIV support organisations are involved in reciprocal training with domestic violence support organisations.

A specific project, which grew out of recognition of the high levels of GBV experienced by women living with HIV, is the Reassure project run by Positive East in Stepney, London. This project provides one-to-one psychological support and workshops on, for example, physical and emotional wellbeing.[18]

It was also raised that Multi Agency Risk Assessment Conference (MARAC)[19] panels would benefit from increased understanding around the intersection between HIV and domestic violence. Ensuring that high quality professional skills and knowledge are on offer to support women living with HIV who disclose GBV was seen as crucial. One respondent used the expression 'rottweiler advocacy' to describe the assertive and tenacious approach needed by services, if they are to assist women with complex and multiple needs. To support a woman effectively, it was seen that the following would be imperative:

- Knowledge of legal rights (to include both criminal justice system and entitlement to services for non-UK citizens)
- Practical help (to secure housing and benefits)
- Understanding and challenging the impact of stigma
- Counselling and managing the expectations of the women
- Flexibility to address multiple needs.

At the same time it was recognised that a parallel empowerment approach was vital and could be addressed through the following:

- Provision of peer support
- Educating women about their human and legal rights and recognising abuse
- Supporting women with children to access childcare (both to assist with disclosure and accessing services).

Access to appropriate supported housing was seen as integral to providing effective responses to support women living with HIV who experience domestic violence. Of particular concern was discrimination experienced by some women in refuges due to their HIV status. In addition, women using illegal drugs are usually refused refuge accommodation. It was also noted that it becomes difficult for women to continue to access support around HIV and GBV if they are re-housed far away from support services.

Finally, the pressure sometimes placed on women to stay in abusive relationships was discussed. Respondents described the need consistently and constructively to challenge cultural norms of acceptability of violence against women as expressed both by women and men who used their services.

The need for training and resources

Respondents discussed the challenges of maintaining up-to-date knowledge amongst non-specialist professionals. Non-HIV professionals may be unaware of the changing bio-medical and social aspects of living with HIV and as a result are not updating their practice accordingly. For example, housing workers may not recognise vulnerability in someone with HIV unless they have a low CD4 count (blood test marker of immune damage used to monitor the health of those living with HIV).

It was also recognised that HIV support professionals may need training in identifying and supporting women with GBV (including training in how to ask about women's experiences of GBV and use of appropriate care pathways). For example, there is limited professional guidance for HIV-specialist

18. http://www.positiveeast.org.uk/pdf/courses/reassure_overview.pdf

19. The MARAC is a client-focused meeting where information is shared, on the highest risk cases of domestic abuse, between criminal justice, health, child protection, housing practitioners, Independent Domestic Violence Advocates as well as other specialists from the statutory and voluntary sectors. A multi-agency safety plan for each client is then created.

physicians about screening for and managing GBV. There is currently insufficient evidence to recommend universal screening for intimate partner violence (IPV) amongst women living with HIV. However, based on the Homerton study (see below for more details) it was suggested that it could be a good practice point to include in future guidelines.

Previously HIV-specialist social workers were often the repository of knowledge in the areas of both HIV and GBV and could bridge the gaps between HIV clinical services, social services and the voluntary sector. These specialist roles are unfortunately disappearing.

There was discussion about the cost of resourcing effective interventions to support women living with HIV who experience GBV and that the impact of funding cuts is being felt by those who need the support most (women in this situation requiring some of the most resource intensive support). Some organisations have used volunteers to deliver aspects of their service, but there is recognition that this sort of reliance is not sustainable and can often create conflicts of interest in the delivery of services.

Lack of resources was also identified as an issue in terms of enabling community based organisations that run support services to develop data collection systems that would enable them to record incidences of GBV. One interviewee stated that community groups *"struggle to compile the basic data of demographic monitoring let alone more specific data around GBV"*.

Bridging the gap between HIV and GBV organisations

It was identified by a number of respondents that there was often a reluctance to develop partnership working between HIV- and GBV-support organisations. However, there was an acknowledgement that both sectors could benefit from reciprocal professional training, as well as broader dialogue to understand the reasons for the reluctance to collaborate.

4. Themes from interviews with institutional stakeholders

Differing institutional approaches to the HIV epidemic

When asked to identify why the gendered nature of the HIV epidemic and the reciprocal links between HIV and GBV are poorly described and understood in the UK, institutional stakeholders commented that the HIV epidemic is perceived to affect Africans and men, in particular men who have sex with men (MSM), and that women living with HIV are largely invisible. Differing institutional cultures will affect the lens through which HIV is approached, so, for example, BHIVA as a biomedical organisation will approach HIV as a largely scientific and clinical issue while an organisation like the African Health Policy Network will approach HIV from an African cultural perspective. Neither of these approaches is particularly gendered and indeed there are often cultural (meaning both organisational and geographical) norms that reinforce these perspectives.

Collaboration between different institutions and sectors

Tensions between institutions, usually related to finite resources, may adversely affect collaboration. One interviewee stated that in the UK, *"This issue belongs to two different sectors (HIV and domestic violence) and there can be a power struggle – who gets to explore the work and deliver on it – should it be the HIV organisations or the domestic violence organisations? Resources are finite, so in reality, partnerships can be competitive."*

It was noted that the legal, human rights and international development sectors have been developing work streams on tackling violence against women for some time and that the UK HIV sector should consider how it could best engage with this work.

In response to the question of whether institutional stakeholders knew of examples of 'joined up' working at the intersection of HIV and GBV, it was noted that within the National Health Service specifically there is a paucity of structurally embedded services (i.e. services that are commissioned within NHS institutions).

5. Themes and questions that emerged from interviews with academics

Homerton study on intimate partner violence

A study carried out in the HIV clinic at Homerton University Hospital NHS Foundation Trust in Hackney, East London was mentioned by interviewees from HIV-support organisations and institutional stakeholders. It was described in detail by two of the academics interviewed, who were researchers on it. A summary is shown in Box 2. This is the first known study of its type in England and provides some important baseline information about the intersection of HIV and GBV for women living in England.

Addressing GBV in relation to HIV prevention

One way of attracting more interest in GBV in relation to HIV is to see how it fits into other on going work streams such as HIV prevention. Getting GBV onto the HIV prevention agenda may increase interest amongst clinicians and researchers working in the area of HIV prevention and thereby attract funding for further research and policy work at the intersection between the two issues. One way to do this might be to gather evidence enabling an economic argument to be made that effective screening for, and responses to, GBV amongst women living with HIV will ultimately be cost effective. In order to do this more research needs to be done to understand the association between GBV and HIV, how best to identify women who are affected and determine the most effective responses.

Should there be universal screening for GBV amongst women living with HIV?

The UK National Screening Committee criteria[20] for a screening programme include the need for a valid and reliable screening tool; knowledge of effective interventions once the screened for issue is identified; acceptability of screening to women, health professionals and the public; and cost effectiveness. These criteria are used in relation to screening for medical conditions. Feder et al. use some of these criteria to assess the public health benefits of screening women for partner violence as it is clear that women often present to health services with problems related to such violence.[21] Health services therefore need to respond to this issue. From this perspective, current evidence does not support screening all women for GBV (both with and without HIV). However, screening may be appropriate in a research setting to properly quantify and contextualise the problem.

20. UK National Screening Committee Programme Appraisal Criteria. http://www.screening.nhs.uk/criteria (accessed 20 July 2012).

21. Feder G., Ramsay J., Dunne D., Rose M., et al. 'How far does screening women for domestic (partner) violence in different health-care settings meet criteria for a screening programme? Systematic reviews of nine UK National Screening Committee criteria'. *Health Technology Assessment*, 2009, Vol. 13: No. 16.

Future research

Recommendations for future research include a multi-centre research collaboration to build on the Homerton study. This should be multidisciplinary, involving both quantitative and qualitative research methodologies. It was highlighted that it can be difficult to get ethics approval for research in such a sensitive area and that it is important to provide good training for researchers who ask about GBV.

Key questions and areas for future research were identified:

- What is the best way to identify women with HIV who have experienced GBV?
- What is the impact of GBV on clinical outcomes?
- What are the risk factors for GBV?
- How should individuals and organisations respond effectively to women who disclose GBV?
- Understanding the men who perpetrate GBV.

6. Stakeholders' Event

This section lists additional points, which arose during the Stakeholders' Event and that had not come up previously during the interviews.

- It is necessary to consider how to access women who are lost to follow-up or are hard-to-reach, who may have no or limited contact with medical services, by screening for GBV in different settings.
- The scope of GBV should include financial abuse issues, which one delegate stated were reported more often to her in her clinical practice than physical violence.
- It is not just African women or migrant women who are affected by HIV or GBV. It affects women of all ethnicities and backgrounds, (including white UK-born women) as well as women who use drugs, women in prisons, sex workers, lesbians/women who have sex with women – and women who identify with none of these.
- Different ways to frame future work include both human rights and public health frameworks.
- Suggested research questions and methodology:
  - What are barriers to implementing appropriate interventions?
  - How do the experiences of HIV-negative women who have experienced GBV differ from those of women living with HIV?
  - Need for cost-benefit analysis of screening for GBV and providing appropriate interventions.
  - Suggestion to carry out a nested pilot intervention within a larger survey in sexual health clinics.
- It is important to respond appropriately to disclosure of GBV. A fear was expressed that disclosure may lead to more change and anxiety, including pressure on the woman to leave a relationship where there is undue financial or legal control, instead of exploring mediation as a potential option where there is no perceived risk of serious assault, suicide or murder.
- Additional time may be needed by clinicians if they are going to screen women for GBV, although this may save time and money in the long term in relation to, for example, improved health outcomes.

LIMITATIONS OF THE STUDY

Some problems have already been highlighted in relation to logistical issues with the surveys including organisational firewalls and the requirement for clearance before interviewing individuals working for certain institutional stakeholders which limited the breadth of institutional responses.

It was not possible to get accurate data on the numbers of women affected by both issues. Many organisations were unable to state how many women they were working with who were both living with HIV and had experienced GBV, partly because they were not routinely asking women about these issues.

The short time scale for this study imposed limitations on how comprehensively it was possible to investigate and describe the work being done by HIV organisations across England to support women accessing their services who have experienced GBV. Some HIV support services reported work streams internally to support women who had experienced GBV and there were examples of formal and informal joined-up working at this intersection, between HIV and GBV organisations. It is likely that there are other examples of such good practice from which more could be learnt.

HIV+GBV

RECOMMENDATIONS

The findings from this study demonstrate that it is both feasible and desirable to continue to investigate the intersection between HIV and GBV in England. The study illustrated examples of excellent professional practice as well as major gaps in knowledge and evidence. Based on this, short-to-medium term and long term recommendations have been developed that reflect the potential for relatively 'quick wins' as well as the need for more extensive and in-depth research.

It is recognised that inherent in the recommendations below, there are some key challenges. These include:

- Getting the intersecting issues of HIV and GBV onto health, research and political agendas given the low absolute numbers of women affected by both these issues
- Resourcing future work
- Clearly defining the scope of future research to maximise the chances of obtaining funding.

However these should not reduce the impetus to carry forward the work started with this feasibility study.

1. Short-to-medium term

More thorough mapping of HIV support services

It is recommended that a more thorough mapping of the work of HIV support services across England in relation to supporting women who have experienced GBV is carried out. This would enable Sophia Forum to understand the recurrent GBV issues that are common to women living with HIV throughout England and to identify what work HIV support organisations are doing. Examples of good practice should be highlighted and used to contribute to the second recommendation.

Good practice guidance

In recognition of the variety of challenges faced and ensuing excellent practice developed by some HIV support services around the HIV/GBV intersection, Sophia Forum should consider the development of a national good practice guidance toolkit. This resource would be aimed at a range of services supporting women living with HIV and would recognise the unique HIV/GBV intersection and the need for specific and appropriate responses. A good practice guidance tool is a tangible and relatively swift narrative response to the numerous issues identified in the feasibility study. It would capture the breadth of knowledge and experience of services that already support women living with HIV who have also experienced GBV, describe models of exemplary practice and could become an invaluable resource to services without the experience and knowledge of specialist HIV support agencies. It is important to reflect the range of issues and approaches experienced throughout England and a good practice guidance toolkit would do this. It could be published online.

Training packages

A more pedagogic approach through which to challenge cultural norms of acceptability of GBV against women living with HIV would be to develop a range of training tools. These should be aimed at:

- Women who have experienced GBV – in order to enable them to recognise the various forms of GBV – including physical, psychological, economic and legal – and increase knowledge of their rights and support available to them.
- Individuals and organisations involved in providing support for women – targeting specific professions such as: health care, law, the police and staff working in community-based organisations to increase skills and knowledge amongst professionals who will inevitably work with women living with HIV who experience GBV.
- Men who perpetrate GBV – in order to challenge belief systems and cultural norms about the acceptability of GBV and to understand how the law will act against them if they perpetrate GBV.

Multi-sectorial collaboration

Recognising that there are other sectors already involved in elements of this work, (i.e. the legal, human rights and international development sector) it is recommended that Sophia Forum seeks the development of partnerships where appropriate. It is also recommended that links are made with women's prisons, refugee organisations and drug services in order to ensure that the breadth of women's experiences and institutional responses can be heard.

2. Long-term

Research to fill in the evidence gaps

Mixed-method (i.e. qualitative and quantitative) research is needed to delineate the true extent of the problem and how best to respond.

Research questions and issues that need to be addressed are:

- What is the prevalence of GBV in women with HIV, and what are the associated risk factors?
- What is the impact of GBV on women living with HIV at the individual (including health such as adherence to anti-retroviral medication; mental health; attendance at clinic; child protection issues) and societal level?
- What are the mediating factors?
- What is the best tool for screening for GBV?
- Who should perform screening? When, where and how should it be done?
- How should information about GBV be shared amongst members of the multi-disciplinary team, if at all?
- What interventions are effective following a disclosure of GBV?
- What are the experiences of women living with HIV and affected by GBV of accessing health and other support services such as the police, housing, Social Services?
- Understanding the male perpetrators of GBV

Important issues to consider are the need for the meaningful involvement of women living with HIV from diverse groups (e.g. women who use drugs, women in prison, refugees and asylum seekers) at all stages of the research (including design and implementation stages) and collaboration with the GBV sector. It is important to have a good operational definition of GBV linked to an appropriate screening tool. Researchers need specific training on how to ask about GBV and how to respond to disclosure of GBV.

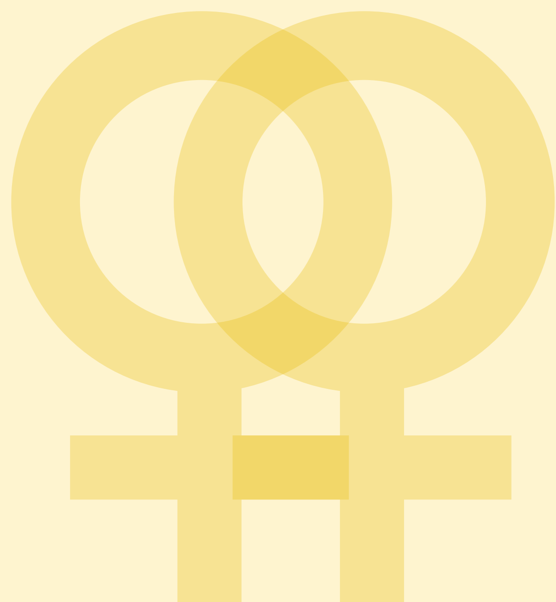
SEIZE THE MOMENT

In conclusion, it is important and feasible to develop work at the intersection of HIV and GBV to clarify the needs of women affected by both issues and determine the best ways to support them.

It has been clear while carrying out this feasibility study that the issues of violence against women in general and against women living with HIV in particular, as well as the broader needs of women living with HIV are being increasingly recognised and that these issues are rising up a number of agendas.

- Professor Jane Anderson, Chair of BHIVA until 2014, and Patron of the Sophia Forum, has made it clear that she will aim to raise the profile of issues that relate to women and HIV during her time in post.
- The National AIDS Trust convened a round table meeting to discuss issues facing women with HIV in the UK today, in which GBV was discussed (June 2012).
- The African Health Policy Network planned and held an autumn conference with a focus on women living with HIV; GBV was one of the themes.
- The National Institute of Clinical Excellence (NICE) is currently developing public health guidance on preventing and reducing domestic violence.
- The BASHH sexual violence group reported that the Pan London policy on adult safeguarding has prompted individual NHS trusts to look at the training needs of their staff including those working in Genito-Urinary Medicine clinics.
- In June 2012, the UK signed the Council of Europe Convention on Violence Against Women (CAHVIO). The Convention is the first legally binding instrument in the world creating a comprehensive legal framework to prevent violence, to protect victims and to end impunity of perpetrators.

This is an opportune moment to seize and capitalise on the above developments.



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APPENDIX 1

Work plan

Consultancy to co-ordinate feasibility study on connections between violence against women and HIV in the UK.

WORK PLAN		
Task	**Methodology**	**Outcomes and timescale**
Literature review	• Meet with intern to determine scope and outcome of literature review. As well as published academic work, ensure this includes search of organisational grey literature (e.g. conference proceedings, internal reviews and policy documents of relevant national and international organisations, position papers). • Consultants will add value by providing access to medical journals via NHS search facility.	• Comprehensive literature review produced as appendix to report. By end of February 2012 2.5 days – 29 February 2012
Survey organisations accessed by women living with HIV and organisations accessed by women who have experienced gender-based violence	• Map range of relevant organisations and services throughout the country and select representative sample to survey. • Devise a letter of introduction plus briefing paper to introduce this work and its wider aims and objectives to survey sample. • Devise a brief semi-structured questionnaire to use for telephone or Skype interviews with key informants working in relevant HIV organisations to determine: » If they are collecting data on GBV » prevalence of GBV amongst clients of these organisations » existence of care pathways and supportive policies for women affected by GBV » if they are collecting data on outcomes for women affected by GBV » stakeholder interest/commitment to further research.	• Clarifying extent of data collection in relation to GBV and HIV by relevant organisations. • Clarifying extent of attempts to support HIV-positive women who have experienced GBV, by relevant organisations. • Determine stakeholder interest in participating in further research. 6 days – March to May 2012
Consult with institutional stakeholders about evidence gaps in respect of HIV and GBV	• Scrutiny of national surveillance data. • Devise key questions to ask a range of institutional stakeholders (identified in collaboration with the Sophia Forum) that will determine how legal frameworks, national strategies and policies relating to GBV and HIV are implemented and monitored and what gaps exist.	• Understand current uses and limitations of data in relation to HIV and GBV. • Determine the feasibility of developing national mandatory targets against which performance and outcomes can be measured. 2 days – March to May 2012
Survey with women living with HIV. (Further to discussion around concerns and limitations of this methodology – this has become a series of in-depth telephone interviews with organisations supporting women with HIV)	• Develop thematic understanding of issues affecting women and via in depth telephone interviews with various HIV support groups across England.	• Rich narrative data describing the perspective of support organisations of this area of work, i.e. experiences of HIV-positive women who have experienced GBV and their access to social, medical and emotional support. Emerging themes to be synthesized into questions recommended for use within further national study. 4.5 days and 2 days for transcribing – April to May 2012
Produce report	• Brief interim report delivered describing findings up to this stage. • Full report summarising findings of feasibility study and making recommendations. • Oversee production/printing of report.	• Full report will be a high quality document that will inform the design and implementation methodology for any further research. Interim report (0.5 days) – 30 April 2012. First draft final report (4 days) – 5 June 2012 Final draft of final report (1 day) – 30 June 2012
Organise Stakeholders' Event and manage dissemination of report findings and build support for recommendations	• Event involving stakeholders interviewed for feasibility study as well as larger selected group (to be identified in partnership with Sophia Forum). • 'Call to action' as part of stakeholders' event inviting those present to take part in and lobby for further research as per recommendations.	• Well attended stakeholders' event to generate wider interest in future research. • Hand over high quality document for use in fundraising for further research. 2 days – End June 2012

APPENDIX 2

Briefing paper

Feasibility study to look at the potential for a national investigation into violence as a cause and consequence of HIV for women in England

Globally, women are the fastest growing population with HIV and made up over 50% of adults living with HIV in 2009.[1] In the UK, sex between men and women is now the most common route of transmission of HIV and more than half of the estimated 91,500 people living with HIV in the UK are heterosexual.[2] Of these, 60% are women. Ensuring good health is not the only challenge for women living with HIV; they frequently face issues related to gender inequality that may manifest as physical, sexual or emotional abuse.

International research has identified significant correlations between being a woman living with HIV and experiencing gender-based violence (GBV). Women living with HIV in Tanzania have reported ten times the level of violence of women without HIV[3] and in India the rate of HIV amongst married women experiencing physical and sexual violence from their husbands was higher than that amongst women in non-violent relationships[4]. Explaining these observations is complex; studies have shown that HIV and GBV can interact in a number of ways. For example:

- Negotiating condom use can be adversely affected by being in a relationship with an abusive partner.[5]
- In some populations, childhood sexual abuse and current partner violence are linked to increased sexual risk-taking by women such as having multiple partners and engaging in sex in exchange for money and goods.[6]
- Women with violent partners are more likely to report having HIV.[7]
- Violence against a woman can interfere with her ability to access HIV treatment and care.[8]

In the UK this remains an under-researched and relatively unacknowledged issue. There is no reference to gender violence in the House of Lord's 2011 report on the state of the HIV/AIDS epidemic in the UK and the Government's action plan published in March 2011, 'Call to End Violence Against Women and Girls: Taking Action' does not have a specific action related to HIV. At present, specialist HIV and GBV services tend to act independently of one another.

This may lead to missed opportunities for identifying and/or adequately supporting women affected by both issues as well as a failure to reveal the extent of the complex relationship between HIV transmission, living with HIV and violence. Although several stakeholder organisations have called for multi-sectoral policies to address these overlapping issues, there is very little in the way of co-ordinated policy.

With funding from the Big Lottery Fund's Awards for All programme, Sophia Forum is conducting a feasibility study into the potential for a national research project into violence as a cause and a consequence of HIV for women in England. Using the Hale and Vazquez[9] definition of violence against women living with HIV as a basis, this study will involve consultations with key HIV and gender violence organisations as well institutional stake holders such as the police, government departments and academic institutions. The study aims to identify key areas for further investigation and opportunities for collaboration among HIV and GBV services and organisations at local and national level.

The feasibility study is being conducted by Georgina Perry, Jane Hutchinson and Kate Seeley. For further information about the study or to be involved, please contact Georgina or Jane at georgina@sophiaforum.net or Kate at kate@sophiaforum.net

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APPENDIX 3

Advisory Board members

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Eunice Simyenu
Trustee of Sophia Forum

Sophie Taylor
Action Against Violence and Abuse

Alice Welbourn
Sophia Forum Chair; Founding Director, Salamander Trust

APPENDIX 4

Survey Monkey questionnaires

A: Questions for HIV support organisations

SURVEY FOR HIV ORGANISATIONS ABOUT HIV AND GENDER-BASED VIOLENCE

This survey should not take you longer than 10 minutes to complete. Your help will assist our study greatly.

The questions are about the work your organisation does with women with HIV in relation to gender-based violence.

Using the following definition of gender-based violence against women with HIV, please can you answer the survey questions.

'Violence against positive women is any act, structure or process in which power is exerted in such a way as to cause physical, sexual, psychological, financial or legal harm to women living with HIV.' Hale and Vasquez, Development Connections, 2011.

The women you work with …

1. Would your organisation be aware if a woman accessing your services had experienced gender-based violence?

   Yes / No / Not sure

2. Do you collect this information routinely?

   Yes / No

3. In 2010/11 how many women with HIV did your clinic look after or see?
4. Please say approximately how many of the women you worked with in 2010/11 reported experiences of gender-based violence.
5. Was 2010/11 a typical year in respect of the women using your services reporting experiences of gender-based violence?

   Yes / No / Comments

6. How have you found out that women with HIV using your service have experienced gender-based violence? (choose any that apply)
   - There is a specific question on an assessment pro-forma that we use
   - Structured one-to-one sessions that we run with women in the clinic
   - Peer support
   - Self-disclosure by the women we work with
   - Women have been referred by or are accessing other services
   - Existing practice would not inform us if women using our service have experienced gender-based violence
   - Other (please specify)
7. Does your organisation have written policies about gender-based violence women?

   Yes / No / Comments

8. Does your organisation have any protocols that staff would be expected to follow if a woman living with HIV discloses that she has experienced gender-based violence?

   Yes / No / Comment

9. What would you do if a woman discloses that she has experienced gender-based violence? (You can choose more than one option?
   - Offer one-to-one support session within your organisation
   - Refer to a health advisor in clinic
   - Formally refer to a violence against women organisation (e.g. Women's Aid, Rape Crisis Centre)
   - Formally refer to Social Services
   - Formally refer to the police
   - Formally refer to Sexual Assault Referral Centre (SARC)
   - Assess situation in relation to child protection issues
   - Signpost to another organisation
   - Take no action because woman already appropriately supported by other services
   - Other (please specify)
10. If you refer women with HIV who have experienced gender-based violence to another organisation or service, do you have a mechanism for following up on the outcomes of these referrals (e.g. joint case management protocol or feedback from the service around continuing needs of women)?

    Yes / No / Not applicable

11. We are planning to conduct more in-depth telephone interviews with staff from some of the clinics that have answered this survey. Would you be willing to take part in such an interview? (maximum 45 minutes)

    Yes / No

12. We will be holding a stakeholder consultation event in Central London on Thursday 14 June 2012. Would you or someone from your clinic be interested in attending this?

    Yes / No

13. Please tell us any possible barriers to attending this event.
14. If one of the recommendations resulting from this feasibility study were for further research into links between HIV and gender-based violence, would you or your clinic continue to be an interested stakeholder?

    Yes / No

15. If you have answered Yes to either question 19, 20 or 22 please tell us your name, clinic, postal address and email address.
16. If you are willing to give us your contact details and have not already done so please can you do so here.

B: Questions for GBV support organisations

SURVEY FOR GBV ORGANISATIONS ABOUT HIV AND GENDER-BASED VIOLENCE

This survey should not take you longer than 10 minutes to complete. Your help will assist our study greatly.

The questions are about the work your organisation does with women who have experienced gender-based violence and who are also concerned about or living with HIV.

Using the following definition of gender-based violence against women with HIV, please can you answer the survey questions.

'Violence against positive women is any act, structure or process in which power is exerted in such a way as to cause physical, sexual, psychological, financial or legal harm to women living with HIV.' Hale and Vasquez, Development Connections, 2011.

The women you work with …

1. Would your organisation be aware if a woman accessing your services was living with HIV?

   Yes / No / Not sure

2. Do you collect this information routinely?

   Yes / No

3. In 2010/11 how many women did your organisation work with?

4. Please say approximately how many of the women you worked with in 2010/11 reported they were living with HIV.
5. Was 2010/11 a typical year in respect of the using your services reporting that they were living with HIV?

   Yes / No / Comments

6. How have you found out that women with HIV using your service are also living with HIV? (choose any that apply)
   - There is a specific question on an assessment pro-forma that we use
   - Structured one-to-one sessions that we run with women in the prison clinic
   - Peer support
   - Self-disclosure by the women we work with
   - Women have been referred by or are accessing other services
   - Existing practice would not inform us if women using our service are living with HIV
   - Other (please specify)
7. Do you have written policies HIV?

   Yes / No / Comments

8. Does your organisation have any protocols that staff would be expected to follow if a woman accessing your service discloses that she is living with HIV or is worried that she may have contracted HIV?

   Yes / No / Comment

9. What would you do if a woman discloses that she is living with HIV? (You can choose more than one option?
   - Offer one-to-one support session within your organisation
   - Formally refer to a medical organisation (e.g. GP, A&E, HIV specialist clinic, Sexual Health Clinic)
   - Formally refer to an HIV organisation
   - Signpost to another organisation
   - Take no action because woman already appropriately supported by other services
   - Other (please specify)
10. If you refer women to another organisation do you have a mechanism for following up on the outcomes of these referrals (e.g. joint case management protocol or feedback from the service around continuing needs of women)?

    Yes / No / Not applicable

11. Does your organisation have any protocols that staff would be expected to follow if a woman discloses that she is worried she has contracted HIV?

    Yes / No / Comments

12. What would you do id a woman discloses that she is concerned that she has contracted HIV?
    - Offer one-to-one support within your organisation
    - Formally refer to an HIV organisation
    - Formally refer to a medical organisation (e.g. GP, A&E, HIV specialist clinic, Sexual Health clinic)
    - Signpost to another non HIV organisation
    - Other (please specify)
13. If you refer women to another organisation do you have a mechanism for following up on the outcomes of these referrals (e.g. joint case management protocol or feedback from the service around continuing needs of women)?

    Yes / No / Not applicable

14. We are planning to conduct more in-depth telephone interviews with staff from some of the organisations that have answered this survey. Would you be willing to take part in such an interview? (maximum 45 minutes)

    Yes / No

15. We will be holding a stakeholder consultation event in Central London on Thursday 14 June 2012. Would you or someone from your clinic be interested in attending this?

    Yes / No

16. Please tell us any possible barriers to attending this event.
17. If one of the recommendations resulting from this feasibility study were for further research into links between HIV and gender-based violence, would you or your clinic continue to be an interested stakeholder?

    Yes / No

18. If you have answered Yes to either question 19, 20 or 22 please tell us your name, clinic, postal address and email address.
19. If you are willing to give us your contact details and have not already done so please can you do so here.

C: Questions for refugee support organisations

SURVEY FOR REFUGEE ORGANISATIONS ABOUT HIV AND GENDER-BASED VIOLENCE

This survey should not take you longer than 10 minutes to complete. Your help will assist our study greatly.

The questions are about the work your organisation does with women who have experienced gender-based violence and who are also concerned about or living with HIV.

Using the following definition of gender-based violence against women with HIV, please can you answer the survey questions.

'Violence against positive women is any act, structure or process in which power is exerted in such a way as to cause physical, sexual, psychological, financial or legal harm to women living with HIV.'
Hale and Vasquez, Development Connections, 2011.

1. In 2010 /11 how many women did you work with?
2. Would you be aware if a woman accessing your services was living with HIV?

   Yes / No / Not sure

3. Do you collect this information routinely?

   Yes / No

4. Please say approximately how many of the women you worked with in 2010/11 reported they were living with HIV.
5. Was 2010/11 a typical year in respect of the using your services reporting that they were living with HIV?

   Yes / No / Comments

6. How have you found out that women with HIV using your service are living with HIV? (choose any that apply)
   - There is a specific question on an assessment pro-forma which we use
   - Structured one-to-one sessions that we run
   - Peer support
   - Self-disclosure by the women we work with
   - Women have been referred by or are accessing other services
   - Existing practice would not inform us if women using our service are living with HIV
   - Other (please specify)
7. Do you have written policies HIV?

   Yes / No / Comments

8. Do you have any protocols that staff would be expected to follow if a woman accessing your service discloses that she is living with HIV or is worried that she may have contracted HIV?

   Yes / No / Comment

9. What would you do if a woman discloses that she is living with HIV or is worried that she may have contracted HIV? (You can choose more than one option?
   - Offer one-to-one support session within your organisation
   - Formally refer to a medical organisation (e.g. GP, A&E, HIV specialist clinic, Sexual Health Clinic)
   - Formally refer to an HIV organisation

- Signpost to another organisation
- Take no action because woman already appropriately supported by other services
- Other (please specify)

10. Would you be aware if a woman accessing your services had experienced gender-based violence?

    Yes / No / Not sure / Comments

11. Do you collect this information routinely?

    Yes / No

12. Please say approximately how many of the women you worked with 2010/11 reported experiences of gender-based violence.
13. Was 2010/11 a typical year in respect of the women seen in your service reporting experiences of gender-based violence?

    Yes / No / Comments

14. How have you found out that women with HIV using your services have experienced gender-based violence? (choose any that apply)
    - There is a specific question on an assessment pro-forma that we use
    - Structured one-to-one sessions that we run with women
    - Peer support
    - Self-disclosure by the women we work with
    - Women have been referred by or are accessing other services
    - Existing practice would not inform us if women using our service have experienced gender-based violence
    - Other (please specify)
15. Do you have written policies about gender-based violence against women?

    Yes / No

16. Do you have any protocols that staff would be expected to follow if a woman accessing your services discloses that she has experienced gender-based violence?

    Yes / No / Comment

17. What would you do if a woman discloses that she has experienced gender-based violence? (You can choose more than one option?
    - Offer one-to-one support session within your organisation
    - Formally refer to a medical organisation (e.g. GP, A&E, HIV specialist clinic, Sexual Health Clinic)
    - Formally refer to an HIV organisation
    - Signpost to another organisation
    - Take no action because woman already appropriately supported by other services
    - Other (please specify)
18. If you refer women to another organisation (in relation to concerns either around HIV or gender-based violence) do you have a mechanism for following up on the outcomes of these referrals (e.g. joint case management protocol or feedback from the service around continuing needs of women)?

    Yes / No / Not applicable

19. We are planning to conduct more in-depth telephone interviews with staff from some of the organisations that have answered this survey. Would you be willing to take part in such an interview? (maximum 45 minutes)

    Yes / No

20. We will be holding a stakeholder consultation event in Central London on Thursday 14 June 2012. Would you or someone from your clinic be interested in attending this?

    Yes / No

21. Please tell us any possible barriers to attending this event.
22. If one of the recommendations resulting from this feasibility study were for further research into links between HIV and gender-based violence, would you or your clinic continue to be an interested stakeholder?

    Yes / No

23. If you have answered Yes to either question 19, 20 or 22 please tell us your name, clinic, postal address and email address.
24. If you are willing to give us your contact details and have not already done so please can you do so here.

D: Questions for HIV physicians

SURVEY FOR HIV PHYSICIANS ABOUT HIV AND GENDER-BASED VIOLENCE

This survey should not take you longer than 10 minutes to complete. Your help will assist our study greatly.

The questions are about the work your organisation does with women who have experienced gender-based violence and who are also concerned about or living with HIV.

Using the following definition of gender-based violence against women with HIV, please can you answer the survey questions.

'Violence against positive women is any act, structure or process in which power is exerted in such a way as to cause physical, sexual, psychological, financial or legal harm to women living with HIV.' Hale and Vasquez, Development Connections, 2011.

The women you work with …

1. Would your clinic be aware if a woman with HIV, who was accessing your services, had experienced gender-based violence?

   Yes / No / Not sure

2. Do you collect this information routinely?

   Yes / No

3. In 2010/11 how many women with HIV did your clinic look after or see?
4. Please say approximately how many of the women you worked with in 2010/11 reported experiences of gender-based violence.
5. Was 2010/11 a typical year in respect of the women seen in your clinic reporting experiences of gender-based violence?

   Yes / No / Comments

6. How have you found out that women with HIV using your service have experienced gender-based violence? (choose any that apply)
   - There is a specific question on an assessment pro-forma that we use
   - Structured one-to-one sessions that we run with women in the clinic
   - Peer support within the clinic
   - Self-disclosure by the women we look after
   - Women have been referred by or are accessing other services
   - Existing practice would not inform us if women using our service have experienced gender-based violence
   - Other (please specify)
7. Does your clinic have written policies about gender-based violence women living with HIV?

   Yes / No / Comments

8. Does your clinic have any protocols that staff would be expected to follow if a woman living with HIV discloses that she has experienced gender-based violence?

   Yes / No / Comment

9. What would you do if a woman discloses that she has experienced gender-based violence? (You can choose more than one option?
   - Offer one-to-one support session within your organisation
   - Refer to a health advisor in clinic

- Formally refer to a violence against women organisation (e.g. Women's Aid, Rape Crisis Centre)
- Formally refer to Social Services
- Formally refer to police
- Formally refer to Sexual Assault Referral Centre (SARC)
- Assess situation in relation to child protection issues
- Signpost to another organisation
- Take no action because woman already appropriately supported by other services
- Other (please specify)

10. If you refer women with HIV who have experienced gender-based violence to another organisation or service, do you have a mechanism for following up on the outcomes of these referrals (e.g. joint case management protocol or feedback from the service around continuing needs of women)?

    Yes / No / Not applicable

11. We are planning to conduct more in-depth telephone interviews with staff from some of the clinics that have answered this survey. Would you be willing to take part in such an interview? (maximum 45 minutes)

    Yes / No

12. We will be holding a stakeholder consultation event in Central London on Thursday 14 June 2012. Would you or someone from your clinic be interested in attending this?

    Yes / No

13. Please tell us any possible barriers to attending this event.
14. If one of the recommendations resulting from this feasibility study were for further research into links between HIV and gender-based violence, would you or your clinic continue to be an interested stakeholder?

    Yes / No

15. If you have answered Yes to either question 19, 20 or 22 please tell us your name, clinic, postal address and email address.
16. If you are willing to give us your contact details and have not already done so please can you do so here.

E: Questions for prison doctors

SURVEY FOR CLINICIANS WORKING IN PRISONS ABOUT HIV AND GENDER-BASED VIOLENCE

This survey should not take you longer than 10 minutes to complete. Your help will assist our study greatly.

The questions are about the experience of gender-based violence amongst the women with HIV that are looked after in the clinical service you provide in prison.

Using the following definition of genderbased violence against women with HIV, please can you answer the survey questions:

'Violence against positive women is any act, structure or process in which power is exerted in such a way as to cause physical, sexual, psychological, financial or legal harm to women living with HIV.' Hale and Vasquez, Development Connections, 2011

1. Would you be aware if a woman with HIV, who was accessing your services in prison, had experienced gender-based violence?

   Yes / No / Not sure / Comments

2. Do you collect this information routinely?

   Yes / No

3. In 2010 / 11 how many women with HIV did you look after or see in prison?
4. Please say approximately how many of these women reported experiences of gender-based violence.
5. Was 2010/11 a typical year in respect of the women seen in the prison clinical service reporting experiences of gender-based violence?

   Yes / No / Comments

6. How have you found out that women with HIV using the prison clinical service have experienced gender-based violence? (choose any that apply)
   - There is a specific question on an assessment pro-forma that we use
   - Structured one-to-one sessions that we run with women in the prison clinic
   - Peer support within the prison clinic
   - Self-disclosure by the women we look after
   - Women have been referred by or are accessing other services
   - Existing practice would not inform us if women using our service have experienced gender-based violence
   - Other (please specify)
7. Does your prison clinical service have written policies about gender based violence against women living with HIV?

   Yes / No

8. Does your prison clinical service have any protocols that staff would be expected to follow if a woman living with HIV discloses that she has experienced gender-based violence?

   Yes / No / Comment

9. What would you do if a woman with HIV who you are looking after in prison discloses that she has experienced gender-based violence? (You can choose more than one option?
   - Offer one-to-one support session within your prison clinic
   - Formally refer to a Violence Against Women organisation (e.g. Women's Aid, Rape Crisis Centre)
   - Formally refer to an HIV organisation
   - Formally refer to another medical organisation or service (e.g. GP, A&E, Sexual Health clinic)
   - Formally refer to Social Services
   - Formally refer to the police
   - Formally refer to Sexual Assault Referral Centre (SARC)
   - Signpost to another organisation
   - Take no action because woman already appropriately supported by other services
   - Other (please specify)
10. If you refer women with HIV who have experienced gender-based violence to another organisation or service do you have a mechanism for following up on the outcome of these referrals (e.g. joint case management protocol or feedback from the service around continuing needs of the woman)?

    Yes / No / Not applicable / Comments

11. We will be holding a stakeholder consultation event in Central London on Thursday 14 June 2012. Would you or someone from your clinic be interested in attending this?

    Yes / No

12. Please tell us any possible barriers to attending this event.
13. If one of the recommendations resulting from this feasibility study were for further research into links between HIV and gender-based violence, would you or your clinic continue to be an interested stakeholder?

    Yes / No

14. If you have answered Yes to either question 11 or 13 please tell us your name, clinic, postal address and contact email address.
15. If you are willing to give us your contact details and have not already done so please can you do so here.

APPENDIX 5

Programme of Stakeholders' Event

Feasibility study to look at the potential for a national investigation into violence as a cause and consequence of HIV for women in England

14 June 2012
The Diana Princess of Wales Memorial Fund
The County Hall, Westminster Bridge Road, London

12:00	Lunch
1:15	Welcome and introduction by Alice Welbourn, Sophia Forum
1:20	Introduction to feasibility study: process and sharing of findings by Georgina Perry and Jane Hutchinson, Study Consultants
1:55	Immediate questions and clarifications
2:00	Working in break-out groups: questions, comments, surprises to be discussed and scribed in groups
2:30	Feedback from break-out groups to plenary
3:00	Tea and coffee break
3:25	Recommendations and identifying challenges for the future by Georgina and Jane
3:40	Questions, comments, surprises to be discussed and scribed in groups
4:10	Feedback from break-out groups to plenary
4:40	Round up by Alice Welbourn

APPENDIX 6

Document summarising methods and themes for Stakeholders' Event

Summary of process and findings from feasibility study carried out to understand the intersection between women living with HIV who also experience GBV.

Methodology

This study took place over 15 days between February and June 2012.

Questionnaires

We identified: HIV, domestic violence, immigration and refugee support organisations, HIV clinicians and doctors working in women's prisons in England and sent Survey Monkey questionnaires to them asking about the work they do with women living with HIV who have also experienced GBV.

Interviews

Based on the responses to the questionnaire we invited a selection of respondents to provide more narrative detail about their experiences of supporting women who have also experienced GBV. We carried out face-to-face and telephone interviews with eight individuals working for HIV support organisations and one individual from an immigration organisation

We also interviewed four academics working in this field and representatives from the following institutional stakeholders: British HIV Association, Terrence Higgins Trust, African Health Policy Network and Rape Crisis.

We also had email responses from British Association of Sexual Health and HIV Sexual Violence group and the National AIDS Trust.

Findings

Survey responses indicate that in general data are not routinely collected by HIV organisations about GBV and by GBV organisations about HIV. Therefore organisations are often reliant on self-disclosure. Few organisations have policies about how to respond to such disclosures but many describe providing appropriate support.

From the interviews we conducted with individuals from HIV support organisations and one immigration organisation we identified several themes, which we have grouped under the following headings. In this section we have also included related themes from the interviews with institutional stakeholders.

Recognising the impact of GBV in the following areas:

1. **Exploring the experiences of women living with HIV who have experienced GBV**
    - Reality of women having to deal with multiple issues simultaneously
    - Impact of GBV on women's health and social networks
    - Fear of children being taken into care
    - Fear of accessing statutory services for migrant women abused by state authorities in country of origin
    - What types of services do women want to access?
    - Vulnerability of women involved in transactional sex

2. **Impact of stigma**
    - Double stigmatisation of HIV and GBV leading to fear of disclosure
    - Prioritising when faced with multiple-stigma

3. Understanding the perpetrators

- Issues of male disempowerment and emasculation
- Changes in gender power dynamics for migrant men and women

Considering how to identify those affected and how best to respond:

4. Appropriate screening for GBV

- Who and where to do screening?
- How best to ask the question?
- When to ask?

5. Responding to GBV

- Good practice guidance and sharing models which work
- Effective needs assessment and case management
- Need for specialist case manager role
- Appropriate responses to disclosure of GBV
- Providing peer support
- Educating women about their human and legal rights and recognising abuse
- Housing
- Need to bring specialist knowledge to MARACs
- Recognising and addressing the impact of immigration status

6. Challenging cultural norms of acceptability of violence against women

Addressing the following issues:

7. Training

- Updating non-HIV professionals about biomedical and social aspects of HIV
- Training non-GBV professionals around identifying and managing GBV
- Relevant clinical guidelines and associated e-learning modules

8. Resources

- Complex interventions cost money
- Impact of funding cuts
- Using volunteers
- Capacity issues for community-based organisations

9. Bridging the gap between HIV and GBV organisations

- Develop partnership working between to include reciprocal professional training
- Understanding reasons for reluctance to collaborate between the two sectors

From the interviews we conducted with institutional stakeholders we identified some additional themes, which we have grouped under the following headings:

1. Perception that the UK HIV epidemic is male-driven

- Women living with HIV are primarily African migrants and invisible

2. NHS has few structurally embedded interventions responding to HIV and GBV

3. Institutional/organisational cultures

- Lens through which approach issues not necessarily gendered
- Organisational cultural pressures re-enforce that lens
- Power struggle between organisations related to finite resources

4. Under reporting of GBV within HIV sector

5. Monitoring translation of policy into practice

6. Engagement with other sectors who have expertise e.g. legal

From the interviews we conducted with academics we identified some more themes:

1. **Challenges of getting ethics approval for research in this area**

2. **Key questions for future research**
   - How best to identify women who have experienced GBV?
   - What is impact of GBV on clinical outcomes?
   - What are risk factors for GBV?
   - How to respond effectively to women who have disclosed GBV?

3. **Should there be universal screening of women living with HIV for GBV?**

4. **Need for good training for researchers to ask about GBV & respond effectively to disclosure**

Georgina Perry and Jane Hutchinson
12 June 2012

APPENDIX 7

Presentation given at Stakeholders' Event

Feasibility study to look at the potential for a national investigation into violence as a cause and consequence of HIV for women in England

Methodology

1. Survey questionnaire
   - Identified and contacted:
     - » HIV, GBV and refugee support organisations
     - » HIV clinicians and GUM/sexual health doctors working in prisons
   - Asked to complete survey
2. Questions
   - Do you collect data about women's experiences of GBV or living with HIV?
   - How have you found out that women have experienced GBV or are living with HIV?
   - Do you have policies or protocols to follow if a woman discloses GBV or that she is living with HIV?
   - How do you respond to disclosures of GBV or HIV?
   - Do you follow-up referrals that you make?
   - Are you interested in being involved in further research?
3. Interviews to gain more in-depth information
   - Respondents from HIV organisations who indicated willingness to be contacted were invited to be interviewed
   - In addition we approached for interview/response:
     - » key academics
     - » institutional stakeholders
4. Constraints
   - Also approached for interview:
     - » London Metropolitan Police
     - » Prisons via Clinks (supports 3rd sector organisations who work with offenders)
     - » Department of Health
     - » Home Office
     - » Health Protection Agency
   - Unable to interview due to:
     - » insufficient time to obtain ethical clearance
     - » resource issues (availability of personnel to talk)
5. Questions for in-depth interviews with HIV organisations
   - Impact of GBV on health/ability to access to health care of women living with HIV
   - What training given to staff to identify women?
   - What specific support services provided?
   - Who have you referred to?
   - Experiences of referring to other organisations
   - Feedback from service users
   - Barriers to accessing other services
   - What needs to change and what resources needed?
6. Questions for institutional stakeholders
   - What policies do you have at intersection of HIV and GBV?
   - Are you collecting relevant data?
   - Are you developing or delivering work at this intersection?
   - International literature shows gendered nature of HIV epidemic and reciprocal links between HIV and GBV – why not the case here?

- Is it feasible to develop mandatory targets around:
  - » recording incidences of women who are living with HIV and who have also experienced GBV
  - » support offered to these women
- Do you know of examples of good practice in relation to joined up working around HIV and GBV?

7. Questions for academics
   - What research are you doing at the intersection of HIV and GBV?
   - What are your conclusions and recommendations for future research?
   - Feasibility of national mandatory targets around data collection and offering support to women
   - Do you know of examples of good practice in relation to joined up working around HIV and GBV?
   - International literature shows gendered nature of HIV epidemic and reciprocal links between HIV and GBV – why not the case here?
8. Analysis of interviews
   - Most interviews were taped and transcribed
   - Remainder were written up from contemporaneous notes
   - Recurring themes and concepts were identified

Findings

1. Summary of survey responses
   - In general, organisations and HIV clinics are not actively collecting data on this issue
   - Main route of identifying women who have experienced GBV or were living with HIV was self-disclosure
     - » Prevalence of GBV lower than Homerton study suggests
   - Protocols for managing the women largely based on safeguarding vulnerable adults
   - Appropriate referrals being done
   - HIV clinics reported appropriate referral pathways in place
   - High level of interest from respondents in future research
2. Interviews
   - 8 individuals from HIV support organisations and 1 individual from immigration organisation
     - » Cornwall, Coventry, Huddersfield, London, Manchester, Slough
   - 4 academics
   - Representatives from the following institutional stakeholders: AHPN, BHIVA, Rape Crisis, THT
   - 2 email responses from NAT and BASHH Sexual Violence group
3. Overall
   - GBV is definitely a recognised problem amongst HIV support organisations who agreed to talk to us
   - A few have developed good partnerships with local GBV organisations

Themes from HIV support organisations

1. Describing the scope of GBV
   - Power dynamics in relationships, i.e. using HIV status to control women in relation to disclosure and criminalisation
   - Use of social media
   - Institutional abuse
   - For migrant women (in home country, en-route and on-going)
2. Immigration status and GBV
   - No recourse to public funds means that violence is not recognised by the state
   - Public health implications of inadequate support
   - Financial and social dependence on perpetrator if on spousal visa
   - Isolation
   - No recourse to public funds should not be a barrier to safety

All contributors described the need to increase knowledge and effective practice in the following areas:

1. Exploring women's experiences
   - Women having to deal with multiple issues simultaneously, e.g. feeling overwhelmed, needing to prioritise, lots of appointments
   - Impact of GBV on women's health social networks, e.g. adherence to medication, mental health issues
   - Fear of children being taken into care
   - Fear of accessing state services for women abused by the state in home country
   - Identifying the types of services women want to access
   - Vulnerability of women involved in transactional sex, e.g. housing, reporting violence
2. Impact of stigma
   - Double stigmatisation of HIV and GBV leading to fear of disclosure
   - Prioritising when faced with multiple-stigma – an issue for both organisations and individuals
3. Working with perpetrators
   - Understanding issues of male disempowerment and emasculation
   - Understanding shift in gender power dynamics when migrant men and women first arrive in England

Contributors affirmed the need to identify women's experiences and questioned the best way to respond

1. Appropriate screening for GBV
   - *Who and where?* Clinicians (GPs, specialist doctors, psychologists), HIV support organisations, immigration groups, refugee groups, specialist women's services (e.g. sex workers), drug services
   - *How?* Development of appropriate screening tools or await self-disclosure, and training in how to ask
   - *When to ask?* At initial assessment or later?
2. Responding to GBV
   - Good practice guidance and sharing models that work
   - Effective needs assessment and case management
   - Need for specialist case manager role, e.g. specialist midwives screening and acting as first tier case managers
   - Assertive responses to disclosure of GBV – 'Rottweiler' advocacy, and multi-disciplinary approach to give holistic management including: knowledge of legal rights; practical help; understanding impact of stigma; counselling and managing expectations of women; need for flexibility to address needs of women
   - Providing peer support.
   - Educating women about their human and legal rights, and recognising abuse
   - Women with children – need childcare to assist disclosure and access to services
   - Housing
     - » Discrimination in refuges for women living with HIV
     - » Needs of women who use drugs
     - » Inappropriate move-on
   - Need to bring specialist knowledge to MARACs
   - Challenging cultural norms of acceptability of violence against women (expressed by both women and men)

Contributors identified the need to address the following issues:

1. Training
   - Updating non-HIV professionals (i.e. social workers, lawyers, GPs) about the biomedical and social aspects of HIV
   - Training non-GBV professionals around identifying and managing GBV (including training on how to ask)
   - Relevant clinical guidelines and associated e-learning modules
     - » Current BHIVA consultation, *Guideline on Treating Women with HIV*

   - » Insufficient evidence to recommend universal screening for IPV amongst women living with HIV; could be a good professional practice point.

2. Resources
   - Complex interventions cost money
   - Impact of funding cuts
   - Instability of using volunteers
     - » Peers
     - » Student social workers
   - Capacity issues around more complex data collection for community-based organisations
3. Bridging the gap between HIV and GBV organisations
   - Develop partnerships, working between HIV and GBV organisations to include reciprocal professional training
   - Understanding reasons for reluctance to collaborate between HIV and GBV sectors; market forces encourage competition not collaboration
   - Identity of sectors

Institutional stakeholder responses

1. Themes which emerged from institutional stakeholders
   - Epidemiology of HIV in UK
     - » Perceived to be male-driven
     - » Women living with HIV largely invisible
   - Institutional cultures affect lens through which issues approached, e.g. BHIVA as a biomedical organisation, AHPN as an African organisation
     - » Approaches are not gendered
     - » Cultural pressures may re-enforce that lens
   - Power struggle between institutions (related to finite resources) affects collaboration
   - Under-reporting of GBV within HIV sector
   - Need for monitoring when translating policy into practice
   - Little that is structurally embedded within statutory sector around HIV and GBV
   - Possibility of engaging with other sectors who have expertise, i.e. legal

Academic responses

1. Study based in HIV clinic at Homerton University Hospital: *Intimate partner violence in women living with HIV attending an inner city clinic in the UK: prevalence and associated factors* by Rageshri Dhairyawan, Shema Tariq, Rosalind Scourse, Katherine Coyne, Homerton University Hospital and City University.
   - Headlines
     - » 191 women completed anonymous questionnaire to determine exposure to IPV
     - » 70% black African
     - » 52% reported experiencing IPV ever
     - » 14% in last year
     - » 14% during pregnancy
     - » Associations: i.e. being of 'black other' ethnicity and being younger, having a mental health problem
2. Themes from interviews with academics
   - How to get GBV onto the HIV prevention agenda?
     - » Make economic argument
     - » Need to engage clinicians (seen as pivotal because they potentially have contact with most women).
   - Should there be universal screening of women living with HIV?
     - » Evidence from public health perspective to do so for all women is lacking
     - » Yes… in research setting to quantify and contextualise the problem
3. Future research
   - Multi-centre research collaboration to build on Homerton work
     - » Multidisciplinary
     - » Quantitative and qualitative

- Potential difficulties getting ethics approval
- Need for good training of researchers who ask about GBV

4. Key research questions
   - How best to identify women who have experienced GBV?
   - What is the impact of GBV on clinical outcomes?
   - What are the risk factors for GBV?
   - How to respond effectively to women who disclose GBV?
   - Understanding the men who perpetrate GBV

Recommendations – short to medium term

1. Development of national good practice guidelines
   - Recognise the unique landscape of HIV/GBV intersection
   - Tangible and relatively swift response to the issues identified
   - Capture the breadth of knowledge and experience to suggest models of excellence
   - Involve the voice and experience of service users in their development
   - are invaluable to services without the experience and knowledge of specialist HIV support agencies
   - Can be made widely accessible through online publication
2. Multi-sectorial collaboration
   - Consultation and development of partnerships with other sectors involved in this area of work:
     - » Legal
     - » Human rights
     - » Police
     - » Government departments
     - » Prisons
     - » Drug services
     - » Refugee organisations
3. Training packages
   - Development of training packages to challenge cultural norms (societal and institutional) of acceptability of violence against women
     - » For women who have experienced GBV
     - » For men who perpetrate GBV
     - » For individuals and organisations involved in providing support for women
       - – Health care workers
       - – Lawyers
       - – Police
       - – Community-based organisations

Recommendations – long term

1. Research
   - Fill in evidence gaps
     - » Delineate the true extent of the problem and associated risk factors to aid targeted screening
     - » Understanding impact of GBV at individual (including health e.g. ARV adherence, mental health, attendance at clinic, child protection issues) and societal level
     - » What are the mediating factors?
     - » What is best tool for screening? When and how and who to do it?
     - » What is the best intervention?
     - » Understanding male perpetrators
2. Issues for consideration
   - Need involvement of GBV sector
   - Meaningful involvement of women living with HIV
   - Be prepared for difficulties around ethics approval
   - Need good operational definition of GBV linked to appropriate screening tool
   - Training for researchers on how to ask and how to respond to disclosure

3. Seize the moment
   - Professor Jane Anderson is Chair of BHIVA (has made it clear that she will be focusing on women's issues while in post)
   - Impact of Homerton study
   - Pan London policy on adult safe guarding – prompted individual NHS trusts to look at training needs of their staff including those in GUM clinics

Challenges

1. Resourcing future areas of work
2. Ethical approval
3. Getting the issue onto health, research and political agendas given low absolute numbers of women affected
4. To define scope of research

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14 June 2012

GBV+AIH