

# “Listen to us, learn from us, work alongside us”

## UK findings from a global participatory survey among women living with HIV

### BACKGROUND

- \* Women living with HIV are vulnerable to gender-based violence (GBV) pre- and post-diagnosis, in multiple settings, and experience more mental health (MH) issues also.
- \* A values and preferences survey of women with HIV explored how GBV and MH issues affect their sexual and reproductive health and human rights (SRH&HR), determined priorities, and then assessed implications for policy-makers.

### METHODOLOGY

- \* A global community-based, participatory, user-led, mixed-methods study was conducted on SRH&HR of women with HIV in 94 countries.
- \* The study was based on an appreciative enquiry approach.
- \* The women's life-cycle experiences were researched by online survey and focus group discussions.
- \* Simple descriptive frequencies were used for quantitative data.
- \* Thematic coding of open qualitative responses was performed and validated with key respondents.
- \* **The UK results are analysed separately here.**

### Health professionals/ abuses

"I have also given up complaining about the yellow stickers on all my tests saying "danger of infection" because I just feel that I am not listened to and I don't want to alienate my HIV doctor."

### Violence

"In active addiction I had knives put to my throat, a gun to my head, [was] assaulted numerous occasions."  
"A partner used derogatory comments like 'no-one will ever want to touch you!'"

### RESULTS

- Of 95 participants from, or now living in, the UK:
- \* 64 (67.4%) responded to each of two optional sections on GBV and MH.
  - \* 79.6% of those who responded reported having experienced at least one form of violence.
  - \* 83% of UK respondents cited experiences of depression and feelings of rejection, with over three quarters reporting self blame (78%), anxiety (77%) and insomnia (75%), and 70% or over reporting very low self esteem (74%), body image issues (72%) and loneliness (70%).
  - \* In all categories, HIV diagnosis appears to be a major trigger for MH challenges.
  - \* In comparison with global survey data, UK-based women experience less violence overall (80% vs 89%), but similar levels of mental health issues (such as depression at 83% for the UK and 82% globally).
  - \* Qualitative recommendations from open-ended questions included "Empowerment, counselling and support", "Support and more support" and, "Be in their shoes".

### CONCLUSIONS

- \* The complex needs and rights of women living with HIV require a stronger health-sector response.
- \* HIV diagnosis acts as a trigger for GBV – especially in community and healthcare settings – and for MH issues among women with HIV in the UK.
- \* Measures of GBV must be sought and monitored, particularly within healthcare settings.
- \* Respondents offered policymakers a comprehensive range of recommendations to achieve their SRH&HR goals.
- \* Interventions addressing intersecting stigmas, and any especial impacts of diagnosis during pregnancy, are required to ensure women's SRH&HR.
- \* National policy guidelines regarding women with HIV must address mental health and GBV.

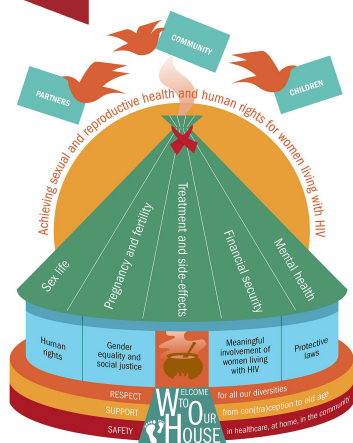
Original report: <http://tinyurl.com/BuildingASafeHouse>

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### Mental health issues

"Mental health issues have been much larger for me than I originally realised. When I was diagnosed with clinical depression, I felt ashamed all over again. I have since learnt how widespread this is and now feel OK to talk about it publicly but this took some time."



### Peer support

"Being actively involved in forums that provide services to positive people and I do not necessarily take clinicians opinions as gospel. Having lived with the condition for 23 years I trust my own experience above all."  
"Be in their shoes. To understand."

### Approach

"Dignity and respect should lie at the heart of the updated guidelines."  
"Women with HIV need multi-disciplinary teams to support them. HIV is often just the tip of the iceberg in terms of many different social, economic and legal problems facing women."



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