Minutes, CPG 26-06-19
Topic: Women & HIV
Venue: Committee Room 5

Attending: Patrick Harvie MSP (Co-Chair), Tom Arthur MSP (Co-Chair), Dylan Morris (Secretariat), Nathan Sparling (Secretariat), Nicoletta Policek, Jo Josh, Fiona Gilbertson, Hosanna Bankhead, Grant Sugden, Lesley Bon, Alan Eagleson, Martin Hutcheson, Joy Cowan, Mark Steven, Mhairi McKean, Yvonne Kerr, Neil Macdonald, Kevin Snell, Callum Sinclair, Rosie Ilett, Nicola Boydell, Carolyn Blake, Will Dalgleish, Mavie Collins, Kyle Howlett, Jo Smith, Gabrielle Harrison

- Introduction from Patrick Harvie MSP
- Minutes from previous meeting, Rosie Ilett’s surname incorrectly spelled – to be corrected, minutes otherwise agreed
- Nicoletta Policek, University of Cumbria and Chair of the Board of HIV Scotland
  o Divided into two sections: biography as someone living with HIV, time as an academic
  o Since diagnosis in 1982 NP has been asked what it’s like to be a woman living with HIV
  o Since diagnosis NP has also been asked how she contracted HIV
  o Edinburgh University was male oriented – NP was the only woman studying a PhD in a male dominated environment
  o When NP went to new GP and was told that it depends on how she contracted HIV, and there were two men living with HIV and that they might not be able to manage a woman as well
  o NP went to Western General and was asked again about how she contracted HIV despite being at the hospital for kidney stones and it not being relevant at all
  o “I don’t understand how someone who is an academic and so articulate could have HIV” from someone who had worked with men living with HIV for twenty years
  o Research undertook with people that self-identified as woman, 87 participants, 21 involved in sex work, mean age of 31. Out of 87 women, 44 were Scottish. 10 were willing to disclose their status to close friends and relatives. 0 were willing to disclose to someone they didn’t know well in case they were asked “how did you get it?”
  o Very few people, not even medical professionals, understand that how HIV was contracted doesn’t matter – and the question itself is patronising and difficult to answer, not just for herself but for lots of woman who are living with HIV
  o We all have different voices, but we all have the same power
  o As a society we want migrants to behave in the “proper way” to attain citizenship. Women living with HIV have expectations on them also
  o Most women can’t tell the people that they work with or are treated by that they’re in the wrong as they have other priorities
  o Quotes from interviews conducted:
    ▪ RE: clinic, “I don’t mind being here, but I do mind other women living with HIV looking at me and asking how I got it.”
They ask you all the time ‘how do you get it,’ is it because you’re a sex worker or because you’re using drugs? But there’s nothing I can do but answer the question.”

Closed with a quote from Angie Spoto, Artist in Residence at HIV Scotland, contributor to Disclosures

- Fiona Gilbertson, Recovering Justice
  - FG always tells people how she contracted HIV
  - Before the deaths of the women that FG were diagnosed at the same time as they were arrested more often than they were helped
  - Drug use was problematic at times, but the interventions of the criminal justice system were catastrophic
  - Contracted HIV due to Edinburgh had a policy where every chemist that was giving out clean needles, and we became the AIDS capital of Europe as a consequence, and 60% of people that FG knew contracted HIV
  - Stigma is created in policy. Stigma is created in Holyrood or destroyed here. Through policy we can choose to make humane choices. If we continue to criminalise the use of drugs, then we will continue to have an issue with HIV.
  - Scotland has been too scared to tell England that we desperately need to devolve drug policy to Scotland
  - Ruth Dreyfuss in Switzerland had open air drug markets, and despite social pressures she brought people who use drugs into a room and asked them how best the government can meet their needs. As a result, Switzerland introduced heroin assisted treatment facilities (HATF). Nobody has ever died in a HATF, nobody has ever contracted a BBV in a HATF, and no politician in Switzerland would ever advocate going backwards
  - We know the answers in Scotland. We know we need drug consumption rooms (DCRs). One person a week dies in Dundee from drug related complications. If this was terrorism, then this would be addressed tomorrow.
  - Unless we link up with poverty-related charities and other forms of social isolation then we will never succeed

- Hosanna Bankhead, Hwupenyu
  - Hwupenyu is a project that is people-led and works with African people
  - Project was started because of HB’s struggle with her own diagnosis as an asylum seeker due to a lack of African people in Edinburgh that could support her through it and explain the realities of HIV to her
  - Problem within the African community around late diagnosis due to people not wanting to seek treatment and therefore CD4 count is low
  - HIV is 4 times more frequent amongst African women in the UK
  - Most African women find out when they get pregnant, and assistance is not always sought until they are seriously ill
  - There are other pressing issues amongst the community which pushes healthcare to a lower priority (healthcare, immigration issues)
- Many African women lead double lives – one here, and one in Africa – often involving further working hours to send money back to Africa
- Black African and Caribbean women experience greater social isolation and mental distress than white women and yet are less likely to have been diagnosed
- Black African and Caribbean women experience higher levels of poverty despite being more likely to have been to university
- There is a glass ceiling amongst Africans that live in Scotland – we do not have diversity
- Lots of people leave an abusive partner and then have no access to public support
- “What covers the home is the roof,” meaning you should never leave abusive relationships whatever the situation
- Motherhood is a rite of passage for an African woman, and it’s incredibly important for them to have children both to the women themselves and to their families
- Part of motherhood in African culture is breastfeeding, BHIVA says that women living with HIV should not breastfeed and when women cannot breastfeed then there are always questions asked about why
- HIV has huge stigma in the African community and people have stopped taking medication because they don’t want to be seen to be having HIV
- Churches play a large role in the African community, and there have been cases in which pastors have told people that they have been cured of HIV and stopped taking their medication
- African women in the UK should be given a place to discuss, design, and implement services
- Africans are not hard to reach, but they are easy to ignore

- Jo Josh, Sophia Forum
  - Sophia Forum is a women’s HIV charity
  - “There is a binary judgement: you are a victim or a survivor”
  - JJ has been asked in the 11 years since her diagnosis about how she got HIV and she openly says that she got it through sex, just like 97% of all HIV transmissions
  - STIs going up and the Daily Telegraph has blamed promiscuity in women over 60
  - It’s easy as a gay man to make a lot of a noise about HIV, but as a woman it is far harder
  - When JJ did her first television broadcast about HIV, she did it because she was articulate and didn’t fit a stereotype
  - We have won a lot of battles with HIV, clinically we’ve drugs that work, and patients are now living a normal life expectancy – the scope of our clinical work now has to broaden to deal with all the other things that come along with living with HIV
  - “If it was cancer, you’d get sympathy, but HIV is different”
  - If you’re a mother, then you’re fulfilling expectations of other mothers
  - When JJ was told that she was HIV-positive she thought she was going to die, and even with A girl who contacted her last month didn’t know that she wasn’t going to die or that she was going to live a normal life
  - Women avoid health services because of discrimination – lots of GPs did their training years ago and are entirely unaware of the stigma of their actions (double gloving, etc)
  - We need to make HIV normal, and stop women feeling invisible
There are not as many services for women as there are for men and this leads to a fragmentation of the community with so many women never speaking about their own experience of HIV.

Peer support isn’t just supporting someone else – it’s a human right we should have to be allowed to help other people.

If women can get together in the same space, then all of us feel better about the issue being discussed.

Conclusions are always the same: loneliness, mental health issues, and a lack of understanding from the health system.

MC (Umbrella Lane): Sex workers aren’t officially considered in the highest risk groups but it’s very difficult to gather the statistics on this. Of the 50-70 that MC knows personally she knows of nobody that has disclosed their status as a sex worker. Sex work is never a reason to break confidentiality for mothers. Sex workers are not a ‘hard to reach’ population and should be consulted.

MM (Waverley Care): Research by the Lancet shows that women are disproportionately affected by the outbreak in Glasgow, and the outbreak isn’t going away. Homelessness, imprisonment, transactional sex. There is a lot of stigma around a lot of these social issues. These issues are apparent in the street testing done by Waverley Care.

PH: Anybody from a service provider point of view that could speak about the efforts that have been made to overcome the structural barriers?

LB (SDF): One of the issues we’re facing in Glasgow is that access to services for women is so poor. Women are getting a three to four month wait from Sandyford and are being referred to third sector providers. Lack of funding and no sign of any increases in that funding. We cannot change this and increase access without funding.

MM (Waverley Care): Women are fearful that they may be judged, mothers are worried that their kids will be taken away and are more reluctant to test than men. Rapid testing at Waverley Care means that people with issues outside of their sexual health – homelessness, poverty – don’t have to wait for weeks for the response to their test, reducing stress and anxiety.

PH: Would anonymity help?

MM (Waverley Care): We’ve not heard that as feedback, but the extra pressures on women are a contribution. PWID may only have that they inject with as their only peer support group.

FG: I don’t how we beat generational trauma. HATRs and DCRs would change things fundamentally, but how will we get there?

LB (SDF): Glasgow is trialling a HATR later this year.
NP: There should be sexual health education available to everyone. Putting people into clusters means that people don’t feel welcome and feel divided. Stigma does not discriminate. Use of “chaotic lifestyles” when it comes to PWID is patronising.

GS (Waverley Care): Needs of WLWHIV are invisible when it comes to policy. We need to use the opportunities like the review of the SHBBV framework and Fast-Track Cities to bring the needs of women to the forefront.

NS (HIVS): In Glasgow we brought together all the relevant stakeholders as the FTC Board and now we are working to make sure people can have a house, and working to make sure that the PWID population in Glasgow is seen as transient and not a homogenous group.

JS (NHS): Research being done in the trans and non-binary population and one of the things that she has discovered is that peer-led services are beneficial in certain communities, i.e. services for certain people are led by certain people.

MM (Waverley Care): Funding for testing at Waverley Care is non-existent and that doesn’t seem like it’s going to change.

LB (SDF): Women don’t access needle exchanges as much as men, and yet in the cohort of people living with HIV that access them women are over-represented. It is ridiculous that we are still in this situation five years later with no action.

YK (NHS Lothian): We do have a women-only service that isn’t HIV-specific, limited scope just now but looking to expand the service. A woman could come in and be there for an hour if that’s what she needs.
  o PH: Why has Lothian been able to manage this where other areas have not?
  o YK: Dogged consultant determination.
  o PH: Evaluation reports from women-only spaces would be beneficial if the MSPs are to ask questions in Parliament.
  o YK: There are areas in which we can provide information but it’s difficult to track a woman’s journey through the system.

JS (NHS): How good are the links between the sexual health department and the third sector providing testing?
  o GS (Waverley Care): Not as good as they could be. Always opportunities to do better.
  o WD (Lothian Patient Forum): Lots of figures available via Hilda Stiven.
  o YK (NHS): Could always be better. Recent work has been done to ensure that systems are talking to each other in a better way.
- **AOB**
  - NS (HIVS): Trans Sexual Health Enquiry. 18 months ago, the CPG agreed to do an enquiry into the sexual and reproductive health of trans people. Open call for evidence running from 27/06-27/08 followed by thematic discussions hopefully led by our MSPs. Report to be released in November or December with a parliamentary event.
  - PH: Do we think it would be useful to get the government to give evidence?
  - NS: No approach has been made yet but would be very beneficial, so sessions will be organised soon, and government will be invited to give evidence.
  - YK (NHS Lothian): Suggestion of RSHP review as a topic of discussion at future meetings.

- **CLOSE OF MEETING: 19.42**