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Pre-Exposure Prophylaxis (PrEP) and Early Treatment

In 2014 Scarlet Alliance undertook a short consultation with sex workers to inform the Global Network of Sex Work Projects (NSWP) international study on PrEP and Early Treatment. The timeline available to feed into the study was short and the Australian content was provided to NSWP in May 2014, with the Global Report released in July 2014. This document is an excerpt from the Scarlet Alliance submission.

Conducting this survey

Scarlet Alliance conducted an online survey to canvass the views of our membership on PrEP and Early Treatment. This survey was distributed online via Survey Monkey to our membership; through our sex worker-only E-list, our individual member email list, and our member organisation contact list. Sex workers were provided with background and context about the NSWP study, the PrEP factsheet provided by NSWP, and required to give their informed consent before completing the survey. Respondents were informed that they could choose whether or not to participate in the survey, could stop at any time, and that their responses would remain anonymous. Names were not collected, and are not included in our submission. There were 21 questions in total, including multiple choice and comment boxes, according to the template of questions provided by NSWP.

Demographic information

NSWP requested specific 'diversity criteria' to ensure that survey responses were representative from diverse sectors of the sex work community in Australia. This required collecting specific demographic information from survey participants, as instructed by NSWP.

Number of participants - A total of thirty three (33) sex workers completed the survey.

Place of residence - Thirty-two (32) currently reside in Australia and one in the USA, who was working as a migrant worker. Most participants were born in Australia (27), and others in Russian Federation (1), England (1), New Zealand (1), United States (1), China (1), and Republic of Korea (1).

Gender - Respondents were given a comment box to state their gender (rather being asked to tick male, female or transgender) and gave a number of different responses including: male (n=12), M (5) cismale (1), female (n=11), female (cisgender) (n=1), identify as female (n=1), trans woman (n=1), transgender/nonbinary (n=1).

Age - No respondents were under 18. Respondents had diverse ages: 39.39% of respondents were between 18-30 (n=13), 24.4% were between 30-40 (n=8), 24.24% were between 40-50 (n=8), 9.09% were between 50-60 (n=3) and 3.03% were over 60 (n=1).

Urban/Rural - Most (84.85%) lived in an urban/city environment (n=28), while 15.15% lived in a rural/village environment (n=5).

HIV Status - While 6.06% preferred not to disclose their HIV status (n=2), 12.12% were HIV positive (n=4) and 81.82% were HIV negative (n=27).

Time of last sex work - Most (72.73%) had sex worked in the past 30 days (n=24), 12.12% more than 30 days ago but within the past 6 months (n=4) and 15.15% more than 6 months ago (n=5).

Place of last sex work - Respondents were asked where they last did sex work: 18.18% answered in a brothel (n=6), 3.03% answered on the street (n=1), 18.18% answered migrant/travelling around (n=6) and 78.79% selected Other (n=26). The respondents who selected Other reported to have worked: privately, on outcalls, incalls, online, in a parlour, from home, soliciting in public venues, own business premises, BDSM house, and private room for hire.

Sex workers are familiar with PrEP and Early Treatment

In the current legal and policy environment, sex workers are highly aware of current developments in PrEP and early treatment. Many respondents reported being 'very familiar' with emerging treatment and prevention strategies such as PrEP and test and treat (n=11). Others reported being 'pretty familiar', 'quite familiar', 'fairly familiar', 'somewhat familiar' and 'well informed', 'a bit familiar', 'vaguely familiar' and 'up to date'. One said they had heard of PrEP but were unsure what it was. Another said PrEP was being 'pushed by the HIV sector quite strongly' and 'being seen as the magic bullet to HIV transmission.'

This submission addresses PrEP and Early Treatment including new measures used to reduce the transmission of HIV, including PEP Post Exposure Prophylaxis, PrEP Pre Exposure Prophylaxis, Test and Treat (regular testing of priority populations and the treatment of people with HIV to reduce their viral load and reduce their transmission risks). The submission also addresses other new technologies such as rapid testing and home self-testing which are impacting on the current HIV landscape.

Potential benefits of emerging treatment and prevention strategies

Sex workers surveyed were skeptical about any perceived benefits of emerging treatment and prevention strategies. One listed the benefits as 'hardly any due to the risks involved'. Another responded that the benefits were 'Very little. I think the only benefit is to drug companies.'

There is significant concern among the sex work community that these new approaches are eclipsing strategies that have proven successful and effective for sex workers for many decades. Respondents expressed concern that condoms were more effective and useful for sex workers than treatment as prevention, stating: 'Sex workers don't need this strategy, condoms work for us'; 'condoms work for male workers who work with positive guys, and also for positive workers'; 'sex workers already protect themselves with condoms, and test and treat will undermine this'; and the benefits are 'not much as condoms already work for us'.

There is also a concern that these strategies are not and should not be applicable to or targeted towards sex workers who already have very low rates of HIV and STIs. While one respondent said these strategies might be useful in the wider community among sero-discordant couples, one predicted 'no real benefit [to sex workers] as HIV rates are lower than the community already'.

Some anticipated benefits in terms of 'less community viral load', reduced risk of HIV infection, and a recognition that PEP being available 'allows us post incident protect against HIV transmission if we encounter an HIV risk situation'. One responded that PEP was a 'better option' rather than PrEP and the prospect of 'going on a daily drug regime "in case" of HIV exposure.' One noted that treatment has already benefited HIV positive sex workers by virtually eliminating the risk that they may transmit HIV when they have viral loads below 150. However, the currently high rates of condom compliance by HIV positive sex workers means that current risks of HIV transmission by positive sex workers are already extremely low.

Overall sex workers responded to this question with caution. This was compounded by concerns about potential misuses of early treatment and prevention in the current policy and legal environment:

There is no benefit that I can see in wide scale use of PrEP for sex workers. As individuals, they may choose this as an added protection particularly if they are engaging in sex work in a population with higher than average HIV prevalence. But the reality for sex workers is that safe practices have protected us in the past and will continue to provide the same protections without need of voluntary or forced PrEP use.

Potential negative impacts of emerging treatment and prevention strategies

Sex workers were also concerned about the side effects listed on the PrEP fact sheet, saying, 'the side effects seem to outweigh the pros' and another fearful that the 'health impacts of the treatment drugs raise concern and it is too early to know what the long term impacts may be.'

Sex workers were concerned that these strategies would impact on negotiations with clients resulting in 'a sense of false security'. For example, that clients 'won't be scared of HIV anymore', will want unprotected services, will want the worker to be on PrEP: 'negotiating condom use may become harder/ as clients perception of risk is already low and it is only that we as sex workers have such highly developed skills at negotiating condom use'; 'it concerns me that condom use amongst sex workers could be impacted'; 'In Australia we have a culture of condom use and safer sex practices that is high. It is likely that messaging around this will impact on the continued success of sex worker org messaging'. Sex workers said there would be more pressure to provide unprotected anal intercourse (UAI) and that workers were already receiving more requests to bareback on the basis of undetectable viral load and sero-sorting. One respondent said there could be a perception that PrEP/Test and Treat had 'replaced' condoms, and another believed that PrEP would result in decreased numbers of individuals being tested due to a perception that transmission has not occurred.

These strategies also detract from a comprehensive approach to sexual health and other STIs. A sex worker stated that 'everyone is too HIV focused' and noted that PrEP is insufficient to protect against STIs, another saying 'condoms are more than just a barrier to HIV'. One said, 'Marketing PrEP and Test and Treat as post-condom strategies, rather than additions to a prophylactic suite, will ultimately increase HIV and STIs.' One respondent believed that it was expensive and a waste 'of medicines, clinic staff time and government money to place over 10,000 sex workers on a drug as prevention, given Australia has other cheaper less cumbersome, less intensive options.'

These responses illustrate the very real concern that sex workers have about mandatory PrEP and Treatment as Prevention. The survey demonstrated significant risk in terms of what governments or owners of sex industry businesses may require from their workers, specifically that PrEP would be 'made compulsory for workers'. The looming availability of rapid tests and home tests also have implications: one sex worker feared 'home testing may mean brothels and clients wanting workers to test on the spot' or that 'sex workers could be forced to take PrEP.' In some states in Australia, brothel owners are required to take 'all reasonable steps' to ensure that their workers are not working with HIV or an STI. This legislation would act as an incentive for owners/operators to, as another respondent said, 'insist on sex workers taking PrEP' to protect the business. In states where sexual health screening and certificates are mandatory, PrEP certificates could also become mandated. 'PrEP might be forced upon sex workers, as they are already seen as "vectors of disease" – non-sex workers could use it against us to feel "safe"'.

The response overwhelmingly was that sex workers would bear the cost of these new prevention approaches and be 'victims of our own success', the result being stigma, criminalisation, mandatory testing, mandatory PrEP, decreased funding for peer education and outreach, and clinics focused on Test and Treat rather than STI management. As one respondent stated, 'sex workers would be placed on drug regimes which are relatively harsh on the body, for no particularly strong benefit.' The consequences of this were also noted to be 'higher invasion into private lives and status, increased stigma, increased intervention into the community, with less trust and less support given to 'empower' sex workers to manage our own health; with greater intervention, would also come greater blame'. These new technologies, combined with the current HIV landscape and legal framework, could take agency away from sex workers: 'Individual sex workers may be coerced into using treatment/prevention strategies that aren't their desired option.'

Of great concern was the impact of these policies in a legal environment in which sex workers with HIV are criminalised: 'it is common for sex workers living with HIV to have an order placed on them preventing them doing sex work when they are detected. It is not such a stretch to consider mandated treatment may be the next step.' These technologies increase surveillance of sex workers, and in a legal environment where positive workers are criminalised, the risk of public health intervention, criminal law investigation and media vilification is heightened.

There was also a concern that the new strategies may be seen to make 'sex worker organisations/peer education strategies redundant', that it will mean 'a loss of funding for HIV and STI peer education prevention programs' and that the 'understanding of sex workers as safe sex educators is going to be undermined by the message that everyone just needs to take a pill a day to keep HIV away.' Sex worker organisations already face systemic underfunding. This shift to a medicalised approach to prevention, said one respondent, 'does not support the community mobilisation, engagement, community development, law reform and advocacy that has resulted in long term, sustained behaviour change outcomes amongst sex workers in Australia'.

This community approach cannot be replaced by a medical approach. While there is discussion that PrEP and Early treatment simply add to the toolbox of prevention options there are strong signs of funders seeing this option as the more palatable. A certain level of dumbing down of messages to result in a 'pill=prevention' message has already impacted on policy and programming discussions with funders and national strategies. It is likely it will impact on the ability for sex worker activists to get/keep more complex issues, essential to HIV, including human rights and enabling environments on the policy agenda.

Sex workers also noted that trial and study data testing prevention strategies among gay men were not applicable to the sex worker community: 'Testing of the success of these approaches has not

been within sex worker communities. Results are not simply transferable between affected communities.'

Effects across community

A number of respondents felt there would be 'greater pressure on male and trans workers to adopt these new strategies' and that the consequences would be 'most neg[ative] in male and trans [workers] as this is where TASP will focus in Aus'. These strategies were seen to be targeting gay men and MSM. One respondent reiterated that male sex workers are already receiving requests for bareback services due to sero-sorting and undetectable viral load or because a client is 'doing Party PrEP that weekend'. Another respondent commented that while 'Currently we have low rates of HIV among female sex workers, I think that the push for PrEP and early treatment will invisibilise this success, and instead we will be seen as the pariahs who won't take our pill.'

One respondent wrote:

MSM organisations are entirely focused on TASP as they see it as the only available way to reduce the rates of HIV infection in their community. Their focus is sharpened by the fact that they actually lack proper funding support from government to achieve this and believe failure to achieve reduced rates of infection will be used by government against them.

MSM orgs are only just themselves starting to mature in their own attitudes to TASP. Within their organisations and communities there is division and uncertainty about TASP probably best illustrated by the lateral violence of the "bare back war".

This means that sex work issues are being sidelined. It also means that nothing else much is being discussed and few people are looking at long term implications.

The sheer size and influence of the MSM organisations means that they will get all aspects of TASP even though they may not get enough funding for TASP to be ultimately in reducing MSM HiV transmission rates.

Failure by the MSM orgs to reduce transmission rates carries big dangers for sex worker organisations in that it will result in either funding being increased to the MSM orgs at the expense of others in the HIV sector whilst failure may see funding taken out of the hands of all community based HIV orgs.

Success of TASP may lead to increased emphasis on bio medical intervention to reduce HIV transmission and less funding to the strategies that we know work for sex workers of community peer education, peer outreach and advocacy and community development.

Sex workers experiences of testing

Sex workers reported awful experiences of testing in jurisdictions where mandatory testing policies were in place, such as Queensland and Victoria. Sex workers reported 'excessive levels of testing that are not matched with risk' resulting in 'discrimination by health care providers, stigma attached to accessing testing, [and being] treated like cattle or a pin cushion'. One described their treatment as 'judgemental, belittling,' and another experienced 'prejudice, lectures'. Another reported 'a couple of really bad experiences around confidentiality and some moral judging'. Other terms used to describe services were 'whorephobic', 'poor' and 'frustrating'. One said, 'It has impacted negatively on my self esteem and my ability to work.'

All of my testing experiences have been negative. I have been treated like a pin cushion, nurses and doctors have no regard for my human rights, as soon as you say you are a sex worker you are assumed to be either 1) diseased or 2) wasting the clinics time. Mandatory testing regimes have by far been the worst examples of this, however I have also experienced this in voluntary testing situations.

The testing environment also affected people's willingness to disclose their sex work status. One said 'I never disclose my sex work [be]cause of bad experiences [of] friends who have' and another said that when staff were aware they were HIV positive they did not say they were also a sex worker.

In my experience, sex workers test regularly of their own volition. The sex workers I have known and worked with/around have tested for HIV/STIs with greater frequency and commitment than any other demographic I have encountered.

Best practice testing is voluntary, anonymous and confidential

Sex workers were asked to provide examples of a successful sex worker testing project and/or strategy. Sex workers reported positive experiences in New South Wales, where sex work is decriminalised and testing is voluntary: 'NSW is good 'cause you go when you want, its free, use work name and they are nice'. The requirements that sex workers listed as necessary for testing were: 'informed consent', 'voluntary', 'anonymous', 'free', 'discreet', 'appropriate', and 'being able to use a false name.' One respondent also said that peer education was important: 'What I have found most helpful and useful is having access to resources like the [STI handbook] Red Book, which help me to understand my level of risk. I think sex workers are more than capable of determining how often they should have an HIV and STI check-up.'

Requisite conditions to meet human rights principles

The survey participants were asked about what conditions were necessary to meet to ensure testing was performed according to human rights principles. Again, participants responded that testing must be 'voluntary', 'confidential', 'free', 'non judgemental', 'not compulsory', 'readily available', 'open at hours that suit sex workers', 'peer run', 'not coerced, anonymous', 'respectful', 'no criminalisation', 'not part of registration and not making you a criminal', 'not be putting undue pressure on people to test', 'pos workers just as safe as neg', 'results not being on a database and unable to be accessed by the public or those outside of the worker and doctor', 'provide translation opportunities', 'appropriate follow up and continuity of care', 'being able to use a false name' and 'free of discrimination with sensitivity training where needs arise in order that staff acknowledge that sex work is work'. Respondents made clear their opposition to mandatory testing:

Mandatory testing goes against the principles of human rights. If sex workers want to go on PrEP or early treatment or have a rapid HIV test, then that should be up to them. There shouldn't be any pressure from community groups or governments to make sex workers go on treatment or be tested.

PrEP and Test and Treat should not be rolled out in the sex worker community

The next question was phrased by NSWP as 'What conditions needed to be met for PrEP and test and treat programs to be rolled out within the sex worker community?'

The response to this question was that PrEP and Test and Treat should not be rolled out within the sex worker community. For example, some responses were: 'No rolling out. Should be something sex workers do voluntary', 'would hate to see them "rolled out"'. Simply made fully available and easily accessible', 'I don't think it should be "rolled out" as a specific program anywhere near a sex worker clinic. Should be available on individual request only' and 'I don't think PREP and test/treat programs are appropriate for sex workers.'

Again, respondents reiterated the importance of testing, treating and PrEP being anonymous, voluntary with informed consent with safeguards for privacy, and not part of a mandatory testing or treating environment and without pressure from workplaces. One said 'honestly, I don't think having

it as voluntary is enough..... I am very concerned about the potential for test and treat programs are a slippery slope to sex worker mandatory testing, to which I am utterly opposed.'

Sex workers also supported more information being available through peer education and sex worker organisations 'so people can decide if they want to opt in' and have 'choices and alternatives. Some people don't like to take chemicals and would prefer natural medicines.'

Sex workers need to be involved in the dialogue on the value and problems with this approach at a local, national, regional and international level. To date this hasn't happened and while its great this consultation is happening in some ways 'test and treat' has steam rolled forward over sex workers concerns. Human rights approach to determining programming and policy would need to be seriously taken up - to date it hasn't been. Once sex work is decriminalised globally and there is a even playing field then we can discuss equitable access – we are a long way off.

Sex workers must not be left behind

Survey participants were asked about their experience in engagement in decision making around HIV prevention and treatment related strategies at the national and local level.

While there is a great fervour in Australia over new HIV treatment and prevention technologies, sex workers feel that their issues are persistently ignored and that they bear the cost of this shift in focus. As one respondent put it: 'Sex workers always come (equal) last (with injecting drug users)'. Another felt that the response had been overtaken by gay men's health organisations. One replied the approach is 'All about gay guys. Nothing about women or trans or anyone else'. Another believed the respond was 'dominated by the gay/MSM agenda'.

Sex workers have been invisibilised, it has been very disappointing. Gay men throw us under the bus. Doctors think we are annoying if we don't comply with what they want. Everyone bows down at the alter of the drug company and partakes their wafer. I'm totally disappointed with the lack of critical understanding by decision makers in regards to drug company control of our health.

Sex workers are frustrated by a lack of political will to address our needs and lack of government funding to support our organisations. There is a feeling that consultation is hollow, token and not meaningful. As one sex worker wrote, 'Committees sit around and decide polices and strategies without sex worker input, or hold a multiple community consultation without briefing papers then say they have consulted our communities before doing whatever they want.'

One sex worker felt that there was 'Not enough (if any) consultation at a ground level with the communities directly affected by high transmission rates of HIV, or communities that fall into the high risk categories (perceived high risk or actual high risk)' and another stated that 'the priorities of culturally and geographically isolated communities within Australia are rarely featured in the national discussion'. One said that 'other community groups do not seem to understand sex workers' perspective, or consider the legal and social ramifications for our community around legality, being outed and stigma with being a sex worker.'

Further, respondents commented on the inequities in availability of HIV treatment worldwide, one stating that 'sex workers in countries that lack consistent access to treatment are appalled at the idea that people without HIV will be placed on treatment.'

Sex workers in Australia are suspicious: 'To me, PrEP and test and treat programs seem like mandatory testing under the guise of elimination of HIV.'

Engaging the sex worker community

Survey respondents were asked how they think the sex worker community should be engaged in these discussions and decisions. Responses raised issues of consultation, representation and funding.

Respondents felt that sex workers should 'be part of decision making', a 'widespread consultation' and that this consultation should be 'peer led'. These processes should be available 'at a grass roots level', with 'national and international sex worker [organisations]... consulting priority communities and then given air time to share their findings and recommendations with policy makers.' There was a feeling that 'too much lip service is given to consulting with communities instead of engaging in relevant discussions with community members and peer representatives.'

Respondents believed that sex workers should be able to contribute through peer organisations and forums, online surveys that protect anonymity, and that 'local outreach programs should prepare education information for sex workers, update local sex workers on what's happening, the pros and cons, and ask for input and feedback.' One suggested 'PrEP and test/treat fact sheets for sex workers that are accessible online for us to distribute in workplaces and to other sex workers' and having information available in workplaces.

Another consideration that came up was funding. One respondent stated that 'at all levels and at all times sex workers should be supported, paid to attend meetings and never left out.' Another noted the systemic under-resourcing of Scarlet Alliance to engage the breadth of the sex worker community.

Preparing the community for meaningful participation

Lastly, participants were asked how the sex worker community, our leaders and advocates, can be better prepared in ensuring our meaningful participation in these discussions.

Sex workers replied that sex worker organisations require funding for peer education and consultation, briefing papers, guides to terminology, meetings, discussions surveys, outreach and forums to provide more information to their membership about these new treatment and prevention strategies. Information relevant to sex workers should be sent out by other community health organisations, not just sex worker organisations ('sex workers aren't mentioned ever by ACON, only SWOP sends me stuff', 'I only know this stuff cause pos clients tell me and I get SWOP news'). Sex workers also wanted more information 'about the history of drug company corruption, report upon their profits, point out the differences between access in 1st world countries and majority nations'. Again, funding appeared as a crucial consideration: 'resourcing the process so it can happen well', 'Education and discussion will be difficult without funding.' One sex worker wrote:

Ensure leaders and advocates are consulting directly with affected communities and community members. embrace and relate all opinions extracted from the community and not just the opinions that slot into the desired paradigm or outcome. Leaders and advocates should be encouraged to hold forums, go on outreach, engage one on one with community members in an effort to glean a true cross section of voices from the sex worker community. Sex worker orgs need to produce clear and concise resources addressing the PrEP and test and treat options so that community members are able to understand the process and the issues at hand; subsequently giving them the tools to participate in conversations in a coherent and relevant fashion.

'We should be advocating for processes and decisions that circumvent any testing regimes that can be used against sex workers doing their job or increasing myths and stigma around our bodies and what we do. Sex workers should be making the decisions.'

Further questions

This survey illustrates that sex workers in Australia are suspicious about PrEP and early treatment and how they may be used against our communities. The responses highlight genuine concerns and real risks that face sex workers if these new approaches were to be targeted or rolled out among sex workers.