Title: Sex worker-driven research: best practice ethics

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Abstract: Research into sex work is all too often perpetrated upon the sex worker community by outsiders who use individual sex workers as a bridge to gain access to participants. In recent times, sex workers have begun to demand appropriate payment from researchers who need our assistance and have critiqued research that is sloppy or morally biased.

Horror stories exist within sex worker communities of lives ruined and discriminatory laws made as a result of outsiders researching and reporting on our activities. Positive research experiences are few and far between, but we are determined to create them by leading our own research and having input into the research projects of others in formative stages.

In order to create a more reflexive practice, non-sex worker researchers must better interrogate their own motives for researching sex work, and sex workers must be positioned as active, not passive, voices in research about our work.

This paper discusses proven best practice ways of involving sex workers so as to produce better quality research that informs law-making, policy, wellbeing and other regulatory outcomes. The paper is based upon the August 2009 International Sex Worker Think Tank on Research, and parts of this paper were originally presented at the National Centre for HIV Social Research conference at UNSW in April 2010.

Article:

I am an Australian-born sex worker with tertiary qualifications in political science and have been directly involved in the activities that I will explore in this article. Discussion about sex worker involvement in research has been a theme of Scarlet Alliance's work; many within the Australian sex worker rights movement have documented and advocated for improved sex worker research in the 21 years since Scarlet Alliance was formed. The first part of this article gives a précis of contemporary sex worker discussions on research through the lenses of Australian sex workers advocates.

Contemporary sex worker discussions on research in Australia, Asia and the Pacific

Janelle Fawkes, then President of Scarlet Alliance, in 2004 took on anti-sex work feminist academics' use of "false consciousness" theory to silence sex worker voices that were in opposition to their own (Fawkes 2004). This paper has gained much popularity among sex workers in Australia and specifically asserts:

> The re-writing and misinterpretation of our positive sex work experience is the main strategy used against us [by anti-sex work feminists].

Janelle also presented at Pan Pacific HIV/AIDS Conference in 2005 in Auckland, New Zealand, on the experiences of Cambodian sex workers in a failed HIV PREP trial (Fawkes 2005). In the same year Janelle was a member of the National Centre for HIV Clinical Research Biomedical Prevention Working Group, assessing the human rights impact of research into biomedical HIV prevention, and presented again on this issue in 2008 (Fawkes, 2008). Both the impact of feminist theory and the human rights abuses inherent in medical trials involving sex workers have been explored in detail by Janelle.

Maria McMahon as manager of the Sex Workers Outreach Project in NSW and as elected representative of Scarlet Alliance also has done extensive work in this area, often focusing on migrant or "CALD" (Culturally and Linguistically Diverse) sex workers (McMahon 2004, 2006a , 2006b)

In 2007 Roberta Perkins radically decided to let sex worker voices speak without a filter in the presentation of a decades' research by herself and Francis Lovejoy. The result was the book "Call Girls" (Perkins, 2007) which included improved methodology for sex worker participants including verbatim publication of eighteen sex workers stories in their own words in dispersed among drier chapters that explored quantitative data from surveys by Perkins over a ten year period. This use of sex workers voices *as having the same research status and validity* as statistical data was applauded by the sex worker community when compared to approaches including that of Sheila Jeffreys' (University of Melbourne) students, discussed further in this article (Jeffreys, 2008).

I have previously published summaries of existing reliable research with migrant sex workers in Australia (Jeffreys 2008 and 2009) and critiques of academics approaches to using sex workers personal stories (Jeffreys 2010); asserting:

> Academic writers self-identify particular personal experiences in their non-fictional writing, for the purposes of laying bare their social position as ethnographers, creating a distinction between themselves and the ethnographic subjects of a study, contrasting their own expectations or social experiences with an anecdote of their topic that is typically shocking to a Western non-sex work audience, and maintaining a distance between themselves and the study participants. (Jeffreys 2010, para 1)

Women's Network for Unity (Cambodia) played a lead role in campaigning for ethical clinical trials, and their engagement (or attempts to engage) with Gilead Sciences, the company that makes Tenofivir, and UNSW is well documented (2003 – present day). This article does not comment upon their work in the field of research ethics except to say that Women's Network for Unity is a leading expert on the subject of sex worker involvement in clinical trials and is looked to by sex workers internationally for the important campaigning the organisation has done in the area of improved ethical approaches to sex worker involvement in clinical research: it has immeasurably influenced thinking on these issues. A new

policy paper on microbicide research with sex workers has been endorsed by a number of sex worker groups is due for publication this year (Forbes 2010).

This article does not review existing academic thought on methodology in relation to sex worker research. I focus instead on the approaches and thoughts of sex workers on sex worker research, as developed through community development processes run for and by sex workers.

The first part of the article sets the scene on Australian sex worker organising and the utopian role that we envision for research within our communities, i.e. that it will lead to good program development by sex worker organisations and better policy and law-making by governments.

The second part of this article explores the recent history of Scarlet Alliance's involvement in local and international sex worker discussions about research and discusses the example of Melbourne University PhD research conducted by Mary Lucille Sullivan, who was supervised by tenured Melbourne University Political Science academic Dr Sheila Jeffreys.

The third part of this article extensively documents and reports upon a one-day Think Tank held in Bali in 2009 and funded by AusAID's HIV Consortium for Partnerships in Asia and the Pacific facilitated by Scarlet Alliance's regional partnership program. This was coordinated by Nicolette Burrows, International Project Officer for Scarlet Alliance's HIV Consortia work.

1) Australian sex worker organising—good research is indispensible

Scarlet Alliance is the national peak body representing sex workers and sex worker organisations in Australia. Our membership collectively oversees peer education and funded outreach in Australia through autonomous state and territory based sex worker groups, each of which negotiates their own funding contracts with the relevant state/territory government jurisdiction. This peer education is funded for, amongst other things, HIV and STI prevention peer education delivered directly to sex workers all over Australia.

In particular, the Australian Government has maintained funding to state and territory peer-based organisations for the life of the Australian response to HIV:

> **Priority actions in HIV prevention**
>
> • Using the expertise of community sector agencies within the partnership, develop and implement an expanded and comprehensive national program aimed at…maintaining low rates of HIV among priority groups (sex workers and drug users) through the implementation of peer education and community led health promotion.
>
> • Continue to invest in and monitor prevention programs for priority risk populations.

• Monitor research developments to inform policy and program development on new prevention technologies prior to their introduction to local populations.

• Continue professional development of the HIV prevention and health promotion workforce, including investing in a new generation of peer education and [HIV] prevention workers.

• Invest in evaluation and evidence-building approaches to support evidence based and innovative policy and program decisions. (DOHA 2010a: 14)

Investment in Australia has paid off exponentially for the Australian government. Sex workers' HIV rate is less than 1% (DOHA 2005a: 19). Our rate of sexually transmissible infections is "among the lowest in the world." (DOHA 2005b: 28). This is epidemiologically irrefutable data that proves the success of the two decade investment into sex worker peer education in Australia.

As outlined in the recently released 6th National HIV strategy (DOHA 2010a), quoted above, sex worker peer education in Australia is intrinsically linked with research, evaluation and a workforce of sex worker peer educators who are able to draw from, and discern among, available evidence. A strong evidence base of reliable research leads to good program and policy development for sex worker peer education for HIV and STI prevention. Research reinforces to the sex worker community the trends and issues that may be already known and acknowledged on the basis of anecdotes and the firsthand experiences of individuals. Another function of research is to inform analysts, policy makers and their advisors and funding bodies of emerging issues as well as corroborate for sex workers' allies the key issues that need attention or focus by sex worker communities. Reliable research contributes to improved program development. This theme continues into the current Australian National STI Strategy:

Research focusing on patterns of sex work, mobility and migration, barriers to accessing services, as well as identifying particularly vulnerable or marginalised groups of workers to support improved program development is important and should continue in consultation with sex worker organisations. (DOHA 2010b: 19)

However, compared with other affected communities in Australia, evidence-based research is comparatively lacking when it comes to sex workers. While there are some stand-out research projects, particularly in relation to sex workers from non-English speaking backgrounds[1], these are undoubtedly

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[1] For a review of research with non-English speaking background sex workers in Australia see: Jeffreys, Elena Migrant Sex Workers Research in Australia, Scarlet Alliance National Symposium, Brisbane, 2008 <http://www.scarletalliance.org.au/library/jeffreys08/> Accessed 06 May 2010. For an analysis of this research

outnumbered by research that has overwhelmingly been against sex workers' best interests. To date, research partnerships in Australia with sex workers have been grossly underfunded and their impact upon sex work policy is all too often not properly considered by the researchers involved.

Contemporary engagement by sex workers in research

Researchers who are part of the sex work milieu—those who are either sex workers but not attached to a sex worker organisation, or those who are not sex workers but consider themselves to have an affinity with the sex worker community—are important allies of sex worker organisations seeking access to/leadership within good research. However, many of these researchers have made countless mistakes and created numerous unintended consequences as a result of poorly planned or under-resourced research projects; importantly however, they did not intend to stigmatise sex work or sex workers.

Some common problems with sex work research in Australia include the following:

- Researchers try for a best-practice approach to sex work involvement and leadership in their projects, only to find that their budget and infrastructure were not sufficiently informed for the resources necessary to make it happen effectively.

- There are unintended consequences resulting from good research being misinterpreted and/or misused by the media, government, policy makers and anti-sex work campaigners, which leads to heartbreakingly negative media and devastating policy outcomes for the sex workers that the researchers were trying to assist.

- Some researchers deliberately create outcomes that support the criminalisation of sex work, such as the work of Mary Lucille Sullivan and Dr Sheila Jeffreys, whose impact on sex work is widely noted and condemned by the sex worker community.

This last kind of research is different to that which I have previously mentioned. It may be a fine line, but I think it is possible to crudely separate those researchers who are morally opposed to sex work from those who are not. Researchers who are morally opposed to sex work have attracted the ire of sex workers across the globe.

In May 2007, 40 signatures on a letter of protest were sent to Spinifex Press and Melbourne University. The signatories were shocked and outraged at the whorephobic PhD dissertation submitted by Mary Lucille Sullivan, titled "*Making Sex Work*", supervised by Dr Sheila Jeffreys and subsequently published by Spinifex Press. Among the signatories were sex work researchers, sex worker organisations, human rights activists and individual sex workers, who demanded a right of reply to Mary Sullivan's work. Text from the letter included:

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see: Jeffreys, Elena, Anti-trafficking measures and migrant sex workers in Australia, *Intersections*, Issue 19, Feb 2009

This book… incorrectly concludes that sex workers have and continue to suffer great harms as a result of the decriminalisation and legalisation of the sex industry in Australia… Sex worker groups, projects, networks and organisations in Australia and around the world have a right to expect accurate and non-malicious representations of their work to be maintained, particularly in academic contexts such as PhD theses. Mary Lucille Sullivan's educational institution, Melbourne University, and her supervisor, Sheila Jeffreys, must take some responsibility for this, as well as Spinifex Press, the publisher of "*Making Sex Work*." As sex worker groups are one of the primary targets of Mary Lucille Sullivan's book, one would expect that these groups would have been formally interviewed. That they were not, calls into question Mary Lucille Sullivan's intentions and ethics. …. Mary Lucille Sullivan has in no way tested, challenged or proven her own thesis—by choosing not to allow sex worker groups to participate, she conveniently silenced any opportunity sex workers had of having a voice in her work. There is no practical barrier to Mary Lucille Sullivan choosing to accurately represent sex workers—sex worker organisations are transparent and open entities that participate in research regularly. The sex worker networks, groups, organisations and projects that are extensively misquoted and misrepresented by Mary Lucille Sullivan in her book now request a formal right of reply to her case. (Scarlet Alliance 2007a)

This right of reply was not granted and Melbourne University's response was a deafening silence. I know what many academics would say in response—that anyone can review the book or publish contrary articles in peer-reviewed journals to discredit Mary Lucille Sullivan's work. The question that sex worker communities ask is, "Is this fair?" Is it fair that those with access to academic structures use academic institutions to publish material about sex work that deliberately silences sex workers' voices and presents an anti-sex work moral agenda? Mary Lucille Sullivan is an extreme example, but significant because if 40 people who allege to have been specifically and purposefully harmed by a University PhD thesis don't even receive a courtesy reply from the university, the more moderate or seemingly less harmful slip-ups that occur as a result of a lack of consultation or sensitivity, in relation to research with sex workers, are even less likely to have room for correction after publication date.

There is another consideration for sex workers protesting perceived or real problems with researchers' work. Publicly challenging researchers from the sex worker milieu, through negative reviews or other means, may damage long term partnerships between sex workers and those who research us. As such, the sex worker community in Australia has shied away from discrediting researchers, even when their work has a harmful effect on sex workers' confidentiality and dignity, or impacts sex worker laws and policies in ways that frustrates sex worker lobbying and advocacy efforts.

Sex worker communities have concluded that it is not appropriate or good enough for us to have to wait until after the fact to then fight for a right of reply to research about us. Increasingly, we prefer to take

our fight into the academic realm of ethics approval, research planning, question formulation, methodology development, data collection, analysis and promotion. We have the skills and resources to participate at this level. In short, we no longer want to be simply 'subjects' or 'outsiders' to the academic process of the study of our work—we want 'in', or else we don't believe it should happen.

This is not a new issue and is not confined to Australia. There has been huge concern about this issue internationally. Research contributing to negative effects on sex workers' lives was a key issue at the regional networking meeting of sex worker organisations at the International AIDS Congress in Bangkok, 2004. The top three issues from a meeting of 60 sex workers from 20 different countries at the Bangkok conference were:

- Police harassment, entrapment, condoms as evidence, bashings, assaults and corruption.

- The anti-trafficking lobby and its impact on the funding of services and sex worker rights globally.

- The lack of research which aims to improve the conditions and health of sex workers and the unacceptable level of unethical research on sex workers, e.g. forced testing. (Fawkes 2004)

It should be noted that none of these priorities were about improving workplace conditions or changing client behaviour. When reaching consensus among a diverse group of sex workers, the main concerns of sex workers were related to the impact that structures of authority—police, army and academics—have upon our work. Fawkes went on to explain:

> Unethical research on sex workers was identified as a key issue affecting most of the 20 sex worker communities represented at the conference, and many examples were provided of research conducted on sex workers which does not seek to either improve conditions for sex workers or respect those involved. In particular, examples of studies in India, which include the forced testing of sex workers, contribute the communities' feeling of mistrust and vulnerability. (ibid)

{insert pictures}

I was honoured to be one of the facilitators of the multi-lingual workshop in Bangkok and observed the passion and anger expressed by leaders of sex worker organisations at the practices of researchers.

{insert pictures}

3. Sex Worker Research Think Tank: Bali August 2009

In August 2009, twenty-one sex worker leaders of diverse gender and sexual identities representing six very different countries—Fiji, Timor Leste, Australia, Indonesia, Papua New Guinea, Thailand and Pakistan—gathered in Bali, Indonesia, for a full-day workshop on sex worker research in the Asia Pacific.

This workshop formed part of a week of sex worker meetings, presentations, protests and networking, as part of the International Congress of AIDS in Asia and the Pacific (ICAAP).

{insert pictures}

This Think Tank was particularly for sex workers to discuss how to change the landscape of research that affects us in a proactive manner, rather than acting as passive bridges for researchers to access our communities, or collecting data on behalf of projects that are run by others. The Think Tank sought to develop ways of engaging meaningfully with researchers to have input into, and influence on, who, how, when, where and why research is undertaken with our communities.

Broad consensus on three key issues emerged from the sex worker Think Tank. The first was a shared understanding of our role within the research process. As sex workers, we identified ourselves as subjects (participants in research), gatekeepers (acting as a bridge between researchers and the sex worker community), researchers (gathering our own data) and critics (analysing the data and the research of others). As sex workers, we have also been called upon to act as translators for researchers who only speak English.

Secondly, we had a shared understanding of the tools that can improve research on sex work. Some of the ways sex worker research can improve include: establishing sex worker steering committees/reference groups; providing compensation for input during the consultative processes; allowing sex workers to determine aims, objectives and methodologies; and giving sex workers control over the representation of outcomes.

Thirdly, we had a shared understanding of a range of possible negative outcomes when research is undertaken unethically; not the least of which is the total exposure of one's confidentiality; exposure of the location of working areas resulting in a wide range of negative impacts for sex workers including increased policing, arrest and media attention; demeaning research impacting on the reputation of the sex workers involved in the research; and researchers poorly paying sex worker researchers. These possible outcomes lead to a mistrust of researchers, and sex worker participants experience feelings of exploitation, as well as being subjected to poor policy as a result of decisions based on incorrect, or incomplete, information.

The Think Tank was run in English with translation into Bahasa, Thai, Tetun, and Urdu. Other first languages among participants included Mandarin and Fijian. Sex worker representatives from sex worker organisations, including Empower Foundation (Thailand), Friends Frangipani (Papua New Guinea), SAN (Fiji), Scarlet Timor (Timor Leste), Sex Industry Network (Adelaide) and Scarlet Alliance (Australia), were present. Also in attendance were individual sex workers from Pakistan, Indonesia, Papua New Guinea and Australia, who were not attached to a particular sex worker group. The Pakistani participant and Empower Foundation had their own translators present. Bi-lingual Australians who spoke Bahasa and Tetun as second languages provided translation also. The training was delivered in

English, with regular breaks for translation. All participants had come to Bali for either the Pre-ICAAP sex worker meeting[2] or for the ICAAP Conference.

A handout with definitions of key research terms was discussed at the beginning of the Think Tank. Using words in English, we worked through the terminology listed below for about 40 minutes, taking time to allow for translation and discussion of each term among the language groups present. This process ensured that all participants shared a common understanding of terminology, and we discovered that our skills levels were very similar. As a result of this exercise, all participants were enabled to collectively recognise an understanding of the following concepts:

> Qualitative, quantitative, social research, clinical research, randomised trial, placebo, blind, double blind, double dummy, phase one testing with animals, phase two testing with humans. (Scarlet Alliance 2009)

Something surprising, which in hindsight should have been expected, was that ALL the sex worker organisations and individuals present, with the exception of one, had previous exposure to these concepts while participating in research in their own countries. The one individual, from Indonesia, who had not had experience with researchers, did however have an understanding of social research concepts through experience of long-term police harassment. This individual identified that the police had used both quantitative and qualitative approaches to collecting intelligence on sex workers and drawing conclusions about sex worker activities.

The Think Tank then identified key issues around research that we had experience with in our own countries. The question was, "In your direct experience, what is the main research issue that you would like to share with the group?" Everyone in the group shared specific examples of research they had either been directly involved in or affected by, as well as the issues it raised in their community. The following is a list of these issues; each statement is a summary of the key issue from each example. The wording of each statement was agreed to by the speaker prior to documentation—this included back translation. I have clarified the agreed statements slightly using square brackets:

> How the data is released
> Identifying sex workers [non-consensually through research]
> Pay sex workers to participate
> Don't ask intrusive questions or [questions] inappropriately
> Sample [group]: In or Out of the city, [sex workers outside cities are
> often excluded from research due to lack of
> infrastructure/resources/will within research projects]
> Sex workers research their own organisation
> Research = finding friends!
> Sample: Cross-border [sex workers cross borders but often research
> projects do not]

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[2] See Sex workers statement to ICAAP 2009; endorsed by 80 sex workers from 14 countries, 8 August 2009, http://www.scarletalliance.org.au/events/09_10/icaap_09/ for outcomes of that meeting.

Memorandum of understanding [between researchers and sex worker organisations is important]
Advocacy by sex workers' voices for inclusion/voice
Sex workers who are more marginalised are also harder to reach = regional, Indigenous peoples, language groups, IDU[3] street based, migrant/cross-border
HIV status/hierarchy in our community [can be reinforced through research]
Motivation of researchers [is important for us to know].

The examples of research given were diverse. The research ranged from that which sex workers had total control over (i.e. stats collection on peer education outreach; this example was from a developing country sex worker organisation) to church groups giving out food vouchers to sex workers in brothels and then using it as 'proof' that sex workers were malnourished (notably this example was from Australia). Some participants identified unexpected positive outcomes of participating in research. For example, Empower Foundation in Thailand discussed using research as a way of expanding their knowledge of sex workers they had not previously met before—making new friends in the process. Other examples demonstrated the problems caused when a research sample size cannot encompass the diversity of a sex worker community. The examples were of research in Papua New Guinea, Fiji and Timor Leste that was limited to cities, to one side of a migratory border only, or that did not include sex workers who were experiencing particular marginalisations based on language, drug user status, illegality or migrant status.

The exclusion of certain groups from research samples can have lasting negative effects on these groups. In the examples given, such research was used as a basis for sex worker program development; those sex workers not included in the original sample found that their needs were unmet in the subsequently funded services. These unintended consequences are created when researchers are not sufficiently familiar with the diversity of a community prior to undertaking research, or deliberately limit research to members of a community who are the most visible or convenient/ easiest to access (e.g. those possessing English language skills, accessing NGOs or other services with which the researcher has a relationship, etc.), i.e. research projects are created to fit budgets, cut corners on their sample size or are unable to reach certain sex worker groups.

These can have a devastating and long-term effect on those groups that are made invisible; not only in the research data, but also in subsequent policies and programs developed as a result of the data.

The next step of the Think Tank was perhaps the most exciting one, where we began to document how best to research the work of researchers from outside our community when we are approached to do research with them. A list of questions was drawn up with the aim that the answers to these questions would better inform any given sex worker community when deciding if and how to participate or support a proposed research project. As with all the processes of the day, each question was back

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[3] The term IDU is used here to mean "Injecting Drug Users." However across Asia and the Pacific the preferred term for drug user communities is "People Who Use Drugs Illictly" (PUDI). The use of IDU in this list as a term is referring specifically to a subset of sex workers who *inject* drugs, and the particular marginality or needs that this community faces.

translated to all individuals and then documented in English. See appendix 1 of this article for the full list of "Questions for researchers"

This part of the workshop exposes the detail and extent to which sex workers must obtain information in order to be able to make effective decisions about participating in/advising researchers. The amount of time and effort sex workers go to in order to collate such information, and the strength of conviction sex worker communities possess in relation to these issues, is not recognised within research projects. In some cases, researchers may not even know the answers to some of these questions—they are issues a research project may not have considered or taken into account. In other cases the answers may be deemed by researchers to be of little importance to sex workers and as such, not shared with the sex worker community. And in some cases, the answers may lead a sex worker organisation to advise a researcher that their research is going to have negative consequences for sex workers and that the project should not go ahead, or should be returned to the drawing board while certain issues are resolved.

As sex workers, we have to be researchers in our own right—researching the background, context, approaches and possible outcomes of any given research project. This is not accounted for in research projects conducted by those outside the sex worker community—and also not budgeted for. The leadership, governance, decision-making, liaison, negotiation and, sometimes, detective work that sex worker communities undertake to answer the questions listed above, particularly in relation to ascertaining the possible impacts of research on a community, take thousands of human resources hours. This component of ethical research needs to be planned and resourced by non-sex worker researchers who are approaching sex worker communities as subjects/participants/data collectors/facilitators/translators.

The next part of the workshop sought to document the negative effect research can have on sex worker communities if not done properly:

> Negative impacts of bad research on our organisation and sex workers individually when we are involved:
> Organisations lose credibility among sex worker community.
> Trust of sex workers is lost.
> Organisation will collapse—lose members/lose supporters.
> Without capacity, our organisations cannot follow-up mistakes or conflicts [created as a result of bad research].
> Other organisations may take [our] funding if they have done the research and use the data to develop credibility.
> Bad research may not impact immediately, but situations may change (i.e. change of government) and impact later.
> Other researchers will see [we] are an easy research target and chase us for more bad research.
> It may be used against other sex workers organisations [in other places or countries].
> Some researchers involve only _some_ sex workers i.e. bars/brothels but leave out sex workers in rural or regional areas. Then the research

doesn't acknowledge the needs of certain groups, but policy ends up being made for everyone, even those not involved.

[Bad research can] create conflict in the sex worker community.

There is a need to coordinate outreach and research so that sex workers are [not] harassed multiple times during the same time period. (Scarlet Alliance 2009b)

This list of concerns takes for granted that the two worst outcomes of poorly planned research are betraying sex workers confidentiality and negative policy consequences, including bad advice to government. The list explores, in detail, very specific impacts bad research can have on the structures of our sex worker community, on the lives of individual sex workers themselves, and on the credibility and reputation of sex worker organisations; including whether or not sex worker organisations are recognised by sex worker communities as genuinely representative. This is unacknowledged by ethics committees and their risk assessments of research projects. Often researchers will feel that if they have ethics approval, it is a license to gather data and publish results regardless of the local sex worker organisation's opinion of the work.

The negative outcomes of exposing sex workers' identities non-consensually can include a sex worker community developing mistrust of the local sex worker organisation. This was experienced by Australia's Scarlet Alliance, in 2005. Since that time, Scarlet Alliance has developed policies to prevent this exposure happening to particularly vulnerable groups, including sex workers affected by trafficking (Scarlet Alliance 2009c).

Another point of consensus of the workshop was that "Researchers go to developing countries but don't offer skills of benefits to the sex workers" (Scarlet Alliance 2009b). Researchers and research institutions who, whether deliberately or inadvertently, view sex workers as passive participants in research projects are doing more than reinforcing a negative stereotype—they are starving local sex workers of information and skills that would be otherwise well received. The reality is that most research projects do not consider capacity development, education or training for the sex workers who are the subjects of the project.

Conclusion and Outcomes

Sex workers and researchers need to work together on research aims, data collection, analysis, outcomes, related media and policy. In recent years, for example, there has been an important body of work developed against mandatory sexual health testing (Scarlet Alliance 2007b and Fawkes). This work is now beginning to have an influence on policy. However, the overwhelming challenge is to ensure that research with sex workers does not reinforce stigmatising stereotypes of 'good' sex worker citizens and 'bad' sex worker citizens—labelling those of us who live with STIs and BBVs, drug use, HIV, on the streets, or working in unregulated or illegal sectors—as 'bad'. Breaking down those crude misunderstandings is vital in sex worker policy and programs. At worst, we can hope that these stereotypes are not reinforced through research and at best, we hope that an evidence base that can be used for program and policy development will be established through ethical research.

Upon returning from the Balinese think tank, Fijian sex workers facilitated community workshops exploring strategies for their community to utilise when approached by researchers. These workshops

proved both timely and effective, in that research undertaken in Fiji in 2009 by international academics resulted in improved research outcomes and, in particular, stronger sex worker input. Similarly, sex workers from Timor Leste reported increased engagement with, and control over, proposed research on Timorese sex workers by international academic institutions.

Sex workers in Fiji and Timor Leste utilised the work from the Bali Think Tank when approached by researchers to collaborate. This resulted in improved research outcomes and, in particular, strong sex worker input.

It is everyone's responsibility to approach sex worker research from the starting point with the following questions:

- What are sex workers saying are the key research questions worth exploring?
- How do I support sex workers in areas of policy and program development, in ways that sex workers themselves have identified?

These are the questions sex workers are asking prior to working on research projects. Are you?

Appendix One

Questions for researchers who are working on sex worker social and clinical research:
What other research have you done?
Who is funding you? What kind of research [are you seeking to do]?
What target groups?
Why do you want to research?
What are your aims?
How will you do it?
Who will facilitate?
How is it useful to us?
What will be the role of the support group [of sex worker consultants you wish to engage]?
What age group will you research?
Where will the person/participant be referred if they need services?
How can we sue/complain/resolve conflict?
If our organisation refuses to participate in the research, will this damage our relationship with the researcher? Are they qualified to do the research?
How will you report on the research?
Who will you report to?
Researcher must have skills to listen.
How will you protect the confidentiality of sex workers?
Consent forms? What will they say?
Will the sex workers organisation receive a draft of the report to edit?
Can we change our minds [and choose to not support your project after you consult us]?
Disclosure issues: Friends /peers are the only people that have the trust to work on research. [Do you respect that?]

Peer support during research, having peer educators present who can halt the research interview and go to a private space to debrief. [Have you planned for this?]

Sex worker organisation—Will we have total control over the outcomes of the research? We decide what is written.

Looking through the questionnaire and consulting with the community. Is it possible for the researcher to work with a peer?

Sex workers who are not literate—we need the report back in our <u>own</u> language—not English.

Where will the questionnaires be stored? How are they stored? Is it in a confidential place? Will it be anonymous?

Literacy: the longer the interview/questionnaire the more they should be paid. People can be intimidated by pages of questions.

Will you have the surveys in all dialects?

Will you pay us?

There should be a community benefit if they are not paying individual workers (e.g. Landrover/school)

We want to look at the research plan to decide what will work and not work for our community.

Sex workers may decide not to use surveys on paper.

Paper surveys make people want to be paid—"I won't share info if I'm not paid"

We don't want any information collected that might put our community at risk.

How much money is the researcher paid? We want to see the budget.

Don't take files and papers into the research site (sex workers may think you are police or authorities).

One-on-one research must be conducted without a 3rd person present. (Confidentiality)

Researchers must have respect for sex work as work.

What is the researcher's timetable?

What could be the negative repercussions for the sex worker? The participant may need to maintain the confidentiality of the questionnaires as well: don't blame the sex worker for shame on family/community.

Is the researcher pro-gay?

Is the researcher pro-sex work?

Researchers must not use emotional manipulation to get sex workers to participate (e.g. using weakness (poverty) to get people to participate)

Researchers must be directed to the sex worker's organisation, <u>not</u> go through an individual. (Scarlet Alliance, 2009b)

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