Nothing about Sex work without Sex workers: Ethical Standards for an Inclusive Consultation with Sex Workers

National Network of Sex Workers (NNSW), India

The National Network of Sex Workers [NNSW] India believes that collective wisdom gives depth to and empowers policy, and that people in sex work have the right to be involved in formulating policies affecting their lives. People in sex work have valuable contributions to make and they have the right to a participative space that is non-judgmental and safe.

Sex workers in NNSW have collectivised in many forms of organisation. Community based, Nongovernmental organisations and networks of sex worker-led groups among others. Allies and supporters of sex workers have also joined NNSW with the primary objective of promoting the rights of sex workers and the right to sex work. Collectives are organised on the principles of self-determination, self-organisation and self-articulation of the right to work and livelihood in the sex business. Sex workers and their allies believe that the lived experiences of sex workers should inform any sex workrelated policy, laws and guidelines for implementation. There are ethical obligations for the greater and meaningful involvement of people in sex work in the formulation of policy and laws pertaining to sex work.

There should be equitable allocation of all resources in every aspect of programming in interventions with sex workers: finance, time, space, representation, meaningful participation (to be ensured by translation, and adequate time); documentation and policy drafting exercises. The rhetoric of rights must be reflected in the manner in which interventions take shape. A set of indicators that accurately reflect these processes will help to translate the principles of equitability into practice.

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A meaningful and inclusive consultation with sex workers is guided by the gold standard of communityled processes that use peer-based and/or participatory methodologies. Community participation requires strategy, resources, commitment, time and a planned approach¹. In order to ensure participation and engagement on a more equal footing, attention must be paid to capacity building in partner agencies as well as communities.

The fundamental requirement for meaningful involvement is consistent with the commitment made by governments in 2001 and 2006 when they endorsed the UN General Assembly's Declaration of Commitment on HIV/AIDS and Political Declaration on HIV/AIDS, which calls for the greater involvement of people living with HIV and of people from marginalized communities.

The International Guidelines on HIV/AIDS and Human Rights, 2006 by the Office of the United Nations High Commissioner for Human Rights [OHCHR] and the Joint United Nations Programme on HIV/AIDS

¹ Making community participation meaningful A handbook for development and assessment Danny Burns, Frances Heywood, Marilyn Taylor, Pete Wilde and Mandy Wilson

https://www.jrf.org.uk/sites/default/files/jrf/migrated/files/jr163-community-participation-development.pdf

[UNAIDS] used the principle of Greater Involvement of people living with AIDS [GIPA] in a process of participatory consultation and cooperation that was undertaken in the drafting of the Guidelines, so that the Guidelines reflect the experience of people affected by HIV, address relevant needs and incorporate regional perspectives.

This participatory method of involving sex work communities in policy making and guidelines for implementation is a process executed in the sex worker implementation tool (SWIT) authored by the WHO, UNFPA, UNAIDS, Global Network of Sex Workers NSWP], World Bank and UNDP². **Guidelines**

NNSW promotes community-led consultations using peer-led participatory strategies to reach all sex workers. In a situation where peers and or participants are not literate, documenters guided by the network will be used.

The safety and well-being of sex workers is paramount and should guide all decisions during the course of the participatory consultation. Sufficient consideration, time and resources must be dedicated to ensuring that rigorous ethical standards are met during the process of consultation and documentation.

With the following standards in place, the process of the consultation itself has the potential to be transformative for peers, documenters and the participant sex workers:

Respect for persons: A basic respect for human dignity must guide the process. All questions should be posed sensitively in a supportive and non-judgmental manner. There must be no discrimination on the basis of gender, caste, class, geographic origin, creed or race. The questions must be meaningful and enable participants to respond in an informed manner. Documenters should be transparent about the objectives of the consultation and make these clear at the outset. Confidentiality of both the sex workers and the peers should be maintained and their responses should not be identifiable without specific consent. The consequences or potential misuse of quotes must be evaluated and accountability mechanisms discussed. The dignity, privacy and interests of the sex workers are paramount and should be protected at all times.

Justice: The consultation is intended to benefit the interests of sex workers. Care should be taken to ensure that any outcomes of the consultation are communicated in ways that authentically reflect the views and interests of the participants. It is the duty of the documenters to report back on the outcomes to the communities prior to public dissemination. When released publically, the outcomes of such a consultation should be disseminated in a rigorous manner and particular attention should be paid to ensure that dissemination in no way reinforces negative stereotypes or attitudes toward sex worker communities. All outcomes should be communicated with the intention of effecting positive change in policy and discourse.

² Implementing comprehensive HIV/STI programmes with sex workers: practical approaches from collaborative interventions: http://www.who.int/hiv/pub/sti/sex_worker_implementation/en/

Confidentiality: Privacy and confidentiality are particularly important in such consultations given that identification as a sex worker can lead to sanctions and/or violence. The consultation should establish – in partnership with sex workers– protocols for the safe and secure management of information; for protecting anonymity; and for handling breaches in confidentiality. Participants should be informed of any potential limitations to the confidentiality of any information supplied. Procedures should be put in place to protect the confidentiality of information and the anonymity (if so desired) of the participants in all materials and outcomes produced by the consultation.³ The specific mechanisms to protect confidentiality; names, sources of information or personal identifiable markers should be recorded only with informed consent; recordings should be kept in a protected digitized format to avoid misuse.

Effective information and communication: Information should be provided in verbal, visual and written formats in easy to understand terms, avoiding jargon, and in languages and dialects used by the sex workers participating in the consultation. Participants must be well-informed about the need, purpose and objectives of the consultation. The objectives should be made available to participants in writing, while remaining mindful of the fact that possession of such written material might carry with it the possibility of identification as sex workers, which could prove risky for participants in some situations. Organisations need to ensure that professionals chosen to consult with sex workers are persons who have not professed anti sex work/anti sex worker rights sentiment in any forum. At the very least organisations need to ensure that professionals they engage possess some understanding, knowledge and skills to work in partnership and engage meaningfully with communities of sex workers.

Representation and interpretation: Consultations with sex workers and their allies involve the communication of information and ideas that might be unfamiliar and complex. All efforts must be made to translate written, audio and visual (sub-titles where relevant) material into languages and dialects used by sex worker communities. Translators, interpreters and documenters must be committed to empathetic listening and interpreting the voices of the sex workers as authentically as possible in order to ensure that sex workers, narratives are communicated without bias, prejudice or distortion of any kind.

Voluntary participation: Documenters must stress that participation is completely voluntary and not conditional on inducements or coercion of any kind. Where appropriate, incurred expenses (such as for transport or meals) may be reimbursed. Participants must be clear that refusal to participate should not result in any negative consequences. Participants should be made aware that they can withdraw from the consultation at any time. Such withdrawal should not affect any travel reimbursement/compensation already handed over. The participant should also be free to terminate the consultation at any point, and can also refuse to answer specific questions.

³ Drawn from Ethical Guidelines for International Comparative Social Science Research in the framework of Management of Social Transformations programme under UNESCO (1994-2003).

Informed consent: The consultation should be rigorous in its efforts to ensure genuine informed consent on the part of sex workers. Transparency is crucial, and all participants should be informed of the purpose and nature of the consultation through an informational handout and consent procedure that should be developed in conjunction with sex workers to ensure that the language used is clear and appropriate, and that methods used can overcome the challenge of low levels of literacy. Consent must be obtained at the outset of the consultation, ensuring that the individuals participating have obtained consent from the organisations they represent. Such consent must be recorded orally or in writing as appropriate.

Accountability and safety mechanisms: Organisations and individuals who undertake to consult with sex workers must be held accountable and ensure that ethical standards are rigorously adhered to. A robust redressal mechanism which includes sex workers must be put in place to address any violations that occur during and after the process of consultation.

These Guidelines were collectively evolved by the National Network of Sex Workers October 2016.