SEX WORKERS ARE FREQUENTLY AMONG THE FIRST TO BE TARGETED BY RESEARCH AND CLINICAL TRIALS ON NEW HIV-PREVENTION AND TREATMENT TECHNOLOGIES OR SERO-PREVALENCE STUDIES. UNFORTUNATELY, THEY ARE OFTEN THE LAST TO HAVE ACCESS TO THE INFORMATION, NEW TECHNOLOGIES AND TREATMENTS WHICH THEY NEED, ONCE THESE ARE DEVELOPED. HOWEVER, MANY STUDIES AND TRIALS INVOLVING SEX WORKERS DO NOT CONFORM TO RESEARCH ETHICS AS DEFINED IN THE HELSINKI TREATY.

RESEARCH INVOLVING SEX WORKERS MUST ABIDE BY THE FOLLOWING PRINCIPALS:

ACCESS TO APPROPRIATE PREVENTION MATERIAL

MANY CURRENT STUDIES INVOLVING SEX WORKERS, WHO ARE DRUG-USERS, REFUSE TO PROVIDE SAFE PREVENTION MATERIALS SUCH AS LUBRICANT, CLEAN SYRINGES AND OTHER DRUG-USE EQUIPMENT (I.E. CLEAN PIPES) TO STUDY PARTICIPANTS. THIS IS UNACCEPTABLE.

NO EXPOSURE TO UNDUE RISK

IN 2006, THE MONTREAL SITE OF THE EVA/STEP HIV VACCINE CLINICAL TRIALSRecruited sex workers. They planned to distribute condoms with nonoxynol-9 to these participants and to require they use a spermicide and a condom during sexual intercourse. A sex workers’ group was obliged to open negotiations to prevent these conditions from being applied given the heightened risk of HIV-infection associated with nonoxynol-9 (one of the most commonly used spermicides). The negotiations were successful in MONTREAL, however, this study is taking place in many other cities and countries.

IN CAMBODIA, A PROPOSED CLINICAL TRIAL PLANNED ON REQUIRING THAT SEX WORKERS RECRUITED TO PARTICIPATE ONLY USE CONDOMS OBTAINED AT THE TRIAL SITE. GIVEN THAT CONDOMS WOULD ONLY HAVE BEEN AVAILABLE DURING THE SITE’S OPENING HOURS, HAD THE STUDY GONE AHEAD, SUCH CONDITIONS COULD HAVE CREATED SITUATIONS OF UNDUE RISK FOR PARTICIPANTS.

PROVISION OF CLEAR, ACCURATE AND COMPLETE INFORMATION ON THE RESEARCH AND/OR THE PRODUCT BEING DEVELOPED

IN CAMBODIA, SEX WORKERS REPORTED NOT HAVING BEEN INFORMED OF THE SIDE-EFFECTS AND OF THE RISKS OF THE PRODUCTS TO BE TESTED. RESEARCHERS MUST PROVIDE CLEAR AND COMPLETE INFORMATION ON THE RISKS AND SIDE-EFFECTS OF PRODUCTS BEING TESTED, ON THE CONCRETE MEASURES PLANNED IN THE CASE OF A PARTICIPANT BECOMING HIV+ DURING THE COURSE OF THE STUDY, AND THE RIGHT TO DROP OUT OF THE STUDY WITHOUT PENALTIES SUCH AS LOSING ACCESS TO MEDICAL TREATMENT AVAILABLE TO PARTICIPANTS.

THIS INFORMATION MUST BE AVAILABLE IN A LANGUAGE THAT THE SEX WORKERS RECRUITED TO PARTICIPATE IN THE STUDY FULLY UNDERSTAND. SPECIAL MEASURES MUST BE TAKEN WHEN RECRUITING POPULATIONS OF SEX WORKERS WHERE THERE ARE LOW LITERACY LEVELS.

PARTICIPATION FREE OF COERCION

IN 2001, A GROUP OF SEX WORKERS IN MALI DENOUNCED TO THE WHO THE RECRUITMENT METHODS OF A TEAM OF RESEARCHERS DOING A SERO-PREVALENCE STUDY WITH SEX WORKERS. THE RESEARCHERS HAD GONE INTO BROTHELS ACCOMPANYED BY POLICE OFFICERS WHO HAD INTIMIDATED SEX WORKERS INTO PARTICIPATING IN THE STUDY. IT IS ABSOLUTELY UNACCEPTABLE TO USE HARASSMENT OR COERCION TO RECRUIT PARTICIPANTS FOR A STUDY.

RESPECTING OBLIGATIONS TO PARTICIPANTS

IN MALI, SEX WORKERS HAD GREAT DIFFICULTY OBTAINING THE RESULTS OF THEIR HIV-TESTS FROM RESEARCHERS AS PROMISED. IN NIGERIA, AN INVESTIGATION BY THE HOSPITAL WHERE A STUDY INVOLVING SEX WORKERS WAS TAKING PLACE REVEALED THAT BREACHES OF CONFIDENTIALITY WERE OCCURRING.

RESPECTING SEX WORKERS’ CONFIDENTIALITY IS CRUCIAL GIVEN THE WIDESPREAD STIGMATIZATION OF THEIR WORK IN MOST CONTEXTS AND THE CRIMINALIZATION OF THEIR WORK IN MANY COUNTRIES.

ACCESS TO TREATMENT AND CARE

IN CONTEXTS WHERE TREATMENT IS NOT FREELY AVAILABLE, SEX WORKERS WHO SERO-CONVERT DURING A STUDY MUST BE GUARANTEED TREATMENT.

IN CONTEXTS WHERE EVEN THE MOST BASIC PROVISION OF TREATMENT OR CARE COULD BE CONSIDERED AS AN INDUCEMENT TO PARTICIPATE IN THE STUDY, IT IS IMPORTANT TO FOLLOW THE EXAMPLES OF CERTAIN STUDIES AND TO STRENGTHEN HEALTH INFRASTRUCTURE AND ACCESS TO TREATMENT FOR THE LOCAL COMMUNITY AS A WHOLE.

ACCESS TO RESEARCH RESULTS AND THE DEVELOPED PRODUCTS

SEX WORKERS COMMUNITIES WHO HAVE PARTICIPATED IN RESEARCH SHOULD BE THE FIRST TO HAVE FREE ACCESS TO THE PRODUCTS DEVELOPED AS A RESULT, WHEN THEY JUDGE THESE TO BE APPROPRIATE TO THE PROTECTION OF THEIR HEALTH.

TRUE AND MEANINGFUL PARTICIPATION OF SEX WORKERS AND OTHER MARGINALIZED GROUPS

SEX WORKERS MUST BE CONSULTED IN EACH LOCALITY WHERE A STUDY INVOLVING THEM IS TAKING PLACE, AT EACH STEP OF THE RESEARCH, FROM PLANNING, TO IMPLEMENTATION, TO DISSEMINATION OF RESULTS. THIS PARTICIPATION CAN PREVENT ABUSES AND SUPPORT THE ADVANCEMENT OF ETHICAL RESEARCH.

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