



Marginalised Lives: Infertility, childlessness, and healthcare seeking in resource-poor settings in Nepal and India

SNIS Funded Project (2018-20)

EXECUTIVE SUMMARY

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ABSTRACT

The main goal of the project is to contribute to a robust and in-depth understanding of infertility as a major public health concern in Nepal and India. It is based on the assumption that exploring the social and cultural implications of infertility is essential to develop strategies that are responsive to a universal human rights perspective on sexual and reproductive health. In the course of the project, researchers have undertaken in-depth terrain mapping of infertility, its lived experience at the community level and the access to biomedical and alternative traditional modes of health care. The overall research showed that perceptions and health-seeking behaviour were strongly informed by socio-economic status and support from wider family. On the other hand, national and local stakeholders have an important role to play in creating an enabling environment for infertility prevention and in improving health care-related options. To ensure these objectives are met, the research and outreach activities will continue beyond the timeline of the project and even expand further via a dedicated initiative: the Platform for the Study of Reproductive Disruptions (PSRDs). PSRD aims to dovetail region-specific expertise with global policy developments in setting and formulating an agenda for action.

1. RESEARCH PLAN

The main goal of the project is to contribute to a robust and in-depth understanding of infertility as a major public health concern in Nepal and India. The project seeks to dovetail region-specific expertise with global policy developments in setting and formulating an agenda for action. It is based on the assumption that exploring the social and cultural implications of infertility ought to be central to developing strategies that are responsive to a universal human rights perspective on sexual and reproductive health.

1.1 Research design

Our research methods were predominantly qualitative and allowed us to document experiences of affected couples, while highlighting the social, cultural and institutional contexts in which infertility and its treatment are envisaged. The project was designed to build on our pro-active partnership with organisations that have ongoing work (integrated programmes combining activities on health, education and livelihoods) in our research sites. The validity of this strategy, combining research and outreach in the project sites, was established since the first phase of the project. On the one hand, the background data on the research sites (population, family structures, health care facilities) made the data collection even more precise and targeted, and its analysis fine-grained. On the other hand, the established relationships with the communities has given access to the afflicted couples as well as to a range of stakeholders who are already active on the ground.

An important aspect that the team agreed on was that we would let local articulations emerge, without focusing too much on terminologies. In fact, the definition of infertility according to the WHO is the failure to achieve pregnancy after 12 months. But the notion of infertility is context-sensitive. Therefore, in our focus groups we asked questions about childlessness in order to understand what our informants define as “infertility” and how they speak of childlessness. This captured a range of social dynamics (stigma, but also agency) that were then further explored during the in-depth interviews. The individual interviews were focused on infertility. Additionally, following therapeutic journeys allowed us to examine a “typical” experience and what afflicted individuals/couples do every day. We agreed on the type of interview respondents we would involve in our research sites: women who experience infertility and also, wherever possible but separately, their husbands and mothers-in-law. This helped us to gain a better understanding of how the family experiences and larger community perceives infertility. In addition, we decided to conduct key informant interviews with service providers (frontline workers, medical officers and traditional healers) in every research site.

The in-depth interview schedules included qualitative data subthemes on marital history; respondents’ perceptions of social and cultural norms around fertility and the failure to conceive; their conceptions and misconceptions regarding causes of infertility; their own experiences of support or mistreatment by family and society because of these norms and their failure to conceive; respondents’ knowledge and perceptions regarding a failure to conceive; and details of the process undergone to seek treatment, including providers chosen, reasons for choices made, experience of care, costs of care, and involvement of other family members.

1.2 Research sites

In India, the neighbourhoods of Delhi and Bodhgaya, where project partners SAMA and Agrabami are active, were selected as the main research sites. In Nepal, we concentrated on Udayapur and Dang, in the Eastern region where project partner WOREC has ongoing projects, and on Budhanilkantha Municipality, located north of Kathmandu. In fact, research collaborator BPWN is active throughout Nepal and the pilot focus group discussions that they conducted with project partner IFPD in several regions revealed that the stigma faced by infertile women seemed to be the strongest in Budhanilkantha.

Together with the coordinators from the Graduate Institute, we developed a common interview guide. It was finalised in March 2018, translated into Hindi and Nepali, and adapted according to the context (some researchers in Bodhgaya and Madanpur Khader, Delhi, have prepared bespoke guides based on informant type – spouse, mother-in-law, etc.). In the interest of respecting and adhering to local gender sensitivities it was decided that only female researchers would interview women respondents. SAMA and Agrabami in India and WOREC and BPWN collaborated closely as they prepared the data collection logistics.

1.3 Sample selection

In India, the researchers from SAMA collected data in two peri-urban areas in the North-East district of Delhi, Johripur and Sonia Vihar. Anganwadi workers (AWWs) and Accredited Social Health Activists (ASHAs) helped us to identify couples and their families in the area who were seeking infertility treatment. We located and reached out to AWWs and ASHAs at Anganwadi Centres, Primary Urban Health Centres (PUHC), and Dispensaries in the research sites. Some AWWs and ASHAs also referred us to their colleagues in the area, who in turn helped us to identify respondents. On occasion, a snowball sample of potential interviewees emerged as some of the women who we interviewed put us in touch with other women who they knew had undergone infertility treatment.

In these research areas we interviewed eight women who had infertility. In this cohort six had primary infertility, and the remaining two women had given birth to children after undergoing fertility treatments for about 8 years. We spoke to 3 other women, who were mothers-in-law of the respondents. We also spoke to the husband of one female respondent undergoing fertility interventions. Further, we spoke to a male respondent who had male factor infertility, and also interviewed his wife. Finally, we conducted interviews with 13 frontline health workers, of which 2 were Auxiliary Nurse Midwives (ANM), 8 were ASHAs, 1 Anganwadi Sahayika, 1 Medical Officer and 1 traditional healer/*vaid*.

In Madanpur Khader, Delhi, the project benefitted from the existence of a comprehensive listing of all households. Agrabami compiled this list a few years ago (the population is about 72,000 persons). To identify our respondents, we selected the population of women who had been married for between 2 and 10 years but had no living child. There were 107 women in this situation and research teams visited all 107 of them to get an update on their status. Of them only 43 were still residents in Madanpur Khader. 13 of the 43 refused to participate in the study. Out of the remaining 30 women we interviewed 11, moving down the list of 30. We selected the required number of

husbands or mothers-in-law from the 19 infertile women remaining on our list. In Bodhgaya, Bihar, the method used to select respondents was similar to those used in Delhi. However, here we used the Government Front Line Health Worker's register of "eligible couples" (all women between 15 and 49 who are married). The data in this register includes age of the woman, and parity. The register is maintained for the purpose of identifying couples in need of family planning advocacy. From out of this list, 112 women who had been married 2 years and had no living child were identified. In Bodhgaya, 2 women with no children refused to participate in the study. All in all, 15 infertile women refused to be interviewed, one husband of an infertile woman, as well as 4 mothers-in-law of infertile women.

In Nepal, in the two district areas where WOREC focused its data collection, the sample consists of 20 childless couples in each district. Key informant interviews were conducted with community members and the Female Community Health Volunteer (FCHV) who helped identify couples without children. In Budhanilkantha, the research process first commenced with a focus group discussion with a group of local resident women of various age groups. Women who experienced infertility as well as their friends and relatives took part in this activity. Second, local health assistants were assigned as social mobilisers in our research sites. They identified respondents and introduced our researchers to them. They continued to be involved in the project's outreach and dissemination activities. The researcher from BPWN conducted face-to-face interviews with 80 individuals: infertile women or men, their spouses, in-laws and friends. Finally, we selected 12 infertile women for the in-depth interview.

2. RESEARCH RESULTS

The results obtained not only correspond to those expected at the beginning of the research but also further deepened our working hypotheses. The results have laid a robust foundation for a more detailed follow-up initiative in the region triangulating the state, health care professionals and the afflicted as key stakeholders.

2.1 Analysis of demographic and health surveys

Definition of infertility: The definition of infertility has long been contested. How should infertility be conceptualised? Who should be considered infertile? How should straightforward definitions (such as that of Indian Council of Medical Research, ICMR) be expanded to include the experiences of women, especially those who may be classified as "infertile" but who do not view themselves as such (cases of medical and/or voluntary childlessness)? These were some of the questions and challenges that emerged as the research project gained traction. The reference period during which infertility or childlessness was identified as a "problem" by the women also varied from that adopted by the medical fraternity. Community understandings were useful for examining the actual experiences of couples/women, the relevance of medical definitions for communities, as well as the deviation between medical and cultural understandings of infertility.

The quantitative analysis undertaken by the project team at UNIGE (Michel Oris and PhD researcher Rojin Sadeghi) was based on the data from large demographic surveys. In phase 1 of the project, they focused on the Indian data by using the National Fertility and Health Survey (NFHS) (2015-16) that was released in January 2018. This data source has the same structure as the Demographic Health Survey (DHS) routinely carried out in most developing countries.

Defining the childless population was the first methodological step. A working definition was enacted that considered as childless those women who have zero child while aged 30 and over, with at least 5 years of sexual activity. This working definition was found to be the most convincing. This helped create a subpopulation of 241,834 women (out of the population of 699,686 in the survey). Once our subpopulation was defined, we worked up descriptive statistics and cross tables using several socioeconomic variables: age in 5-year groups, education, religion, wealth, castes, and first sexual intercourse. The analysis shows that there is a higher probability for urban women to be childless, compared to those living in rural area. Looking at the socioeconomic variables, the most significant result to emerge relates to education. Women with higher education have more probability to be childless, compared to women with no education. This result has a high coefficient value compared to other socioeconomic factors and is highly significant. It suggests that voluntary childlessness may be higher amongst these two subpopulations and also supports one of our hypotheses since this indicates that the subpopulation of childless women is becoming more heterogeneous. Moreover, the proportion of women remaining single (and without children) grows but remains rather low. The percentage of childless married women remains stable but they actually include two contrasted groups: the first one suggests that in an emerging economy like India there are still large pockets of poverty with high prevalence of malnutrition, especially among the uneducated rural Scheduled Castes and Scheduled Tribes; and the second subpopulation is totally different since it is associated with high human and socioeconomic capital concentrated in urban settings. The latter group is quite similar to the Indian married women who only have one child. This suggests that being childless is now also the result of choice, probably a choice constrained by the tensions between family and professional lives, and a choice that can be exercised by favoured women. Indeed, contrary to the poor, wealthy women can access the burgeoning assisted reproductive technologies if they face fertility problems.

2.2 Social and cultural dimensions

Construction of parenthood: Reproductive capability emerged as a constitutive, essential element of marital relationships in our research sites in India and Nepal. Both the male and female partners held strong expectations of having a child/children after marriage, and these expectations were shared by and enforced by their families and relatives. Having children was seen as a necessary goal for the completion of their family, for perpetuating the family lineage, for future social security, and for achieving salvation after death. Not having children after marriage on the other hand, is frequently considered a personal tragedy and a curse, impacting the entire family and even the local community. Having children is seen as an essential part of life in Hindu culture: progeny/offspring manifest a couple's wealth and prosperity in a given community.

Impact of being infertile: experiences, views and prejudices: Respondents understood childlessness as a very significant lack in their familial and social lives. Women internalised the blame and tried to rationalise the taunts and stigma that they faced. For instance, female respondents spoke of feeling stigmatised and 'impure' if their relatives stopped them from playing with their children. Women felt that, because they are viewed as inauspicious, they would be blamed if something happened to the children, and often expressed this anxiety.

Gender dimension: In a patriarchal and patrilocal society the ability to have children is considered as the main source of power for a new bride. The lack of such power makes women vulnerable. For men, remarriage was the most commonly mentioned solution for infertility in a marriage, based on the belief that women are the source of the problem. The majority of women participants

expressed the fear that their husbands might remarry or divorce, and their mother-in-law may further instigate these threats. Although the majority of the women interviewed indicated that they had supportive husbands, several of them also expressed constant fear of possible remarriage under social and family pressure.

Violence and discrimination: The violence, shame, and discrimination associated with infertility were most distressingly evident in many interactions with respondents in India and Nepal. Societal abuse directed at childless women, as well as physical violence and emotional trauma were prominent themes. In the case of men, casting aspersions on an infertile man's sexuality and virility, often calling into question culturally accepted notions of manhood and masculinity were observed.

Respondents' views on adoption: Respondents held a range of views on the practice of adoption. While some were open to the idea of adoption in general, others expressed their unwillingness to adopt a child. There were different opinions on whether a child should be adopted from within or outside the family, payment for adoption, and the age of the child at the time of adoption. Participants expressed the apprehension of growing old and infirm without children as care providers and support. This fear was also evident in the informants' view that children adopted from "outside" i.e. children who were not born within the wider family, or telling adopted children about their origins would lead to the children abandoning their adoptive parents and leaving them to fend for themselves.

2.3 Understandings of infertility and treatment-seeking practices

The overall research showed that perceptions and health seeking behaviour was informed by socio-economic status and support from the wider family.

Respondents' understanding of the symptoms and causes of infertility: Respondents (health workers, women with infertility and *vaid*/traditional healer) shared their views on what they believed to be the causes of infertility. Some believed it was because of changing lifestyles and food habits, consumption of packaged foods, and use of pesticides in agriculture. In general, when the cause of infertility is not evident or identified, women were blamed more than men because of social beliefs, misconceptions, and myths. In Nepal, overseas migration was also perceived as a reason for childlessness.

Trajectories of treatment seeking pathways: The respondents had adopted several treatment seeking pathways to realise the ultimate goal of having a child. Throughout our interviews in India and Nepal, most of the infertile couples would go to the hospital (gynaecologist) *after* trying some traditional treatments. It was also evident from our study that women seek treatment more than men. In practice, usually women sought medical care alone and had to go through all the check-ups and tests primarily on their own, whereas the health check-ups for men were of secondary concern. There are discernible gender-based biases in the *responses* received as many men continue to believe that they have undiminished fertility capacity, placing the onus for treatment and screening on women. Constrained by time and finances, but doing their utmost to fulfil their dream of having a biological child, the couples visited government hospitals, private clinics and practitioners of traditional medicines. They usually followed the recommendations of family members, friends and neighbours, and those of the doctors that they visited. The treatments did not follow any particular or consistent logic or a linear pathway, but was rather guided by chance

recommendations, financial considerations and convenience. The couples availed multiple options at the same time, adopting complex and intersecting pathways towards the treatment of infertility.

Treatment seeking among couples was informed by their economic situation. The interviews conducted in Dang and Udayapur in Nepal showed that couples with resources and economic means sought treatment in Kathmandu and couples with modest economic resources went to traditional healers. Modern methods of treatment were considered more expensive than traditional healers. Both medical treatment and follow-up visits added to the financial burden. Because of this, most couples discontinued the treatment. Couples who visited a doctor or specialist clinics spent anything from around NPR 50,000 (\$500) to 9 lakhs (\$9000) on various diagnostic tests and medical procedures. Some couples also expressed that they could not manage to find the time since most of them were farmers and had to work in the fields or had government jobs. This was both a major barrier and a huge inconvenience. Few could therefore afford the luxury of travel to Kathmandu for treatment. Hence, some of the participants also felt that the services were inaccessible since most tertiary-level health care was centralised in major urban centres. Male participants also expressed low self-esteem as one of the barriers to seeking treatments.

Views about traditional healers: Largely, the respondents believed in the skills and powers of traditional healers. Some respondents, who had been trying for several years to have children, believed that the interventions offered by *dais* or *babas* (traditional healers) would be their only chance to have children. An ASHA worker in Delhi told us that she has referred women to a *dai* that she knows and trusts. Other respondents (health workers and infertile women/their family members) did not espouse much faith or trust in traditional healers. One Anganwadi worker observed that popularity of traditional healing methods was declining among young and educated groups, and such methods would not work if one did not believe in them.

Information about treatments: Few knew about modern infertility treatment services/service providers. Those who did know had an unrealistic time frame and frequently changed providers. Some respondents in Delhi had received information about different doctors, healers and treatments through their family, friends or other health professionals. Some had gleaned information from the internet. In Delhi, a few respondents were aware of biomedical technologies and practices such as surrogacy and IVF. Their main sources of information were various media channels, advertisements, and celebrity news.

Issues with public and private healthcare facilities: Several respondents who had approached public healthcare facilities complained of the long queues and delays, and the apathy of the doctors who would not inform them about the diagnosis and possible options for treatment. They preferred the treatment offered in private clinics. Private clinics, mostly unregulated, were marketing treatments with unrealistic “guarantees”, or very high chances of success. This was further corroborated by several respondents who were undergoing treatments for infertility. As indicated above, in Eastern Nepal, the issue of the high cost of treatment was made even more salient due to the long and often difficult travel to far away Kathmandu, the only place where treatments were reportedly available.

3. PRACTICAL AND POLICY RECOMMENDATIONS

The practical and policy recommendations that emerged from the project refer to two overarching actions: 1) enhance equitable access to reliable healthcare treatments, information and awareness; and 2) address acute social marginalisation on account of infertility and childlessness. These actions involve a variety of stakeholders from local to global levels.

3.1 Produce data on infertility

The generation of reliable data related to infertility was seen as an important way forward. Data is important to plan strategies and policies. This aspect was extensively discussed in Nepal at the high-level workshop organised under the auspices of the SNIS project on “Infertility: Causes and Consequences of Violence Against Women”. The workshop brought together representation from the highest levels of the federal Health Ministry, with the Head of the federal Planning Commission joining the conversation together with a range of civil society actors and academics (see details p. 12). The workshop deliberations identified the need for data representative of rural municipalities, urban municipalities, provincial and national levels. The responsibility of local authorities for data collection was also acknowledged.

3.2 Increase competences and expertise in identifying, preventing and treating infertility as well as a range of communicable/non-communicable causes. In particular, it would be important to:

- Include infertility management in the national policy guideline and service standards for sexual and reproductive health and rights;
- Reinforce linkages between different services, service providers and referral channels to specialized tertiary-level facilities;
- Increase resources of government programmes addressing preventable factors that cause infertility.

3.3 Make information accessible

There is a great need for better infertility-related information flow to the general population, particularly regarding its main causes and possible diagnostic and remedial measures. Families are quick to detect childlessness and seek treatment for it without adequate information on where to go and what to expect. If community influencers and government frontline health workers were better informed, they could address concerns of women and provide them with appropriate advice on when and where to go for help. In general, there would be an important role for health workers, community groups and religious leaders in addressing the issue of stigma and in facilitating access to treatments in resource-poor areas. Specifically, there is a need to:

- Raise awareness about reproductive tract infections (RTIs), sexually transmitted infections (STIs), and menstrual problems, and preventive care, and the broad causes of infertility among women and men;
- Commit resources at the local and federal levels towards creating awareness and sensitizing people at the community level regarding fertility issues;
- Train family planning counsellors at primary health centres in order to provide counselling to childless couples;
- Raise awareness locally about the existence of facilities for counselling and treatment;

- Train and sensitise frontline workers on the need to better understand and communicate the complex issues linked to infertility – this would be an invaluable input and would go a long way to ensure the mental health and emotional wellbeing of affected families.

3.4 Decentralise infertility prevention and treatment

To make infertility prevention and treatment accessible to rural communities, as well as offer support to affected couples, it is essential to decentralise the counseling and treatment services. For example:

- Nepal has centralized infertility treatment services, including provision of IVF. The state should commit resources to ensure the rapid decentralisation of infertility treatment and IVF provision at province or district level.
- Develop mobile health camps that would also cover infertility-related issues through counselling, prevention and treatment: this aspect emerged strongly in Eastern Nepal where informants recommended setting up of infertility centres and access to trained specialist doctors at the province level. They also advocated mobile health camps (screening) within the rural municipalities and wards, developing IEC materials for reorienting perspectives on the causes, consequences and treatments of infertility and provision of free infertility check-ups by specialist doctors.

3.5 Reduce treatment costs

Governments, global bodies, and the range of stakeholders involved in public health should commit action and resources towards low cost IVF and infertility treatment services to make treatment accessible and affordable for everyone, including people in low socioeconomic strata. This approach should be fast tracked in tandem with identifying and checking infectious and communicable causes of infertility and via timely screening and treatment. This complementary intervention would lessen the overall burden of infertility through proactive primary health care interventions.

3.6 Address social marginalisation on account of infertility and childlessness

The actions led by IFPD and its partners Agragami in India and BPWN in Nepal were instrumental in ensuring the true impact of the project on the participating communities. In the course of the SNIS project, IFPD, Agragami and BPWN have taken initial steps to integrate stigmatized women into vocational training and microbusiness programs. Employment and self-employment opportunities were promoted in the project sites. Some women have been provided with infertility treatment free of cost or at low cost after co-coordinating with infertility clinics. A few of them even chose to work as social activists in order to create awareness for empowering others as well themselves. The practical recommendations emerging from the action-oriented part of the SNIS project are therefore related to addressing social marginalisation on account of infertility and childlessness through:

- Awareness building in communities and the identification of stigmatised women and couples;
- Targeted empowerment, employment and income generation activities;
- The involvement of a broad range of stakeholders, including community leaders, social activists, health workers and (women) entrepreneurs.

4. PUBLICATIONS, KNOWLEDGE CREATION AND DISSEMINATION

4.1 Knowledge creation and community engagement

The project findings suggest that the main thrust ought to be a commitment to ensuring visible change through increased information dissemination on infertility that is readily available within communities so as to: (1) check rampant social stigma, (2) better inform members of targeted communities about the appropriate sources of medical assistance for infertility. This would help couples facing difficulty conceiving seek appropriate and qualified care at the earliest, minimizing anxiety and wasteful expenditure. To this end, partners in India and Nepal conducted activities locally to engage communities. The largest such activity was conducted by Agrabami in Madanpur Khader, Delhi. Women volunteers who are members of community health groups called Mahila Arogya Samitees (MAS groups) and government frontline community health workers called *anganwadi workers*, participated and co-created a major workshop on infertility. Thirteen workshops were held for groups of 15 to 20 women each, and a total of 281 women (200 MAS group members and 81 *anganwadi workers*) participated (see details in IFPD report, p. 5).

4.2 Policy engagement

Two of our partners, WOREC in Nepal and SAMA in India, have significant experience in policy engagement at the national level. WOREC, as one of the leading national organisations, have worked since 1991 to prevent violence against women, its causes and consequences, and to ensure economic, social and cultural well-being of women as well as other marginalised groups by promoting their access to rights and social justice. SAMA is a regionally and internationally recognised resource group working on issues of women's health and rights. It locates concerns of women's health in the context of socio-historical, economic, and political realities. Since its creation in 1999, the group has made major policy contributions and has actively initiated several international consultations on issues of reproductive health and infertility in the South Asian region. In relation to the SNIS project, SAMA provided inputs to the WHO as part of a major initiative to evaluate current jurisprudence on human rights and infertility. SAMA highlighted the gaps in current approaches to infertility and showed how a human rights frame redresses these gaps. SAMA's inputs, critiques and recommendations vis-à-vis the Draft Surrogacy Regulation Bill and the ART Regulation Bill, initiated by the Indian government in conjunction with the ICMR, touch upon the definition of infertility, equity and access to ARTs and Surrogacy, as well as regulation of fertility clinics.

As part of the SNIS project in Nepal, WOREC organised in January 2020 a multi-stakeholder conference involving highest representation from: Ministry of Health and Population, National Planning Commission, Parliamentarians, Government Officials, People Health Movement, Representatives from UN Agencies, Representatives of Human Rights Organizations, Representative from civil society organizations. Partners of the SNIS project were also represented (Graduate Institute, IFPD, BPWN). As a result of the workshop and the successful lobbying by WOREC, the National Planning Commission in Nepal decided to include infertility and childlessness as key indicators in the federal Census. This represents an immense achievement and a giant leap forward in mapping and addressing the issue.

Our team has liaised with officials and engage with national policy-makers while continuing to follow the developments at the international level. On the occasion of the review of Nepal's legal framework by the Committee on the Elimination of Discrimination against Women (CEDAW) of the OHCHR in Geneva, Renu Adhikari from WOREC was invited to participate as the NGO representative and made a stellar contribution on question of reproductive rights and infertility. Christine Lutringer from the Graduate Institute participated in the discussions.

4.3 Documentary film

Drawing on our research findings the project has produced a major documentary film. We aim to use the documentary film as a dissemination tool in order to: (a) engage governmental policy mavens and relevant civil society actors; (b) dovetail informational meetings with the view to destigmatising infertility in the research sites; (c) target primary healthcare staff and the general public, through planned film screenings during 2021. This communication and dissemination strategy has been worked out in consultation with the project teams in Nepal and India. We believe that proactive distribution of the documentary film will leverage the project impact.

It is our sincere hope that the film will prove to be an enduring dissemination tool beyond the project timeline. We are also exploring formal channels of distribution and aiming to submit the film to national TV channels as well as documentary film festivals in India and Nepal. In 2021 we are planning to submit the film to the International Film Festival and Forum on Human Rights (FIFDH) in Geneva.

4.4 Participation in conferences

Bharadwaj, Aditya:

- “Remaking Reproduction: The Global Politics of Reproductive Technologies”. Keynote, Cambridge University, June 2018.
- “Fertile Failures: Marginalized Life of Infertility in South Asia”. Changing (In)Fertilities in Asia and Beyond: An International Conference Sponsored by the Wellcome Trust, Yale-NUS College, Singapore. Plenary, 18 October 2019.
- “Infertility, Taboos and Stigma”. Elbi Foundation and the UNFPA, “Let’s Talk!” Event to tackle taboos around women’s health. Keynote, Antalya, Turkey, October 2018.
- *The “Let’s Talk!” event convened thought leaders, influencers, activists and global policymakers who are challenging women’s health taboos with the goal of galvanising further progress on women’s health and gender equality.*
- “Unraveling Bio-markets: Employing a Lens of Ethics, Gender, Race and Political Economy”. Plenary Speaker, Bengaluru, December 2018.
- “Chronic: Life, Malady and Repro-generation”. Chronic Living: An International, Interdisciplinary Conference on Vitality, Quality and Health in the 21st Century. University of Copenhagen, Denmark. Keynote, forthcoming, 4-5 March 2021.

Nadimpally, Sarojini:

- “Breaking the Silence on (In)fertility” at the Women Deliver Conference, Vancouver 3-6 June 2019.
- “Infertility and Human Rights” 43rd session of the Human Rights Council by the Center for Reproductive Rights, 2 March 2020.

4.5 Launch of the Platform for the Study of Reproductive Disruptions (PSRDs)

The SNIS project set in motion a series of research and outreach activities that had a sizeable impact, much beyond what was hoped for when we first conceived the research proposal. To ensure that these activities continue beyond the timeline of the project and even expand further, the team has decided to create a new initiative: the Platform for the Study of Reproductive Disruptions (PSRDs). PSRDs is dedicated to nurturing collaborative research examining entrenched and emerging reproductive disruptions around the globe. The platform defines *reproductive disruptions* as an all-encompassing phenomenon impacting every aspect of human reproductive health and viability. The notable disruptions range from maternal and infant mortality to infertility and childlessness. In the 21st century, reproductive disruptions are set to expand into a rapidly evolving spectrum and a critical global health challenge. As a research led initiative, the platform is dedicated to identifying structural issues *disrupting* reproductive health and wellbeing.

Launched in March 2021, the platform – www.psrds.org – builds on the project and would disseminate all publications, working papers, multimedia resources emerging from the SNIS project. The platform already features the documentary film trailer and is shortly launching a series of video logs. The SNIS project team are the founding members of this initiative. It is committed to supporting biomedical, social, cultural, economic and institutional responses to a spectrum of reproductive disruptions in partnership with global and local communities of researchers, practitioners, frontline workers and a variety of organisations. Through its research and outreach activities, PSRD would create an enabling environment for improving reproductive healthcare and wellbeing in diverse contexts.