

Annual Report
April 2012 - March 2013

Sama-Resource Group for Women and Health

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Overview of Activities

This report presents the activities / initiatives by Sama during the period April 2012 till March 2013. The report includes highlights of the activities that were undertaken by Sama during this period and provides an update of previous initiatives as well as those that were begun following the last Board Meeting in February 2012:

I. Advancing Right to Health and Health Care

I.A. Strengthening capacities and perspectives through state and regional workshops / consultations

I.A.i. Workshop on Advancing Right to Health as a Human Rights issue: The Context of Marginalised Groups

The two and a half day workshop in Delhi emphasized the intrinsic link between health and human rights and that public health policies and system need to be inclusive based on equity and social justice to address the neglected needs and rights of marginalized groups (Dalits, Adivasis and Muslims). The workshop also sought to integrate the perspectives, expectations and demands of the marginalized groups into the right to health campaign. The workshop participants were primarily from grassroots organizations for rural as well as urban areas, from the states of Madhya Pradesh, Bihar, Jharkhand and Uttar Pradesh working on women's issues, health and health rights, on issues of violence against women, etc.

The workshop provided the space and opportunity to learn about varied issues vis-à-vis right to health from existing strategies – for example, the right to health and health care and patients' rights, Maharashtra; the action for free medicines in Chittorgarh, Rajasthan, the initiative for maternal health and rights, Barwani, Madhya Pradesh and the process of community monitoring. The presentations and discussions enabled an understanding of these areas and provided for collective deliberation and planning for follow up action in respective organizations and states.

I.A.ii. Workshop - Dead Women Talking

The workshop on maternal mortality was organized through the collaboration CMC Vellore, CommonHealth, Sama and Human Rights Watch on 2-3 June 2012 at Muttukadu near Chennai.

The workshop was a starting step to what is envisaged as a longer term process to develop a framework to look at maternal mortality in the Indian context which evolves from the various case studies, the evolution of tools for the collection and analysis on a larger scale, collection of evidence that goes beyond numbers and is respectful of the experience of women, families of women and communities. In the longer run, this initiative also seeks to develop a critique of the present policy focus on narrow technical interventions and focusing on the social determinants of

health and the impact of other policies on health as well as to develop alternate approaches that are rigorous, systematic based on the ground realities.

It was also decided to simultaneously widen the process of Maternal Death Reviews –in terms of content (as outlined in this meeting), actors (inclusion of community and civil society actors and professional groups) and processes (transparent, accountable and in the public domain). There was consensus among participants of the need to have independent reviews because of the possibility of incomplete and/or biased reporting by people from within the health care system.

A report of the workshop was prepared and post workshop follow up has been ongoing. Draft guidelines and tools for the conduct of social autopsies have been developed and are in the process of review and finalization for social autopsies, etc. The independent maternal death review (MDR) will also serve as a ‘watchdog’ which will identify health-system gaps; and advocate for programmatic and policy changes. Attempts will also be simultaneously made to reform the current MDR process of the government towards greater transparency and inclusion of civil society actors.

Sama also participated in ‘Chronicles of Death Foretold’- A seminar on maternal death that was organised by NAMHHR on 8th and 9th October 2012. Presentations of the maternal mortality status from different states to deliberate on possible strategies for prevention of maternal deaths towards informing policy.

I.A. iii. Workshop on Right to Health: Sexual Violence and Mental Health

This workshop was conceived following the public furore and action in the context of gender violence, with renewed attention particularly on sexual violence, precipitated by the brutal violence against the young girl and her friend in Delhi in December 2012. A two day workshop on Right to Health with particular focus on Sexual Violence and Mental Health was organised on 22 and 23 March 2013 at Bhopal, Madhya Pradesh towards (a) strengthening understanding of gender violence, particularly in the context of sexual violence and its impact on health – physical and mental health, (b) deliberating ways to improve response (institutional and community based) response of the health system to gender violence – especially sexual violence, including focus on mental health needs, (c) discussing strategies towards integration of mental health and sexual violence concerns into the demand and advocacy efforts of right to health. The workshop was able to facilitate discussion on the provisions and concerns with mental health legislation, related international conventions with regard to mental health and disability and on sexual violence. The workshop was attended by 25 participants from around 12 community based organisations and networks working in rural as well as urban Madhya Pradesh as well as four mental health professionals.

I.A.iv. Sama was also invited as resource persons for the following workshops / institutes:

- Orientation for women and young girls in urban resettlement areas, Delhi on Reproductive and Sexual Health: were conducted in March and April 2012 in Madanpur Khadar, organised by Jagori who is working with the communities here.
- Session on Women's Health at the National Gender and Development Course (Hindi): organised by Jagori in April 2012, for participants from varied organisations across the country on social determinants of health, the right to health and health care campaign.
- Two day session on gender and health for 2nd batch of Madhya Pradesh Community Health Fellows organised by SOCHARA: The sessions over two days built an understanding on the relation between gender and health, implications of population policies, ARTs.
- Session on 'Free Treatment in Charitable private hospitals in Delhi' in a session organised for All India Women's Conference (AIWC) members- branch managers from Delhi, who worked closely with communities across Delhi through their branches.

I.B. Meetings on Universal Health Care with People's Health Movement (PHM) India (JSA) and PHM global

Sama, as part of JSA has been actively involved in the access to free medicines initiatives, right to health care, universal health care, etc. during this period. Sama was involved in the planning, coordinating of several initiatives - national conventions, meetings, press conferences, policy engagement as well as through participation in meetings and assemblies at the PHM global level.

- Specifically, a National Consultation on *Restructuring of Public Health Services and Universal Health Care* was held on 30th August 2012 in Delhi. During 28th, 29th and 30th November 2012, a National Level Convention on *Universalization of Health Care for All*, was organized by JSA in Delhi. This enabled the building of a broad alliance of movements and groups for universalizing health care and opposing privatization of health care. The convention also led to articulating concrete demands for free access to medicines and treatment. These conventions / meetings led to mobilisation of newer constituencies, and strengthened linkages with networks.
- A declaration based on the deliberations in the Convention was drafted and adopted. Information resources in the form of two booklets on Universal Health Care, were also prepared for wider dissemination, building capacities of JSA members and wider mobilization on these issues. Sama was also involved in planning and participated in the *National Convention on issues relating to Medicines* in August 2012, organized by Federation of Medical Representative and Associations in India (FMRAI) and JSA .Sama also presented on *Clinical Trials Regulatory Framework*; a resolution from the convention was adopted and presented to policy makers, towards access to medicines in public facilities, regarding issues such as drug price control, irrational medicines, quality control standards, etc.

- The Third People's Health Assembly (PHA3) took place in Cape Town, during 6-11 July, 2012. Sarojini from Sama was involved in the conceptualising, planning and coordination processes of the assembly's programme – particularly the plenary and workshops under the Gender, Health and Equity Theme. Sama team was invited to participate in the assembly from India. A presentation *ReproTourism, Reproductive technologies; the current trends* was made by Sama. Sarojini was also invited to attend the Steering Committee Meeting which is the governing body of the global PHM.

I.C. Evaluating the Impact of Health Insurance on the Right to Health

This study based largely on review of literature, which aimed to review the evidence base on social health insurance in India from a right to health perspective, was concluded during this period. The main objectives of the study were: (a) to review literature on social health insurance in India and summarise emerging conceptual debates and discourse underlying it's potential to address health care needs of the poor populations; (b) to critically review the evidence on community based and social health insurance schemes to assess the extent to which they address the various dimensions of right to health care; (c) to highlight the policy relevance of ongoing debates and to chart future directions for research and practice.

A working paper based on the findings of the review was also completed in this time. The paper presents the background to the debate on health insurance by discussing the political economy of health care in India, summarises the health insurance landscape by highlighting the extent of coverage, taxonomy of health insurance models, and crystallise the focus of the paper to examine social/community health insurance targeted at the poor, the conceptual framework on right to health to review the literature and analyse the findings.

II. Strengthening the Health System Response to Gender Based Violence

II.A. Capacity Building through Trainings, Workshops and Orientations

II.A.i. Community Level Trainings on Violence as a Public Health Issue for Health activists, organizations, networks and young people

Four workshops were conducted in Jharkhand (Ranchi), Madhya Pradesh (Jabalpur), Assam (Guwahati) and Manipur (Imphal), with activists, academics, health workers, lawyers from local/ regional organisations and networks. The four workshops were attended by participants from community based organizations and networks - working on women's health, child health, education, livelihoods / work, sustainable development, disability, law, conflict and peace, tribal rights, LGBTQ rights, food security, RTI, etc. - from the states of Assam, Nagaland, Tripura and Meghalaya, Madhya Pradesh, Jharkhand and Manipur. A total of 98 persons were part of the workshops, of which 81 were women and 17 men, from 57 organisations and 5 networks from 36 districts across seven states.

The workshops also facilitated interaction between experienced / thematic resource persons – including organisation representatives, members of judiciary, doctors, etc., on the issue, working in the state or region and the workshop participants.

The diversity of the participants and the issues that the organisations and networks engage with bore testimony to the primacy of the issue of domestic violence and the need to strengthen understanding of its linkages with health.

Sama has through these workshops strived to create and strengthen links at the local levels which facilitated building of local resources and strengthening linkages between organisations in a particular geography or region, towards sustained action.

II.A.ii. Workshop on Violence as a Public Health Issue at Bhubaneswar, Orissa

This workshop was organized in February 2013 as a part of Sama's continued initiatives to strengthen capacities of communities and community based organizations, health workers and others to situate domestic Violence and sexual assault in a framework of gender, public health and rights, towards improving community and health care response. The workshop was attended by 27 participants from different organisations, sangathans, JSA members working on issues of health, reproductive health, women and child rights, youth, etc. The workshop was able to strengthen linkages between GBV and health, discuss existing strategies to address them in the state and possible future ways of engagement particularly vis-à-vis linking with the health sector.

II.A. iii. Workshops with State Institutions and Actors to address violence against women

- ***Workshops with health providers to respond to health consequences of violence at Safdarjung Hospital, Delhi***

Workshops were conducted in collaboration with the Department of Obstetrics and Gynecology, Safdarjung Hospital for the faculty, senior residents, nurses and nursing students on *Strengthening Health Care Response for Survivors of Domestic Violence (DV)*. The workshops in July 2012 followed on from previous workshops in the hospital, building on providers' knowledge and perspectives on the issue. While previous workshops were able to construct a deeper understanding about Domestic Violence and Sexual Assault, the current workshops enabled a better understanding of roles/Response of health system/Health care Providers to survivors of violence in the context of the law. Seventy one persons participated in the sessions, including doctors (senior residents, senior specialists, medical officers), nursing staff, medical students, and researchers.

The workshops formed a part of the larger initiative that was ongoing in the hospital for better response to survivors. While response to sexual assault has been to an extent streamlined, efforts were on to consolidate them.

- **Engagement with Association of Obstetricians and Gynaecologists (AOGD)**

Deliberations with the South Delhi Forum of Obstetricians and Gynaecologists, a forum akin to the AOGD comprising doctors from the public as well as private sectors took place during this period. While orientations for the doctors were to be conducted before the end of the project period, this was postponed to March – April 2013 based on the availability and convenience of the members, particularly coordinators of the forum. The interactions with the forum were encouraging and will be carried forward in the next months.

II.B. Advocacy Initiatives

II.B.i. National Consultation on Public Health Response to Gender Violence

Consolidation of health care system policy and practice response to gender violence raises a plethora of questions and challenges for critical engagement. What are the different sites and levels for effective health care intervention? How do we engage with the private health sector (for profit and not for profit) in this context, given that a large percentage of people access health care here? Lessons and experiences of organisations, practitioners in this area, existing resources, protocols and guidelines are important to examine and deliberate towards informing and crafting future strategies for action/ intervention.

This clearly necessitates the need for a wider, systematic and collective process to take stock of the public health response to gender violence. The 16 Days of Activism Against Gender Violence Campaign (25th November – 16th December) provided an opportune time to plan future action, and collectively visualize a strengthened, comprehensive, appropriate, gendered and rights based response. A two day national consultation was organized in November 2012 at New Delhi with the following objectives:

- To strengthen perspective and action vis-à-vis violence as a public health issue; role of health professionals (with specific focus on domestic violence and sexual assault).
- To examine experiences and challenges emerging from existing initiatives, strategies, policy-legislations.
- To prepare recommendations for the future directions – policy and practice - of a gender sensitive, rights-based and comprehensive public health response.

The consultation brought together about 40 participants from around 18 women's and health organizations, human rights groups, legal organizations, medical professionals, and other key stakeholders to deliberate on current practices in different states / regions of the country and discuss future directions. The national consultation included a keynote address, four panels and a way forward session. The national consultation enabled exchange of information, experiences and drew attention to different initiatives in the country that were ongoing to strengthen health care response for survivors of domestic violence and sexual assault. These were placed at

different levels of institutions – included primary, tertiary, etc. causing insights into what has worked and challenges faced.

The national consultation was able to identify specific areas / action plans in the short as well as long term, including inputting into the CEDAW Shadow report, influencing / inputting into the medical curriculum, need to compile and exchange existing information and resources – for ex, data from research, protocols, reports, etc. to enable wider mobilization, strengthening perspectives and facilitating collective inputs – for example, in development of uniform protocols / guidelines for examination and evidence of sexual assault, screening for domestic violence in health institutions.

II.B.ii. Advocacy on the Protocol for Examination and Evidence Collection of Sexual Assault

Advocacy on the protocol by the Directorate General of Health Services (DGHS) continued during this period. The DGHS, however, was steadfast in its position that a case on the matter was sub-judice in the Delhi High Court and hence no revisions were possible. Inputs to the committees set up in the aftermath of the horrific sexual violence in Delhi on December 16, 2012 – the J S Verma Committee and the Usha Mehra Commission (Delhi level) - were made on a range of issues, including with regard to the protocol.

During the forthcoming period, the following will be followed up / consolidated:

- Follow up meetings with the DGHS as well the National Commission for Women (NCW) will continue.
- Sama's initiatives / workshops also flagged the importance of such protocols / guidelines that were being used in the different states. Participants in Sama's workshops expressed complete lack of information with regard to such a protocol / guideline. As a first step it was discussed that the guidelines / questions / process being used will be documented in states where possible, towards the possibility of a standardised guideline / protocol that was gender sensitive and not based on archaic understandings and practices with regard to examination and evidence collection vis-à-vis sexual assault survivors.

II.B.iii. Advocacy for Effective Implementation of the PWDV Act in Delhi

The workshop for the protection officers in Delhi raised critical issues with regard to the status of implementation of the PWDV Act as well as challenges that they faced in its operationalisation. A meeting with the Delhi Women and Child Department (DWCD) was carried out by Sama with Jagori (who had jointly organized the workshop for protection officers). The DWCD which is the nodal agency for protection officers expressed its interest in continued orientations for the POs and was willing to provide space and schedules for the same. While this was a welcome step that could be initiated through a collective process involving diverse organizations and expertise, it was also critical for the DWCD to address other fundamental issues vis-à-vis the POs and implementation of the PWDVA. Recommendations with regard to improving the working

conditions of the protection officers that emerged from the PO workshop (2011) were shared with the DWCD.

II.B.iv. Other Advocacy initiatives:

- **Advocacy for Strengthened Implementation of the PWDVA:** Sama participated in a national consultation organized by the NCW to discuss the Centrally Sponsored Scheme (CSS) for the implementation of the PWDVA. Although concerns were expressed about dilution of the Act as a ‘scheme’, the main objective was to ensure matching grant assistance to the state for its implementation. Allocation of resources needed for the operationalisation of the PWDVA, almost six years following its initiation continued to be abysmal flagging concerns by organizations and networks working on these issues. A memorandum to the Finance Ministry to increase allocation for increased budget with an indication of the likely budget for implementation of the PWDVA was submitted and a response awaited. Advocacy on this front is expected to gain momentum in the coming year.
- Sama also participated in the following action – advocacy initiatives to build on the organisation’s understanding as well as to inform ongoing debates / discourse on the issue:

Through submissions to committees and conventions:

- Sama sent a submission to the Justice J S Verma Committee with regard to the health care response for survivors of sexual assault.
- Sama was part of coalitions that collectively submitted to the Usha Mehra Committee set up by the Delhi Government; Sama specifically provided inputs with regard to the roles and responsibilities of the health system in responding to sexual assault.
- Submission to the CEDAW shadow report on violence as a health issue was initiated by Sama with a few other interested individuals / organizations.

Through participation / discussions as part of larger fora:

- As a member of AMAN: Global Voices for Peace in the Home, which is an International Network to End Domestic Violence. It comprises of organisations and individuals in India and abroad, working on the core issue of violence against women, particularly domestic violence. During the last meeting Sama, as one of the groups present and working on the inter-linkages between violence and health, facilitated a brief session to initiate / consolidate members’ understanding on the issue.
- Participation in a meeting on Violence – Policy Perspectives in Domestic Violence organized by MAITRI, Delhi and Southall Black Sisters, UK, on emerging concerns in this area.

III. Action Research, Advocacy on ARTs and Commercial Surrogacy

III.A. Action Research on Commercial Surrogacy in India

Fieldwork: The field work which started in December 2011 continued till April 2012. The research team, overall, met with doctors in 15 centres in Punjab, 8 centres in Delhi, one medical tourism agency and one surrogate recruitment agency in Delhi and two independent agents in Jalandhar. From these meetings, eventually interviews were conducted and recorded with 12 surrogates, two agents, five doctors and one commissioning parent.

Recording data: All the interviews that were recorded were transcribed in the language in which the interview was conducted to maintain the authenticity of the data and to ensure that no data was lost in translation. The transcribed interviews were then translated in English. Detailed notes for the unrecorded interviews and generally about the visits were taken, including the researchers' observations and comments, which were also typed and recorded.

Literature Review: The review of secondary material was undertaken and a draft completed that was sent to the Advisory-cum-Ethics Committee members as well as reviewed internally.

Advisory-cum-Ethics Committee Meeting: The second meeting with the Committee was held in June 2012. The members were briefed on the progress made regarding fieldwork, the nature and quality of interviews, challenges faced and observations from the field. A discussion was held whereby their comments were sought regarding analyzing the data and writing the report. The members gave suggestions on how to rework the literature review and how to develop a relevant framework for analysis.

Data analysis and report writing: Various members of the team took responsibility for writing individual chapters while keeping in regular consultation and discussion with each other. Keeping the research questions in mind, the data was analysed and presented while foregrounding the surrogate's central position in the industry. The team critically examined various aspects of the surrogacy arrangement, the processes adopted in practice, and the relations between the various actors in order to understand the power relations that determine or influence their organization and interrelation. Various cultural references deployed as part of the surrogacy practice and the processes of generating new meanings and subjectivities for the smooth functioning and growth of the industry were also looked at. The report included Introduction and Methodology section, followed by Literature Review. This was followed by six chapters focusing on analysis of the interviews that presented the profiles of the various actors, looked at the processes of recruitment of women for surrogacy and the role of other actors such as agents, the decision-making process of the surrogates in entering the work, the medical regimen part of the arrangement and the surrogates' experiences of undergoing that, the patterns of remuneration, the impact of stigma and the importance of relinquishing the child and how that structures the practice. The concluding chapter maps the important debates and concerns regarding commercial surrogacy that the research revealed as well as outlines the lack in the present proposed policy climate.

Review: The chapters were reviewed internally by the other members of the team and reworked according to the feedback. The draft of the report following this was sent for review to two experts for external review. Select individual chapters were also reviewed by various other experts to sharpen the analysis and factual validity based on their expertise. Following the reviews, the chapters were reworked to accommodate the changes.

Editing and printing: The final draft was sent to an external reviewer for copy-editing. The report was titled ‘Birthing a Market: A Study on Commercial Surrogacy’. An executive summary of the study has been developed and widely disseminated

III.B. Study on Reproductive Tourism in India: actors, agencies and contemporary transnational networks

This initiative is collaboration between the Centre of Social Medicine and Community Health (CSMCH), Jawaharlal Nehru University, Sama, and King’s College London.

Selection of sites: The project team collectively finalised four sites in India for the research: Mumbai, Delhi, Chandigarh and Hyderabad, to capture the regional heterogeneity of India and those that have a history of commercialization of medical care, outmigration of doctors to UK, USA and Canada and more recently reverse migration. To map the other end of the chain, given the important role of the Indian Diaspora in reproductive tourism, London has been selected as the other site to map the network. London was selected as the site to map the other end of the chain, given the important role of the Indian Diaspora in reproductive tourism.

A meeting held in September 2012 was attended by all the members of the research team, members from UNFPA and select experts. Presentations were made from the four sites in India and findings from the intensive web search from the UK end.

Release of the Report: A meeting was organised for the release and dissemination of the report Reproductive tourism in India: actors, agencies and contemporary transnational networks based on the research, in the month of December. A summary presentation based on the report was made which was followed by a discussion with invited experts / panelists.

III.C. Can We See the Baby Bump Please? A film on commercial surrogacy in India

The film, it was decided, should primarily be constructed with lives of a selected number of women who are in different stages of surrogacy, issues relating to surrogacy, the different players and the resultant conflicts and/or confusions will be woven around these lives to tell a human story of women who are in a flux to cope with the rapidly changing situation around them.

The initial months into the film were focused on research preceding the actual filming. The shooting schedule was begun in June and extended till August 2012. The film team faced many hurdles in accessing surrogate women for the film. The team managed to get interviews with six

doctors and two of the clinics had given access to agents/surrogates in their premises, but only under their supervision. Shooting outside the clinic setting, in the *bastis*, was difficult, owing largely to women not wanting to be visible within their communities. In such situations, alternative ways of presenting narratives were explored. Interviews with three surrogates were conducted and the team got consent from two lawyers involved in surrogacy contracts for interviews. Additionally, one in-depth interview with a commissioning parent who also went through six cycles of IVF and other fertility treatments was conducted.

A rough cut was developed using all the material - visual and conversational. Some of the full interviews with a lawyer, surrogacy agency, and doctors were edited and added to the DVD with the film, as important resource material and tool to be used in advocacy workshops.

The film followed a process of review through September; the rough cut was shared and viewed by the Sama team and feedback on the film and possible desired changes were communicated to the filmmaker. The filmmaker was then engaged in working on incorporating these suggested inputs and on finalizing the sound, graphic edit, subtitling and credits.

III.D. Information Toolkit

A tool-kit was compiled to be used in the workshops for participants and for wider dissemination. It included the reading list, the brief on regulation of Surrogacy in India, an article on ARTs by Sama, which mapped the main debates and concerns regarding the industry as it operates currently. The kit also included an executive summary of the exploratory research and a list of Sama's earlier published reports on ARTs.

III.E. Advocacy Initiatives

III.E.i. Capacity-Building / Dissemination Workshops

Four capacity building workshops during October to December 2012 were organised in Delhi, Mumbai, Chennai and Kolkata, for initiating wider deliberations on the issue through dissemination / discussion of the research findings and the film. Specific issues and concerns with regard to the provisions to the draft bill (2010) were also discussed.

Towards wider outreach, apart from the above, screening of the film and discussion on commercial surrogacy was also done in Trivandrum (Kerala) at the Achutha Menon Centre for Health Sciences and for members of the Madhya Pradesh Jan Swasthya Abhiyan Members in Bhopal. Participants included activists from women's rights groups, grassroots networks on gender and health, mental health, child rights groups, academic researchers, professors and students from local universities, institutions, journalists, medical professionals and practitioners such as gynaecologists and providers of ARTs as well as policy makers.

III.E.ii. Workshop on Reproductive Tourism: Issues and Challenges

A workshop was held over two days in October in Kathmandu, Nepal on reproductive tourism there, which was organised by the local non-governmental organization 'Women's Rehabilitation Centre' (WOREC) in collaboration with Our Bodies Ourselves (OBOS), United States (US), and Sama. Three sessions, outlining the context of infertility and ARTs, practice of surrogacy and growing medical tourism and lastly regulation, from a women's rights and feminist framework was facilitated by Sama.

The film (roughcut) 'Can we see the baby bump please?' was screened in one of the sessions to initiate discussion on the practice. The workshop concluded with identifying emerging issues and possible strategies to be taken up by various women's groups and networks in strengthening the rights of women and children who are part of the arrangements in the industry.

III.E.iii.Seminar on Advancing Feminist Debates Around Reproductive Technologies

The seminar brought together feminist scholars, activists, writers and policy makers from across the country. It was organized in two sessions. There was a discussion on the increasing use and expansion of ART technology and its consequences on the ideology and structure of the family. Participants raised questions regarding what kind of feminist response should be offered to this changing understand of biological reproduction and access of hitherto excluded identities such as those of gay, lesbian, transgender etc. The debate centered on questions of access, models of care and desired technological intervention in our lives. Specific concerns regarding donor anonymity, eugenic trends and ideology of infertility and comparison with adoption were also addressed additionally. Focus was also brought upon the political economy in which these technologies operate and the dilemmas that exist in charting out feminist advocacy.

The second session addressed the dilemma engendered by the differential response of feminists on the issue of abortion in the context of sex selection and disability. The discussion highlighted the necessity to see both gender and dis/ability as social constructs and participants critically discussed how the trajectory of feminist politics has responded differently to right to abort in these two instances and what are the steps to be taken that are needed to address these concerns through advocacy and multiple action platforms. Focus was brought upon the imagery and tools used by the women's movement and collective reflections in hindsight. The concern for eugenic selection in the use of ARTs was also articulated, as was the need to highlight it since it has not been part of public debate. Regarding the PCPNDT Act, it was also emphasized that there is a need to reflect upon the selective demands made by the movement, in relation to MTP (Medical Termination of Pregnancy) Act.

It was emphasized that there is a need for people from various movements like queer movement, child rights movement to get involved with ARTs as an issue at the advocacy level as well as at the policy level and to continue to engage in similar sessions and spaces of debates timely. There

was deliberation regarding the use of technology, the desired basis of setting limitations, feminist responses in legal advocacy. The participants also expressed the need to further discuss medical ethics in these practices and the consequences of feminist politics till now.

Advocacy through participation in other events / meetings:

- Sama made a presentation on the issues emerging in the practice of commercial surrogacy before the Commission on Global Governance for Health, Lancet-University of Oslo, in November in Delhi. The Commission has been examining the following key issues for consideration –trade/finance/aid/investment, agriculture, environment, industries, migration, education, security/conflict, etc. Sama focused on commercial surrogacy under reproductive tourism and the present global governance gaps.
- Sama made a presentation on commercial surrogacy in the workshop organised by Global People’s Health Movement (PHM) at the 3rd People’s Health Assembly in Cape Town, South Africa in the month of July which was attended by many PHM representatives across the world.
- The film, ‘Can we see the baby bump, please?’ was selected for screening at OUR LIVES...TO LIVE (NO! to gender violence) Film Festival held on 23rd November in Delhi. A member of the research team represented Sama as a panellist for the session ‘Our Bodies, Our Rights & A Question of Privilege: caste, class, occupation/labour’, in which the film was screened, to talk about the rights of surrogate women and the current scenario of the industry.

IV. Advocacy on Sex-selection

IV.A. Addressing Sex-Selection: Strengthening Capacities to Address Continued Challenges and Emerging Concerns

Sama is currently conducting a process of review in Punjab to map reasons / determining factors, take stock of initiatives, strategies in Punjab that may have contributed to the improvement in the sex ratio (as per the 2011 census) through review of literature, meetings, discussions with key informants (organizations, activists, academics, etc.) engaged on the issue. A regional workshop is also planned towards strengthening the understanding about the intersections of gender, the ideology of son preference, technology and its social and ethical consequences.

IV.B. Advocacy / Policy Monitoring and Advocacy:

IV. B. i. Sarojini was invited to be a part of a **committee to devise suitable regulatory mechanism for effectively monitoring of the sale of imported/ second hand/ refurbished ultrasound machines, including use of technology for effective tracking of ultrasound machines.** The meeting took place on 28th September 2012 during which, follow up plans including possible tracking mechanisms in ultrasound machines, data regarding sales of ultrasound machines, data on imported and locally assembled machines were to be furnished to the Committee.

IV.B. ii. Sama was invited to participate in the National Consultation on *Reviewing the Strategies to Improve the Provisions of the PC and PNDT Act* organised by the National Commission for Women (NCW) on 20th December 2012 in Delhi. The review was to take stock and assess the efforts being undertaken by the State Commissions for Women and state governments in the context of sex selection. Issues, concerns regarding pre conceptive sex selection through ARTs and other concerns with regard to compromising on abortion rights were raised by Sama. The consultation through the NCW submitted a memorandum with regard to the Delhi sexual assault.

V. Action Research, Advocacy on Clinical Trials

V.A. Action Research on ‘Participants’ Perspectives on Clinical Trials’

The research sites originally in 3 states of Delhi, Gujarat and Maharashtra was expanded to include the city of Hyderabad in Andhra Pradesh, due to restricted to no access in some of the areas in the afore mentioned sites. While access remained restricted even in Hyderabad, the team was however able to conduct a few interviews with principal investigators and research coordinators at trial sites and few with participants as well.

Data collection was done through Community based interviews and Hospital/ Trial site based interviews. Community based interviews however, have been few and far in between to come by. The research team approached community based organizations working with a range of different communities in the chosen cities. However, in the cases where the team was able to conduct these interviews, special care was taken to maintain the anonymity of the participant and protect the confidentiality of the information they were giving. Interviews were conducted at a place and time of their choice. The purpose of the research was explained to the participant in great detail following which the consent form was also read out and explained.

Simultaneously, based on the lists drawn up from the Clinical Trial Registry of India (CTRI), at the research sites, a mix of both public as well as private hospitals and smaller clinics were approached and permissions were sought to conduct interviews with participants of trials at these sites. Wherever the team was granted permission, interviews were conducted with the Principal Investigators (PIs), hospital staff, Heads of Departments/ Deans to name a few, and further permits were sought to conduct interviews with participants through the method of a layered consent. Along with this, interviews were also conducted with representatives of Contract Research Organizations (CROs) and research heads of pharmaceutical companies (both international as well as domestic) situated in the three states; to further inform the research.

Literature Review: A review of secondary material for the research study has been started to develop a theoretical understanding of the issue, and to gather information on the status of the research undertaken on the subject. This was to identify the gaps in the existing literature, sharpen understanding of the subject under study, and aid in strengthening the research, so as to

enrich, rather than duplicate, the existing body of literature. For this purpose we began by sourcing and collecting as much data as was available on the internet in the form of academic papers, newspaper and magazine articles and comments in online journals. These papers were sourced using online search engines using several key words such as ‘clinical trials’, ‘Good Clinical Practices’, ‘informed consent’, ‘regulation of clinical trials’, ‘compensation in clinical trials’, ‘participants’ experiences’ to name a few. Similarly, journals such as the British Medical Journal, Indian Journal for Medical Research, New England Journal of Medicine etc. were also sourced for articles.

Advisory Committee and Ethics Committee: An Advisory Board, consisting of eminent researchers and practitioners in the field of public health, ethics and clinical trials was constituted and intensive correspondence was undertaken with each member of the board via email and skype discussions wherein, the members critically reviewed the research objectives and questions as well as the tools and methodology of the research.

An Ethics Committee (EC) as per the Indian Council of Medical Research (ICMR’s) *Ethical Guidelines for Biomedical Research on Human Participants* was constituted. The EC comprises social scientists, lawyers/ advocates, scientists, lay person. The first meeting took place on 19 May 2012 and reviewed the research schedules, consent forms, etc.

Developing Research Tools: With intensive inputs from the Advisory Board, and also from Sama’s Ethics Committee, the team has developed research tools that will be used during the field work and come up with a methodology for the research. The schedules/ open-ended guiding questions and informed consent formats have been prepared in English, Hindi, Marathi and Gujarati, to be used according to the convenience of the participants and the research team. The consent form will be signed both by the respondent and the researcher, and a copy of the form will be given to the respondent.

A field diary is also being maintained by the research team to maintain notes as well as larger observations related to the processes under review. Similarly guidelines for FGDs have also been prepared. Primary data will be collected in the three states of Maharashtra, Gujarat and Delhi, through ‘field notes and observations’, ‘intensive interviewing of participants as well as other key informants’ and ‘focus group discussions (FGDs)’.

The data collection / field work will be concluded by end March, while the analysis of data will begin in April 2013.

V.B. Study to document on the ethics and conduct of clinical trials by Swiss Pharma in India

Sama is partnering with The Berne Declaration¹ to identify and document on the ethics and

¹ Berne Declaration is an independent Swiss NGO with more than 22 000 members.

conduct of “Swiss” clinical trials that are underway in India. During this period an initial exercise was undertaken to identify clinical trial sites that were conducting drug trials for Swiss pharmaceutical companies in the cities of Delhi, Lucknow (Uttar Pradesh), Jaipur (Rajasthan), Ahmedabad (Gujarat), Mumbai, Pune (Maharashtra) and Hyderabad (Andhra Pradesh). As a part of this process, an extensive search was conducted through two trial registries –*clinicaltrials.gov* (US based registry) and *the Clinical Trial Registry of India* – using keywords such as the names of Swiss companies [Novartis/ Roche]/ trial drugs/ diseases in conjunction with the name of the city. This exercise yielded the team with the lists of various hospitals (both private and public), medical colleges, nursing homes, clinics and research institutes in the above-mentioned cities where the trials were been conducted. The seven sites were selected based on geographical criteria, importance in terms of number of clinical trial sites and their distribution and ease of access to the study team.

Along with this, interviews have also been conducted with representatives of Contract Research Organizations (CROs), Representatives of Regulatory Authorities (members of the CDSCO/ MoHFW) as well as the research head of the Indian subsidiary of Swiss pharmaceutical companies to further inform the study. Sama has also been monitoring and following up on parliamentary committee reports that have earmarked cases of lapses in the delivery of compensation including in those trials that have been conducted by Swiss pharmaceutical companies. The team is also keeping a keen eye on the media reporting of conduct of trials in India. The final phase of field work is ongoing, while preliminary categorisation of data and analysis has been started with the first draft of the report to be submitted to Berne Declaration by April 30th 2013.

V.C. Fact Finding Visit to Piduguralla, Andhra Pradesh

As part of Sama’s work and engagement on the issue of clinical trials, Sarojini visited Piduguralla in Guntur district, Andhra Pradesh, to meet and interact with trial participants, and organisations to understand what transpired during the course of the trials with the people who participated as well as the scenario post-trials.

During the visit some very serious continuing concerns regarding clinical trials violations came to light. The violations vis-a-vis clinical trials in Piduguralla case were reported by media last year. Majority of those who were part of these trials were women from extremely poor and marginalized communities, largely working as daily wage workers in lime kilns in the area. They have no access to proper housing, road, electricity. The communities are extremely poor, living in very difficult circumstances. The participants were mostly women, single, muslim, dalit and dalit Christians and were taken by local agents from the community to Hyderabad for trials and were given a drug (for breast cancer). No proper processes for consent were followed. These women and two men who were a part of the trials went through major side effects and the issue became public. The women after one year are still suffering from these side effects and cannot afford any treatment. The hemoglobin of some women is 5 gms.

The DCGI had initially cancelled the license of the Pharma company, but later withdrew the cancellation despite the fact that the company did not pay any compensation to these victims. Following local outcry and media reports a fact finding was carried out by a team from National Human Rights Commission (NHRC) in July 2011. Although some action towards treatment of participants was carried out at the time, even now no compensation has been paid.

During the visit, it emerged that people are commonly recruited for trials by agents, Clinical Research Organizations (CROs), etc. that are taking place in Hyderabad and even as far as Chennai. Follow up action and further investigation is being planned. Based on the visit findings, the issues and concerns have been raised with Dr. Syeda Hameed, Member Planning Commission, and will be taken up with Mr. Anand Grover, the UN special rapporteur for health.

V.D. Advocacy on Regulation of Clinical Trials

- Invitations from the MoHFW to be part of review committees provided spaces and opportunities to ensure wider participation in such processes of organizations, individuals towards policy formulation and enable some measure of public critique for the first time.
- Advocacy was ongoing with members of the Drugs Controller General of India office, the MOHFW and others. The 59th Report of the Department Related Standing Committee on Health and Family Welfare, on “Functioning of the Central Drugs Standard Control Organization (CDSCO)” was released on 8th May 2012. Sama, along with several other groups and networks has been extremely appreciative of this report and came out with a press release stating the same. Similarly, a memorandum was also sent to both the Prime Minister of India as well as to the Minister of Health and Family Welfare, demanding that immediate cognisance be taken of the directives in the report and to immediately put into action the remedial steps as suggested in the report.
- Sama participated and presented on clinical trials regulation, post trial access at the fourth National Bioethics Conference, Hyderabad in December 2012.
- Towards processes at the global level for monitoring unethical conduct of clinical trials and also demanding for accountability of the pharma industry along with the national governments, Sama along with WEMOS, SOMO based in Netherlands has been working on these aspects collectively.
- Two two-day capacity building workshops on *Ethics and Regulation of Clinical Trials in India*, were organized in Delhi (21st-22nd February, 2013) and towards informing and initiating dialogue and building capacities of students, fellow activists, media persons and others in the regulatory and ethical aspects related to the conduct of clinical trials in India.

VI. Enhancing Adolescent SRHR through Health Systems Engagement

This three year project was initiated during this period with the broad aim of (a) building and strengthening the perspectives and capacities of organizations and networks engaging with adolescents on adolescent SRHR by sharpening health system engagement and advocacy efforts, (b) enhancing perspectives and capacities of healthcare providers towards provision of gender sensitive and adolescent friendly SRHR services, (c) informing the JSA mandate and the campaign for Right to Health and Health Care vis-à-vis adolescent SRHR, (d) building linkages and strengthening alliances between and within civil society actors and networks, and state actors and health care providers towards comprehensive action for gender sensitive and adolescent friendly health system response. While the overall project will have national applicability, specific project activities will be implemented in five states - Orissa, Jharkhand, Madhya Pradesh, Chhattisgarh and Rajasthan.

A preliminary review of literature, mapping of schemes / programmes in the health context for young people was initiated to gain insights into existing realities, especially in the five states. Visits and interactions with organisations from the states towards mapping and assessing issues, experiences and challenges in the context of young people's health / SRHR was begun and will be continued and consolidated in the forthcoming months.

VII. Knowledge Creation and Dissemination

- Hindi booklet *Niji Kshetra Mein Muft Upchaar; Mythic ya Sacchayee*, was developed based on Sama's study report *Free Treatment: Myth or Reality* was developed, to enable wide outreach and access to information on free treatment in private hospitals in Delhi; to mobilize involvement of communities, particularly the vulnerable about their entitlements as well as towards building the accountability of the hospitals. These information resources are also expected to facilitate monitoring of provision of free treatment by hospitals, through local community / people's watch groups.
- *Birthing a Market - A Study on Commercial Surrogacy* based on Sama's research on surrogacy was published.
- *Can We See the Baby Bump Please?* – explores questions and concerns through the experiences of surrogate women. The film's narrative examines the ethical challenges, medical malpractice, and potential exploitation that can occur when surrogacy is practiced in a legal vacuum, while also highlighting and understanding the interplay of surrogate women's choices, contexts and compulsions.
- *Reproductive tourism in India: actors, agencies and contemporary transnational networks* – a draft report based on the study was completed during this period. Sama, Prof Rama Baru, Prof Mohan Rao and Dr. Ramila Bisht (JNU), Dr Susan Murray (Kings College London) contributed to the report based on the multi site study.
- An information / resource kit is being developed as a part of work on Violence as a Public Health Issue. Information and material on different aspects of domestic violence

and health care response was compiled and developed during the project period. Presentation and designing of the material for the kit was undertaken during this period. The resource kit is envisaged as an important reference / resource that can be used particularly by community level organizations / networks to mobilize around action to strengthen health care response to survivors.

- A working paper –*Evaluating the Impact of Health Insurance on the Right to Health* based on review of existing literature, was completed during this period.

VIII.D. Capacity Building for Sama Staff

Apart from ongoing internal process for building capacities, the following were some of the workshops / trainings that Sama staff participated in towards enhancing their capacities:

- Training on Zotero: The training on Zotero was organised by Jawaharlal Nehru University and Kings College London to build skills and capacities in use of Zotero which is a tool to enable collection, organizing, citing, and sharing research sources.
- Workshop (in house) on *Reproductive Justice, Health and Rights* organised by Sama in November 2012 Delhi, to discuss the concepts of reproductive justice and rights and reproductive health; trace the historical and political trajectory and debates, particularly in the feminist movements and deliberate the limitations of the concepts / framework.
- Two day workshop (7th -8th, Dec. 2012) on *User Charges, Public Health Facilities and Universal Access* organised by Centre for Women's Development Studies and Centre for Social Medicine and Community Health, Jawaharlal Nehru University to explore and understand the state level trajectory of user charges in public health facilities along with the experiences cutting across caste, class and gender.
- Sama participated in a Seminar on Adolescent Reproductive and Sexual Health organised by TRIOS in June 2012 That presented the research by TRIOS on ARSH. This was useful for Sama's initiative vis-a-vis engagement with health systems for adolescent health.
- A workshop on issues around R & D and Access' organized in December 2012 by the Delhi Science Forum, Third World Network, Sama and MSF-Access Campaign. A session on Clinical trials in India was coordinated by Sama, which examined the market based model that drives clinical trials in India. Discussions also focused on the need to address the current policy framework also looked at different models for conducting clinical trials, including public funding of trials. The workshop also gave an opportunity for Sama members to develop an in-depth understanding of the larger issues related Research and development.