



DEAD WOMEN TALKING

Report of a workshop

June 2nd and 3rd 2012

at

Center for Research on the New International Economic Order (CReNIEO), Muttukadu ,
Chennai, Tamilnadu

Organizers

CommonHealth

Department of Community Health (CHAD), CMC, Vellore

Sama

Society for Community Health Awareness Research and Action

DEAD WOMEN TALKING

Learning from women's experience

Maternal mortality continues to be an unjustifiably significant problem in India. In spite of the issue garnering a lot of attention and being the focus of policy and programme by the Government of India and international bodies, the solutions proposed often fail to capture or be relevant to the lived realities of people. In the past year or so, there have been a number of documentations of maternal deaths by civil society groups from different parts of India including from the so called 'developed' states like Tamilnadu and Kerala. All of these reports bring out the purely technical and indicator oriented approaches without looking to the social determinants, health systems and other broader aspects.

Civil society groups have been using a number of innovative methods like community monitoring and planning, '*jan sunwais*', media campaigns strengthen health systems using a rights based approach stressing on accountability of the system, deepening democracy and governance.

In this context it is being proposed to start a process whereby all those working on women's health and maternal mortality in particular in the various fields come together to enable the center staging of the lived experience of communities and families of women who die unnecessarily as well as the voices of those who have died. It is hoped that this process will lead up to a coordinated plan for taking learnings from these various sets of documentations forward into policy and programme.

The overall process will have the following components;

- The development of a framework to look at maternal mortality in the Indian context which evolves from the various case studies that is collected and collated.
- The evolution of tools for the collection and analysis of these in the future and on a larger scale.
- Collection of evidence that goes beyond numbers and is respectful of the experience of women, families of women and communities.
- Developing 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.
- Developing alternate approaches that are rigorous, systematic and at the same time grounded in the experienced reality of the women who died.

As a first step it is proposed to have a two day meeting in Chennai to launch the process and fine tune its various aspects. The overall objectives of the first workshop were:

- Sharing of various experiences of maternal mortality from different settings.
- Evolving / clarifying the framework and technical expertise to analyze maternal mortality in India.
- Evolving / modifying the tools to make sense of this reality in a way to contribute to real solutions.
- Clarifying and agreeing upon future steps in the process.
- Evolution of a longer term plan including the core group that will facilitate the process, time lines, funding etc.

The workshop was held on the 2nd and 3rd of June 2012 at the Center for Research on the New International Economic Order (CReNIEO), Muttukadu near Chennai. The workshop was attended by 27 individuals from all over the country and with diverse backgrounds. (List of participants with contact details in Annexe I

Day 1 – June 2nd, Saturday

Morning Introductory session

The workshop began with a welcome by Subhasri.

There was then a round of introductions by the individual participants who also briefly shared their expectations from the workshop. These were then summarized and there was some time for discussion around some of the points that were raised.

The expectations shared broadly reflected the various concerns that the attendees came with.

- One of the most important aspects that came forth in the session was the need to go beyond maternal mortality statistics. There was the need to see the faces behind the numbers, to see the 'near misses', and the need to discern the concerns of women and letting the voices of the community be heard.
- Towards this end there was a hope that the workshop will lead to the evolution of an alternative framework. That is robust, scientific and rooted in the lives of women, that understands what is happening in the larger health and macro system and that critiques policy. Thus there was a clear call to evolve an alternative approach to measuring and learning from maternal deaths and near-misses. One of the clear messages that came out of the discussion was the fact that the maternal mortality was seen as social injustice and the whole process was seen as a step towards building a body of knowledge to increase the accountability of the system.
- There was also the expectation that the workshop would lead to the evolution of a long term perspective of working together of the group, with an aim of bringing together diverse organizations and networks with varied skills to make every death / near-death count. This would include working together, sharing and evolving tools and creating a body of evidence that would reflect the reality of women's lives, the state of health systems and decision making within health systems and also influence policy and practice. As part of the discussions on the form that this coming together would take, the idea of setting up a sentinel surveillance system was introduced.
- During the discussions some of the practical aspects of working on maternal mortality were also shared. These need to be kept in mind while evolving any system of collecting and collating evidence. These include:
 - ✓ The difficulty in accessing information regarding maternal deaths. This difficulty includes community level hesitancy to talk about these, system reluctance to record and share accurate data and the capacity / training / tools of those who go to collect the information.
 - ✓ Similarly there was the difficulty of gathering data regarding deaths in early pregnancy and especially after / related to abortion.
 - ✓ It was also pointed out that different pieces in the puzzle required different skills

and approaches. The skills required to collect technical treatment-related information, information regarding the gender power relationships at the household level and the systemic issues at different levels contributing to the death respectively would be very different. Thus there is the need of a coming together of different skill sets.

- ✓ Similarly there is a need to assess / plan the skills / capacity needed for such a comprehensive documentation. One approach would be to map out already existing skills, while another would be to plan on the development of such skills.
- There was also some discussion on a possible tool for the process of collecting this information. The points raised in this connection were,
 - ✓ While the tools need to be comprehensive in the sense that they will need to aim at capturing the whole experience / chronology of the maternal death, the larger the tool the more the chances of it becoming unwieldy and thus not serving the purpose.
 - ✓ Since maternal mortality is a complex and multi-layered issue, we need to develop a tool / tools that capture this complexity.
 - ✓ The possibility of developing smaller tools focused on specific aspects of the problem was discussed.
- There was also the call for the need for clarification of three crucial questions at every step of the process, and make sure that there is a broad consensus on these in the group.
 1. WHO is collecting the information?
 2. WHY are we collecting the information?
 3. WHO is doing the analysis?

After this round of introductions and discussion there were a series of 4 presentations of studies on maternal mortality from different regions of India. The first presentation was by Jithesh who was presenting a qualitative study of maternal deaths and near-misses from Wayanad District in Kerala. The second presentation was by Ajay Lal from SATHI, Barwani, who presented the mobilization and subsequent legal action initiated by JADS following a series of maternal deaths in Barwani district. This was followed by the presentation by Priya John, which highlighted the work of Soumik Banerjee in Godda in Jharkhand, the final presentation was by Mudit Mathur who presented the investigation of the series of maternal deaths in Jodhpur at the Ummed Hospital.

Kerala

Jithesh made a presentation titled, “Dual burden of Tribal Status and Pregnancy”. This was a qualitative study of maternal mortality and near-misses in Wayanad district in Kerala. This district has the highest tribal population in Kerala. The study underlined the regional and social disparities within Kerala, which is considered one of the most advanced states in India on a number of fronts. Jithesh used the methodology of “social autopsy” (which was the use of qualitative methods to explore the social reasons leading up to the death. These include

assessing gender power relations, decision making, instances of neglect and violence etc.), and one of the key findings was the “social distance” between the tribal population and the health system that was one of the key contributors to maternal deaths. Some of the key points made in the presentation were about, the important contribution of gender power relations in the maternal deaths. It was also shown that women had to travel huge distances many times having to retrace their tortuous journeys just to fit in with the referral chain of the government, despite the fact that these hospitals are not fully equipped to handle these complications. Jithesh also highlighted the systemic causes including the fact that some complications were not recognized and staff were more interested in getting the complicated case “off their hands” than trying to treat them. Thus the combination of sheer physical distances, a lack of faith in the health system, inflexibility in the way the health system sees and treats tribals, inherent quality issues and social factors all contribute to Wayanads disproportionately high contribution to maternal mortality in Kerala.

Madhya Pradesh

The next presentation was by Ajay Lal of SATHI, Barwani, Madhya Pradesh. He described in detail the case study of the Jagrut Adivasi Dalit Sanghatana (JADS) which took up the issue of maternal deaths after a series of deaths in the district came to light. JADS undertook massive mobilizations and rallies, brought out the issue in the press and facilitated a number of fact finding missions by government (both central and state) as well as civil society teams. This brought huge pressure on the state government too to respond. Subsequently JADS has used the route of filing a Public Interest Litigation in the Indore High Court on the issue of maternal deaths based largely on the recommendation of the Advisory Group on Community Action (AGCA, which is a standing committee of the NRHM). Thanks to this continuous pressure JADS now reports improvements in a large number of areas in the functioning of the district hospital. Ajay also highlighted though the need for continuous follow up as well as monitoring the implementation of various court orders and the maintenance of these improvements.

Jharkhand

The next presentation was by Priya John who made a presentation on the work of Soumik Banerjee. This was the follow up of 23 maternal deaths among nearly 3150 live births in the Godda in Sundarapaharia and Poreyahat blocks. This is a predominantly tribal area with Paharia and Santhal tribes. The health status of the community itself is pathetic with huge amounts of malnutrition and poverty dominating. Among those who died a huge majority were from the tribal groups and had very poor educational and socio-economic status. An analysis of the deaths showed the very poor state of Ante-natal care, health education and access to health care. The study identified there were significant delays in all the three phases – in deciding to go to a hospital, in actually reaching a hospital and in the commencement of the treatment. A significant proportion of deaths took place at home and in transit to hospital especially the referral unit which was nearly 70kms away in the neighbouring state of Bihar. The study also documented the utter neglect and callousness the women and their families had to face. It was also highlighted that there was no maternal death audits being conducted by the state.

Rajasthan

Mudit of Prayas in Rajasthan presented the findings of a study conducted to look into the death of 18 women admitted to Umaid Hospital in the months of February to March 2011. The presentation described the extreme difficulty in obtaining basic information about these deaths from the relevant hospital authorities. It was with great difficulty that the study team obtained the list of women who died. However it was unable to meet with any of the doctors or officials of the concerned hospital who refused to talk to the team. There were large inconsistencies between the official causes of death recorded, the hospitals contention that the IV fluids were contaminated etc. It was also highlighted that reports of a central government team pointed out to several irrational practices in the hospital. Interviews with the families of the women who died also pointed to gaps in quality of care and incompetence among staff. Similarly patient's families were asked to purchase from outside and at great cost basic emergency supplies and one of the patients family was also told to arrange for a "ventilator". Issues with the quality of care available at CHCs and FRUs nearer the patient's homes which should have been able to handle many of these complications were also pointed to as many of the these patients were referred to Jodhpur for conditions that should have been handled by these hospitals. At this point it was also mentioned by others who were following the investigation that one of the main reasons for such difficulty in gathering information was that there seemed to be the interests of a number of senior doctors (who are very influential) that was at stake.

After the presentations there was a round of discussions for clarifications as well as for others in the group to share their experiences and insights. Some of the points that emerged during this discussion were:

- It was most obvious that those affected disproportionately were the poorest and most vulnerable groups. It was also plain to see that the public health system was just not responding adequately and questions of accountability arose consistently.
- We are possibly missing out deaths occurring early in pregnancy and especially those due to abortions and particularly unsafe abortions.
- While the maternal death review (MDR) process was not at all happening in a number of places though it has been mandated, and where it was happening it was not happening in a comprehensive manner, feeding back learnings into the system. There was thus the need for significant strengthening of the MDR process. There was a call for greater civil society involvement in the process as a way forward to strengthen these.
- It was further pointed out that all the Verbal autopsy formats in use while having strengths in picking up various technical and some even systemic aspects, there are no formats / tools in wide use that pick up many of the social issues that have been highlighted in the presentations. Thus there was a call to strengthen these aspects of the tools. It was pointed out that there was an urgent need for a larger and more comprehensive tool to capture this complexity. It was obvious that what was necessary was a multi-layered investigation and people with different capacities and perspectives contributing to building up a deeper understanding of the death. Some of these would be primary collection of data, some would be collection and collating of secondary data and the final report would probably be based on triangulation of

the various sets of information. Similarly there is a need to be able to understand the systemic causes behind the technical causes and again tools need to be developed for this. However despite the need to capture this complexity we need to keep the tool simple and doable by communities and civil society groups all over the country. Thus another idea that cropped up was that the proposed investigation could be done in steps of increasing complexity / capturing different and more complex dimensions.

- One of the issues that came up for a lot of discussion was the need to balance the “non-threatening” and “learning” features of such MDR processes and the need to protect the Rights of communities and provide justice and redressal. While the creation of a non-threatening atmosphere depends on the maturity of the whole system, one of the questions is about the ability of such a process to actually question cases of neglect and incompetence of people in positions of power, especially in such a hierarchical system as the public health system is.
- This point led to the discussion around the question of motivation and accountability within the system. It was pointed out that it was well recognized that within the health system staff only recognized accountability to their seniors (ie. within the system) and not to the people. Similarly what drive the system are very different motivations from what is driving civil society groups. Thus unreal targets and pressure to fulfill them as well as power struggles between various levels of the system seem to drive them more than any concern for equity. The system responds based on its internal shared understanding of maternal mortality.
- Given the multiple referrals that women usually underwent and those between the private and public sector it was important to move from the concept of individual responsibility to systemic accountability. At the same time working with communities means the need to get redressal and justice, these various pushes and pulls need to be balanced.
- Another practical issue that would contribute to the design of the tool and the system to collect and collate this is the extremely variable nature of availability of the information. Thus in Barwani there was easy access to technical information got from case sheets, while in Jodhpur there was absolutely no access to original records etc. the tool and system evolved needs to keep these in mind. While filing RTIs and other such methods need to also be kept in mind.
- There was also a discussion around the three delays model that has dominated the studies on maternal mortality so far. This fails to capture deaths during delivery as well as significant contributors like food security, social security and poverty as direct causes. Similarly it may miss systemic causes like human resource issues.
- Of course underlying all of this is the inherent power differentials in – who dies, who collects information, who analyses this information, and who takes action and what results form all of this activity.

Post Lunch session.

In the post lunch session Subhasri summed up the discussion of the morning as leading to two clear emerging collective understandings. These were that maternal deaths went much beyond the health system and that we are setting out to study and collect information regarding maternal deaths with a clear understanding that the overarching framework was

one of increasing the accountability of the health system.

With these in mind it was proposed to engage as a group with the Verbal autopsy tool developed by the National Health Services Resource Center (NHSRC), since this was one of the most widely used tools (See Annex III). It was suggested that we engage with this tool and add dimensions / questions to the tool that we feel need to be added to make the tool more comprehensive and capture the complexity that emerged from the presentations of the morning as well as the discussions.

At this time there was also a discussion on whether we are designing a tool for an ongoing surveillance or as a response to a crisis. It was discussed and clarified that we probably need to be doing both. It was decided that we will first work on listing out all the dimensions that need to be studied / documented to study a maternal death. Once this is done we can decide the exact format of the tools, the number of modules, who will do it etc. It was also decided that the tool would capture all deaths of women between the ages of 14-45 (? Or 49?) and then gather detailed information about all those identified to be pregnancy-related deaths..

During the lunch break the participants were asked to write on cards three issues that emerged from the morning discussion that they feel were most important. These cards were then grouped together and the following major themes – which also formed the themes for the different groups- emerged.

1. Power and exclusion.
2. Social determinants of health.
3. Health system – systemic / quality related issues.
4. Health system – rights and entitlements related.

The participants were requested to choose the group they would like to work in and the groups were requested to deliberate on the particular dimension, work with the NHSRC tool as a starting point and list dimensions / questions that needed to be added. It was also requested that the groups identify the probable source of the information to be collected. The participants then broke into subgroups and it was decided to have the presentations of the groups the first thing the next morning.

Day 2 - SUNDAY 3RD JUNE

GROUP PRESENTATIONS

The second day of the workshop began with report-back from the different groups. Each group presented domains that they would like to see added to the maternal death reviews.

Group 1: Social Determinants

The group reporting on social determinants of maternal deaths identified neighbors, woman's relatives, ASHAs, ANMs, anganwadi workers who the woman might have been in touch with as potential sources from which information for the maternal death review may be sought.

The following were the key dimensions of social determinants identified by the group for inclusion in the maternal death review data-collection instruments:

Individual level information

- Marital status and marriage-related (early or forced marriage? How treated by husband and in-laws?)
- Nutrition
- Work, work burden, care-giving burden and time available for rest
- Socio-economic status
 - Economic status – not to be measured by money spent – difficult – instead look at access to credit, land, assets etc.
 - Access to social networks – participation in village-level activities, access to panchayat members (friends/relatives), whether member of panchayat etc, # of people who attended the funeral
- Poverty (BPL?)
- Whether member of/participating/beneficiary of NREGA, RBSY, JSY, IGMSY
- Power and power relations of the household: links to panchayat members; social networks, people in power official positions held by family members
- Gender-power relations influencing decision-making:
 - regarding fertility choices (# of children, son-preference etc)
 - regarding health-seeking
- History of violence (in the family or external such as rape etc).
- Water and sanitation
 - How far the potable water source is (to assess work burden)
 - Access to sanitation (to determine whether women are able to deal with side-effects from IFA etc keeping in mind hygiene, dignity, and privacy concerns)
- Mobility (migrant workers, movement between natal and marital homes) or involuntary displacement (development-related, natural disasters, or conflict-related etc) and whether there is continuity in terms of access to maternal health services
- Obstetric history and access to contraceptives
- Access to SRH information (especially for adolescents) and information about health and other services

Community-level information:

- Trends regarding discrimination
- Exclusion because of geographic access to health services
- Exclusion related to HIV status, disability

If it is a case of abortion—then some additional questions around health-seeking, stigma, pressure, possible humiliation in public health system therefore approaching unsafe provider etc.

Group 2: Power and Exclusion

The next group presented questions to be added in order to include power and exclusion as determinants of maternal deaths. The representatives of the group said that the group had gone through all the formats and felt that there might be overlaps across various groups in terms of dimensions included.

The first dimension examined was vulnerabilities. This included various manifestations of Gender power inequalities were to be included, such as

- Intra-household dynamics: position, no. of pregnancies and sex composition of the children, violence in the family.
- Community: socio-cultural practices, abortion including sex-selective abortions
- At the facility/with practitioner: disregard on the part of the practitioner for bodily integrity

Other dimensions of vulnerability to be included were membership of scheduled Caste/Tribe; poverty status, and geographical location, esp. residence in remote and under-developed areas.

The second dimension was household characteristics, including caste; the nature of work members of her household were engaged in (formal/informal, whether migrate for work); whether BPL or internally displaced; whether joint or nuclear family.

The third dimension was characteristics of the woman: Age of woman at the time of death; marital status; if married, age at marriage; Position in the family in terms of relationship with husband and with members of the marital family; substance use (both woman and husband); education (both woman and her husband); Till which month was she working during her pregnancy and how soon after delivery she started working (if death postpartum); and whether the woman had any disabilities.

The fourth dimension to be explored included the woman's reproductive and medical history – previous pregnancies and deliveries, sex-composition of children; no. of pregnancy losses and abortion and survival of children born.

The fifth dimension to be included was information on whether the woman had been a victim of intimate partner violence. The respondent may be asked about the kind of violence; history of violence; and to describe any one incident of violence to get an idea of the severity of violence.

The group made several recommendations for better coverage of deaths from unsafe abortion.

Currently, maternal death reviews by default exclude clandestine terminations of pregnancy, which are more likely to be unsafe, and only abortions that have social sanction get reported, if at all. If all deaths in women aged 15-49 are reported, and women's marital status is noted, then identification of unsafe abortion could be done through the primary informer format, based on symptoms such as fever, swollen abdomen and bleeding. For suspected cases of unsafe abortion the MDR – abortion related questions may be used, and in addition, reason for termination of pregnancy may also be asked. The group suggested that abortion queries of both verbal autopsy formats – pg. 3 of format 1, pg 10 of format 2 be combined

The group suggested that the information outlined above may be collected from the person present with the dead woman at the time of her death and in the immediate time-period before death; members of maternal and natal family; neighbours; and that triangulation of information from different sources may be done. Community level FGDs may be conducted to better understand the condition of life of vulnerable communities, their access to and experiences with practitioners and facilities.

Group 3: Health system

This group had worked with the current Maternal Death Review formats and made additions and changes to it. These consisted mainly of details related to characteristics of the woman, the kind of care received and circumstances surrounding the woman's death.

Group 4: Rights

This group identified two sources of information: interviews with members of the family and neighbourhood; and information based on direct observation of the concerned health facilities. Information from interviews were further grouped under five heads: Information received, whether received all entitled services, whether there was informed decision-making, whether the quality was good, and whether there were mechanisms for grievance redressal.

Information

- Did any health worker inform you (family member) about possible danger signs during pregnancy, delivery and postpartum period? If yes can you remember a few points of what they said?
- Did you fully understand what the health condition of the deceased woman was?
- Were you told about all the health related procedures and tests etc?

Received all entitled services?

- Does your family get all relevant entitlements such as nutrition, PDS, livelihoods etc?
- Did the woman get paid leave during maternity /maternity benefits?
- Did the woman receive all entitled services like ante-natal checkup (all tests like HB Urine and BP) transport support, etc ?
- Whether abortion services received (or not) and whether there were any barriers? ** Needs thinking through on how this question may be crafted and posed to a family member.*

- Did you get documents (records) about all the services, all the medicines, all the tests, all payments made?

Decision-making

- Were you informed and asked about the decisions regards treatment, to carry out any procedure, referral etc
- Were you informed about all possible options?
- What was the process followed for taking informed consent? Were there any unexplained declarations of non-responsibility that a relative was asked to sign?.

Quality, dignity

- Were you happy with the way the woman was treated?
- Did you face any discrimination, abuse, violence or anything which made you uncomfortable?
- Did the care provided ensure privacy and dignity? (Covering up the body, preventing men or others from coming in etc etc)

Grievances

- Suppose you had any grievance, question or complaint, did you know whom to approach or how to register the grievance? Was there a notice or a toll-free number displayed, or a help-desk?
- (If there had been an attempt to make a complaint/seek redressal for a grievance) Did anyone try to put any pressure on you to change the grievance or complaint?
- Did anyone give you any compensation? Apology?
- In case of the death in the hospital, were you told about the cause of death, how was it explained?
- Did you get a death certificate, a post-mortem etc?
- Was there any support to take the body home?

Checklist of what to look for in a health facility

- Presence of a help-desk, notice board, toll free number displayed?
- Mortuary van?
- Doctors on duty – list? Nurses on duty – list?
- Are all records regarding the treatment of the woman available on request?
- Was the doctor on duty when the woman died? Where did the woman actually die, who was attending at that time? Who was handling the birth?
- What is the condition of the labour room, how many beds, how many women usually come?
- Does the Labour Room clearly display charts/instructions about what to do if something goes wrong? Protocols for managing complications?
- **Health workers' rights** – their workload, duty hours, their level of recent training and supervision?

DISCUSSION AND AGREEMENTS

After the presentations, issues to bear in mind when finalizing the expanded MDR tool (intended to provide insights on the ‘causes behind causes’ of maternal deaths) were highlighted. These included:

- Access to the information sought by independent reviewers
- Competency required for collecting the data, which will have a bearing on who should be a part of data-collection teams
- Achieving a balance between desired information and its cost implications
- Triangulation through multiple sources for establishing the validity and reliability of the information
- Analysis and presentation of the information collected to facilitate identification of crucial determinants and facilitate policy and programmatic changes

Surveillance, in-depth MDR or both? Towards what end?

There was extensive discussion to reach an agreement on the ultimate purpose of this exercise. What did we really want? Sign posts which will alert about what is happening across the country? Or a detailed in-depth review each time a woman dies?

It was agreed that we are talking about the need for both, a surveillance system and independent maternal death reviews. Places where there is under-reporting of cases may have to start with establishing a good surveillance system while in other places where most cases are identified, in-depth reviews can be done.

As for the surveillance system: there would be ‘reporting’ of maternal deaths with a minimum set of indicators from many different groups/sites within India, starting with but not limited to those present at this meeting. The system can be web based and the information could be logged in from the identified centers on a pre-determined format. CMC Vellore would be happy to host the web-based surveillance system and collate the information received from different parts of the country. This will help identification of emerging trends in different parts of the country and alert us to sites and issues that call for further probing.

We also want 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. The independent MDR team should have credibility and independence, and be able to negotiate the powers within the system. It would therefore be important to include within the team people such as senior public health and medical professionals.

In addition to the surveillance and independent MDRs, there may also be need for ‘Fact-finding’ missions and reports like those done in Barwani and Jodhpur following a large number of hospital deaths. These were more in the nature of crisis-response, whereas the others were more sustained and long-term endeavors.

What do we hope to achieve through these processes?

Outcomes are visualized at multiple levels. At the community-level, the members of VHSC and other local accountability mechanisms would be involved in collecting the information and also in initiating action on the local level determinants of maternal deaths. The independent MDR review will also serve as a 'watchdog' which will identify health-system gaps; and in advocating 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. The entire process may be seen as one intended at 'deepening democracy' and enforcing accountability for maternal deaths of the health system and the government to its citizens.

Fine-tuning the content and process of MDR tools

- Indicators need to be identified pertaining to the various dimensions of information on which we planned to include questions. This will help optimize the number of question and to eliminate repetition.
- Questions needed to be prioritized and the tool be designed such that the entire interview does not take more than 45 minutes. We had to be mindful of exhaustion on the part of respondents.
- The tool would consist of both, structured and open-ended questions to allow for gathering qualitative information; and at the same time, there would be a guide for the kind of qualitative information being sought.
- Collecting information on maternal deaths from a bereaved family is a delicate task requiring sensitivity on the part of data collectors. Special training will be required. The quality of information will differ depending on whether data is collected by an 'outsider' and someone who has the community's trust.
- At the first level primary reporting should be done by the sustainable source like VHSC members. The MDR data collecting team should include public health/medical professionals working in partnership with and guided by local activists and members of community-based organizations in order to be able to gather valid and in-depth information of relevance to the community.
- A detailed set of 'guidelines' for information collection will be developed to accompany the MDR tool. This will include definitions, tips for data collection and guide for eliciting qualitative information. The guidelines will also include a 'code of conduct' and ethical guidelines for those collecting the information so that the process of data collection does not become an undue burden to the bereaving family. The Sanghatan in Barwani had developed such a code of conduct and we could draw on this.

Rakhal shared about the action-reflection cycle which is in practice in Tamil Nadu. This involves analysis at the local level to evolve action plans for handling the grievances and service delivery.

Sandhya shared about software called 'Usahidi' which was being used by Sahayog to generate data from the local level and report in visual form. Jashodhara shared about the voice based system for screening of deaths.

NEXT STEPS

Post lunch, the group decided on the next steps, divided responsibilities and developed a time line for the activities. These are summarized in the following table

Content	Responsibility	Suggested Date
Report of the workshop	Dr. Rakhal and Dr. Sundari	Draft- 25h June Comments to send by 30 th June Finalization by 7 th July
Tools and Process-		
• Putting together	Dr. Subhasri, Aditi, Shashi	19 th June
• one tool		30 th June
• Separate instruments (sources, scenarios including core sentinels)	Dr. Subhasri, Aditi, Shashi	15 th July
	Jashodhara, Jasmine, Leela, Shobha	
Guidelines, analysis and framework	Renu, Ajay, Sandhya	31 st July
In depth reviews	Leelaben	2 nd and 3 rd July
NAMMHR meet (capacity building on reviews)		September
Sentinel Surveillance	CHAD	August 31 st
web based startup	CHAD	November 1 st
Piloting		Early November
Review after 6 Months		May 2013

ANNEXE I

LIST OF PARTICIPANTS

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ANNEXE II

FINAL PROGRAM OF THE WORKSHOP

DEAD WOMEN TALKING

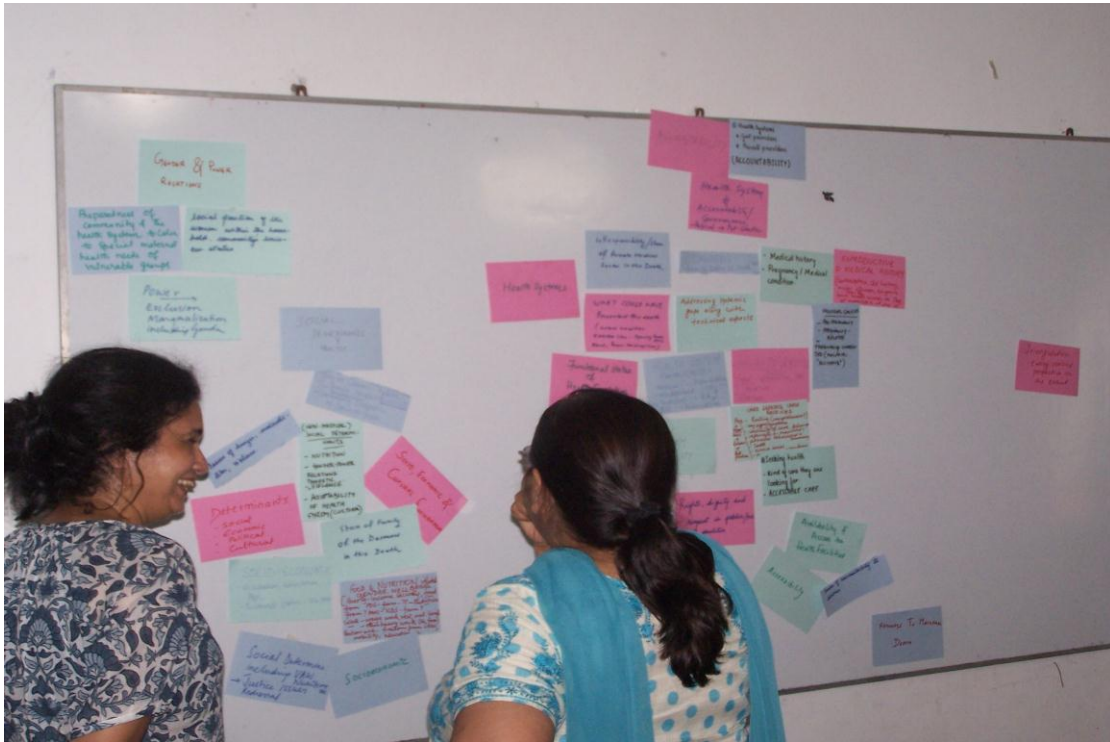
Date	Time	Programme	Facilitation
02/06/12	8.30 am onwards	Registration	
	09.00am – 09.15am	Welcome and introduction to workshop	Subha Sri
	09.15am – 10.15am	Introductions of participants with expectations	Moderator: Renu Khanna
	10.00am – 10.30am	Open Discussion	
	10.30am – 10.45am	Tea break	
	10.45am – 1.00pm	Presentations from different regions (4 presentations), followed by open discussion.	Moderators: Jashodhara & Aditi Jithesh – Kerala Ajay Lal – Madhya Pradesh Priya John – Jharkhand Mudit Mathur - Rajasthan
	01.00pm – 02.00pm	Lunch	
	02.00pm – 02.30pm	Summing up emerging themes and introduction to group work	Subha Sri
	02.30pm – 05.00pm	Small group work on tools	Groups
03/06/12	09.00am – 10.00am	Presentation of Group Work and finalization of tool	Moderators: Leela Visaria & Rakhal Group Presentations.
	10.00am – 12.30pm	Discussion on processes of data collection and analysis.	
	12.30pm – 01.30pm	Lunch	Moderators: T.K.Sundari Ravindran & Sarojini Open Discussions.
	01.30pm – 03.30pm	Next steps and division of responsibilities	Moderator: Renu Khanna

ANNEXE III

NHSRC MATERNAL MORTALITY VERBAL AUTOPSY TOOL

Source URL:

GLIMPSES OF THE WORKSHOP



(I) Classifying the emerging priority areas



(II) Group discussions in progress



(iii) A section of the participants



(iv) A section of the participants



1. An evening at the beach

Report Prepared by:

T.K. Sundari Ravindran & Rakhal Gaitonde

Individual session rapporteurs:

Day 1 AM: Deepa & Shelley

Day 2 PM: Sandhya & Priya John

Day 3 AM: Sanjitha & Rohini Kumar