Report of the Planning Meeting of Dead Women Talking Process Forward and Right based monitoring of Contraceptives

JP Naik Centre, Pune (9-12 March, 2016)

9th March, Day-1

Dead Women Talking Phase-II Planning Workshop

Session: Welcome and Objectives of the meeting

The four days planning meeting started with introduction of the participants. The design of the meeting was explained by Renu Khanna. She said that during the first two days, the discussion would be around how to take the Dead Women Taking process forward and in the last two days, rights based contraceptives monitoring would be discussed. She shared the background of the meeting - in the last DWT advocacy meeting in Jan. 2015 (report of which is available at: http://www.commonhealth.in/resourses/DWT%204%20Report-%20Final%20Draft,%208th%20April.pdf) it was discussed that one more round of DWT is required. To plan what issues should be focused during the second round, a meeting was proposed to collectively decide on a framework for the second round. Should perinatal deaths, near miss audits be part of the second round? In Annual General Meeting of Bhopal, the Advocate's Guide was introduced to the participants and many showed an interest in monitoring PPIUCD. Though the purpose of two meetings is very different, to economize members' travel time, these two have been organized one after another.

Subhasri opened the DWT phase –II planning meeting by sharing that partners from DWT-I will be participating in the second round as well. In this phase along with maternal deaths quality of maternal health services could be monitored. The scope of 2nd phase can be widened to include maternal morbidity. She added that piloting of perinatal deaths audit was done last year so should perinatal deaths be part of this round as well? We need to discuss this. The purpose of this two days' discussion is to concretize a methodology for the second round. She requested everyone to share their interest in attending this workshop so to arrive together at a common ground.

Sharing from participants

A.S. Nagpal, Punjab: after reading the DWT report, his curiosity was aroused - why is Punjab's MMR is high as 114 despite good transportation and good referral system, good infrastructure and good HR staffing available in the state in comparison to other states? MDR meetings are also conducted regularly. Before reading the report he never tried to know why the numbers are so high, never thought that these deaths are preventable, why social audit is not being done and why causes of deaths are not being analyzed. He shared his critique of the National Health Mission. He gave an example - total population of Ludhiana is divided into 34 PHCs and services are of poor quality. These PHCs can't cater to the needs of the entire population. They don't think about issues of slum dwellers, their maternal mortality and morbidity. Despite him being the member of District Health Society, he has been denied

data on MDR. The insights of this meeting will help in working with DHS officials for improving maternal health.

Sundari felt that maybe we were being too ambitious - in the second round we want to do perinatal mortality audits, maternal morbidity and near miss audits in addition to social autopsies? We need to be clear on what can be covered during this phase. Some people will be interested in doing both maternal mortality and near miss audits; some would want to do either perinatal or maternal mortality audits. Finally, a call can be taken what is feasible. Also, while discussing this change in policy context needs to be seen what is feasible.

Rahi Riyaz, Jammu &Kashmir: his interest is to understand the issue of maternal health as he has seen women bleeding profusely in the health centres and they are denied health services. This issue is very important in the context of Jammu & Kashmir especially in conflict areas and remote areas of Leh and Ladakh where women die because of lack of referral transport. Rahi informed that the situation under Governor's rule in J&K is grave. 100 doctors were terminated from employment recently. Causes of deaths are not analyzed, medicines are not provided free of cost. Patients are referred from one district to another. Motivation among ASHAs is low. In last two years institutional deliveries are decreasing. ASHAs are not getting payment. When ambulance is available, staff is absent; no one is available to attend the patient. There is overcrowding - one bed has three patients

Munin, Assam: maternal deaths are high in Assam. 300 maternal deaths have been recorded. The district Dibrugarh has tea estates; health facilities are close by still women die. If services are not available, and people die – this is understandable. But why do they die when services are available is a matter of denial of services. Tea estate management is not very supportive. In this context human rights are very important. Learning from this workshop will help in initiating some further work in the state.

Shobha Shah, Gujarat: institutional deliveries are high and still maternal deaths happen. In this phase, institutional deaths, deaths during transit and quality of care in the institutions should be monitored. Women come to health facilities with an HB of 1-2 gram, why is anemia is so high in the first place? This should be looked into. Government wants to do the near miss audits; CommonHealth should also address this issue. Perinatal deaths are linked to quality of care. Within perinatal deaths, still birth is very important. WHO has a standard near miss tool, NAHMR has developed one tool. CommonHealth (CH) can develop learning from both tools. She also said that the Government is investing in Skilled Birth Attendant trainings - how are these trainings used practically; she needs insights from this meeting to develop an understanding for this. She said that in the new areas that are joining this second round, J&K and Punjab, the DWT would/could be like the first round. In the old organizations who want to repeat the DWT. quality of care and other aspects facilities' deaths could be added. We would need to try to find out causes (including social causes) of deaths and form backward and forward linkages

Subhasri, Bihar: accountability among doctors is a problem. She shared that doctors don't pick up phone even when on call, decisions are left with nurses. Nurses deal with high risk patients like eclampsia. She narrated the incident of one patient who died in 2-3 minutes immediately after reaching the hospital. There was no pulse, pupils were fixated. Gynecologist didn't declare her dead, the case was referred

further. In PHC records it is recorded as referral. About 800 MDRs are reported by the health system as opposed to 6000+ deaths estimated from extrapolating SRS figures. Where are they reported, when deaths in front of everyones' eyes are not recorded?

In Punjab deaths in private hospitals are not reported. In Ludhiana, there was one death in nursing home, it created uproar. The doctor covered up the death with the help of the ASHA and the ANM. He decided not to report the death. Doctors feel pressure from the community.

Subhasri added that rational medical practices should be looked into. In urban areas C-section deliveries are conducted based on auspicious days, doctors don't reason out medically. She said that she knew of two maternal deaths that happened because of this.

Session: Laying the ground for next round

Reflections after the sharing of experiences by Sundari

Till now, CH has done no work in urban slum areas. She cited findings of a study of Chandigarh slums where more than 60 % deliveries were home based. Somehow, hospital deliveries were unacceptable for various reasons. The inequality is more in urban areas.

In J&K what aspects should be focused upon because it is a vast area and different regions may have different issues.

Institutional maternal death reviews are possible when institutions are NGO based. Abuse would be included under quality of care. Social determinants have also to be studied, how feasible is it to see the material circumstances after the death. How does poverty interact with women's health? Vulnerabilities need to be analyzed deeply.

Specific things emerged from the first phase. Anemia came out as a major concern covering a range of issues related to social dimensions, clinical management and blood availability. In the second round of DWT, deeper analysis can be done of the referrals, including cases of multiple referrals.

While Phase-I was exploratory, phase-II can be more specific. In the end specific recommendations can be drawn. She emphasized for pointed data collection and pointed policy recommendations. As CommonHealth what do we want to advocate, two- three critical pieces need to be advocated.

Renu's response

What is the purpose of 2nd round of data collection? There are implications and limitations of data collection. How much more data do we want to make recommendations? There is data from first round there to take advocacy agenda forward. What should be the focus of the second round: perinatal deaths, near miss or only perinatal deaths or strive for deepening of data. She said facility based maternal deaths can be reviewed from the community perspective; partners need not go to the facilities.

She suggested that we need a discussion to build a common understanding of advocacy. She shared that in Jan Swasthya Abhiyan (JSA) public hearing in Jan in Mumbai, they did advocacy for access to medical records. Patients' relatives have right to records. Quality of medical record is very important.

Responses to Renu's questions:

In Punjab, records are shared when social audit is done.

Media advocacy is very important. Media should be trained to give proper perspective to see news beyond sensationalism. Renu reported that under the WRAP project that she recently evaluated, in Pakistan, exposure visits of selected media professionals to grass root champions were organized, and this helped in increasing media coverage on reproductive health.

History of DWT, advocacy experience sharing and directions for exploring next round

Subhasri made a presentation on Dead Women Talking process so far. She recapitulated the earlier process. Many state level reports along with one national report were the outcome of the documentation of maternal deaths since DWT process started in June, 2012. Reports of the meetings organized for DWT (I-IV) are available at CommonHealth website.

Sharing of advocacy experiences

Maharashtra- Vijyalakshmi's suggestion was to involve local bodies to build pressure at system. Advocacy through panchayati raj institution members have yielded some results in other projects. Women have 33 per cent reservation in Panchayats, SHGs leaders are vocal and empowered, and also AWWs have strong presence. These groups together can form a pressure group to bring changes.

Gujarat – Renu shared that a state level consultation was organized around World Health Day in 2014. Results of engaging with government have not been positive. District level advocacy had some impact. As part of the SAHAJ MH Project efforts, one District Collector called a meeting of all the Block Medical Officers and discussed the Maternal Death Review (MDR) work being done by ANANDI and SAHAJ. She enquired about other blocks. In district MDR meeting she has engaged with ANANDI staff and has asked for the MDR reports done by them to compare with the health system MDR reports. In the next round of SAHAJ's collaborative project, there will be conscious decision to involve PRI members, SHG leaders and at Taluka level Women and Child Development and Rural Development officials.

During National Human Rights Commission (NHRC) and JSA public hearing in Mumbai in Jan 2016, they focused on the maternal health agenda. Questions around out of pocket expenditure despite JSSK were raised. A number of case studies were presented. Five state's medical college representatives were present. Recommendations were presented during public hearing in front of Gujarat and Maharashtra representatives. Director, Maternal Health of Maharashtra was receptive and announced that two of the recommendations suggested by Gujarat JSA for the Govt of Gujarat, viz., publishing the MDR report and Referral Audits, would be done by them in the current year.

Renu reported that after the public hearing, some improvements are reported by local women w.r.t. to the Community Health Centers.

Directions for exploring next round

Sundari- Higher levels of government are aggressively hitting back or are unresponsive. In this scenario what should be our strategy of engaging with the government? She suggested that interface at local governance level increases the legitimacy of the process. It is very important to think about strategizing, how we mobilize local governance and engage the state government.

Subhasri – we need to identify who are the change makers? What does it take to sensitize people at different level? She gave the example of the State Human Rights Commission, Assam who refused to address maternal deaths as a human rights issue on the basis of the Assam DWT report. Karnataka JSA documented a death in a big corporate hospital and took up the issue. What do we want out of this DWT-2 process?

Session: Near Miss Audits- the tool and piloting in Gujarat

Process and results of the piloting were presented by Renu. Subhasri made a presentation on the identification criteria for near miss cases, and adaption of the near miss tool. The summary is as follows:

A piloting of near miss audits was done in three blocks of three districts of Gujarat. Two districts were tribal, Panchmahals and Dahod, and one developed district was Anand. Since 2012 the MDR /Social Autopsy work has been going on. It has been challenging to engage with the local/district government. Through near miss audits an attempt is being made to highlight the positive aspects and the efforts taken by the system to save a woman's life. Government of India has started doing Near Miss Audits. The WHO standard definition of Near Miss is used to identify the cases.

To do Near Miss Audits by the community, the challenge is how to identify facility based Near Misses and how to audit them. The standard definition is clinical and biomedical. For community based near miss audit in the pilot, the definition was modified, and learnings from maternal deaths were added into the near miss criteria. Referral was added. It was discussed that a few clinical markers would also be helpful in identifying near miss. Based on the discussions, clinical marker of jaundice in pregnancy was inserted. The existing WHO tool was modified, as we didn't want to introduce a new tool to the community volunteers.

Stories of documentation of near miss

The analysis of the Near Misses documented, did not show that the women's lives were saved through the health system's efforts. Those who were involved in doing documentation talked about challenges - challenge was to clearly identify severe anemia or jaundice in pregnancy. Non Communicable Diseases especially Rheumatic Heart Disease (RHD) contributing to death was discussed. Gestational Diabetes Mellitus, ratio of 1:5 is reported in South India was also discussed at length. Question was what the ways to factor in these diseases are.

Response to the discussion on what will be the conditions and markers to identify a near miss case

The suggestion was that instead of listing the clinical diagnosis, and conditions, use a series of signs and symptoms like *delirious, extraordinary bleeding, gasping, unconsciousness,* and *almost dead* as these will be easier for community volunteers to identify…. change the language. Instead of Post-Partum Hemorrhage (PPH) use bleeding. Women who were admitted into the ICU are easier to identify. Near death conditions, talking about extreme symptoms will be easier to pick up. Another marker is ratio of maternal death to near miss is 1:2.

The question asked was 'should CommonHealth members be doing near miss audit and why?'

There was a lot of discussion between Shobhaben with the experiences of SEWA Rural and others. She said that Near Miss Audits really help to identify what all was done to save the woman. The others felt that many times near miss audits do not show anything positive, it is just by chance that they woman survived so why do we need near miss exercise? Other responses were:

- Near miss Audit might show an alternative
- Can contribute to relationship building

The conclusion as that we need to have a broader understanding of what a Near Miss is, as discussed above.

Session: Maternal Morbidity: a neglected issue

Sundari made a presentation; the summary is as follows:

Maternal mortality in the world has been decreasing. From limited studies available, high maternal morbidity is reported in many parts of the world. Survival of women in the face of maternal deaths doesn't mean good health and well- being. Some conditions have long term sequelae and some compromise health permanently. Interventions with a morbidity prevention focus need to be very different from those we have adopted so far.

A consensus on new definition on maternal morbidity was achieved during a WHO stakeholder meeting in Istanbul, Turkey. Globally, very little is known about maternal morbidity. There is lack of a common definition and identification criteria for maternal morbidity, lack of standardized assessment tools and lack of common indicators to measure morbidity. In India maternal morbidity studies done from 2000-2014, show that most obstetric studies are focused on morbidity during labour and immediate postpartum. Large numbers of studies are on gestational diabetes and post-partum depression as compared to infectious diseases. Studies examining social determinants of maternal health were not found in this search. Studies in India have examined pregnancy outcome largely about infant. We do need to assess both short and long-term consequences of pregnancy-related problems. There is need to look at abortion and miscarriage related morbidity, which impact on women's physical and mental wellbeing in complex ways, but have not received attention.

Way forward- A life-course approach, using a social determinants framework will help us document women's lived experiences with surviving a complicated pregnancy. She made a case for generating evidence on maternal morbidity, document women's reproductive histories from their own perspective and advocate for interventions to address short and long-term maternal morbidity.

Discussion points

Ethical issues were flagged while doing research – morbidities needed to be addressed and the woman supported to seek care even while researching and documenting them. It was suggested that experimentally, it can be started with 1-2 organization ready for it. It is a new issue even for the organizations. It would be useful to explore how women's health remains in the post-partum period. Post-partum depression will come out from this exercise. This exercise can be done at 3-4 field areas, 3-4 near miss cases can be followed up in one year. These cases can be followed up three or four times through a 12 month period. In this way we would have around 20 to 30 good case studies of maternal morbidity.

It was suggested that this should be done with community based organizations as action implications are there. There is ethical dilemma, whether organization should wait for sequelae for studying morbidity or should intervene for improving her health. Obviously the CBOs would be committed to mitigating her symptoms. The WHO tool can be translated into a simpler one. The gendered dimensions, eg. Women are seen as liability – should be captured.

The process will start with capturing near miss and following it up for a year. An exploratory different type of 3-4 cases for long term follow up in a year, the greater the variety, the greater the number of things to follow up.

Why- because we think that the discourse should be focused on **maternal health well -being**, to study longer term consequences, also to know health needs of a woman.

Session- Monitoring of Maternal Health, presentation by Renu

Renu shared experience of community monitoring of maternal health services project in Gujarat. It was process oriented where outcomes were incremental. Healthy Mother (Warli-Madi) Tool was used by community members. Broader awareness on maternal health rights and entitlements was raised through this process. Report cards were produced based on the compilation of information in each tracked woman's tool. Findings of the report card were shared with medical officers of PHC in project area. The community members, women and project staff valued the project for improving maternal health awareness. The project expanded maternal health beyond bio-medical and health system. Community, PRI members and SHGs leaders were instrumental in improving accountability of maternal health services.

10th March, Day-2

Session: Recap of previous day and introducing way forward followed by open house discussion

The second day started with the recap of first day given by Renu. In the second round what changes should be introduced, what are the aspects to be focused, which issue requires greater attention, can there be focus on inequities, can these be explored from urban health perspective. Two new states J&K and Punjab are added. What could be advocacy message, how this exercise should be structured. In past didn't get success from MDR, near miss audit or perinatal death audit is it likely to be less threatening. Is this an assumption? Are women surviving because of health system efforts? Experience says it is only by chance women are surviving. Criteria for near miss was modified multiple referrals were added. The context and the learning of DWT were incorporated while modifying the tool. It was clear from Sundari's presentation that there is not much literature in the field of maternal morbidity. What can be done in this field, what are the implications of near miss in longer terms in women's lives? Women fall out of health system. There are ethical issues in reviewing maternal morbidity. The objective and verifiable criteria was also discussed for near miss which includes unconscious/fits, abdominal surgery, hysterectomy etc. What has to be captured under morbidity? What are the changes in her mental status, what is her physical morbidity and changes in her sexual relations?

Open discussion-

Leela Visaria- the concern is why our findings haven't made any impact at policy level. She added that valid suggestions have been made, why lot of them is still not incorporated in the system. So, she suggested doing the second round with rigor and emphasizing the issues which bother, have been addressed, still need to be addressed. She asked if this requires a campaign approach to take it forward. She pointed out that there are limitations in our methodology but this is straightaway mentioned. Environment in the hospital is equally important the way the maternal health issue is addressed. She gave the reference of quality of indicator- in Common Review Mission of MP, 2/3 of women on one bed and women deliver on floor. Our work is not addressing inequity when generalizing the work. Quality of care in institutions is questionable. It hasn't improved.

Rajdev- the situation doesn't look likely to be improved. During this round, how voices can be amplified at state and national level

Arun Gadre- how to catch near miss and morbidity? Responding to Leela's point he said that the strong campaign point is safe delivery checklist. Someone in the group pointed out that there are challenges as community members will not be allowed to monitor. He suggested getting a permission letter to check institutions for practical issues. For observation, nobody can stop. He further added that for improving quality of care the work need to be done at community level as well as with the institutions. For observation of facilities- PRI women can be trained as they have locus standi. Trained community members can be observers along with PRI members. It is important for elected women as they will be raising the issue.

Safe delivery criteria- Common Health has already developed a checklist, Jhpiego also has developed a checklist. Now in this checklist, behavior of staff should be added. Corruption could also be included. This whole issue can be raised in campaign mode. Social media hasn't been utilized to its potential. The

voice of community should make an impact on community of facebook and you tube. Advocacy plans should be prepared well in advance. Need to make maternal health issue a broader alliance issue.

Session- group discussions on taking forward maternal deaths documentation work

The participants were divided into three groups. The groups were asked to discuss on the following:

- What is the change we want to see? Who are the change makers?
- What kind of intervention do we need to focus towards this?
- What methods/ processes are needed towards this?
- How do we build synergies between ourselves?

Change we want to see- improved quality care, bringing down MDR, functional MDR by system for program strengthening, increased reporting, PRI members and community become part of MDR and community awareness

Kind of interventions- first round of documentation in Punjab, In Tamil Nadu- anemia management, in UttarPradesh- referral transport, blood storage and anemia.

Presentation from group-1

State- Maharashtra

In the context of Maharashtra, community based monitoring is strong, as a mechanism for community monitoring is established. What is happening in urban health can be explored through this network. Maternal deaths are being recorded in the system. Only the numbers of deaths are recorded, details are not mentioned. Therefore, social autopsy is very important. Need to analyze data of last five years to see the concentrated pockets of maternal deaths then organize training in those areas through CBM network. Make inroads for specific discussion on maternal deaths and maternal health in Maharashtra Arogaya Sabha. Try bringing maternal well-being in discussion of MaharashtraArogyaHaqParishad. Make efforts to include urban health partners to cover urban health inequities.

Presentation from group -2

States- Gujarat, Aasam and Madhya Pradesh

In Aasam, there is a network of 22 organizations, vulnerabilities are also identified. Bengali muslims, tea garden workers and tea tribes, a training for these marginalized groups will be organized. Will focus on anemia and blood availability, will engage media for advocacy. So, there is a clarity now what can be done.

Madhya Pradesh- government doesn't pay attention, so at local level it will be started from PHC and people from CHC will also get involved in this process.

Gujarat- it can be started from district level, will try on how other people can become part of Common Health and how other NGOs will get involved in this process. There is no data from urban slums, which can be collected and work can be taken further. In May, to moot the idea will conduct a meeting and to diversify the group will include CHETNA and Anandi organizations. These organizations will be updated on discussion happened during this meeting. Will work on inequities - tribal, urban slum, silicosis affected women groups will get involved. SEWA Rural can do the analysis. Leela Visaria can look at the social autopsy tool for the second round requirement. Timings of referrals should be refined, an additional module can be incorporated but the core elements should be short and crisp.

Presentation from group -3

States- Punjab, Bihar, Uttar Pradesh and Jammu Kashmir

MMR has gone down and maternal care is increasing, audits of maternal deaths are happening. The community participation should be increased and there should be complete monitoring of maternal health services. Awareness about rights and entitlements should be raised among PRI members. Civil society should be the part of MDR committees. There will be focus on improved referral, anemia management and blood transfusion. Each blood bank doesn't have list of –ve blood group donors. There should be training of informal practitioners.

Advocacy – will revive existing committees as a strategy, will engage with District Magistrates. Will carefully identify people in media ?

In Annual General Meeting of Common Health, there will be a session on how to engage with media and how to do political advocacy. How video volunteers can train for community level activism.

Discussion- In the areas where maternal mortality has gone down it doesn't imply that maternal morbidity also has gone down. Obstetric maternal deaths have decreased but it doesn't mean that eclampsia also has decreased. So, now beyond maternal survival need to look at women's need, what kinds of health interventions are required. Need to build systematic documentation on health problems of longer term. For SEWA Rural it is easier to do near miss documentation as they are already doing it. Maternal morbidity requires a follow up that can be added into this round. Selected samples of near miss can be followed up in outreach area. Definition should be minimalistic, WHO criteria can be added. In UP, work has been done on near miss. Criteria of four-five markers have to be set up. One pamphlet on near miss identification should be prepared. Change the name from near miss and long term morbidity to serious complications and long term consequences otherwise will have to defend the definition.

The states showed readiness to do the work, UP, Gadchiroli in Maharashtra, RUWSEC in Tamilnadu and J&K. Only if eight organizations are able to do this, there will be good documentation in the end. There will be iteration in the definition, tool and follow up. A training for tool will be organized, a time frame to meet the iteration. Leelavisaria shared that near miss of 34 cases was done six years ago. There is detailed write up on the analysis of data. For definition, what criteria have been used can be seen from there. It would be good to follow up those women what is happening to them now. Sarika shared that

she has four years old data on women availed services of complications. Lindsey Barnes is following up on complications after six months follow up. She can help CH in fine tuning the tool.

Session- Planning the next phase- logistics, training and resources

In the first round of DWT, 23 organizations were involved. This discussion has to go out to everyone involved in phase-I. For new tool will call a DWT meeting. But before this, state level meetings are required to mobilise people with in the state and calling them for training.

Collate methodology, a common methodology and a common advocacy methodology.

If necessary, should plan for regional trainings. Through a Training of Trainers (ToT) a pool of 10-12 people can be drawn and these trainers can go and conduct regional level trainings. Trainers will emerge out from 23 organizations already involved in this work.

Three options are suggested to take the work forward-

1. One large meeting with various people from all organizations involved and keen doing work
2. ToT for a pool of master trainers
3. Regional level meetings

ToT plus regional meetings seem good options.

Action required before meeting:

Revise the existing DWT tool - LeelaVisaria and Sanjeeta

Morbidity tool – Shobha Shah, Sarika, Neelangi, Subhasri and Sundari

Suggestions:

Explore Amplify Change SRHR for fund raising.

Usha Rai has developed a directory of development media professionals across the country. She has identified journalists, mentored young journalists. A training of identified media people can be planned. This directory can be shared with everyone to have a list of state level journalists.

Ideas to explore:

- Advocacy campaign
- Workshops
- Media fellowship

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11th March, Day-3

Monitoring Rights-Based Provision of Contraceptive Information and Services- Planning Workshop

Session: About the Advocate's Guide and expectations from the monitoring exercise

Renu presented the context why there was a need for making the Advocate's Guide. Globally, there is push for contraceptives. In Family Planning Summit in London in 2012 a large sum of money was pledged to direct towards family planning. Within the FP2020, there is a Working Group on Rights-based contraceptives and ARROW is a member of this working group. ARROW requested Common Health to develop a guide on Rights- based contraception. A consultation was organized in Mumbai in 2014 to review the draft guide. The tools developed in guide were field tested. Politically the title of the guide was changed as family planning doesn't cater to contraceptive needs of single, adolescents and queer groups. In Bhopal Meeting, 2015 there was a demand to monitor PPIUCD services and also now maternal health agenda is broadened as maternal well -being so it is important to monitor contraceptive services.

Sundari shared that the guide has legitimacy as it is prepared with the view to contextualize the World Health Organization's rights – based principles and recommendations. At present there is emphasis on technology and vaccines, in coming days push is harder for contraceptives so in two days as an outcome we need to concretize the agenda for monitoring contraceptive services from rights perspective.

Session: Interests in monitoring and experiences from the field about Contraceptive Services

UP - Sandhya Mishra and Rajdev: Sandhya shared her angst that why it is called family planning programme it should be named as population control. Though there are not declared targets but pressure on ANMs and ASHAs is indirect and it is evident from the fact that sterilization is the only method talked about in the field. In review meetings FLWs are asked about meeting sterilization targets. In hospitals, oral contraceptive pills are not distributed. The focus of government is on sterilization, basket of choices is not provided, and alternative methods are not informed. There is lack of awareness about other methods. Rajdev from UP further added that in Shravasti district which is the most backward district of the state where sterilization services are not available in muslim community. No compensation is offered for failure of sterilization. It is provided only if it is reported within three months of operation but it is difficult for a woman to detect in the said period. He informed that Engender Health is doing social audit of PPIUCD and sterilization in 5 districts of UP in two rounds. He expressed his concerns that he believes in family welfare not in family planning and how the learnings from this workshop will help sharpening in understanding and expediting the social audit work. During one of his encounter with Civil Surgeon, he shared the mindset and attitudes of health service provider towards muslim community. "Muslim women bear 10 children and their increasing population is threat to Hindu majority and that's why he always ensures double ring in tubal ligation so that the procedure never fails. "

He informed that social marketing of condoms, oral contraceptive and emergency pills is done by ASHA. ANM is out of this work. For social auditing work, the health care providers will provide list of PPIUCD and sterilization users. Every month meeting with males and females is organized for creating awareness on PPIUCD and sterilization. In second round after a year, another exercise of social audit will be carried out. There is need to monitor whether consent of a woman is being taken or not.

Jammu & Kashmir-Rahi : he shared that the sex ratio of J&K is 883. There is lack of information about contraceptive services in the community. He cited an example of a college girl was found murdered when her pregnancy was discovered. AWWs should be providing the services but they also lack information.

MP, Bhopal- Nidhi: she shared her experiences of both rural and urban MP. In rural areas where girls are married off at an early age of 18 or before 18 bear first child before 20 and second child at the age of 21 or 22 and go for permanent family planning at the age of 26-27 which has implications on women's health. Need to analyze how it affects their mental health. Once reproductive obligations are over at an early age they find no use of themselves to the family. Social marketing of ASHAs led to an extent that once a whole village was sterilized. In urban areas the situation is even worst where no formal heath structure exists. PPIUCD has been inserted without a woman's knowledge. She shared the example of a woman who was bleeding for six months and after showing to a doctor she came to know about insertion of PPIUCD. For side effects women don't go to public hospitals they seek services of private hospitals which costs them heavily. Adolescent groups are left out from the program. In muslim community women want less children but husband and mother-in-law take call on having number of children.

Sundari informed that while working with RUWSEC in Tamilnadu, a set of pamphlets on various contraceptive methods was developed. Learning from that experience she suggested that information about contraceptives can be developed in simple language from women centered point of view. She cited a comparative study between Kerala and Jharkhand on PPIUCD. In Jharkhand the cohort interviewed was very small. Most of deliveries were home based, it was difficult to find women with PPIUCD. Healthcare providers provided the list but women were unaware of their IUCD status. In Kerela, Total Fertility Rate (TFR) is less than two but knowledge about contraceptives is very low. They know the names of contraceptives but when asked about description they are misinformed. The health system doesn't have a system of providing information on contraceptives. In Jharkhand knowledge level is very low but in Kerela they even don't know that they don't know about it. Adolescent group is completely left out in terms of providing information to them.

Tamilnadu&Bihar - Subhasri: she shared her experience from RUWSEC clinic that there is PPIUCD push from government side. She questioned the rationale behind it. It was explained from the group that globally Indian government was criticized for not emphasizing birth spacing in its family planning program. So, to lessen pressure on females PPIUCD was to be introduced, it is used as a birth spacing method. The problem is that PPIUCD is inserted without a woman's knowledge. In RUWSEC clinic, women after three months of delivery in public sector medical colleges come to check whether it has been inserted or not. Few cases of without consent have been documented which they were planning to

raise it in Southern India regional NHSRC public hearing. There are cultural dimensions to this unethical practice of not taking consent. If a woman doesn't conceive she feels heat from mother-in law and husband whether she has become infertile.

In Bihar, there is desperate need for contraception. Consent is taken but quality and methodological issues are huge. External instrument used for insertion is not sterilized. There is no mechanism of following up on complications. During Bilaspur sterilization camp assembly line was used for laparoscopic procedures. It requires planning of how many laparoscopes will be required depending upon number of patients but the system has given only 1-2 laparoscopes. It is an important issue to be monitored but how it can be done is a challenge. It was added from the group that generally doctors bring their own laparoscope but they are equally insensitive. They are paid per case.

Maharashtra-VijayaLakshmi &Shubda: she shared that quality and side effect problems are huge. Women can't decide, there is systematic pressure on women. Contraceptives for men are not promoted. Women are not informed about Oral Contraceptive Pills (OCPs). Adolescents have no information on contraception. Shubda added that women themselves prefer operation. There are side effects of operation. ASHA workers don't speak up openly with males about vasectomy. If male sterilization fails and woman gets pregnant she bears the consequences of it.

Punjab -ArvindarSingh: he shared that there is unmet need for family planning in urban slum areas of Ludhiana. Urban slums are underserved. The average family size is 3-4. The target approach is generally not seen but in District Health Society, targets are used as benchmark of performance for frontline staff. The focus from female sterilization is shifted to PPIUCD. It is also observed that to an extent consent is also taken but follow up is a major issue and is not being talked about. The declared camp approach is not used which generally was the scene in 1980s using assembly line approach. Adolescent Reproductive and Sexual Health (ARSH) PIP is unspent. Adolescent sexual health is a sensitive topic; no one is interested working on this. Adolescents have no information about Medical Termination of Pregnancy (MTP) Act. The situation in private sector is equally worse. The providers shrug off from their responsibility by saying that counselling is not their job; they are fulfilling their duty by providing services. ASHA/ANM and doctors, who promote family welfare services, should first apply some principles like gendered aspects to themselves first before promoting outside.

Assam-Munin: he shared that the awareness is very low regarding contraceptives. ASHA has no information on usages and description of family planning methods. After sterilization still conception happens. There is a desperate need for information and services.

Nilangi concluded the session by saying that work has not been done on contraceptives morbidity. This needs to be seen separately from availability of information and services while lack of information about contraceptives is a matter of grave concern. She added that there are cultural dimensions in contraceptives. Renu further informed that need for contraceptives are stressors across life span for reproductive health of women. The biggest stressor is that when there will be a child and what will be the sex of the child!!!

Session: Technical information about various contraceptive services

Subhasri made a presentation and key points emerging from her presentation are as follows:

There are various definitions of contraception; it imeans to prevent conception and impregnation through means of devices, sexual practices, drugs or surgical procedures etc. A range of choices are available in both public and private sectors. Private sector provides female condoms, DMPA, LNG - Intra Uterine System, progesterone Only Pill and vaginal Ring. Public sector offers limiting methods, spacing methods and Oral contraceptive pills. She explained each method in detail like emergency contraceptive pill must be started as soon as possible after intercourse and no more than 72 hours after. The effectiveness of OCPs, combined OCP and how to take the pill everyday and what to do when a pill is missed and what are the side effects of the OCPs. She informed health benefits of the OCPs of its protection against endometrial cancer and cancer of ovary, it also helps preventing mensural cramps, heavy bleeding and anaemia. She clarified misunderstanding associated with OCPs like infertility, birth defects, change in sexual behaviour of women etc. She also explained the myths associated with emergency contraceptive pills. Intrauterine contraceptive device, its effectiveness, when to insert and side effects was clarified. It was followed by Depot medroxy progesterone acetate (DMPA), its effectiveness, side effects and when to start etc. In the end she shared a slide on safe abortion service saying that each method has a small failure and has its side effects that is why integration of safe abortion services and contraceptives delivery is critical to to ensure continuity of care and quality comprehensive reproductive health services

She informed the audience that politically we will keep the term contraceptives not family planning as there is a constituency outside family who need contraceptive services.

Discussion - Sundari cited a reference of a Nepal study about DMPA. The study was done in a self-selected group. Initially, there was interest among women, they showed keenness for injectable as one injection protects for longer duration in comparison to other methods. General experiences about DMPA are that it is a painful injection, periods are painful, traumatic, heavy bleeding and most importantly the concern of return of fertility is 1.5 years.

Emergency contraceptive pills are being used as a regular contraceptive which shows that there is gap in information and non-availability of services.

Session: what is Human Rights Based approach towards monitoring of contraceptive services? About Human Right principles and standards

Nilangi made a presentation on human rights principles and methods. Her presentation was drawn from the principles used in Advocates Guide. The key highlights from her presentation are as follows:

Government as duty bearers has obligations at three levels to respect, protect and fulfil every human right. While providing contraceptive services, there should be no discrimination based on caste, class, ethnicity, age, sex, sexuality and disability. She cited an example of Particularly Vulnerable Tribe Groups of Chhattisgarh where they are denied services to limitation methods of contraception because of a

government's decision to maintain their dwindling population. The information and availability of contraceptive services should be provided equitably across geographical areas and communities. She highlighted the physical accessibility and economic dimensions as an important aspect to ensuring rights of the people. While explaining quality in the provision of information and services how body literacy is important and limit the accessibility of information about contraceptives. Government agencies as explained in first slide as duty bearers must be held accountable and actionable for their actions. She emphasized that a human rights based approach is important to contraceptive information and services because of the principle of equality which calls for a focus on the most vulnerable and marginalized sections of society, and makes it obligatory to reach the 'difficult-to reach' sections of the population.

Discussion: contraceptives are provider controlled. Population control is seen as nationalist. In the current scenario rights- based approach is seen as antithetical to the nationalist perspective. System has to put in protective measures for its own people. Frontline workers' rights are violated; they are victim of the system. Hospitals are 24X7 but posts are lying vacant. Vulnerable groups like sex workers should be included while monitoring contraceptive services.

Open Session: Discussion on what contraceptive services and where these can be monitored?

- PPIUCD
- Sterilization
- Services for adolescents

Key points emerged from the discussion: . The consent issue in terms of PPIUCD needs to be studied. Previous experiences of PPIUCD are 20 years old. It used to happen earlier also but the programmatic push is new and because of this it is increasing. It is layered now at global, national and state level. There are many players involved in it. Availability of services is a big issue.

In UP Rajdev said that he can monitor both PPIUCD and sterilization. In Punjab, unmet needs in urban slum areas of Ludhiana can be studied. In J&K focus can be on availability of contraceptive services. Nidhi committed on monitoring of PPIUCD in urban slums of Bhopal. Information about contraceptives needs to be studied in a systematic manner.

The health system has provision to provide information to the community. As CommonHealth what aspects should be monitored can be discussed and it can be in partnership support agenda. The questions are what is the understanding of service providers, when the information to be provided. For example: spacing and delaying methods; when are they giving, who are they giving and what are they giving etc. Need a quick sense how do we go about it? Other aspects need to look into how many ASHAs are trained to provide information, the quality of ASHA and ANM training needs to be monitored. Video Volunteer volunteered to monitor decision making aspect of contraceptive usages but the challenge is how to bring systematic changes. In most places availability of information is very less. Certain myths are created by the system which needs to be busted. Family planning is a propaganda program it is not reaching out to people to provide information. Male participation among these programs is zero. Efforts

have not been made to break myths around vasectomy and condoms usages. At sub centre level services are not available how it can not be expected from a woman to travel 30-35 kms to reach at block level to avail contraceptive services. ASHA and ANM can't persuade male members on this topic, the system has forgotten about male front line worker. The focus and push is on women. The demand generation is low. Overall, availability of services is a major issue. In J&K in remote areas ASHA and ANMs are not present, VHND not happening.

Session: group work on familiarization of standards in the Advocate's Guide for monitoring Rights-based provision of contraceptive information and services

The participants were divided into three groups to look at: the standards in annexure-1 which has standards for contraceptive services, chapter 3 which has WHO recommendations for monitoring provisions of rights- based contraceptive services and linking these standards with monitoring checklists in chapter 2

Presentations from the groups:

Group -1

After going through the checklist and standards the following suggestions were made:

- To increase the awareness questions for male users should have been included like how much contraception is used by them and what are their opinions regarding contraception.
- Questions regarding availability of information of contraceptives
- Questions regarding stock supply

Group -2

The group went through the chapter-3 and came up with the following suggestions:

- Questions regarding availability of services like distribution of condoms, OCPs during VHND days, availability at primary health center
- Questions on interviewing male users, where they are getting information and services from
- Questions on whether health care service providers have been trained or do they possess required skill set like do they advise on missing OCP and infertility related doubts about it

Methods of monitoring are filing RTIs, field based interviews and observations in facilities

Monitoring PPIUCD is challenging, difficult to get information which woman has availed this service. This is breach of confidentiality. The possible way of doing a follow up is seek cooperation from ASHA. For monitoring Engender Health social audit tool can be used.

There are some concerns while monitoring services and these are regarding actual usages of condoms. These are used as balloons by children. There are issues of quality storage and expiry of stock. Another matter of concern is maintaining confidentiality of adolescent. How to ask who used which service

Group-3

Looked at the monitoring checklist and drafted separate questions for policy and programme. The group also, drafted questions for users and front line workers. To increase awareness need to speak with users. The checklist doesn't include questions on dignity and consent. In annexure-2 questions should be on how women take decisions on contraceptives. The checklist should also include community decision making questions, whether they have been lured to opt for permanent option. How ASHA/ANM provides these services and persuades them to opt for various methods. The sex workers need to be included. It is good to see needs of mobile population has been covered and it does have information on adolescent groups.

The session was summed up with the following points:

- Checklists are kind of launchpad, these need to be contextualized and expanded according to the groups partner/ member organizations working with.
- What monitoring tools will be used, each group has drafted questions differently on availability and male users, have pointed out leaving out certain vulnerable groups like sex workers and also discrimination.
- Monitoring and follow up should become part of accessibility of services. Inclusion and access covers nomadic and sex workers group
- Sexuality education is part of contraceptive services, how many are getting with in school and out of schools
- From PPIUCD one time snapshot analysis, few things will require follow up. Need to narrow down to monitor to availability of information and counselling. The group shouldn't attempt to develop a new tool. In sterilization failure cases quality and availability of information issues can be added into it. While trying to monitor failure cases, the main issue of availability should not get left behind.
- Need a checklist for monitoring sterilization as well as failure cases covering both quality and availability aspects.

Discussion points:

What are the ways to do long-term monitoring of morbidity?

What happens to women who go through poor sterilization? Studies have been done, it is established clinically that the women who go through poor sterilization have long term morbidity. Now, the focus is on availability of information and services.

Can we have a draft tool by tomorrow? What are the specific questions for monitoring in the field? Need to generate a list of questions who will be the respondents, what will be the questions and from where the information should be sought. For example:

- Whether contraceptive services are available during VHND
- At what level SC/PHC/CHC the services are available
- How the confidentiality is ensured

Sterlization checklist is already developed. No need to develop a new one. Nidhi volunteered to add community level questions into the checklist. Need to review already developed tools and incorporate additional questions as per the context.

The final outcomes of the meeting that there should be one common definition of availability of information and from each one's perspective need to arrive at one understanding. Each member was given a task to draft few questions as per his/her context which will be reviewed along with existing monitoring tools.

12th March, Day-4

The group was joined by two new members Jessie and Shena from IWHC

Sundari recapped previous three days proceedings to IWHC. First two days were spent on planning for next round of Dead Women Talking to deepen understanding on repeated and irrational referrals, severe anemia, blood availability and focus on marginalized population especially urban slums. In this round two new states of Punjab and J&K are added. It will be an exploratory exercise to document obstetric complications by following up in a period of three months for a year. These will form DWT-II phase in addition to strengthen advocacy at local level by involving PRIs and women leaders. During 3rd day in general meeting of CH partners have expressed interest in monitoring contraceptive services from rights framework especially PPIUCD and sterilization. Apart from monitoring coercive practices viz a viz PPIUCD and sterilization availability of services came up a major issue. Demands are not met in larger part, wide spread lack of understanding even among educated youth. Groups such as sex workers never come in the ambit of family planning. There are indigenous communities whose rights are completely violated. Advocate's guide was discussed in detail and came up with a checklist.

Session: looking at the questions drafted by each member and flashing existing monitoring tools

Questions for urban slums:

Information from Community-

i) Information/ knowledge about contraceptives from three groups:

i)Newly married ii) married having one/ two children iii) adolescent girls

Which method they choose:delaying first pregnancy/ Spacing/ Permanent

ii) Where do they get services from

iii) The gaps between demand and supply

iv) Cite good or bad experience about contraceptive

v) What kind of treatment they receive from service providers

Information from Service Providers:

i) Who do they provide services to

ii) Is there hesitation while asking for a service

iii) Who are the clients

iv) The gaps between demand and supply

v) Is there any follow up

Questions for adolescent groups:

Is the comprehensive sexuality education provided in the schools, how do out of school adolescents utilize services, How confidentiality is maintained, utilization of services in adolescent friendly school clinics, how confidentiality is maintained

Who are the respondents: district education authority, community, teachers of the schools, Nehru Yuva Kendra can be contacted for information related to boys

District level advocacy is why there is low utilization of services

Jammu&Kasmir : nomadic/ floating population who lives six months in Jammu and remaining six months in Kashmir are left out from mainstream public health system in terms of accessibility and availability of services. Questions for this group will be what are the services available and this group will be reached through Pahari Forums and Community based leaders.

MP: two groups will be contacted for information. One is newly married and the other is couples with one child. For newly married group the questions are: Did they have knowledge on contraceptive before, who has provided information, what are their plans of family planning, Did ASHA contact you, Which contraceptives are available, are they getting at ease, are they paying money for these services

The questions for couples with one child are: to check the descriptive information, showing different types of contraceptives, are they using IUCD, whether consent was sought or not,what is their attitude towards using IUCD

Questions for service providers: do they help couples, how does she approach couples with family or without family, where does the supply of contraceptives come from: district hospital or some other source, by showing them asking side effects of contraceptive pills, which contraceptive she promotes, what is her response when a contraceptive is not available, how she maps out the demands.

Questions for single women who are in need to contraceptive services- it will be good to collect 1-2 case studies to know their awareness level, needs and their reaction regarding availability of information and services to assess the situation.

Assam: lack of information is hindrance in availing services especially in tea gardens, no sex education is provided in schools, sterilization failure cases need to be documented, in tea garden hospitals capacity of doctors to be built around these issues. The myths around male sterilization need to be busted.

UP: Vulnerable from two reasons, one it is a TB zone area because of silicosis mining and secondly, below 18 years marriage is common in the community. Front line workers don't engage with these groups. It is not into their outreach program. ASHA and ANMs need to be counselled and need to engage with community where child marriage is prevalent. Another vulnerable group is young widow in the age group of 35-40 years. Mushahar community is also extremely marginalized; there is no monitoring from public health system. There are multiple layers of vulnerability with the entire group. How do we frame questions for these multiple vulnerable groups? There will be common questions and questions with particular needs like: experiences of receiving services, availability of resources, when and from where they do receive services etc.

Nupur suggested that basic questions remain same, larger narrative can be around particular needs. VV will be powerful in showcasing service provisions available in those areas. Sundari made a point that in terms of information, men are nowhere in the radar. What is their awareness level, utilization of services by them, level of information among them can be captured in our files. Nupur offered that she can write a small brief on PPIUCD and send it to the team. Some of the videos can be used to initiate discussion in community. Some positive videos will be made showing attitudinal changes and men taking care of babies with an idea of generating questions.

Leela- from last one and half days discussion following issues have emerged out:

- Availability of contraceptives
- Level of information and knowledge among users and providers
- Restrictions to availability
- Ethical concerns and contentious issues

She suggested formulating questions around each heading above and capturing information around them.

Sundari suggested adding providers' side availability of information and specific vulnerable groups into the above list. She further added that in addition to basic information around these heading needs to document case studies. The whole process will be done in two steps. First step will be the exploratory phase for a situation analysis and second step will be putting together documentation and have rigorous set of questions. Today, we can agree broad set of questions and later we can come up with a draft tool modified for vulnerable groups. She insisted on proper documentation as information is valuable for setting up the next stage. For exploratory phase, will prepare a set of guiding questions, this will require a common broad definition.

Guidelines for Situation Analysis

AVAILABILITY OF SERVICES

- Of service delivery points (per 5,000 population
- Of human resources trained in providing contraceptive services (per 5,000 population)
- Nearest available service delivery point/ provider for each contraceptive method and distance of the same
- Of all contraceptive methods and supplies needed to provide them-[list of contraceptives in public sector]
- Have there been any stock-outs in the recent past
- Availability when the user approaches the facility/ provider
- Availability of services for any side effects or complications or failure
- Any group excluded from one or more contraceptive services

KNOWLEDGE (USER/POTENTIAL USER – single persons, men)

- Range of methods known by name or description
- Know who is eligible to use it and who is not
- Know how to use it (and what to do when a pill is missed etc.)
- Know when to go for follow-up visits
- Know of side effects and especially side effects that require medical attention
- Know where to go to access any contraceptive services
- Know where to go in case of any side effects/ complications following contraceptive use.

- Where did you get the above information? Did you get any information from any health care provider?

DESIRABLE

- Failure rates
- When fertility will return after method is discontinued

KNOWLEDGE AND ATTITUDES (PROVIDERS: ASHA/ ANM/ MEDICAL OFFICERS)

- Range of methods known by name or description
- Know who is eligible to use it and who is not
- Know how to use it (and what to do when a pill is missed etc.)
- Know of side effects and especially side effects that require medical attention
- Failure rates
- When fertility will return after method is discontinued
- Beliefs about who should and shouldn't be provided contraceptive services, about which methods are suitable for which groups of women and men

- Beliefs about why contraceptive services are important, high fertility of marginalized groups, about population control as a national problem

ETHICAL /CONTENTIOUS ISSUES

- Whether specific methods "emphasized" over others
- Circumstances under which women are "motivated" to 'accept" contraception (e.g. during pregnancy, during labour, immediately after delivery, at the time of abortion)
- Third-party consent sought
- Non-consensual provision (user not informed, no consent taken from user)
- Violation of dignity
- Abusive behavior – physical and verbal
- Inflicting pain or no attention to alleviating pain
- Technical quality poor enough to be detrimental to health (e.g. no gloves, instruments not sterilized, dirty rooms and soiled linen, tables, women lying on the ground, no access to toilet)
- Inducement through financial incentives, extortion for services
- Refusal of services
- Refusal of entitlements such as return transportation

PARTICULARLY VULNERABLE GROUPS / CONTEXTS

- Who are they, description of the location
- Livelihoods and living conditions
- Number of children/ beliefs about fertility and its control
- Is there any use of fertility regulating/ restricting methods? What is the source?
- Interface with the health care system
- Experiences of discrimination in everyday life and potential impact on access to health care

Screening of videos:

Nupur screened videos on patriarchy, the link is as follows: https://www.youtube.com/watch?v=3kQD9oaMBRc

https://www.youtube.com/watch?v=ZcbiL7CH77Y

These videos are for internal use as these have yet to be launched. She requested to share feedback on how these are being used.

Tools flashing: a tool for female sterilization user and PPIUCD user were flashed. The purpose of showing the tools was to know what is already existing and covered in these tools which can be modified later in our context.

Planning for next steps:

As discussed in sessions above, a situational analysis will be done around the guidelines agreed along with case studies documentation.

In the months of June- August, data will be collected. Those who are interested can do documentation on sterilization and PPIUCD as well.

September- post data collection, a meeting will be planned sometime between 15-25 September. The point person for questions related in this regard is Nilangi. A first reminder for collection of data will be sent in June and in August, a second reminder will be sent.

Final draft report of the meeting – end of April

Feedback on the workshop

- Organizing two separate meetings together was not a great idea. It would have been great if the timings of meetings were known well in advance, it would have helped in booking tickets accordingly.
- Accommodation was okay, not very great.
- Initially it was felt that there should have been more participants but informal, intimate and face to face discussion among small group enriched the discussion.
- A WhatsApp group of all participants attending this meeting should be formed to discuss the work happening around these areas.

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