



Proceedings of the Workshop on Data Methodologies for Estimating Obstetric Fistula

New Delhi

30th April to 2nd May 2007



Executive Summary

UNFPA and the National Institute of Medical Statistics (NIMS) organized an international workshop on data methodologies for estimating the prevalence of Obstetric Fistula. The meeting was organized following on the outcomes of the Second Asia and Pacific Regional Workshop on Strengthening Fistula Elimination in the Context of Maternal Health where participants agreed on a number of recommendations related to the prevention and treatment of obstetric fistula as part of reducing maternal mortality and morbidity, including the need for improved data.

Participants in the workshop included a senior level delegation from the All India Institute of Medical Sciences (AIIMS), the National Institute for Research in Reproductive Health (NIRRH) and NIMS in India. Expert epidemiologists, public health specialists, biostatisticians, senior DHS consultants, and sampling experts from CDC Atlanta, John Hopkins University, ICDDR'B of Bangladesh and the National Institute of Population Sciences of Pakistan were invited as well as UNFPA staff including HQ divisions (APD, TSD, AD), Nepal CST, and national level UNFPA programme managers on fistula from Pakistan, Afghanistan, Bangladesh and India.

The objectives of the workshop were to review methodologies that have been employed in measuring prevalence of reproductive morbidities in general and obstetric fistula in particular; to discuss issues of sampling and propose appropriate methodologies for measuring fistula prevalence, particularly community based methodologies for countries in the region.

Across all recommendations participants emphasized the need to consider fistula within the context of reproductive health, and particularly the component of maternal health. The main overall recommendations of the workshop are:

1. Countries should develop capacity and mechanisms to identify OF cases routinely, such as the community-based catalyst approach (e.g. utilizing ASHAs in India, Lady Health Workers in Pakistan, other community link workers and volunteers)
2. Countries wishing to collect prevalence data on obstetric fistula should explore the possibility of “piggybacking” on reproductive or demographic health household surveys. If a community-based survey is preferred, other types of chronic obstetric morbidities should be included in the study to ensure maximum benefit. Wherever possible, studies should incorporate components on determinants and consequences.
3. Other research issues in obstetric fistula need similar attention, including classification & prognostic issues, the impact of management on quality of life, and stigma, discrimination and reintegration
4. A sustained and field-based communication & advocacy strategy in Asia, will enable research dissemination and building networks on maternal health issues.

More detailed recommendations can be found later in the report. In addition, each country delegation mapped out a potential plan for next steps in estimating prevalence – considering its specific context and the strengths and limitations of the methods proposed.



Background

The 2nd Asia and Pacific Regional Workshop on Strengthening Fistula Elimination in the Context of Maternal Health in Islamabad (April 2006) recognized the need for measuring magnitude and impact of obstetric fistula (OF) for developing programmatic responses, advocacy and resource mobilization. Participants in Islamabad noted a need for “enhanced collection of data, both quantitative and qualitative... in order to determine the magnitude and impact of the problem.” Obstetric fistula presents many challenges in estimation as it is a “hidden” condition with an inherent culture of silence and is a relatively rare event. The Delhi Workshop was organized to discuss these challenges and make recommendations on methodologies for estimating prevalence.

The Objectives of the Delhi Workshop:

- To review methodologies that have been employed in measuring prevalence of reproductive morbidities in general and obstetric fistula in particular
- To propose appropriate methodologies for measuring fistula prevalence in the region
- To build capacity of countries in the South Asia Region.
- Foster collaboration in the region on actions for eliminating obstetric fistula

Ms. Ena Singh, Assistant Representative, UNFPA India chaired the inaugural session. Workshop objectives were introduced during the inaugural session by Ms. Kate Ramsey. Ms. Geeta Lal provided a presentation on the global Campaign to End Fistula and the initiatives in the region. The opening address was provided by Dr. I. P. Kaur, Deputy Commissioner, Ministry of Health, Government of India, who highlighted the importance of estimating reproductive morbidities and generating a data base for designing programmatic interventions.

The Workshop Structure and Process:

The workshop was spread over two and half days and included sessions by technical experts from CDC Atlanta, Johns Hopkins School of Public Health, Indian Council of Medical Research, ICDDR'B and UNFPA as well as working group discussions.

Presentations

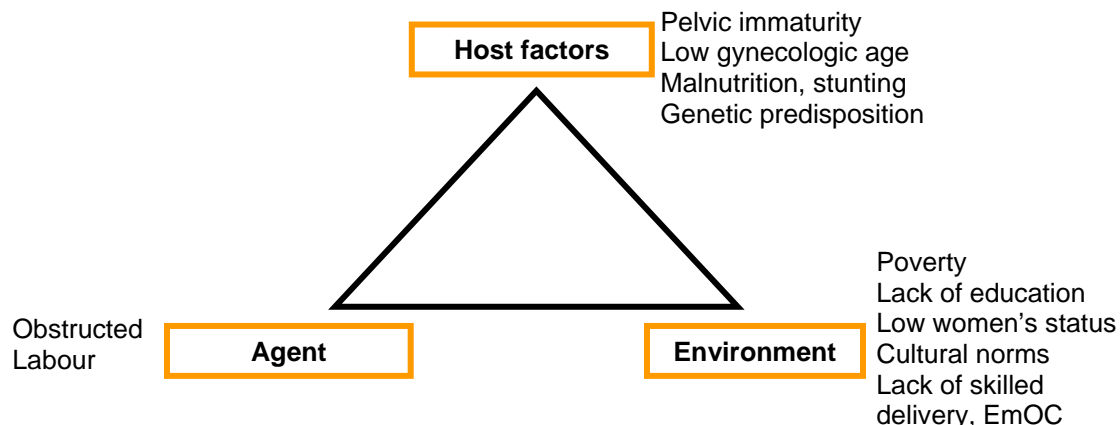
The first day included six presentations over the course of the day. In her opening presentation Ms. Kate Ramsey/UNFPA gave an overview of global research in obstetric fistula and emerging research needs. Her presentation highlighted the work undertaken by a thematic group on data, research and indicators which functions as part of the international Obstetric Fistula Working Group. This group has recommended close attention to measuring the social and economic consequences of obstetric fistula, in addition to measurement of the prevalence and incidence.

This was followed by a presentation by Dr. Florina Serbanescu on the epidemiology of obstetric fistula specifically focused on the distribution and determinants of this condition. The presentation noted that some estimates of obstetric fistula exist, but none are considered to be reliable. Analysis on the burden of maternal death and disability shows that there are about 6 million cases of obstructed labour annually with the risk of fistula in approximately 5 -10% of



cases.¹ Worldwide, more than 80 per cent of vesico-vaginal fistula cases are caused by obstructed labour. The reproductive risk factors related to obstetric fistula include cephalo-pelvic disproportion, fetal malformation, small or malformed pelvis and young age. Lack of adequate services and socio-economic issues also are important underlying risk factors. (See below diagram of the epidemiology triangle presented by Dr. Serbanescu).

The Epidemiology Triangle: Obstetric Fistula



She continued noting that globally there is a lack of reliable data on any aspect of fistula – prevalence, incidence, treatment or other aspects. Much of what exists is not generalizable, making national, regional or global estimates difficult. Therefore, it has been raised as a priority area. The study designs that would be applicable include facility-based statistics, population-based prospective studies, cross-sectional population-based surveys and qualitative studies and their strengths and limitations were reviewed. She noted that measuring morbidity based solely on self-reports will likely result in overestimates unless there is high specificity – but without other viable options it may be best to utilize ongoing household surveys and focus on refining survey instruments and interview techniques.

Mr. Yahya Kane/UNFPA made a presentation on the needs assessment studies conducted across the African region. He noted that the needs assessments included both qualitative and quantitative components and explored issues at both facility and community levels. The assessments looked at health facilities already providing prevention and treatment services – their resources, existing capacities and needs. Community and social needs for helping women to know about services and to facilitate the reintegration back into society were also assessed in many countries. Later socio-cultural and socio-anthropological studies were initiated to understand prevailing social norms and cultural practices and beliefs, perceptions and representations of obstetric fistula. Thirty countries have now completed these assessments in the African region. He then reviewed some of the key findings and noted the usefulness of the assessments in building political support and allowing immediate action.

¹ AbouZahr C. 2003. Global Burden of Maternal Deaths and Disability. British Medical Bulletin:67 (1) 1-11



After lunch, participants from Bangladesh and India shared their country specific studies which are in the pipeline or nearing completion. Mr. Mahbub Elahi Chowdhury shared the ICDDRB study design, “Burden of maternal ill health and death: Research Methodology,” which has recently begun in the Matlab region of Bangladesh. It has several components including a prospective study, a retrospective study, and a cross-sectional study. This large study has the following objectives:

- To compare short-term physical, psychological, social and economic consequences on mothers and other family members following severe maternal complication at delivery or post-partum and perinatal death with normal birth
- To compare short-term social and psychological consequences on mothers and other family members following induced and spontaneous abortion with normal birth
- To compare newborn outcomes (i.e. developmental delays, low nutrition, low education, death,) for mothers with severe maternal complications at delivery/postpartum versus normal birth
- To compare long-term physical, social and economic consequences on mothers and other family members related to severity of maternal morbidity/mortality and perinatal death
- To estimate prevalence of long-term maternal sequelae (including obstetric fistula)

Drs. Sanjay Chauhan and Ragini Kulkarni of NIRRH shared findings and experiences from their recently concluded study on “Chronic Obstetric Morbidities in Nasik District, Maharashtra, India”. The study focused on five direct chronic obstetric morbidities including: Obstetric.Fistula, (VVF/RVF), Genital/Uterine prolapse, Secondary infertility, PID, and Sheehans syndrome. The objectives of the study were to:

- To study the prevalence of defined chronic obstetric morbidities in the study area
- To understand demographic, socio-economic and behavioral correlates of these conditions
- To know the care-seeking behavior, access, acceptability and affordability to care and constraints in seeking services

The study included quantitative and qualitative instruments, as well as clinical examination. Results are still being analyzed, but preliminary results show a variety of information about women’s situation related to childbirth and subsequent sequelae. As has been found in similar studies, there was discrepancy between self-reports and the clinical examination findings – with women reporting more morbidity.

Both studies generated a lot of discussion on issues related to methodology and the feasibility of data collection. The following issues were raised in the discussions.

- Estimation is needed for a variety of purposes, including programme planning and assessing impact of interventions, advocacy and resource mobilisation
- Current weak data availability and issues such as reliability of findings and relative scarcity of cases
- Debate as to whether to collect data nationally or to focus on priority areas,
- Problems in estimation were raised including the culture of silence, lack of proper medical documentation, bigger sample size requirements, robust methodologies and problems in extrapolation to arrive national and sub-national level estimates.

The last session on day one started with a presentation on sampling for reproductive morbidities by Dr. Saifuddin Ahmed/Johns Hopkins. He focused on highlighting the challenges and benefits



related to sampling for different methods. For population-based surveys, the size of sample needed is very large – possibly as large as 60,000. He also noted the typical lack of consistency between self-reports and actual presence of the condition for morbidity. However, while many morbidity self-reports are overestimates, in the case of high stigma such as obstetric fistula, the situation might be the opposite with women failing to report due to embarrassment of their condition. Case finding/non-probability approaches present a challenge due to uncertainty about the accuracy of the estimation, especially with no population-based studies for comparison. He then detailed the possibility of a ‘dual method’ or ‘capture-recapture method’ which would compare those captured through case finding with hospital records and then calculate those that have been missed using odds ratio. This method was first proposed for vital registration by Sekar and Deming in 1949 and is often used in the animal science field.

On day 2, Dr. Arvind Pandey from NIMS made a presentation on a methodological review of studies undertaken in the context of obstetric fistula. Globally, studies specific to fistula are few and most of them are based on hospital data and few community-based studies on reproductive morbidity have included obstetric fistula. He then reviewed the potential of different methods for measuring gynaecological morbidity proposed by Koenig and Sheperd²:

Study Design	Compliance	Cost	Potential for estimation	Potential for research on determinants & consequences
Community based	Low or high	High	High	Moderate to High
Military recruits	High	Moderate	Moderate	Low to Moderate
Community based of client population	Moderate to High	Moderate	Moderate	Moderate
Clinic based studies on clients for other services	High	Moderate	Moderate	Moderate
Clinic based studies on gynaecological morbidities	High	Moderate	Not appropriate	High

He noted that perhaps the snowballing method is the most appropriate as obstetric fistula is a relatively rare event which occurs mostly in rural areas where close kinship ties are intact. For the method to be useful, it requires a skilled investigator on a continuous basis, an exhaustive list of conditions indicating correct response to symptoms associated with OF and the denominator needs to be derived from indirect sources.

Major issues raised in the discussions that followed:

1. Population based surveys: requires validation of questions used in the survey instruments, may wish to introduce screening questions to exclude stress incontinence and traumatic fistula and implications of excluding women above 49 years and below 15 years of age.
2. Community based studies with clinical examination: feasibility of organizing such studies in view of time intensity and cost, requires standardized protocols for clinical examination in order to be comparable

² Koenig M and Sheperd M. 2001. Alternatives to community-based study designs for research on women’s gynaecological morbidity in developing countries. *Reproductive Health Matters*: 9 (18): 165-175.



3. Hospital based review: many records are incomplete in first place and this type of study may not provide an accurate picture due to self-selection biases.

This was followed by open discussions on the country specific needs on and the proposed data collection methodologies. Country delegations presented their plans to move forward on data collection methodologies. Countries were encouraged to continue communicating with one another for further refinements in suggested methodologies.

Highlights of the discussions:

- (a) The question of need for estimation was discussed and it was agreed that:
 - i). Very little reliable information is available on fistula anywhere in the world:
 - ◆ Incidence (global): 73,000 new cases each year
 - ◆ Prevalence (global): from .1% to 3.3% among women of reproductive age
 - ii). Much of the available information is not reliable or generalizable (small scale, facility-based, or population-based with low specificity)
- (b) Problems related to measuring the prevalence/magnitude of fistula include:
 - i) Culture of Silence: Hidden: Stigma/discrimination
 - ii) Absence of hospital based registration system regarding OF cases
 - iii) Large survey sample sizes required
 - iv) Robust methodologies with high specificity to provide accurate estimates
 - v) How to extrapolate from small scale studies to give national estimates
- (c) Study Designs Presented at the workshop were:
 - i) Cross-sectional probability surveys
 - ◆ Self reports only (DHS-type Pakistan)
 - ◆ Self-reports and clinical examination (Nasik District)
 - ii) Cohort studies (e.g. Matlab)
 - ◆ Prospective
 - ◆ Retrospective
 - iii) Qualitative Study (Africa, Asia)
 - ◆ Needs assessment conducted in 32 countries
- (d) Case Findings (providers, snowball sampling, “dual” method)

WORKING GROUP I: Methodologies and Sampling

The group recommended:

1. Piggy-backing on large-scale probability surveys (DHS, DLHS in case of India). Questions about validity including sensitivity of the surveys and ethical concerns about follow-up with women would need to be addressed. In addition the limitations of the age range (only 15-49) should be considered. The benefits include the ability to analyze the findings with a variety of socio-demographic information that is collected in the surveys and a reduction in costs.

The group also suggested exploration of:

- National survey vs. a focus on areas with high probability of reproductive morbidities



- Use of Sisterhood-method for obstetric fistula
- Efforts to improve the snowball sampling approach

2. Where possible, studies should use or draw on qualitative research for understanding the contextual issues and consequences of the disease.

The Group further examined other methods and had following observations to make:

3. Community-Based studies with clinical examination offer perhaps the best method for precision, however, due to the large sample size, these types of studies are time consuming and expensive. They also require standardized clinical protocols for examination. It was recommended that if they are to be undertaken, these studies should include other chronic obstetric morbidities as well as components related to the determinants and consequences.
4. Hospital data reviews are not likely the best option due to the poor quality of hospital records and the low levels of utilization.
5. Regardless, all studies should address ethical issues, for example providing information and referrals for treatment and possibly including support for treatment provision

WORKING GROUP II: Instruments

The group had following observations and suggestions:

1. Use existing instruments but:
 - Expand content
 - Validate Self Reporting using clinical exams
2. Expand focus to chronic obstetric morbidities whenever feasible
3. Focus on women who have ever given birth
4. Ethical considerations:
 - Protecting Privacy and confidentiality
 - Arranging treatment and referrals
 - Meeting cost of care for poor women including opportunity costs

Concluding session:

In the wrap up session, Dr Dinesh Agarwal/UNFPA India and Dr. Florina Serbanescu/CDC made presentations on the summary of deliberations. The presentations captured the essence of discussions and agreed action points. This was followed by the remarks from the Chair on need to follow the discussions with actions, noting that countries in the region have unique opportunity to move forward on the journey to “End Fistula”.

The DHS module was shared with all the participants and participants were apprised regarding field tested questions on OF in various countries. The idea was to encourage member countries use the module for collection of data on OF for assessing prevalence levels and share any improvements to enhance specificity of measurement.



Way Forward

Country Plans for estimation of Obstetric Fistula

- **Afghanistan:** Data collection is not currently the top priority. Therefore treatment services will be established followed by community mobilization and a communication campaign for demand generation. Some data may be collected through the treatment facilities.
- **Bangladesh:** Community based chronic obstetric morbidity study to be conducted (2007-2008) in partnership with ICDDRB including retrospective and prospective cohort components and a focus on social consequences
- **India:** Efforts will be made to incorporate a module on obstetric fistula for screened respondents in the upcoming District Level Health Survey (DLHS). In addition, the focus will be on suspected high prevalence districts in different regions in the country to set up treatment centres connected with case finding. Some of the following will be included:
 - ◆ Community based lay reporting: using cadres of community based health functionaries such as ASHAs
 - ◆ Organization of women's health camps to increase yield of obstetric fistula cases
 - ◆ Organize transport systems to establish linkages with treatment facilities
 - ◆ Introduce Voucher system
 - ◆ Skill up gradation of Doctors may be required in some regions
- **Pakistan:** The DHS 2006 data collection is now complete, which included a module on obstetric fistula. Efforts will be made to determine if it would be ethically acceptable to follow-up with these women for clinical validation and referral for treatment. Also a plan to begin case finding through Lady Health Workers and NGOs working at community level with a focus on high prevalence areas will be considered.

Since Pakistan DHS has provided a base for OF prevalence estimation, only a targeted study will be undertaken to enhance specificity by scrutinizing self reported cases by revisiting them for clinical validation. This exercise will provide necessary guidance to validate the questions / instrument for future studies by other countries. Moreover, an independent study focusing on determinants of Obstetric Fistula was considered essential to see the role of various contextual factors including social, psychological and other issues that perpetuate OF and hinder women from seeking treatment. Pakistan therefore plans a study that will be designed using 'dual approach' in selected high prevalence districts using a) Lady Health Workers at the community level, and b) secondary and tertiary hospitals to ensure all cases are gathered and necessary data collected.

Programmatic directions for campaign countries in the region

1. Build capacity and develop mechanisms to identify obstetric cases routinely
 - ◆ Consider the community-based catalyst approach (ASHA in India, LHW in Pakistan, other Community Link Workers and volunteers)
2. Identify strategies to generate demand for services
 - ◆ Identify OF patients who may refer other cases
 - ◆ Mobilize NGOs and other stakeholders



3. Strengthen the health system to address obstetric fistula
 - Train providers, organize treatment camps
 - Develop treatment guidelines, protocols
4. Integrate obstetric fistula within the reproductive health agenda.
 - Obstetric fistula interventions should be addressed in the context of maternal health and hence focus on prevention (including family planning, skilled birth attendance, emergency obstetric care, transportation and community mobilization approaches)
5. Explore other research issues in obstetric fistula
 - Typology, Classification & Prognostic
 - Impact of Management on Quality of Life – Long Term Consequences
 - Stigma, Discrimination and Reintegration
 - Validation of Screening Questionnaires
6. Design a sustained and field-based communication & advocacy strategy in Asia, which would also enable research dissemination and building networks on maternal health issues.

In conclusion...

300 million women still suffer complications of pregnancy and delivery and another half million die each year from the same causes. For every woman who dies, at least 15-30 face long or short-term morbidities, with obstetric fistula considered one of the most severe. Estimates vary on how many women are currently living with obstetric fistula. The most reliable estimate is that at least 73,000 new cases occur each year, which still may be a gross underestimate.

Obstetric fistula is preventable and treatable and should be embedded in the reproductive health care framework. It reflects many areas of linkage with reproductive health including poverty, lack of girls' education, issues of adolescent reproductive health, lack of skilled birth attendance, and inadequate EmOC. It should be integrated with ongoing family planning, adolescent sexual and reproductive health, gender and safe motherhood programmes.

Obstetric fistula requires a continuum of care from prevention to treatment to reintegration. But above all, as stated by Geeta Lal, in her opening remarks on the Campaign to End Fistula, "it is not just about fistula ...but our commitment to safe motherhood and a life of dignity for all women" that will make the difference.



AGENDA OF THE WORKSHOP

DAY 1: 30th April 2007

0930 hrs To 1030 hrs	<p style="text-align: center;">INAUGURAL SESSION</p> <ul style="list-style-type: none"> - Welcome and Introduction of Participants - Introduction to Workshop Objectives - Global Campaign to End Fistula & initiatives in the region - Remarks from ICMR /NIMS - Remarks from Deputy Commissioner, Maternal Health Division Government of India - Vote of thanks 	<p>Ena Singh, UNFPA Rep a.i. Kate Ramsey Geeta Lal Dr. Arvind Pandey Dr. I.P. Kaur</p> <p>UNFPA India</p>
1030 hrs to 1100 hrs	TEA BREAK	
1100 hrs to 1300 hrs	<p style="text-align: center;">TECHNICAL SESSION – I Estimating Reproductive morbidities/Obstetric Fistula: Experience Sharing</p> <p>CHAIR: Dr. Saramma M. Mathai</p> <p>DISCUSSANT: Dr. (Ms) Nomita Chandioke</p> <ol style="list-style-type: none"> 1. Overview of Current Global Research on Obstetric Fistula 2. Epidemiology of Obstetric Fistula: Determinants and Measurements 3. UNFPA Needs Assessments in Africa Region: Methodologies adopted and findings <p>Discussions on the presentations</p>	<p>Kate Ramsey Dr. Florina Serbanescu Yahya Kane</p>
1300 hrs to 1400 hrs	LUNCH	
1400 hrs To 1530 hrs	<ol style="list-style-type: none"> 1. A study on burden of maternal ill health in Bangladesh: Research methodology 2. Chronic Reproductive Morbidities in Nasik District , India Methodology and findings 3. Experiences in environmental building for data collection in community based studies <p>DISCUSSION ON ALL PRESENTATIONS of Technical session 1: Purpose of the discussions is to seek clarifications from the presenters and also reach consensus on key gaps in methodologies</p>	<p>Dr. Mahbub Elahi Chowdhury Dr. Sanjay Chauhan Dr. Ragini Kulkarni</p>



1530 hrs to 1600 hrs	TEA BREAK	
1600 hrs to 1700 hrs	<p>TECHNICAL SESSION – II Methodological Issues : Sampling</p> <p>CHAIR: Dr. K. Pappu</p> <p>DISCUSSANT: Mr. Tauseef Ahmed</p> <p>1. Design and Sampling for maternal morbidity studies</p> <p>Discussion</p>	Dr. Saifuddin Ahmed

DAY 2: 1st May 2007

0930 hrs to 1030 hrs	<p>TECHNICAL SESSION – III Review of Methodologies</p> <p>CHAIR: Dr. Venkatesh Srinivasan</p> <p>DISCUSSANT: Dr. Saifuddin Ahmed</p> <p>1. Estimating Obstetric Fistula: A Methodological Review and Proposed Methodology</p>	Dr. Arvind Pandey
1030 hrs to 1100 hrs	TEA BREAK	
1100 hrs to 1300 hrs	<p>TECHNICAL SESSION – IV Open Discussion on country specific needs and proposed data collection methodologies</p> <p>CHAIR: Mrs. Tahera Ahmed</p> <p>Summarization of country specific needs and proposed studies</p>	
1300 hrs to 1400 hrs	LUNCH	



	GROUP WORK SESSION	
1400 hrs to 1500 hrs	<p>Introduction to Group Work and Sharing Terms of Reference</p> <p>Three groups will deliberate on following topics:</p> <ol style="list-style-type: none"> 1. Design and Sampling 2. Tools 3. Validation 	<p>Mr. K.M. Sathyanarayana Dr. Mizanur Rahman Dr. Vatsal Dadhwal</p>
1500 hrs to 1530 hrs	TEA BREAK	
1530 hrs to 1630 hrs	<p>GROUP WORK</p> <p>Continued</p>	

DAY 3: 2nd May 2007

	PLENARY SESSION	
0930 hrs to 1100 hrs	<p>CHAIR: Dr. Sajjad Ahmed</p> <ol style="list-style-type: none"> 1. Presentation from groups 2. Discussions 	<p>Rapporteurs from Group Work will made Presentation based on Terms of Reference</p>
1100 hrs to 1130 hrs	TEA BREAK	
	WRAP UP SESSION	
1130 hrs to 1230 hrs	<p>CHAIR: Dr. Florina Serbanescu (CDC)</p> <ol style="list-style-type: none"> 1. Presentation on Summary Recommendations 2. Discussions on follow-up actions 3. Closing remarks by Chair 	<p>Dr. Dinesh Agarwal Dr. Florina Serbanescu</p>
1230 hrs to 1330 hrs	LUNCH	



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