Developing a technology intensive GO-NGO participatory model to improve the maternal health status amongst the vulnerable communities in India – An initiative supported by TATA Trust

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Introduction: Living being including plants have been devising technology and processes to survive and improve their quality of life since the origin of life in this planet Earth. Health & disease remains inseparable. Diseases known to mankind since ancient days such as tuberculosis, malaria, cancer, DM, HT, or maternal deaths as well as emerging infections such as swine flu, HIV, Ebola etc. continues to challenge mankind both in the developing as well as in developed societies. There is also rural-urban divide, more pronounced in India where communities continues to live across three different ages i.e., ancient (Tribal), rural (feudal) and urban (modern) with different value system and practices. Thus, the disease burden may differ based upon many attributes and life style. Vulnerable population such as pregnant women, children and elderly suffers more. Amongst them, women constitutes major economic work force in most developing world. In India, 833 (68.84%) million population are living in rural area and out of that 405.1 million are women i.e. 48.6% of rural population. Such societies can least effort woman-hour loss due to ill-health or child birth, therefore even pregnancy is viewed with fear and neglect. Economic gains of such economies will continue to get severely affected by the High disease burden of women's ill – health considering every 10 minute one woman dies due to complication of pregnancy in rural India. Lack of awareness & trained man power, skewed distribution of health force between urban and rural area, delay in providing quality health care services, unscientific traditional practices affects the health of rural women adversely [1, 2, 3, 4, 5, 6]. Maternal health is not only a biomedical but a socio-cultural issue too so an integrated approach is needed to synergize them for better & optimal outcome of any intervention program. Information and communication technology, e-health or telemedicine (ICT) has a great role to play to bridge the information gap and can

rapidly improve the awareness level of the population [7, 8, 9]. In this paper and presentation, we will discuss some initial observations and outcome of our intervention program.

Aim & Strategy of our intervention program: We aimed at reducing the gaps and delays in the maternal healthcare delivery mechanism in order to break the vicious cycle of socio-economic exclusion and health.

Our strategy was to "Advocate social & economic benefits of evidence based technology intensive program to the rural & indigenous population living in isolation & mobilize the optimal resources to ensure safe motherhood.

Specific long term objectives:

- Identify high risk families, Mothers, New- born, Preventive information, early diagnosis & referrals, improved nutrition
- Providing access to clean water, energy and livelihood close to the home
- Reduce women's workloads, and free up time for other economic and health activities for their young daughters, time can be used to attend school.

Methodology:

Prior to launching the project, we conducted preliminary survey of few poverty stricken villages with respect to women's economic & livelihood activity, customs & social fabric, health status, community need assessment, communication, transport, road connectivity, accessibility, safety & security, health infrastructure, developmental activity. We discussed with the stakeholders about their perceptions of our proposed project and if our intervention would help the local community and the reasons thereof. Preliminary Mapping of the villages, resources & health infrastructure was done along with identification of the village leaders and networking with the local self-governments, SHG's and other peer groups; Linkage with local and Sector health functionaries was done with an objective to assist and participate in state and National government run MCH activities. Village volunteers were trained on survey methods, health care protocols, advocacy & social mobilization techniques, ethical issues etc. We developed scientific enquiry methods – special reference to Contextual enquiry method in addition to conventional GD's, PRA's, transect walk, brainstorming sessions, house to house contacts and sensitization, social mobilization, advocacy at village and hemlet (pada) level and home to home contact etc. We presented our preliminary data to the institutional review & ethics committee for comments and approval to report the base line data.

Results and discussions:

We will discuss some important health issues in this status paper such as: **Lack of awareness on maternal deaths and strong faith in traditional beliefs and limited resources. T**he concept of "woman dying during pregnancy or after birth due to direct, indirect or unrelated causes to be labelled as a maternal death" was completely absent. People do not normally go to any doctor unless they are unable to work and take to bed. Women normally goes to Shira or Guniya (Traditional health practitioner-THP) at first place when they fall sick and then go to modern medicine doctor (allopathic) after some days if they have still not recovered and getting serious. Only when THP's encourage them to go to city doctor then only they go to EBM or allopathic or western medicine trained doctor for treatment. The reason behind visiting THP's is "people think that person is ill because Devi (Goddesses) or Devata (God) had caught him or her and THP's will make him or her free by some magic".

Lack of Trained Man Power & Availability of Services – where ASHA, Anganwadi and ANM (nurse) does not visit them as per her schedule due to many logistic and transport issues. Mitanins or ASHA were not confident while giving medicines to people for minor problems such as cough, cold, fever, etc. National ambulance services (108,102) was readily available but normally took about one hour to one and half hour to reach the place of emergency in remote villages. The energy deficit amongst the reproductive women and adolescent girls was 1490 Kcal with only 0.29% pregnant women not anaemic (Hb% > 12gm %). The HDI of the community we serve was 0.264, one of the lowest in India.

Maternal health practices - The chief causes of maternal mortality were found to be unhygienic and primitive practices of parturition. Some pregnant tribal women reduce their food intake because of simple fear of recurrent vomiting and also to ensure that the baby may remain small and the delivery may be easier which is the evolutionary practice adopted by the community quite often to adjust to the environment and promote home delivery without any complication. More than 90 per cent of deliveries are conducted at home attended by elderly ladies of the household. No specific precautions were observed at the time of conducting deliveries which resulted in an increased susceptibility to various infections.

Community Intervention initiated under our program: We mobilized the entire society through a participatory approach by jointly establishing village hamlet health camps & clinics to encourage

active participation of all the stakeholders & introduced a mechanism to diffuse the affordable diagnostic & ICT technology platforms for health, water and livelihood. Active partnership with the community and the state in jointly monitoring, evaluating & reporting, organizing and conducting task oriented training program for the community based health volunteers have been undertaken. We are also sharing the workload of the state or public appointed health workers and jointly conducting sensitization program for the community, assisting in home visits and social mobilization activity.

Early Pregnancy registration:

We developed a unique way of detecting & registering every new pregnancy at a very early stage within first trimester by using a newly developed festival based LMP calendar and peer group ICT e-health based tracking system. The pregnancy detection rate of 3/100 house hold (eligible couple) was calculated based upon the survey over the previous 6 months period. With the new approach we could register almost 100% pregnant mothers for antenatal care in a short period of time whereas our baseline survey prior to initiation of the program showed only 10% registration of pregnancy. More than 36% women had unsupervised delivery at home conducted by the untrained traditional mid wives that reduced to almost 40% in a short period of time of 1 year. The community has begun to utilize the institutional delivery mechanism developed by the public owned state health service. So, awareness drive using conventional method, human to human interface and assistive technology i.e., human-computer interface, resource mobilization, strengthening of the health network, regionalize the care, are some of the experiments we are conducting. It is making slow but lasting positive impact on the community behavior.

Key questions (Gaps) on the behavior, knowledge and practices were answered:

Gaps 1. Concept of maternal death - The deaths during pregnancy, during birthing or post-natal period was never linked to pregnancy but broadly to general ill-health or bad omen or air as normally occur to anyone in the community unrelated to pregnancy – Well planned constant and persistent ACSM & IEC activities for the women and traditional practitioners including TBA's (birth attendants) , early pregnancy diagnosis using pregnancy kits, AV aids, and linking the women to various social benefits scheme launched by the Govt helped remove many apprehensions and misconceptions.

Gaps 2. Lack of Trust - We also examined the level of trust between the marginalized & most vulnerable indigenous communities and the less proactive state funded public health machinery with a view to evolve a new community led technology intensive partnership model of health care delivery mechanism.

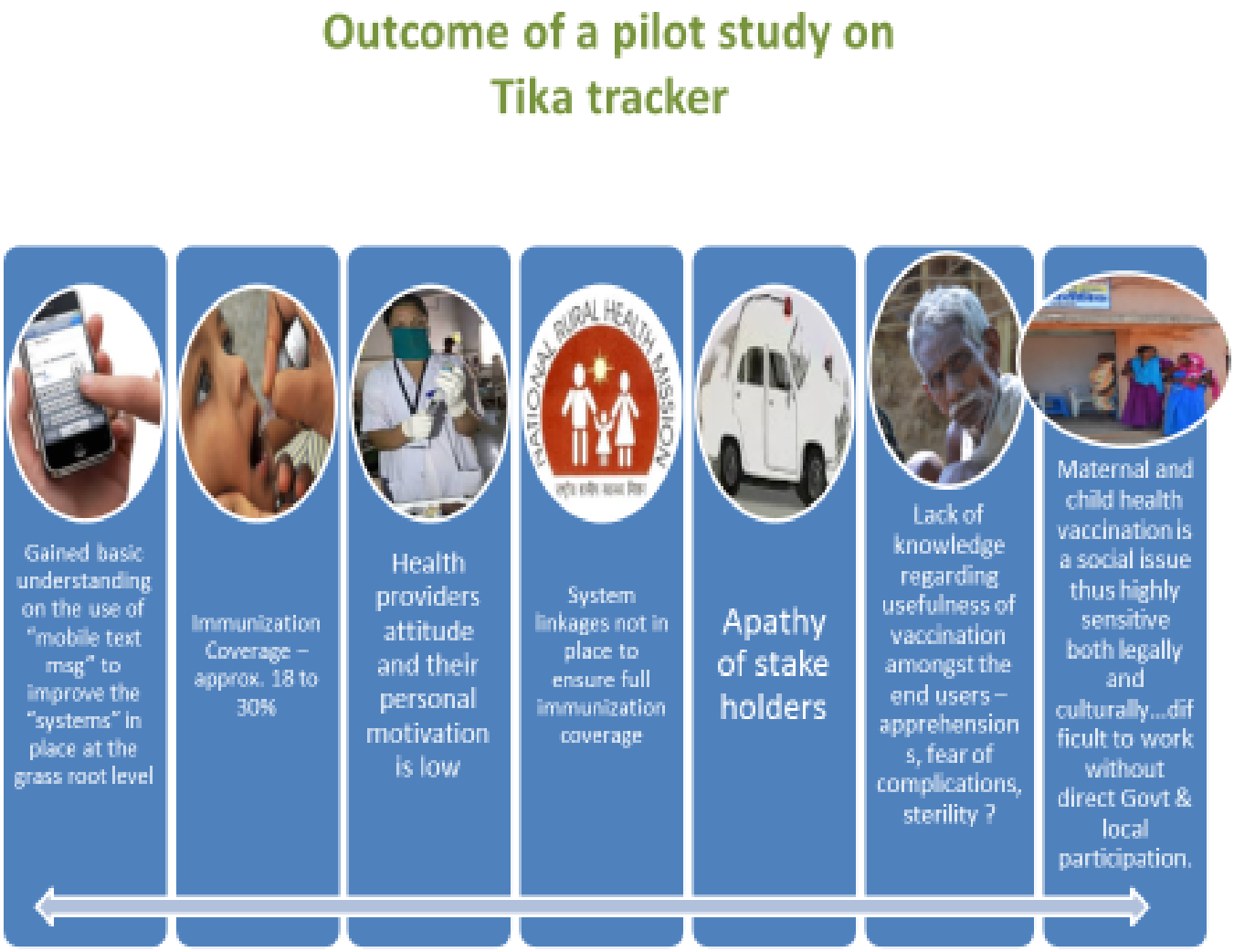
Gaps 3. Lack of health facilities' and apathy of the health providers - Health literacy and health seeking behavior both appeared to be very low regarding modern evidence based curative health care system. We found that the initial reason was not the absence or lack of public health facilities' but the lack of interest amongst the community to seek such quality care.

Key findings " Poor health seeking behaviour, Adolescence pregnancy (early age of conception and consummation of marriage), no concept of perinatal care and safe birthing practices, lack of supervised birthing and some unscientific and unsafe birthing practices, poor nutritional status, low BMI, low literacy, high fertility rate, high incidence of anaemia, inadequate rest and heavy menial work (high energy expenditure), high consumption of alcohol and tobacco, high level of water and environmental (burning dry leaves at home for cooking) pollution, high prevalence of malaria, hook worm infestation, skin infections etc." are some of the hallmarks of maternal health in rural and tribal India.

ICT tool development - There are various ICT tools, to transmit information by electronic means such as radio, TV, fixed telephone, mobile phone, computer, PDA, projector, etc, for health promotion and awareness campaign at community level. There is good penetration of mobile phones and TV so we are working on them as information transmission media. Our special effort was on the use of ICT technology such as **m-health - SMS tracking system (Fig 1) and m-health IVR based & standalone smart phone based system** and point of care diagnostic kits for early disease diagnosis such as malaria, pregnancy, water contamination, typhoid etc at village level while respecting & incorporating the views and ideas of the traditional health practitioners and the traditional health care methods that were found to be more preventive in nature. It helped us to gain huge trust of the community in our effort to reduce the high burden of maternal deaths amongst the most vulnerable communities in our area. We are also designing new ICT tool with consideration of objectives mentioned below, which can also support mobile phones and TV with plug-in/plug-out mechanism.

- Patient's unique health profile
- Accurate recording and reporting of vital health parameters and symptoms
- Decision support system for early diagnosis and early referral
- Context based health promotion, awareness and advices
- Effective report generation, notifications and alerts
- User friendly interface

- Portable & Scalable; portability for providing point of care at home and scalability for different level of health worker (such as ASHA, Anganwadi, ANM, etc)



The Figure 1 showed some outcome of one of our pilot study on introduction of "SMS based m-health immunization tracker system to increase the immunization coverage in rural population "showed general apathy of the population on vaccination, in use of technology and lack of writing & reading skills" – reasons for the partial failure of our "SMS based m-health system" in rural India and as a result we have now added IVR based m-health system for monitoring and counselling pregnant mothers. Most women can receive the call easily by pressing a colour coded key or using single digit number tab.

Conclusion: Our ongoing technology intensive GO-NGO partnership model in one of the highly impoverished conflict zone in India amongst the vulnerable indigenous population is expected to

substantially reduce the maternal mortality rate from 1000/ 100000 LB (currently) to less than 100/100000 LB in the target population in next three years. This innovative model can be replicated in many developing countries to reduce deaths, increase health literacy and quality of life. The expected target is driven by a simple logic that most maternal deaths are preventable in nature however, It may not be possible to reduce MMR to the level achieved by the developed countries because that may require huge investments either by the state and/or by the private players.

References:

1. Sengupta A, Gode AG. A comparative study of the maternal morbidity & mortality in a north Indian teaching hospital. J. Obs. Gynae. India. 1988,

2. Sengupta A, Gode AG. A study of the maternal morbidity & mortality in a north Indian teaching hospital - A 9 years review. J Obs Gynae India. 1987, 394-400.

3. Sengupta A, Muralidhar S, Bhattacharya A, Gode AG. Intensive management of eclamptic patients- An overview. In Recent advances in pathophysiology of pregnancy. Edited by Dasgupta S, Parvez H, and Rippman ET. Rome: CIC edizioni, 1992 *.

4. Benova L, Cumming O, Campbell OM. Systematic review and Meta - analysis: association between water and sanitation environment and maternal mortality. Trop Med Int Health. 2014.

5. Does Empowerment of Women helps in use of Maternal Health Care Services in India: Evidences from North-East Region e*pc2012.princeton.edu/papers/120274*

6. Corrina Moucheraud, Alemayehu Worku, Mitike Molla, Jocelyn E Finlay, Jennifer Leaning and Alicia Ely Yamin. Consequences of maternal mortality on infant and child survival: a 25-year longitudinal analysis in Butajira Ethiopia (1987-2011), Reproductive Health 2015, 12(Suppl 1):S4

7. Shiferaw F, Zolfo M. The role of information communication technology (ICT) towards universal health coverage: the first steps of a telemedicine project in Ethiopia, Glob Health Action, 2012.

8. 5. Chetley A. Improving Health, Connecting People: The Role of ICT in the Health Sector Of Developing Countries. A Framework Paper, Infodev, World Bank, Washington, DC. (2006).

9. [6]. C-DAC: MOTHER Project. http://www.cips.org.in/public-sector-systems-government-innovations/documents/mobile-based-maternal-health-awareness-system-cdac.pdf. Accessed 3 August 2014.

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