Ethical Issues in Community Based Monitoring of Health Programmes: Reflections from India

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With

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This paper is part of a series of papers commissioned by the Community of Practitioners on Accountability and Social Action in Health (COPASAH). Other papers in this series cover the following topics:

- Theories of change in community monitoring
- Tracking and assessing progress and evaluating impacts
- Social accountability of private sector services
- Who are we to care?: Exploring the relationship between participation, knowledge and power in health systems.

COPASAH is a global community of practitioners who share an interest in and passion for the field of community monitoring for accountability in health. The secretariat is based at CEGSS in Guatemala, with regional coordinating offices in east and southern Africa (UNHCO, Uganda) and Asia (CHSJ, India). Members interact regularly, exchanging experiences and lessons learned and sharing resources, capacities and methods in the production and dissemination of conceptual, methodological and practical outputs towards strengthening the field. Member organisations also network and build capacity among themselves. For more information about COPASAH, see www.copasah.net.

SAHAJ Society for Health Alternatives, was founded in 1984, with an idea of providing a supportive and facilitative atmosphere for persons interested in doing original work in the area of health and development. The common thread running through all of SAHAJ's work has been the conscious focus on marginated and deprived communities, with an attempt to make a practical difference to people's lives and social processes. The organization has engaged with the urban poor on issues of child rights, adolescents' citizenship development, masculinities, comprehensive women's health, rights to shelter and other determinants of health. For more details see www.sahaj.org.in

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Executive Summary

This paper explores the different sets of power relationships and resultant ethical dilemmas that arise when developing community monitoring systems. Community Based Monitoring and Planning, as part of the Government of India's strategy to achieve quality health care within the National Rural Health Mission, is used as an exploratory case study. The exploration hopes to benefit and protect the interests of those who are most vulnerable and powerless. The discussions – emerging from a series of conversations between a few community monitoring practitioners in India -- are targeted at a wider community of practitioners who are involved in designing and implementing such programmes. It is hoped that these discussions can be taken further by practitioners and can assist them in ensuring practice which is underlined by a clear set of ethical principles.

The paper consists of three main subsections. The initial section describes what is meant by the process of community monitoring and planning and how it is implemented. This section ends with how community based monitoring and planning fits within the existing power discourse. The second section of the paper begins with a brief history of modern bioethics and then goes on to focus upon ethical principals in community action and different research areas, but specifically shows how community based monitoring and planning, whilst maintaining uniqueness, intersects with several other realms including: community development and social action, community based research, public health interventions and social science research. The ethical principles of *do no harm, maximise beneficence, autonomy and self- determination and social justice*, are explored within each discipline. The final section looks at the various sets of relationships within the process of community based monitoring and planning, the associated differing power dynamics and the ethical issues emerging in each set of relationships.

Syntheses of the aforementioned sections highlight several factors that should be considered in the process of community based monitoring and planning, primarily that autonomy and consent have different meanings when dealing with communities and not just individuals. Having said this, dealing with a community as opposed to individuals often provides strength and protection to individuals. Conflicts around minimizing risks to individuals and promoting greater public good are discussed with several examples in this paper. Thus there is often conflict between ethical principles that need to be identified so guidelines can be developed and conflicting principles can be dealt with in a consistent manner. It is crucial for facilitating organisations to constantly reflect upon their role and who they are accountable to, so that interests of the most marginalised in the communities are put foremost. Finally, it is vital that even while nothing can be done immediately to resolve particular ethical dilemmas, they should be documented to ensure transparency.

Community Monitoring is a unique activity that requires different kinds of preparation as compared to Community Development. Guiding principles and codes of ethics need to be developed by practitioners. But what can these guiding principles be? We can start by suggesting that the Community of Practitioners need to;

At a personal level and within teams

- Promote a culture of reflexivity and open discussion of dilemmas.
- Reflect on how power operates in various situations and relationships. Recognise the dynamic nature of power, and the vulnerabilities within different relationships.
- Recognise discomfort when values are upset/disturbed.

With communities

- Promote community autonomy and self-determination.
- Strive to empower the weakest and the most powerless.
- Build competence and opportunities for co- learning.
- Promote collectivization.

Within partnerships

- Promote values inherent in equitable partnerships.
- Integrate knowledge and action for mutual benefit of all partners.
- Promote system development as well as local capacity building to help people gain control over their own lives.

Community monitoring should result in enhancement of distributive justice. The most vulnerable should find their voice and become active agents. As community based monitoring continues to develop, an important task of the community practitioners that emerges is to promote some ethical guidelines. Most importantly, community practitioners should not ignore the ethical vulnerabilities of various players in the process – including of those representing the health system.

1. Introduction

Practitioners engaged in community development and social action face ethical dilemmas wherever they work. Some of these difficulties flow out of the power inequalities between the facilitators and the community. These power imbalances are further magnified in contexts of poverty. Another set of issues arises due to power relations between communities and public systems and authorities, especially since changing or challenging these relations may be a purpose of various interventions. Also, communities are not homogenous entities – within communities there are the more powerful and the less powerful, and facilitating organizations have a responsibility to distinguish between these and act in the interest of the most powerless. The additional complication is that while ethical guidelines and principles have been codified within several disciplines for research on **individuals** - for example, in bioethics, social work and social science research – ethical guidelines for working with **communities** are still evolving.

The term community participation is used in various contexts – from public health, to environmental conservation, water management, health rights, feminist action, and so on - and is often loosely associated with the concept of 'empowerment', and always associated with positive outcome (Homel et al undated; Kakde and SATHI CEHAT team 2010; Thang Ngo 2009).There is increasing mention, in literature from the 1980s and 90s, of the community's involvement in finding sustainable solutions to local problems (Rifkin 1986). The concept – and practice – of community participation has evolved over the years with communities moving from being 'passive beneficiaries' of development programmes to becoming active agents of their development. Community mobilization and community based research which aims to bring about changes, with the community as an equal partner in the process, are central to many development programs (Kaim 2013, Mansuri and Rao 2013). The Government of India too has acknowledged the role communities can play in positively changing their situations and has incorporated involvement of communities in ensuring quality health care as an integral part of the National Rural Health Mission (NRHM).

This paper explores emerging ethical issues in Community Based Monitoring and Planning (CBMP) as implemented within India's National Rural Health Mission. We first describe the generic model of CBMP as conceptualized in the NRHM Implementation Plan and developed further by the Advisory Group on Community Action for NRHM. The section that describes this ends with situating CBMP within the discourse of power. The next section draws upon related literature: history of modern ethics, ethics in community action, public health ethics, community based participatory research, social science research ethics, framework to evaluate accountability measures, and so on. This is followed by a section which discusses the ethical concerns emerging from CBMP praxis in India. The section explicates the sets of relationships and resultant power imbalances within which ethical dilemmas emerge. The contents draw upon a series of conversations between individuals spearheading the CBMP efforts in various States of India. Finally, we pose a set of guidelines for ourselves as a Community of Practitioners engaged in promoting Social Accountability in the health sector.

2. Community Based Monitoring and Planning within National Rural Health Mission in India

2.1 National Rural Health Mission (NRHM)

The NRHM was launched in 2005 with the goal of improving the availability of and access to quality health care. The Mission aimed to provide universal access to equitable, affordable and quality health care, which is accountable and also responsive to the needs of the people. The NRHM sought to raise public spending on health from 0.9% GDP to 2-3% of GDP. And '*to undertake architectural correction of the health system to enable it to effectively handle increased allocations and promote policies that strengthen public health management and service delivery in the country*'(MoHFW 2005). Some key areas that were identified for concerted action within the NRHM framework of action were:

- Well functioning health facilities;
- Quality and accountability in the delivery of health services;
- Taking care of the needs of the poor and vulnerable sections of the society and their empowerment;
- Convergence for effectiveness and efficiency between health department and departments dealing with determinants of health.

NRHM's vision was that at the community level it would be able to: a) bring about an increased awareness about preventive health; b) place a trained worker with a drug kit for common ailments; c) organise a monthly health day where services related to maternal and child health (eg. immunization, ante-natal check-ups and nutrition) would be available; d) assure good hospital care through availability of doctors, drugs and quality services at PHC/CHC level; e) provide improved facilities for institutional deliveries and the Janani Suraksha Yojna[1] for those below the poverty line; f) provide services to remote underserved areas mobile medical units; and g) ensure provision of safe drinking water and household toilets. In addition to envisioned community level outcomes, concrete service guarantees were specified in the NRHM Framework for Implementation[2].

Community ownership and participation in management was seen as an important pre-requisite to ensure that the outcomes mentioned above are achieved. Community monitoring was seen as an important component of what was termed as Community Action for achieving these results.

The NRHM Framework for Implementation was drafted with significant inputs from civil society organisations and health rights networks like the Jan Swasthya Abhiyan (People's Health Movement in India). These groups brought in right to health as an inalienable right of

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[1] Cash incentive provided to Below Poverty Line women to deliver in health facilities – a major pillar of maternal health policy in India

[2] A few examples of cconcrete NRHM Service Guarantees were: Skilled attendance at all Births, Emergency Obstetric care, Basic neonatal care for new born, Full coverage of services related to childhood diseases / health conditions, Full coverage of services related to maternal diseases / health conditions, Full coverage of services related to low vision and blindness due to refractive errors and cataract, Full coverage for curative and restorative services related to leprosy, Full coverage of diagnostic and treatment services for tuberculosis

all citizens as contained in relevant rulings of the Supreme Court as well as the International Conventions to which India is a signatory. These rights were then incorporated in the monitoring framework of the Mission as citizens' entitlements to guaranteed basic health services.

2.2 Community Based Monitoring and Planning (CBMP)

There are different perceptions about the purpose of Community Based Monitoring and Planning. Community Based Monitoring was envisioned by the Government as a part of 'communitisation' of health services in the NRHM implementation framework. Communitisation, as implemented by the North eastern state of Nagaland (Government of Nagaland 2013), in the post conflict context, marked a paradigm shift in the system of governance. Communitisation was seen as a partnership between the government and communities to harness and strengthen social capital of communities. It included

- Transfer of ownership of public resources and assets,
- Control over service delivery
- Decentralisation, delegation, empowerment and capacity building

Communitisation appears to draw from the concepts of Participation and Accountability as described by Gaventa (2002) -- through participation 'poor people exercise voice through new forms of deliberation, consultation and/or mobilisation designed to inform and to influence larger institutions and policies'. Accountability measures focus on enabling structures for good governance through changes in institutional design. Civil society organisations participating in NRHM clearly viewed CBMP as an accountability measure to increase the responsiveness of health institutions and policies.

Accountability as proposed in the NRHM was conceptualised as a three pronged approach -- internal monitoring by the health system, periodic surveys and studies by third party actors and monitoring by communities including users. The community monitoring process involves a three way partnership between: a. health care providers and managers (health system); b. the community, community based organizations and NGOs, and c. the Panchayati Raj Institutions comprising of elected representatives.

Figure 1 shows the key elements of 'communitisation' and its impact on community participation and accountability.

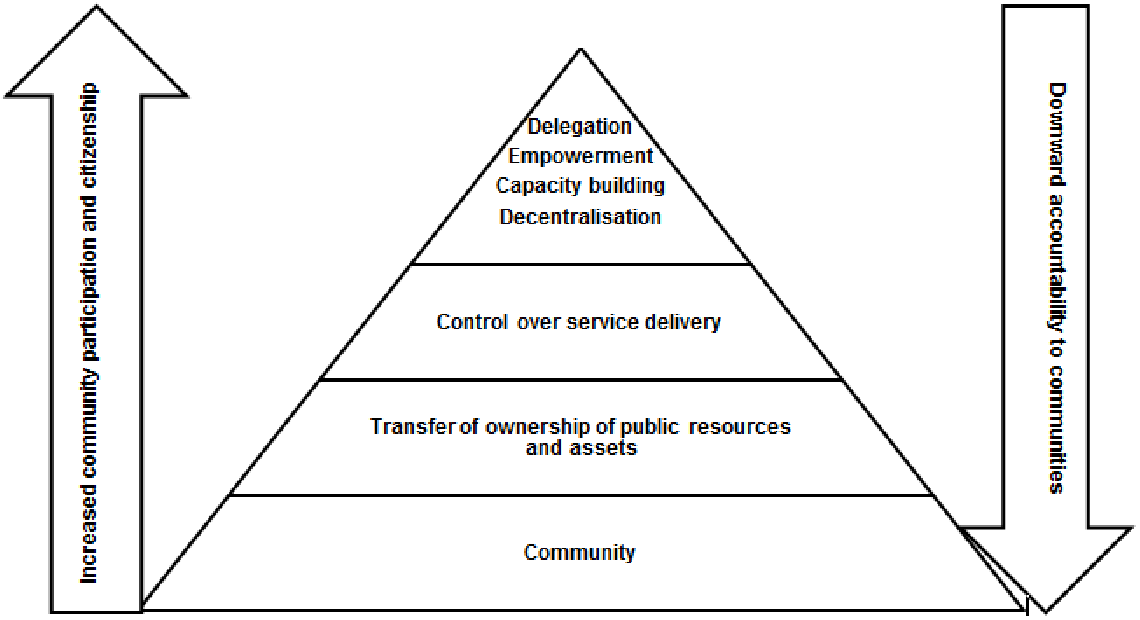

Figure 1 shows the key elements of 'communitisation' and its impact on community participation and accountability.

Process of Community Monitoring – The provision for Monitoring and Planning Committees has been made at the village, Primary Health Centre (PHC), Block, District and State levels – each of these Committees has representatives from amongst the three stakeholder groups. The CBMP framework places people at the centre of the process of regularly assessing whether the health needs and rights of the community -- especially the most marginalised groups -- are being fulfilled.

Box 1: Key institutions for community monitoring under NRHM

- Village Health, Nutrition and Sanitation (VHNSC) Committee.
- The Primary Health Centre (PHC) Monitoring and Planning Committee.
- The Block Monitoring and Planning Committee.
- The District Monitoring and Planning Committee.
- The State Monitoring and Planning Committee

A significant design element in the structure mentioned above, is the inter-linkages between each level of the Monitoring and Planning Committee – the VHNSC is represented in the PHC Monitoring and Planning Committee by two or three members, the PHC Committee is represented in the Block Committee by a few members of the PHC Monitoring Committee and so on. Table 1 below shows broad steps in the process of community monitoring. Box 2 shows how stakeholders are involved in monitoring.

Table 1: Broad steps in the process of community monitoring.

Process	**Stakeholders involved**	**Outcome**
1. Community organizing	Village level stakeholders	Formation of VHNSC
2. Capacity building	VHNSC	Able to identify issues related to health needs, coverage, access, quality, effectiveness of health services, behaviour and presence of health care personnel at service points, possible denial of care and negligence.
3. Assessing health status, access to health care, health needs in a participatory way (initial and periodic)	VNHSC, community, village level health system	Village meetings, interviews with users of services, scrutiny of village health register and other records. Production by VNHSC of village health report card which forms the basis for dialogue with health system and other stakeholders.
4. Unresolved issues according to report card discussed in higher level committee	PHC, block, district level monitoring committees	Issues that are not resolved through actions at one level are presented to higher level committee. Some issues are resolved, those that aren’t are presented to a higher committee, and some eventually reach state level.

Box 2: How are community stake holders involved in monitoring

As members of committees at various levels.

As members of community who share views during meetings. As members of small groups appointed by each committee to visit and review health services / resources / documentations.

By participating in Jansunwais, Jansamvaads and other forums for discussion of issues raised through committee meetings.

Community Based Planning has also been emphasised within NRHM. Village Health Action plans are to be prepared by the VHNSC and submitted to the Gram Panchayat (Village Council). These are supposed to be the basic unit of decentralised and participatory planning - District Health Plans are supposed to be created through this bottom-up approach. A provision of 'Untied Funds' has been made at different levels – the VHNSC and Sub Centres have been provided Rs. 10,000 (USD 200) per year to undertake expenses to improve delivery of health services, each PHC is provided Rs. 175,000 (USD 2750) per year (Rs. 25,000 Untied Fund, Rs. 50,000 Annual Maintenance Grant and Rs. 100,000 Rogi Kalyan Samiti - Patients Welfare Committee - fund) and the facility level Rogi Kalyan Samiti comprising of community representatives and health systems representatives is authorised to spend this money. These are some of the spaces provided by NRHM for community involvement in health planning.

2.3 Institutional Framework to implement CBMP

We described, in the preceding paragraphs, the structure of Monitoring and Planning Committees. To enable this structure, there is an institutional framework within which NGOs or Civil Society Organisations have a crucial role as resource organizations and facilitators of CBMP. Three kinds of roles in the process of community based monitoring were envisaged for civil society organisations:

- As members of monitoring committees
- As resource groups for capacity building and facilitation
- As agencies helping to carry out independent collection of information.

As members of monitoring committees, social organizations working in close, regular contact with communities on health related issues, especially from a rights-based perspective, would be able to present in various monitoring committees the community concerns, experiences and suggestions regarding improving public health system functioning.

As resource groups for capacity building and facilitation, NGOs and community based organisations (CBOs) would have the responsibility for overall facilitation of the initial process of committee formation and capacity building of Community Monitoring committees. In order to shift the balance of power, a considerable amount of community mobilisation, capacity building and facilitation is required before each level of Monitoring and Planning Committees begin to do their job. After the Committees are formed, they have to be oriented to their roles, the framework of participatory democracy and the intrinsic values within which CBMP is being implemented. Skills of participatory enquiry and data collection and analysis have to be built. Communication and dialogue with key stakeholders based on the systematic enquiries have to be enabled. Evidence-based advocacy directed at appropriate decision makers, amplifying the voices of the most marginalised, has to be facilitated.

As agencies helping to carry out collection of information, NGOs and CBOs contribute to the collection of information relevant to the monitoring process at all levels from the village to state.

An entire edifice of Civil Society Organisations -- beginning from the State Nodal Organisation, District Nodal Organisations, Block Coordinating Organisations and other field level community based organisations, people's movements and voluntary organizations -- was envisaged to facilitate CBMP. This network of organisations was then supported by a State Mentoring Group and a corresponding District Mentoring Group. Box 3 provides a summary of the role of NGOs/CBOs as envisaged under NRHM CBM.

Box 3: The role of NGOs /CBOs as envisaged under NRHM CBM

- As members of the committees – advocates of the community (present communities' concerns, experiences, suggestions from rights perspective).
- As resource groups for capacity building and facilitation orient committees to their roles, and the framework of participatory democracy and the intrinsic values within which CBMP is being implemented. Developing skills of participatory enquiry and data collection and analysis.
- Collecting and analysing information in a participatory manner.
- Communication with stakeholders.
- Evidence based advocacy to selected stakeholders.

2.4 Situating CBMP within the Discourse on Power

The essence of Community Based Monitoring and Planning, as it has been conceptualised within the NRHM in India, is to promote citizenship and accountability. This implies a necessary shift in the balance of power between several sets of actors and stakeholders. It is within these sets of relationships of power that ethical issues related to community monitoring have to be located and examined.

The relationships that CBMP attempts to change are between;

- the relatively powerless (and voiceless) users or 'beneficiaries' - especially from marginalised groups - and the powerful health system represented by health care providers and health administrators.
- the facilitating and nodal NGOs/CSOs and the local community based organisations and groups.
- the different kinds of civil society organisations participating in CBMP at different levels.
- the CSOs and the Health Department, which has both mandated CBMP and provides funds for its implementation.

During these early years of implementation of CBMP, the Government, district programme managers, NGOs and the community are all excited about the CBMP process but for very different reasons. These differing expectations from the process are a source of many conflicts. It is in such situations of conflict that power takes on an important hue and a number of ethical considerations arise. As aforementioned, some stakeholders see CBMP as a component of communitisation and others as a mechanism to enforce accountability. Furthermore, some perceive it as a mechanism to enforce "discipline" among public health staff lower down the hierarchy. Whilst both communitisation and accountability may occur simultaneously, the nature and perception of citizen participation differs in these two cases. This too could have ethical implications. The aim of this exercise of examining the ethical issues within CBMP is to protect the interests of the most vulnerable and powerless.

3. Ethics of CBMP and Related Discourses

3.1 Understanding Ethical Principles

Ethics has its roots in the Greek word 'ethos' which means 'character' and is used to describe guiding beliefs or ideals that characterise a community or society. Other derivatives of 'ethos' -- ethicus and ethica -- mean 'moral philosophy' and 'moral character'. 'Values', 'morality' and 'ethics' are often confused (Merriam-Webster Dictionary 2013).

While values and morality are largely personal and individual, ethics are a product of society, a system of moral ideals that the society or community believe in and aspire to follow. Ethics has to do with standards of right and wrong as they apply to relationships between individuals and groups such that benefits accrue to all concerned.

The birth of modern research ethics began during the Nuremberg Doctors' Trial in 1946. Twenty three German physicians and administrators were found guilty of conducting medical research on prisoners in concentration camps without obtaining their consent. As a result most of these prisoners either died or were crippled for life. Consequentially, the Nuremberg Code was established in 1948 and became the first international document to state that consent of participants was absolutely essential and that the benefits of the research must outweigh the risks (Weindling 2004). Another significant milestone in the development of ethics was the 40 year long Tuskegee Syphilis Study (1932-72). This was a research project undertaken by the US Public Health Department on 600 low income Afro American men, 400 of whom were affected by Syphilis. Although free medical examinations were provided, the men were not told that they had the disease and the treatment – penicillin -- even though it became available in 1950s, was withheld. Many of these men died as a result. The study was discontinued only in the 1970s when it was exposed and it became a source of political embarrassment (Gray 1998).

In more recent times and nearer home, in India, the Quinacrine Sterilisation (QS) debate raised fresh ethical concerns. Quinacrine, an anti-malarial drug was used widely in the 1990s in over 25 countries to do nonsurgical sterilisations of over 100,000 women. In 1998, the Supreme Court of India banned the use of Quinacrine for sterilisations because its long term effects on women are unknown and could be potentially harmful. In 2003, five years after the ban, a study found that medical practitioners were still using Quinacrine to sterilise women (Mulay, Singh and Dasgupta 2003). The women interviewed did not know that QS was unauthorised. Most said that they were not asked to sign any paper, or put any thumb impression signifying consent. Those who had signed did not know what they had signed for. Women's health advocates globally raised concerns about QS contextualising this controversy in issues of reproductive justice. They highlighted that generations of poor, powerless women of colour, from developing countries as well as the United States, have been targeted for contraceptive delivery, including forced or coerced sterilization, in order to meet political ends, i.e., reducing the fertility of "problem populations" (Dasgupta 2005) Health advocates argued that the use of QS as a method has occurred within the context of social inequities, and denial of this historical reality further reinforces the invisibility and vulnerability of poor women and women of colour globally.

These and many other experiences have shaped the biomedical ethics discourse globally.

There are four basic pillars of ethics in health care settings – *do no harm* or *non-maleficence*, *maximise 'good'* or *beneficence*, *respect autonomy and promote justice*. The fifth pillar of *community level ethics* is still in a nascent stage of development.

Community based monitoring of health services as a concept and in practice, overlaps with the domains of community action, public health, public health research, social science research, and community based research including participatory and action research. In this section, we discuss frameworks for ethical analysis in some of these disciplines. In the next section, we discuss in greater detail how ethics in CBMP draw upon ethics in these related disciplines.

3.2 CBMP as Community Development, Community Action, Social Action

There is no one definition of Social Action, Community Action or Community Development. However, some key elements that characterise these terms are;

- organizing and mobilizing of groups of people either living within specific geographical boundaries, or having some common features, for example, social grouping, special interests, or needs.
- movement towards a common goal – solution of a common problem, improvement of economic, social, cultural, environmental conditions or quality of life.
- empowerment of those involved – self empowerment through individual action, mutual empowerment that is interpersonal and social empowerment that is collective and a result of social action (Pigg 2002).

CBMP as practiced in India has all the three elements of Community Action mentioned above.

As with community participation, the idea and practice of Community Development has developed over the years to help communities move from dependence to autonomy. The ethical issues become sharper when Community Development sees as its goal self-determination of communities. In the older understanding of Community Development which was based on welfarism, there could also be the possibility of conflating benevolence emerging from paternalistic notions of community development with the ethical principle of beneficence. Practitioners of Community Development believe that the existing social work code of ethics provide little guidance for ethical dilemmas emerging from social action and activism (Banks 2008; Mendes 2002). Others attempt to provide some guiding principles for community development workers like those included in the Community Tool Box from the University of Kansas (Rabinowitz 2013). The guidelines build on the four basic principles of ethics and also warn researchers to refrain from intervening in areas where they lack expertise – the ethical principle of competence.

The Community Tool Box also discusses categories of ethical issues that can emerge in the course of engaging with communities – issues of Confidentiality, Disclosure, Consent (including community consent), Competence, Conflict of Interest, Grossly Unethical Behavior (having sexual relationships in professional relationships in which you hold power, exploiting situations for financial gain, defrauding funders, denial of services, discrimination, outright criminal behavior). The author goes on to state that practitioners need to go beyond the issues specified above in relation to community interventions, to conduct themselves ethically vis a vis donors, staff members, participants, and community at large.

All of the above provide an interesting framework within which to propose a code of ethics for CBMP.

3.3 CBMP as Community Based Research

Community based health research is characterized by its focus on: aspects of health promotion and prevention, populations rather than individuals, a multidisciplinary approach and researchers' partnerships with communities which are often marginalized and powerless-- and is aimed at improving the practice of public health (Blumenthal and Yancey 2004). Capacity building of participants and empowerment of communities for resource management are considered to be some other benefits of community based research (Thomsen 2003). Israel et al (1998) suggested there are eight principles of community based research. CBMP as community based research fulfills these principles. The principles are as follows:

1. Recognizes community as a unit of identity
2. Builds on strengths and resources within the community
3. Facilitates collaborative partnerships in all phases of research
4. Integrates knowledge and action for mutual benefit of all partners
5. Promotes co-learning and an empowering process that addresses social inequalities
6. Involves a cyclical iterative process
7. Addresses health from both positive (physical, mental, social wellbeing) and ecological (economic, cultural, historical, political) perspectives
8. Disseminates findings and knowledge gained to all partners.

CBMP fulfills these criteria and therefore can be considered a community based research initiative. Principles of community partnership (Blumenthal and Yancey 2004) – a central idea in community based research -- apply to CBMP. Partnership between various stakeholders in CBMP evolve based on continuous feedback, as do roles, norms and processes of partnership. The facilitating NGO -- which plays the role of the researcher in the CBMP process -- needs to abide by the principles for building partnerships with communities. According to the models of community partnership in research by Hatch (1993) (cited in Blumenthal and Yancey 2004), in CBMP the community is involved in identifying representatives who play a role as village level advocates as well as in deciding the action on findings. Therefore CBMP can be considered a partnership with the community that is 'difficult to attain but most conducive for ethical and effective community based research' and results in community empowerment. Buchanan et al

(2007) and others point out that there are three distinct purposes of Community Based Participatory Research (CBPR). The first purpose that CBPR fulfills is the ethical function of demonstrating respect for community autonomy. Secondly, it is a research method for eliciting ideas for interventions for improving population health. And third, CBPR is an intervention itself, seeking to enhance community capacities. CBPR is characterized by: Cooperation, engaging community members and researchers in a joint process to which both contribute equally, a balance between research and activism, both systems development and local capacity building, and an empowering process through which participants can increase control over their lives. These characteristics apply to CBMP equally.

Buchanan et al (2007) state that ethical challenges arise when the locus of research shifts from individuals to communities – how do researchers demonstrate respect for the community's right to self- determination? Who represents 'community'? How do we then operationalise the concept of 'community consent'? We will discuss these in the context of CBMP in subsequent sections.

Community Advisory Boards (CAB) are a prominent mechanism for community engagement in international research, especially biomedical research involving minority groups and vulnerable populations (Cheah et al 2010). CABs are composed of members who share a common interest, identity, history, illness experience, language or culture. They are the link between the researchers and the wider community. CABs provide a mechanism to provide the community voice to inform the research design and research process so that it is respectful and acceptable to the community (Newman et al 2011). Establishing and sustaining a CAB is an intensive process, requiring capacity building and ongoing dialogues.

3.4 CBMP as a Public Health Intervention

Public health by definition deals with "all persons and actions that have the primary purpose of protecting and improving the health of the public" and is concerned with aspects of health promotion and prevention with populations at its centre (Childress 2002). CBMP, though considered a strategy or a tool for enhancing accountability of health services, ultimately aims at ensuring better access to quality health care for communities – especially the marginalized, powerless sections. Therefore, CBMP can be considered as a public health intervention and can be examined against the ethical framework for public health proposed by Kass (2001).

CBMP, like other public health programmes and public health research, has an ethical responsibility to contribute to addressing inequalities that influence health outcomes. The facilitating civil society organization plays the role of a public health professional and / or public health researcher, while the communities as well as health care providers/ health administrators are both 'communities' towards whom interventions are targeted. The CBMP process involves empowering people in the communities while engaging health care providers/ administrators to control practices that 'harm' people (non- availability of health services, inadequate monitoring to ensure quality of health care, denial of health care, and so on), and promote practices that would 'benefit' people (responsiveness to people's needs, respectful care, appropriate referrals, and so on). Based on social learning emerging from the CBMP process, health system representatives too have an ethical responsibility to advocate for programs that have positive influence on health outcomes – irrespective of whether they individually are in a position to implement the programme. Because of its nature, CBMP shares some risks inherent to all public health research initiatives. There is a possibility of 'harm' to participants – both community members and health care providers -- if the initiative fails to translate learning into policy and practice. Participants would then have been unintentionally misled to expect improvements and their participation in the process, despite other commitments, could be considered a burden.

The primary purpose of the Public Health system is protecting and promoting the health of the public, i.e. health of populations, rather than health of individuals (Childress 2002). Public health interventions are thus often paternalistic and give importance to public good over individual welfare and autonomy. In the next section, we will discuss how the facilitating organizations in the CBMP context negotiate these conflicting principles.

3.5 CBMP as Social Science Research

Globally as well as in India, evolution of a formal ethical code for social science research is of recent origin compared to ethics guidelines for biomedical research. Guidelines developed by a national committee in 1998 "provide an ethical framework based on four moral or normative principles and ten principles relevant for ethics in research in India."(CEHAT2000)

(i) The Principle of Non-maleficence: **Research must not cause harm to the participants in particular and to people in general.**

Given the nature of CBMP, it is important to define participants. In the context of community based monitoring, 'participant' could be defined to include all persons directly or indirectly involved in the process – the marginalised communities whose rights are denied, as well as the persons working as a part of a 'system' – government department or any other agency who can be considered 'duty bearers'. 'Harm' caused by the process of CBMP would be different for these two groups.

Awareness about rights and denial of these rights is associated with a sense of well-being (which is associated with empowerment), but when faced with an event where their rights are violated this awareness results in increased angst for members of more marginalised communities. In case of CBM, the vulnerable communities' increased awareness about denial of rights may result in negative feelings of anger, etc and less than expected response to actions for claiming rights can lead to frustration. On the other hand, for some sensitive representatives of the system, harm may be more of personal nature – decreased self-worth, feeling that their work is not appreciated by the community, shame at being part of a system which is openly being labelled as oppressor of the vulnerable sections of the society etc.

The CBMP process has also struggled with the fine line between naming frontline health service providers and demanding answerability from them while their higher ups who are responsible for monitoring their work, just because they are not visible to the community, go scot free. The result is that often the weakest, most powerless person in the hierarchical system, is punished and for faults of the system that prevent them from discharging their duties effectively. For example, one northern state in India, is implementing what they call 'reverse tracking of anaemia and malnutrition' in order to pin down responsibility for poor nutrition related statistics on individual frontline health workers. How fair is it to hold this worker (always a woman) responsible if supplies of Iron-Folic Acid, or Take Home Rations through the village anganwadi centres, are not made available by the state and district distribution systems? CBMP should not result in victim blaming when systemic lacunae affect service delivery.

Often in CBMP cases of denial of justice are used for advocating for improvement in services, and in such cases the change does not benefit the person whose case is used but the larger community benefits from the inconveniences experienced by these persons. For example, subsequent to a case of neonatal death because of non-availability of health care providers at a PHC, the village level health committee demanded immediate redressal of issues pertaining to that particular PHC and this resulted in improved access to care for all villagers (SATHI 2012).

(ii) The Principle of Beneficence: **Research should also make a positive contribution towards the welfare of people.**

CBMP, as it is designed, is expected to improve access to health services, improve quality, empower communities to become active partners in health planning and monitoring, provide forums to health care providers for articulating their problems and concerns. There is evidence that community based monitoring results in improved access to health care services and better health outcomes (Kakde and SATHI-CEHAT team 2010). It is important to ensure that access is equitable and the most marginalised benefit from such initiatives. This is also the fourth ethical principle of justice.

Interventions that have the potential to increase the work satisfaction of health care providers will fulfil the ethical principle of beneficence. CBMP, with its creation of structures and processes for multi stakeholder dialogue, has the potential of adding meaning to health care providers' work, and of increasing ownership of health governance issues amongst elected representatives.

(iii) The Principle of Autonomy: **Research must respect and protect the rights and dignity of participants.**

Autonomy and self-determination is an important concept within CBMP. In fact, the direct translation of self-determination in CBMP is decentralised health planning with people's participation based on the gaps identified through the monitoring process. As mentioned in the earlier sections, within the CBMP framework, autonomy and self- determination move away from the domain of the individual to the domain of the collective, the community. And it has been important to define 'community' to mean the most marginalised groups in the village. Autonomy has also taken on different meanings within the context of Jan Sunwais – how is autonomy exercised when individuals decide to testify and depose before the panel? What kinds of processes are put in place before individuals make these decisions, for there are inherent risks in standing up in public forums? These issues are discussed ahead.

(iv) The Principle of Justice: **The benefits and risks of research should be fairly distributed among people.**

How are the risks and benefits of CBMP fairly distributed among different stakeholders? In addition to the most marginalized whose interests have to be kept central, in the section ahead, we will discuss also the tensions of risks and benefits as they apply to users and health care providers.

Table 2 below summarises the common themes which community based monitoring and planning shares with each of the other related disciplines.

Table 2: Commonalities between CBM and related disciplines

	Community development, Community action, Social action	**Community based research**	**Public health intervention**	**Social science research**
Community based monitoring and planning	Focus on: population, empowerment of people for common goal and four basic ethical principles.	Focus on: aspects of health promotion and prevention, population, community as partner. It is a cyclical process which aims to empower community. Combines research and intervention based around the four basic ethical principles.	Focus on population and aspects of health promotion and prevention. Aims at protecting and improving the health of the public possibly through changing policy/practice. Addresses health inequalities in the community and empowers people to take actions for improvement in their health situation.	Has four overriding principles of ethics which are; - Do no harm. - Contribution towards welfare of participants. - Respect and protect rights and dignity of participants. - Benefits and risks fairly distributed among participants.

4. Community Based Monitoring and Planning, Power Relationships and Ethical Issues

4.1 Relationships in CBMP

CBMP is a tripartite partnership between the civil society, representatives of the health system and the elected representatives or PRI members. The partnership operates at various levels as described earlier.

Various stakeholders are involved in the CBMP process - the State Nodal NGO, facilitating organizations at the District and Block levels, other intermediary NGOs, local community groups and CBOs, local animators and activists, communities (especially the vulnerable or marginalised groups), institutional entities mandated by the state (eg the Village Health, Nutrition and Sanitation Committees), elected representatives at different levels, health care providers and health administrators at different levels and administrators from other departments related to determinants of health (like Water and Sanitation, Women and Child Development, Tribal Development and so on). The State Health Department is a key stakeholder because it has mandated the CBMP and provides the financial resources. The relationships between these various stakeholders are complex.

In addition, it is important to recognise that just like the community, the health system too is not a homogenous entity. The peripheral health workers are the lowest in the hierarchy and the most oppressed and take all the blame. In fact, the Auxiliary Nurse Midwives face an additional set of risks arising from a number of gender related issues. Similarly, within each NGO there is a hierarchy – thus the director of the NGO who agrees to implement such a program has huge power over his employees who actually run the program and who are the face visible to the community. These frontline NGO staff generally have a very different understanding of the ground reality -- but they may be required to "show results" to the boss and may have to take different kinds of risks.

In this section we explore various sets of relationships between the stakeholders mentioned above in terms of the nature and dynamics of power in those relationships. Power imbalances result in vulnerabilities and potential for abuse of power. Ethical issues are located within the hierarchies of power and each relationship thus has an ethical dimension.

4.2 People and the System: Ethical Issues

Ethical issues around agenda setting

As mentioned earlier, CBMP's central purpose is to bring about a change in the relationship between the relatively powerless users of the health system (or 'beneficiaries') -- especially from marginalised groups -- and the more 'powerful' health care providers and health administrators. What are some of the ethical issues faced by facilitating organisations at this level? One issue that comes to mind is the **need to balance the ethical principle of autonomy with the struggle for social justice** that facilitating organisations are engaged in.

Leaders of two Nodal organisations (one from a Block level organisation and another from a District Coordinating organisation – both from Maharashtra), stated – at different points in time and in different contexts[3] -- that one of the challenges that they faced was that culturally the adivasis (the indigenous tribal groups) with whom they worked were very peaceful people who accepted their situation and did not question it much. Left to themselves, they would perhaps not really want to undertake an exercise like monitoring health services. The representative from the District Coordinating organisation went on to wonder aloud whether it was then entirely ethical to take them through this effort. What is the meaning of autonomy and consent in this situation? In one sense refusal of the communities to necessarily “fit in” with the ideas of the NGOs facilitating development needs to be considered as an act of agency, that they are active and not passive. This is critical when discussing ethics and especially envisaging the role of NGOs.

A short term and a limited perspective would perhaps lead us to question whether the community consent to be part of the CBMP process is actually a result of an autonomous decision. The justification perhaps lies in the fact that the community monitoring project is just one piece in a larger and longer struggle for equity and social justice that the facilitating organisation has been organising the adivasis for a struggle that actually aspires for a higher level of autonomy and self-determination. The preparatory process in the CBMP initiative includes positioning community monitoring within the larger struggle for rights, building a community consensus on the agenda and defining the roles that the various stakeholders will play. This then is how **informed community consent** is obtained.

Box: 4 Reflections on the Tamil Nadu experience -1

What we are uncomfortable with is the fact that as NGO persons in the Community Monitoring exercise, we are external agents. We raise questions regarding health access and entitlements – not necessarily being able to engage with caste issues or the history of other struggles in the community. In the process we also end up stirring the pot of inequality and inequity in the community which is related to larger socio-economic issues. While we may have the luxury of going back to our comfortable urban middle class security, many of those who actually take part in the process as paid staff or volunteers at the village level and who will have to face the brunt of any backlash, do not have that luxury. For example, while we make a point about having meetings also in Dalit hamlets, the Panchayat President -- a non-dalit -- refuses to come if the meetings held here. We need to think whether openly confronting such caste hierarchies are the only way of overcoming the situation. We feel it is important to explore various solutions based on the realities of that particular community and not be stuck to one formula based on our beliefs.

Community Monitoring necessarily stirs issues in the community but unless we NGO facilitators are willing to put our roots in the rural area for a long-term struggle with those who are at the bottom of the social ladder or even actively link the community with social movements for the same, merely raising issues and providing

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[3] These conversations were part of an ongoing review process of CBMP in Maharashtra that the author was engaged in.

> *'standardised' solutions without acknowledging the local histories and struggles is counterproductive. Our stance has been to not force communities into pre-determined solutions but to encourage them to explore various solutions based on their local contexts.*
>
> *Thus, while in some panchayats, communities and NGOs choose open confrontation, in others NGOs choose to have meetings alternately in dalit and non-dalit areas, and in some they accept that the Panchayat President will not attend and go ahead with the meeting.*
>
> *….Thus the stand is one of encouraging groups to engage with the inequities and corruption and evolve solutions and understanding based on action rather than pre-determined paths. The role of the State NGO is to support these individual struggles and engagements with all support.*
>
> **Conversation with the state team**

Ethical Issues around 'Who is the Community?'

Who is the 'community' in CBMP? Representatives of the (i) marginalised groups according to the context – the dalits, tribals, special interest groups, women, (ii) community based organisations like women's self-help groups, youth organisations, (iii) elected representatives, and (iv) other local leaders like the village school teacher, the health worker form the 'community' for CBMP work. The principle that facilitating organisations should follow is one of inclusivity -- include all those who will represent the interests of the marginalised and the vulnerable – thereby operationalising the ethical **principle of justice**. Facilitating organisations need to constantly check whether the processes are being captured by the elite in the community.

Ethical issues can also arise in relation to questions like 'who monitors health services?' Individuals? Or collectives? Individuals undertaking health monitoring are vulnerable with respect to health care providers who have their professional status and the power of the system to back them. In the health sector where the power asymmetries and vulnerabilities are more than in other public services, there is a risk of harassment, denial of services and other forms of backlash, if individuals are seen to be the monitors. In order to **do no harm,** the role of the facilitating organisations in many states has been to build the power of the collective – even if individuals are seen to do community monitoring, there is public knowledge that they have the collective to back them. In instances of backlash by the system, the facilitating organisation consolidates the collective strength to (i) report the backlash to higher levels, (ii) make the issue of backlash known to wider circle of community actors like the elected representatives who can help in responding to such backlash, and (iii) demand that redressal measures be institutionalised. In fact, we believe that to have a Community Monitoring process without a formal system for redress is in itself unethical. This is an issue that has repeatedly been taken up with State Health Departments and the Ministry of Health at the national level.

Box: 5 Reflections of the Tamil Nadu experience - 2

One of the key issues here is that community monitoring and action is seen more as a backup for a failed governance system (by the health system) rather than as an essential component of any system. Thus communities end up doing the jobs that the system is supposed to do (for example, monitoring entitlements like the JSY) rather than set the agenda. Thus the community monitoring, as it plays out, ends up as an inherently manipulative process - with the communities being stifled by the process, forced to think and work within a pre-set bio medical model.

Conversation with the state team.

Ethical Issues around Backlash

There are instances of misinterpretation of people's expressions resulting in backlash against facilitating organisations. A case of death after laparoscopic tubal ligation procedure in Pune district and subsequent response from the health care providers and the health system are an example of this.

Box 6: Backlash and related Ethical Issues

On June 26, 2011 Ratanbai approached Varvand PHC in Pune district for Tubal Ligation (TL) two months after the birth of her first child after being convinced by the ANM. The doctor initiated the procedure but did not complete TL since some complications were noticed which were a result of a past surgery that Ratanbai had had. She was advised to stay in the hospital for two days but worrying about loss of wages Ratanbai chose to go home. Two days later when she complained of pain in abdomen, the ANM visiting her village gave her some medications and advised her to seek care at the PHC. Ratanbai went to the PHC two days later. The Medical Officer referred her to the tertiary hospital in Pune where two days later she died of septicaemia.

Ratanbai's sister Balubai presented her case in the jansunwai in March 2012. She had been following up with the health department for collecting the promised compensation of Rs 50,000/- without any luck even after ten months. Frustrated with the situation she lost her temper and said "I will burn alive the nurse who encouraged my sister to go for the procedure". This led to a sharp reaction from the district health workers' union threatening an agitation in response to disrespectful behaviour towards health workers. The District Health Officer sent a letter to the NGO that had organised the jansunwai where this incident took place asking for 'explanations'.

(Davandi SATHI, April – June, 2012, pp 16 – 17.)

In addition to the show of power by the District Health Officer and the repercussions for the facilitating NGO, the above story also highlights many other issues related to hierarchies and power of different health care providers within the system. As expressed by the Tamil Nadu team:

Box 7: Reflections of the Tamil Nadu team

Frontline workers are under tremendous departmental pressure to fulfil targets for female sterilisations – the ANM's action of convincing Ratanbai for a TL after the birth of only one child is a result of this pressure. The questions that arise are: what is the ethics of holding accountable and humiliating the person with the least power and no say in an extremely hierarchical system? Should civil society organisations think of ethics only with respect to the violations of the community or do they need to think of the ethics in relation to the health system also – can we forget that those within the system also have rights – while we cannot expect the community to agonize over these (though they do most of the time in my experience) I think the NGO certainly needs to.

Ethical Issues around Jan Sunwais

The ethical principle of Beneficence. One significant lesson learnt by CBMP facilitating organisations across India is that Jan Sunwais – Public Hearings – although a very powerful strategy to increase accountability of the health system, need to be converted into Jan Samvaads or Public Dialogues. In the initial stages, Public Hearings achieved their purpose of demonstrating to the complacent and lethargic public health system, that people monitoring health services, meant business. The Jan Sunwais brought out hundreds, if not thousands, of ordinary people, demanding action on individual and systemic problems like poor referral systems, non-availability of medicines, negligence, dereliction of duty by health care providers, and so on. Such was the power of the people that health care providers and health administrators reported 'fearing' these events. For the first time in all their years of service someone was actually asking them for an account! They were not used to this! They experienced Jan Sunwais as confrontational and humiliating experiences aimed at targeting individual health care providers.

Box 8: Jan Sunwais and Answerability

A woman who approached PHC for delivery was referred to a private facility by the ANM. When this issue was raised in jansunwai, the ANM accepted her wrongdoing. It was decided that ANM would repay the costs the family incurred as a result of this referral and she complied.

Review of CBMP, Osmanabad, Maharashtra

There is an ethical issue here – suppose the facilitating NGO wants to tone down the sharpness of dialogue (in favour of broader beneficence), but specific aggrieved people want to take an assertive stand against denial suffered by them, and demand immediate or definitive action (exercising their autonomy) – how would these be reconciled?

The Tamil Nadu state team has the following reflections on Jan Sunwais.

Box 9: Reflections on the Tamil Nadu experience - 3

We are clear that as part of community monitoring we do not want to target the ANMs or the last person in the link. In fact, it is the community that pointed out to us that it is the ANM (Village Nurse) who actually works and delivers in the field setting. We decided not to let the monitoring process become a trial and disciplining process. Rather than focusing on apportioning individual blame we believe that the Jan Sunwai space should be used to evolve collective solutions. Thus we see the Jan Sunwai as a Panchayat Health Planning Day (as discussed with the health system too). The main aim is "How to change the "red colour services" (poor performance) into "green" (good performance) "together" in "6 months", rather than forcing the system to respond to a "testimony"."

The doctors have told us that they are extremely uncomfortable with the hostile 'auditing' process of Jan Sunwais where they do not know what to expect, which cases will be taken up for examination and for situations that were beyond their control given that they are the lowest in the decision making hierarchy. We thus decided to inform doctors in advance through the animators which issues would be taken up in meetings to give time to doctors to come up with responses and point out what is within their control and suggest what can be done and who to approach for things outside their purview. Wherever punishments or reprimand does need to be effected, we feel the due process of the system's established procedures should be followed.

Conversation with the state team.

Another dimension of the fact that health systems representatives find Jan Sunwais uncomfortable arises from how they are socialized into the system. They have been trained to recognize accountability only as **upward** (to their superiors) and **internal** (within the department). It is then very difficult for them to accept that common people outside of the health system can legitimately ask those questions and expect them to be answered. Thus, it is extremely important that they be oriented to the modalities and requirements of community monitoring before the process is launched in any area. This is both ethical and strategic.

Box 10: Decisions and action taken on issues raised in Jan Sunwai – Bhor Block level Jan Sunwai

Medical Officer of the Primary Health Centre should stay on the PHC premises.

Services such as delivery, contraception are free of cost at government health services. People were asked to file complaints if payments were demanded for these services.

An Order would be issued that payments should not be charged for surgeries and procedures conducted at PHCs. Officers ordered enquiry into fees charged earlier.

District Health Officer ordered that all donation collection boxes be removed from all PHCs.

Action taken on issues raised at Jan Sunway at Saswad Rural Hospital

Medical Officer who did private practice and refused to conduct caesarian sections was transferred based on repeated complaints

New Medical Officer appointed, trained and now conducts caesarian sections

Review of CBMP, Maharashtra

As can be seen from above examples, many issues were resolved at these hearings, what could not be resolved was referred to the next level Monitoring and Planning Committee. The collective learning of civil society organisations is that once major outstanding issues are addressed and public dissatisfaction reduces, sharp confrontation is no longer required and might even be counter-productive. In this situation the tone of the Jan Sunwais probably needs to change to facilitate greater problem solving and constructive dialogue between the health system and the users. Jan Samvaads or Public Dialogues now are a forum where in addition to community members and users, health care providers bring their problems which are then solved with collective wisdom thereby actualising the **principles of maximise good and to diverse stakeholders, the principle of justice**.

Box 11: Maximise Good...

In Shahada the ANM's work was evaluated using the tool and discussed with people from the community. The issues were presented at a Jan Sunwai. The woman sarpanch (head of the elected people's body) of the village discussed the issues with the ANM. She understood the problems of the ANM, provided support to her and work performance improved.

Review of CBMP, Nandurbar, Maharashtra

What can also be seen from the above examples is the conflict between the principles of 'do no harm' to individual health care providers and their confidentiality, and the need to bring home the learnings about professional ethics and their accountability to the public, through ways that appear to work, namely, public shaming. Public shaming in our opinion should be used as the last resort. As mentioned elsewhere in this paper, there is also the danger that the visible frontline health care providers, often the weakest and the most vulnerable, are victimised while their superiors who are supposed to monitor them, continue to not do their jobs and are not held equally accountable.

Box 12: Class Issues

Another aspect of this kind of hybrid accountability mechanisms are that they pit the weakest against each other – both vulnerable communities and the lowest in the rung of health care provision – while there are solidarities of class between the leaders of civil society organisations and the higher levels of health providers and managers.

Conversation with Abhijit Das

Yet another clash between privacy rights of individuals as promoted by bioethics, and the need for public health related information to benefit populations (public health ethics) as pointed out by Bayer and Fairchild (2004), relates to individual testimonies in Jan Sunwais to highlight collective systemic issues. As mentioned earlier, individuals can thus be at risk of punitive action by health system representatives. Informed consent after understanding the risks by these individuals assumes great importance. The facilitating organisations thus have the duty to establish that Jan Sunwais should only be done after the requisite amount and quality of preparation (SATHI 2013). It is important that the strength of collective numbers be visible during the Jan Sunwai, that adequate homework be done in terms of accurate and detailed documentation of the complaints and that a factual and problem solving stance be adopted rather than a blaming one. It is also fair that the health system representatives be informed in advance about the issues that would be taken up in the Jan Sunwai and have an opportunity to prepare themselves.

The Public Health goals of social justice and greater public good -- albeit through individual risk taking -- is reflected in the excerpts from SATHI's case study.

Box 13: Individual Risk and Greater Public Good

The Jan Sunwai not only generates egalitarian aspirations among the marginalized, but it also enhances the confidence of the oppressed (in this case people who are denied proper health care). ***It makes the person suffering denial occupy the public space, not for achieving personal gain but to achieve an egalitarian impact for all citizens (****emphasis ours). Thus, the Jan Sunwai entails enhancement of democracy with moral dimensions. This is an event which reverses the usual formal hierarchical relationship, since the marginalized and the poor no longer continue to be assumed as guilty, while those in the power like doctors, bureaucrats and other health* *officials, are required to respond, are held to be answerable and on occasions are reprimanded by their own senior officials. Jan Sunwai thereby triggers the democratic resurgence of the marginalized and the poor through expansion of spaces for democratic engagement.*

Case Study of Community Based Monitoring and Planning, Maharashtra India
COPASAH 2013

The bottom line that could aid decision making about individual testimonies for collective good within Jan Sunwais is that the individual should get quick justice and reparation.

4.3 Ethical Issues in relationships among Civil Society Organisations and Communities

Recognising Power Differentials

There is diversity amongst civil society organisations engaged in CBMP in India ranging from those with mass base engaged in people's struggles for survival, voluntary organisations, community health NGOs engaged in service delivery, integrated rural development organisations, trade unions, and professional organisations and so on. The two main criteria for their inclusion are either work in the health sector or engagement with rights' issues (although a combination of the two criteria is desirable, such CSOs are not always available in every setting, and organisations that fulfil one of the two criteria have to suffice). Civil society organisations also work at various levels ranging from the village, Block, District, State, National and international. Some of them work across multiple levels. The nature of their work may vary from direct community engagement and action, to research, training, advocacy. They may have different ideologies. Each of these differences contributes to the status that different organisations have and the power base that they operate from in different contexts.

Box 14: Organisations, their Power Base and Ethical Issues

Generally speaking, concern for ethics is a direct outcome of concern to protect the less powerful from abuses of power by the more powerful. Hence it may be postulated that ethical issues generally become more significant as the degree of separation of the civil society organisation from the community increases, and the power relations between organisation and community become more unequal. So ethical issues emerging in context of a village women's self-help group or local youth group vis-à-vis their own community are generally likely to be less complex, compared to say the ethical issues that arise in case of a large, distant and well-funded NGO and the same community.

Abhay Shukla – Maharashtra Community Based Monitoring and Planning

Accountability and Ethical Issues

Another way of looking at this is that if the CSO is locally rooted and is accountable to the community in an organic manner (for example, a local mass organisation which is not externally funded, and relies entirely on its mass membership for work and survival) then gross abuses of power become less likely (though not impossible), since people would respond to these and would either force the organisation to correct itself or would withdraw from it. On the other hand, external organisations which do not have any on-going relationship with the community, and which have no 'dependence' on the community (e.g. an external research organisation which just comes in, gathers data and leaves) are more prone to (deliberate or inadvertent) abuse of power since there is no 'natural' accountability mechanism in place. In the latter kind of situation ethical safeguards and guidelines become much more important.

This is linked with a larger question – to whom are the CSOs accountable? Their legal accountability may be to their respective Governing Boards but the issues of moral accountability need to be articulated. In the Maharashtra CBMP process, based on discussions over the last few years, it has been proposed that each CSO involved in community monitoring and planning is accountable in three dimensions:

a. ***To the communities*** with whom they are working, to ensure their maximum empowerment, sustainable change in power relations and improved access to services with minimum of adverse impacts;

b. ***To the NRHM,*** which is the public authority providing funds and which is expected to demand basic accountability regarding usage of funds and implementation of activities;

c. ***To the collective of implementing Civil Society Organisations*** which has taken up this entire activity as a group, and which needs to maintain certain standards of probity to ensure that the entire activity of CBMP achieves certain credibility in society, which is essential for further development of this process

Ethical issues in Partnerships

Literature on Community Based Participatory Research (Cargo and Mercer 2008) discusses power issues between researchers/academics and community based organisations. With all the dimensions of diversity, the challenge for the State Nodal Organisation is how to build and nurture a partnership based on principles of mutual respect such that each organisation can contribute its strength and area of expertise. Values of equality, fairness, participation, transparency are critical to foster such partnerships. The challenge arises when different partners understand and operationalise the terms of the partnership differently. Channels for dialogue have to be kept open. Conflict resolution methods have to be transparent and fair.

What happens when one partner's conduct can jeopardise the goals of the entire partnership? For example, if one organisation does not render correct and timely financial accounts of the funds received from the health department, this can delay the receipt of funds for all the partners. The State Nodal Organisation then has to exercise its authority to ensure that no harm is done to the larger goal. Others in the partnership may be called upon to play different roles to salvage the situation – if it is a matter of capacity, some organisations in the partnership may intervene to provide the requisite financial management support. If it is a matter of misuse of funds, then organisations will have to get together to take other kinds of corrective action. The ethical principles of *do no harm, maximise good and promote justice* will be used to guide specific actions to manage the partnership.

With respect to how facilitating organisations – 'researchers' in the Community Based Participatory Research parlance – interact with partners who are community based organisations, operationalising ethical principles within the community monitoring process will mean:

- Building a consensus on what will be monitored and how will it be monitored– what are the most important issues that the local communities think should be monitored
- Ensuring representation of the interests of the most marginalised groups in the community, even if their physical representation in decision making fora may be difficult – for example, due to migration
- To the extent possible, ensuring data collection in ways that community representatives can handle it
- Involving community representatives in the analysis of the data
- Ensuring social validation before the data is presented anywhere

All of the above are ways to move the control of the process out of the hands of the facilitating organisations to the actual communities and their representatives. These processes are similar to participatory action research and require considerable capacity building and engagement with the community. The support has to continue through the phases of presentation of the data in dialogues with the health system and other stakeholders. Risks and benefits of each strategy have to be discussed threadbare so that informed community consent is elicited.

The facilitating organisation has the moral responsibility to maintain balance between community good and individual welfare as well as ensuring that all types of participants are protected from harm in the course of the process. Documented examples show that when NGOs play a role of liaison between the people and the system, and when the platforms created through the CBMP are used for bringing forth issues faced by both people and grassroots level health workers, there is a high possibility that CBMP receives acceptance from most stakeholders and implementation is most effective.

Box 15: Promoting Satisfaction of all Stakeholders

Initially the Medical Officer of the PHC resented CBMP – he did not like doctors being questioned in Jan Sunwais. This reflected in his attitude towards the facilitating NGO. Over the course of years when he noticed that in addition to questioning health care providers about their practices, the NGO helped thehealth workers to reach the people and helped present challenges experienced by health care providers to the people thus improving relations between people and the PHC staff, his resentment disappeared. The MO's initiatives have played a key role in improved access to services provided through sub-centres and PHC.

SATHI (2012) Paule Chalati Badalanchi Vaat; pp 38-39

Other Dilemmas

NGO activists have pointed to the fine line between the facilitating role of the civil society organisations and paternalism. For example, the Tamil Nadu team asks, 'Who *mandates the civil society organisations to play this 'facilitating role'? From where do NGOs get the right to 'empower' the community? By taking on so much of "responsibility" for facilitating this process in "the best possible" way, are we in NGOs appropriating more than our fair share?'*

Do efforts to promote women's empowerment actually result in greater gender inequity?

Box 16: Reflections on the Tamil Nadu experience - 4

We have noted on a number of occasions that in the project there are many more women as facilitators (the individuals working directly with the community and who have the lowest salaries) than as we go up the hierarchy with better paid jobs where men predominate. Women are easily forthcoming as volunteers for some of the unglamorous and mostly unpaid tasks they may be paid Rs. 3000 per month (USD 60) for this work. They still need to get back to their homes by 4 pm for cooking and domestic chores. Many of our planning meetings are in the night; they are under pressure to attend these. They also have to put up with the taunts of the men folk at home for unnecessarily disturbing the harmony, etc. It all looks nice and we think that now there is gender balance and gender equity. But have we in fact added to the inequity - in a sense it is a double burden for women?

Conversation with the state team

4.4 Ethical Issues in the State – Civil Society Relationships

There are a whole host of issues stemming from the relationship between the State and Civil Society Organisations and different responsibilities of these different stakeholders.

As stated by Childress (2002) and others, the government has a unique role in public health '*to protect public's health and welfare because it alone can undertake certain interventions….and because public health programmes are public goods that cannot be optimally provided if left to individuals and small groups'.* CBMP should thus be seen as a public health intervention. The positive aspect is that the Health Department at the federal level, as well as Health Departments in several states have 'owned' Community Monitoring and Planning – there is a statement of purpose about CBMP in the official NRHM documents and there are budgetary allocations to support the process in various states in partnership with civil society organisations. While the official mandate is a desirable prerequisite to CBMP being implemented, there are certain contradictions emerging.

Firstly, there are tensions because while the health system wants greater accountability from those lower in the hierarchy, how prepared is it to demonstrate accountability at the highest levels? And how prepared are civil society organizations to hold the highest levels of the health system accountable? Experience of Community Monitoring from several states points to the fact that while structures and processes up to the District level are yielding results in terms of increased accountability, the weakest link in the chain is the state level processes. Systemic problems that need highest level of policy interventions – drug supplies, specialist staff appointments, transfers and postings policies, and so on – are not adequately resolved (COPASAH 2013). Important principles that guide work for community development (Rabinowitz 2013) - build on collective learning and strive to improve the situation, to the extent possible – stand violated. While the Block and District Monitoring and Planning Committees meet regularly and on schedule, State Monitoring and Planning Committees' meetings have not been formed in most states, and where formed these are irregular and do not function in a manner that would resolve major systemic issues. It would seem that the State Health Departments are using the CBMP process to shoot off the shoulders of community groups -- relying on monitoring by communities -- while not proactively strengthening their own internal monitoring systems. This appears as an instrumentalist use of community monitoring and not a commitment to the essence of the initiative and therefore an ethical concern.

Box 17: Response from the Maharashtra team

Our experience in Maharashtra is that often higher officials do use CBM as a channel to pull up their subordinates; hence external accountability processes trigger internal accountability mechanisms to some extent. However, these internal mechanisms should start functioning effectively on their own instead of requiring such repeated 'triggers'.

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The second contradiction is with respect to the power that the State wields because of its position as a donor supporting the process of organization of the Monitoring Committees and their capacity building at each level. Autonomy of the participating Civil Society

Organisations is likely to be severely compromised because they are receiving funds from the very entity that they are supposed to monitor! There is a potential risk of the civil society organizations who are dependent on the government funding of doing a cosmetic and superficial job while engaging with the community monitoring exercise. And there is potential for the State Health Departments to abuse its power as a funder to derail the CBMP process if becomes too uncomfortable. There are several ways in which this derailment can happen – excluding some of the more rights based civil society organizations and individuals who will speak truth to power, delaying release of funds and thereby stalling processes in the field where community representatives have voluntarily contributed their precious time and labour. In fact, right from the pilot phase of CBMP in India (2007-09), there have been delays in release of sanctioned installments, sometimes cuts in the budgets (NRHM 2010). While it can be said that delays in funds release and budgetary cuts (even after budgets are sanctioned) are not unique to CBMP and an occupational hazard of undertaking any government funded programme, failure to 'keep promises and commitments' is a contravention of 'general moral considerations' underlying public health ethics (Childress 2002).

Box 18: Reflections on the Tamil Nadu experience - 5

We knew that the government may not deliver on Community Monitoring all the way. We were also (and are) sanguine of the fact that the hard won gains at the grass root level will fall like a pack of cards once government funding is stopped. Which is the case now - as there has been no funding since July 2012.Not only will this gap in funding affect the human resources of the implementing NGO, but equally importantly will impact the morale and the energy created through the process and negatively affect the credibility of the NGO staff among the community who do not see a continuity in the efforts. We may have the luxury as NGO activists (at the state level) of walking away from the situation if funding stops and "moving on" to other agenda. But is it fair on the people with whom and in whose name we have worked?

Conversation with the state team

Ethical Issues around relations with the government health system

Facilitating civil society organisations often face situations where strategies for empowering communities and highlighting injustice jeopardise relations between the NGO and the government health system. For example, in Maharashtra, "implementing agencies were forced to rethink the strategy of approaching media" after the State health authorities contested the findings and expressed displeasure about choice of strategy (Kakde and SATHI-CEHAT team 2010). A crucial question that arises here is the direction of accountability of the civil society organisations – who are they accountable to? How do they decide when to follow the lead of the community and when to go against the community wishes for the greater common good?

Box 19: Reflections on the Tamil Nadu experience - 6

There are many things we can and cannot do in a government funded people's participatory program. Given a commitment to partnership with the government and the community we need to be sensitive to the requirements of both. While there is a primary commitment to the marginalized groups, we feel it is important to be sensitive to the efforts of the various individuals within the public health system who have opened up spaces for the people to enter in. Too much confrontational radical interrogation will rapidly close spaces (hard earned) within the public health system. This concern however needs to be balanced with the need to raise issues at various levels that emerge from the process. Thus a number of methods need to be evolved to balance these two pressures; this can be very confusing and calls for a lot of reflection and introspection. Call it pragmatism, cynical calculation or what you will. We want to stay on as much as ethically and constructively possible to help further the CM process – if need be by losing the short term battles to win the long term war. We want to create "alternative modes of change."

We therefore take care not to do certain things: for instance, interact with the media in a direct way. It upsets the few motivated people in the government. In fact we have a tacit understanding that we will not approach the media under the CM/NRHM label (but do so for the same issues under the JSA label for example). It sometimes seems a conflict of interest of sorts. You cannot be a party to a triage and take the issues to the media when it suits you.

Conversation with the state team

We would also like to discuss the point about 'ownership' of the CBMP programme by the Health Departments in the context of multi stakeholder partnerships such as the CBMP. Any true partnership is characterized by transparency, trust and democratic and participatory decision making in a spirit of equality (Cargo and Mercer 2008). How then does the Health Department become a 'more than equal' partner failing to respect norms of participatory and democratic decision making, when it decides whom to exclude and include in the process, what amount of funds to allocate, when to release the funds and of what quantum? Is this again not an abuse of power?

People's participation in health planning is also a stated objective of the CBMP process. The idea is that through the monitoring, community groups identify needs which are then prioritized and incorporated in the village health plan. Village health plans are then to be aggregated into Block Health Plans and further into District Health Plans. There is also provision of 'untied funds' at the village, subcentre, primary health centre and higher level of health facilities, such that decentralized and local planning can be done with community participation. While all this is on paper, in actual fact planning continues to be controlled by higher levels of the health system. The formats have not changed. Investments have not been made to enable community groups to contribute meaningfully and in informed ways into the planning process.

Box 20: Tamil Nadu team's perceptions

While expecting the communities to monitor, plan and undertake action for health system strengthening, the government has not shown the necessary commitment to the process in terms of allotting funds for the plans nor taking these plans seriously in the district or state planning process. Neither has the government shown a commitment to the overall process in terms of facilitating the participation of the staff, orienting the staff etc. Some of the ideas that arise from the plans could be for renovating a PHC, or filling up vacant posts. Or for antisnake venom injections. While the government is ready to sometimes invest in equipment or infrastructure, it is unwilling to directly enforce timings for doctors who do not stay beyond 1pm in most PHCs. You have raised people's hopes for meaningful change but you don't have funds for implementing suggested changes, nor the systemic commitment. Indeed, we sometimes feel it is unethical to be party to raise people's hopes without being able to fulfill them.

Conversation with the state team

In the preceding section, we have perhaps raised more questions than suggested solutions!

5. Conclusion and the Way Ahead

The purpose of this paper was to identify some of the ethical issues as they emerged within the context of CBMP in India in the hope that this can be a basis of discussion amongst the Community of Practitioners. Although these issues emerge from the specific context of India's CBMP work, many issues are generic -- accountability of civil society organizations, partnerships with communities, state-civil society-community relationships. Also, ethical principles are universal.

Ethical concerns in CBMP are located in various sets of power relations that characterize CBMP: users and communities vis a vis the health system, facilitating civil society organizations vis a vis local communities and community actors, the coalition of civil society organizations and the health system. Terms like 'autonomy', 'self- determination', beneficence, non-maleficence, justice, transparency and disclosure acquire different meanings in the context of relationships between different stakeholders.

The discussions in various sections highlighted the following;

- 'Autonomy' and 'Consent' acquire specific nuances when we work with communities as opposed to individuals. These nuances need to be captured.

- There is a need to reflect upon the mandate and role of facilitating organizations vis a vis communities. What are the boundaries that must not be crossed, what are the processes that need to be followed so that facilitating organizations not lapse into paternalism and erode self-determination of communities? Facilitating organisations need to become aware that historically engrained power differentials can lead to manipulation. It may sometimes mean that whilst an organization may have shared values with the community, they should not thrust solutions to problems upon them. Rather through encouragement communities can engage with problems and together NGOs and communities can reflect upon action and outcome.

- It is important to build and demonstrate collective strength of communities so that threats to individuals are mitigated.

- In specific situations there may be a conflict between various ethical principles – for example, between individual or group autonomy and beneficence or maximize good; between 'do no harm' to individuals and privacy needs of individuals and 'promote collective good'. It is important that these conflicts are articulated so that guidelines can be formulated.

- There are a host of contradictions and dilemmas when civil society organizations partner with the government health department specifically for people's health rights. These have to be articulated even if within the situation not much can be done about them.

Community monitoring is an activity that requires different kinds of preparation as compared to Community Development. It is an emerging field which is different from Public Health, Community Based Participatory Research, Social Science Research, (although it draws upon them). Hence, guiding principles and code of ethics need to be developed by practitioners. It must be recognized that while these guidelines and code of ethics are useful to guide practice, resolution of specific dilemmas may not always be possible.

What can these guiding principles be? We can start by suggesting that the Community of Practitioners need to;

At a personal level and within teams

- Promote a culture of reflexivity and open discussion of dilemmas

- Reflect on how power operates in various situations and relationships. Recognise the dynamic nature of power, and the vulnerabilities within different relationships.

- Recognise discomfort when values are upset/disturbed.

With communities

- Promote community autonomy and self determination

- Strive to empower the weakest and the most powerless

- Build competence and opportunities for co learning

- Promote collectivisation

Within partnerships

- Promote values inherent in equitable partnerships
- Integrate knowledge and action for mutual benefit of all partners
- Promote system development as well as local capacity building to help people gain control over their own lives.

To conclude, our practice of community monitoring should result in enhancement of distributive justice. The most vulnerable should find their voice and become active agents. Health systems should become responsive to people’s needs. There are no perfect solutions – even with the dilemmas we have to act. How we act to maximise beneficence and minimise harm, within these complex situations, is the lived experience of ethical action. The Community of Practitioners needs to build a reflexivity, engaging with the moral and ethical dilemmas as they balance on the tight rope of relationships, not giving in to cynicism, hoping for change but not blind to the points of ethical vulnerabilities of various players in the process – including of those representing the health system.

6. References

Banks, S. (2008) 'Critical Commentary: Social Work Ethics'. *British Journal of Social Work*. 38 (6): 1238-1249.

Bayer, R., and Fairchild, A.L. (2004).'The Genesis of Public Health Ethics.'*Bioethics*. 18 (6): 1467-8519.

Blumenthal, D.S., and Yancey, E. (2004), "Community-Based Research: An Introduction," in *Community-Based Health Research*, Daniel S. Blumenthal and Ralph J. DiClemente, eds. New York: Springer: 3–24.

Buchanan,D.R., Miller,F.G., and Wallerstein, N. (2007). 'Ethical Issues in Community Based Participatory Research: Balancing Rigorous Research with Community Participation in Community Intervention Studies'. *Progress in Community Health Partnerships: Research, Education and Action.* 1(2): 153-160.

Cargo, M.,and Mercer, S.,L. (2008) 'The Value and Challenges of Participatory Research: Strengthening its Practice'. *Annual Review of Public Health*. 29: 325-50.

Centre for enquiry into health and allied themes (CEHAT). (2000). 'Ethical Guidelines for Social science Research in Health'. Available online at: http://www.cehat.org/publications/ethical1.html (last accessed on 16/05/2013).

Cheah, PY, et al. (2010). 'Community engagement on the Thai –Burmese border: rationale, experience and lessons learnt.' *International Health 2* (2): 123-129.

Childress,J.F. (2002) 'Public Health Ethics: Mapping the Terrain'. *Journal of Law, Medicine and Ethics.*30: 169-177.

COPASAH (2013).'South Asian Practitioners Workshop. Community monitoring and social accountability of health programmes.' COPASAH: Mumbai. Available online at: http://www.copasah.net/uploads/1/2/6/4/12642634/mumbai_workshop_report.pdf (last accessed on 16/05/2013).

Dasgupta, R. (2005). 'Quinacrine Sterilisation in India: Women's Health and Medical Ethics at Large. A publication of the Population and Development Program: New Hampshire College. No. 34. Available online at: http://www.global-sisterhood-network.org/content/view/237/59/ (last accessed on 16/05/2013).

Gaventa, J. (2002) 'Introduction: Exploring Citizenship, Participation and Accountability'. *IDS Bulletin*. 33.2.

Gray, F,D. (1998) 'The Tuskegee Syphyllis Study'. Montgomery: New South Books. Available online at:

http://www.history.ucsb.edu/faculty/marcuse/classes/33d/projects/medicine/The%20Tuskegee%20Syphilis%20Study.htm (last accessed on 16/05/2013).

Government of Nagaland (GoN). (2013) ‘Improving Public Services: The Nagaland Experience, A presentation on Communitisation’. Available online at: http://gad.bih.nic.in/Gallery/Dr-Toko-Presentation-on-Communitization.pdf (last accessed on 16/05/2013).

Homel, R., Hauritz, M., Wortley, R., Mcllwain, G., and Crvolth, R. (Undated) ‘Preventing alcohol-related crime through community action: The surfers Paradise safety action project.’ Available online at: http://www.griffith.edu.au/__data/assets/pdf_file/0014/13370/surfers.pdf (last accessed on 16/05/2013).

Kaim B (2013). Who are we to care? Exploring the relationship between participation, knowledge and power in health systems. TARSC, Zimbabwe, and COPASAH

Kakde, D., and SATHI-CEHAT team (2010). ‘Compiled report of community based monitoring of health services under NRHM in Maharashtra (2007-2010)’ CEHAT: Maharashtra.

Kass, N.E. (2001). ‘An Ethics Framework for Public Health’.*American Journal of Public Health.* 91(11): 1776- 1782.

Mansuri, GhazalaandVijayendraRao. (2013). ‘Localising Development: Does participation Work?’ Washington, DC: WB. DOI: 10.1596/978-0-8213 -8256-1.License:Creative Commons Attribution CC BY 3.0.

Mendes, P. (2002) ‘Social workers and ethical dilemmas of community action campaigns: Lessons from Australian State of Victoria’. *Community Development Journal*. 37 (2): 157-166.

Merriam- Webster Dictionary. (2013) ‘ethos’ Available online at: http://www.merriam-webster.com/dictionary/ethos (last accessed on 16/05/2013).

Ministry of Health and Family Welfare (MoHFW). (2005). ‘National Rural Health Mission: Meeting people’s health needs in rural areas, Framework for Implementation 2005-2012’. Government of India: New Delhi. Available online at: http://jknrhm.com/Guideline/Frame_Work.pdf (last accessed on 16/05/2013).

Ministry of Health and Family Welfare (MoHFW). (undated) ‘Manual on Community Based Monitoring of Health Services under National Rural Health Mission’. Government of India: New Delhi. Available online at: http://mohfw.nic.in/NRHM/Community_monitoring/Implementers_Manual.pdf (last accessed on 16/05/2013).

Mulay, S., Singh, N., and Dasgupta, R. (2003) “Quinacrine Non-Surgical Sterilisation In West Bengal: What We Have Learned From The Women On The Ground,” A report presented in a workshop to discuss the research findings’ Kolkata: India. Available online at: http://www.global-sisterhood-network.org/content/view/237/59/(last accessed on 16/05/2013).

Newman S.D., et al. (2011). ‘Community Advisory Boards in community-based participatory research: a synthesis of best processes.’ *Preventing Chrocnic Diseases.* 8(3): A70.

National Rural Health Mission (NRHM). (2010). ‘Reviving Hope, Realising Rights’. Available online at: http://www.mohfw.nic.in/NRHM/adv_grp.htm(last accessed on 16/05/2013).

Pigg, E, K. (2002). ‘Three Faces of Empowerment: Expanding the Theory of Empowerment in Community Development’. *Journal of the Community Development Society*. 33 (1): 107-123.

Rabinowitz, P. (2013). ‘Ethical Issues in Community Interventions in Choosing and Adapting Community Interventions in Community Tool Box.*Working Group for Community Health and Development: University of Kansas*. Available online at: http://ctb.ku.edu/(last accessed on 16/05/2013).

Rifkin, S.B. (1986) ‘Lessons for Community Participation in Health Programmes.’*Health Policy and Planning*. 1(3): 240-243.

SATHI.(2012) PauleChalatiBadalanchiVaat.SATHI: Pune.

SATHI. (2013). ‘*Community Based Monitoring and Planning in Maharashtra, India: A Case Study.* SATHI: Pune. Available online at: http://www.sathicehat.org/Publications/CommunityBasedMonitoringMaterial (last accessed on 16/05/2013).

Thang Ngo D., et al. (2009) ‘Rapid decrease of malaria morbidity following the introduction of community-based monitoring in a rural area of central Vietnam.’*Malaria Journal*, **8**:3 doi:10.1186/1475-2875-8-3. Available online at: http://www.malariajournal.com/content/8/1/3.

Thomsen, D. (2003) ‘Community-based research: An opportunity for collaboration and social change, PhD thesis submitted to Australian School of Environmental Science, Faculty of Environmental sciences, Griffith University.’ Available online at: http://www4.gu.edu.au:8080/adt-root/uploads/approved/adt-QGU20050323.174017/public/02Whole.pdf(last accessed on 16/05/2013).

Weindling, P.J. (2004). ‘Nazi Medicine and Nuremberg Trials; From Medical war Crimes to Informed Consent.’ Palgrave Macmillan: Great Britain.

7. List of Abbreviations and acronyms

ANM - Auxiliary Nurse Midwife

Anganwadi Centre – children’s centre for early childhood education and nutrition

CAB - Community Advisory Boards

CBMP - Community Based Monitoring and Planning

CBO – Community Based Organisation

CBPR - Community Based Participatory Research

CM – Community Monitoring

CHC – Community Health Care

CSO - Civil Society Organisations

Gram Panchayat – local governance body

JSA – Jan Swasthya Abhiyan – People’s Health Movement

JSY – JananiSurakshaYojana

NGO - Non Governmental Organisation

NRHM - National Rural Health Mission

PHC- Primary Health Care

PRI – Panchayati Raj Institution (Elected members body)

QS - Quinacrine Sterilisation

VHNSC - Village Health Nutrition and Sanitation Committee