MAPPING OF EXISTING MEANINGFUL INVOLVEMENT/COMMUNITY ENGAGEMENT IN INDIA'S NONCOMMUNICABLE DISEASE SPACE AND BEYOND

DRAFTED BY: HEALTHY INDIA ALLIANCE

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Abbreviations

AG	Awareness Generation
AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
ASHA	Accredited Social Health Activist
ANM	Auxiliary Nurse and Midwife (ANM)
CAG	Community Action Groups (Lived experience)
CBM	Community Based Monitoring
CBOs	Community Based Organizations
CBPR	Community-Based Participatory Research
CC	Care Coordinators
CHCs	Community Health Centers
CHW	Community Health Workers
CKD	Chronic Kidney Disease
CSC	Community Score Card
CRPs	Community Resource Persons
CSO	Civil Society Organization
CV	Community Volunteers
DS-EHR	Decision-Support Electronic Health Record Software
EDSS	Electronic Decision Support System
HIV	Human Immunodeficiency Virus
HRGs	High Risk Groups
LSST	Lok Swasthya SEWA Trust
MAS	Mahila Arogya Samiti
MoHFW	Ministry of Health and Family Welfare
NACO	National Aids Control Organization
NACP	National AIDS Control Program
NCDs	Noncommunicable Diseases
NHSRC	National Health Systems Resource Centre
NGO	Non-Governmental Organisation
NPCDCS	National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases, and Stroke
NRHM	National Rural Health Mission's

NVBDCP	National Vector Borne Disease Control Programme
PHC	Primary Health Centre
PR	Participatory Research
PRIs	Panchayati Raj Institutions
RBSK	Rashtriya Bal Swasthya Karyakram
RCH	Reproductive Child Health
RCCE	Risk Communication and Community Engagement
RKS	Rogi Kalyan Samiti
RKSK	Rashtriya Kishor Swasthya Karyakram
RMNCH	Reproductive, Maternal, Newborn, Child and Adolescent Health
SC	Score Card
SEWA	Self-Employed Women's Association
SSK	SEWA Shakti Kendras
SHG	Self-Help Groups
STI	Sexually Transmitted Infections
T2DM	Type 2 Diabetes Mellitus
TB	Tuberculosis
VCCs	Village Coordination Committees
VHSNCs	Village Health Sanitation and Nutrition Committee
VHND	Village Health and Nutrition Day
WG	Women's Groups
WHO	World Health Organization

Context

This mapping exercise was conducted under the NCDA's Advocacy Institute NCDs and UHC Accelerator Programme 2020-2022 (Year 2). The goal of the project is to accelerate the agenda of people living with NCDs, through strategic multi-stakeholder advocacy and action, informed by the development of the Global Charter on Meaningful Involvement of People Living with NCDs. In order to inform the strategic advocacy efforts, post the release of the Global Charter, HIA conducted this mapping of past examples of meaningful involvement within and outside the NCD landscape in India to documenting strategies and pathways of meaningful involvement adopted by other health and/or non-health movements in India.

What is meaningful involvement/community engagement?

As per the World Health Organization (WHO), the term "community involvement" is generally preferred to "participation" and points to the idea of partnership and shared responsibility with health services rather than to the notion of using the community to reduce the burden on the health services[i]". Community involvement can increase access to and sustainability of health services by enabling communities to explore consequences of health behaviour[ii]. Beyond its usage to enhance effective implementation of health programs, it also has a positive impact on social capital, which enhances community empowerment, leading to improved health status and reduced health inequalities[iii].

Community engagement points towards a level of control that communities command in an initiative, though the term covers a wide range of processes from mobilization to empowerment. While mobilisation is viewed as an external push to the community, community empowerment expands the opportunity to participate in, negotiate in, influence, control, and hold accountable institutions that affect the wellbeing of the community[iv].

Justified need towards Community Engagement for Noncommunicable Diseases

The burden of Noncommunicable diseases (NCDs) is high and attributable largely to a few preventable risk factors, -tobacco use, unhealthy diet, lack of physical activity and harmful use of alcohol. Combined with high health care costs, they pose a major threat to public health. There is enough evidence on cost-effective and evidence-based interventions to prevent and control various NCDs which are best delivered in an integrated manner through the existing health system. Health promotion activities to reduce exposure to risk factors, early detection and management and enhancing surveillance to monitor trends in risk factors and diseases. In order to deliver these interventions in an integrated manner, a shift is needed from addressing each disease/risk factor separately to collectively addressing a cluster of diseases, as well as a public health approach embedding an intersectoral "whole of society" response[v].

Mechanisms of community involvement

Review of the literature and systematic reviews point towards community engagement being used across a variety of health and non-health domains. Within the domain of health, different fields such as health promotion, inter-sectoral collaboration, service delivery, governance, supply chain management, financing, human resource management and information systems have utilised community participation mechanisms[iv]. Non health domains include use of community participation mechanisms for insurance, linkages to schemes, water, education and sanitation, housing/city development and budget formation.

Strategies going forward

Evidence from HIV and Polio interventions highlight the importance of having guidelines in place for community engagement to guide process. The National Strategic Plan for HIV/AIDS and STI 2017 – 2024 also recognizes the importance of community engagement as a "critical enabler" towards reduction of prevalence of HIV (Human Immunodeficiency Virus)/AIDS (Acquired Immunodeficiency Syndrome). The engagement of diverse stakeholders including civil society and people living or affected with HIV, have all been identified as essential features of the Indian response to HIV/AIDS over the last 30 years. Similarly, The National Framework for Malaria 2016-2030 mentions formation of community action groups for

sensitization about malaria prevention, intensified control and elimination. These groups are meant to comprise of community volunteers such as Non-Governmental Organisations (NGO) staff, teachers or local leaders. Similar guidelines if instituted at National/sub-national level for NCDs would enhance community participation by virtue of it being a mandate.

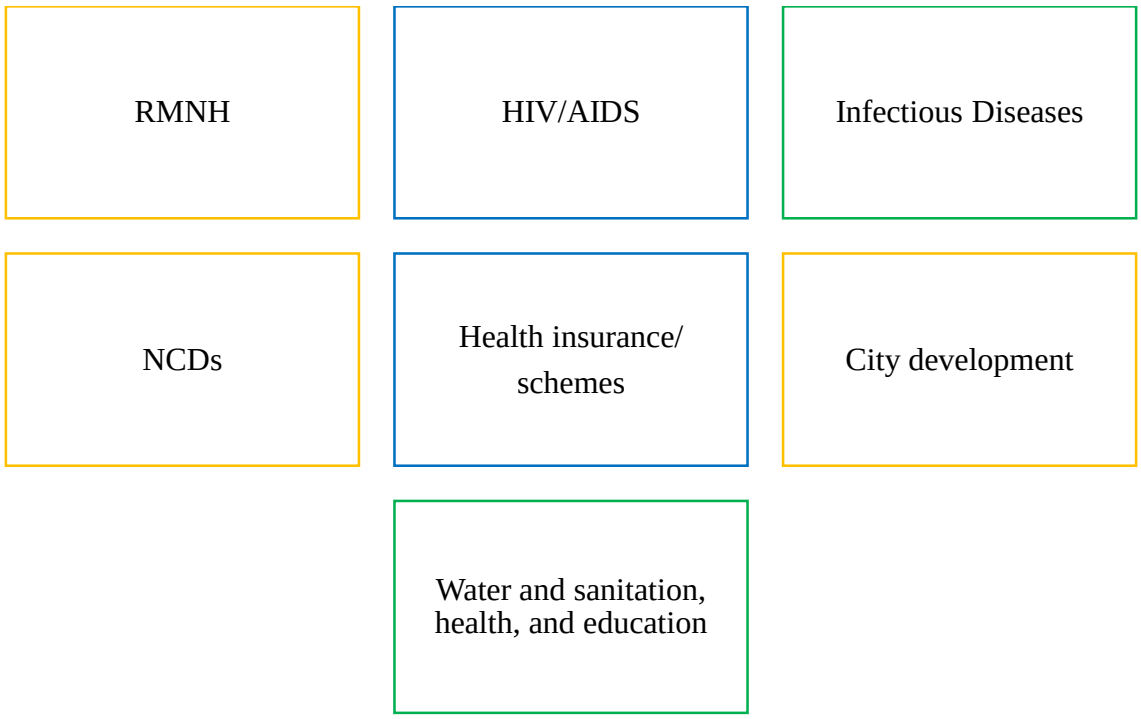
Many interventions mentioned are smaller scale studies conducted at district or block level but have shown success. Such smaller interventions which show promising results maybe scaled up or replicated in other states. Robust monitoring and evaluation is required to assess success and feasibility of replication and scale up of such interventions.

A Bottom-up approach is necessary which involves two-way communication and feedback to promote participation and inclusion. Bottom-up approaches emphasize the participation of the local community in development initiatives enabling them to select their own goals and the means of achieving them.

Learnings from Covid- Risk Communication and Community Engagement (RCCE). It is critical to enable communities with information regarding health risks and actions they can take to protect their health and lives during public health emergencies. RCCE provides accurate information provided early, often and in languages and channels that people understand, trust and use. It enables individuals and communities to make choices and take actions to protect themselves, their families, and communities from life-threatening health hazards. Whilst this is still focusing on awareness generation, it focuses on the need to transform complex scientific knowledge into simple, understandable, and accessible information for communities.

Synthesis of scientific literature

The following section details out interventions included in this mapping exercise. Literature was found on community engagement mechanisms across the following thematic areas:



Community engagement within Health Sectors

1.1 Maternal and Newborn Health

Ekjut cluster-randomised controlled trial

Within India, the **Ekjut cluster-randomised controlled trial** of a participatory learning and action cycle with women's groups aimed to improve maternal and new-born health outcomes in Jharkhand and Orissa. The intervention included monthly meetings of 244 women's groups to discuss problems related to pregnancy, childbirth, and the post-natal period. These discussions were led by local facilitators trained in participatory communication methods who had received basic training to discuss health problems during pregnancy and childbirth. A 45% reduction in neonatal mortality attributable to improvements in safe practices for home deliveries was noticed. The process evaluation highlighted factors influencing pathways to change including acceptability, a participatory approach to the development of knowledge, skills and 'critical consciousness'; community involvement beyond the groups; a focus on marginalized communities; the active recruitment of newly pregnant women into groups; and a high population coverage leading to successful implementation of the intervention[vi].

India Local Initiatives Program Model

The **India Local Initiatives Program Model** (India-LIP) is a reproductive and child health program designed to stimulate community involvement in health care using local committees and health volunteers to create partnerships with other agencies, including private and public healthcare providers. This model originated from Bangladesh where it was used exclusively for family planning. The approach centers around mobilizing community support; increasing demand for and access to essential reproductive and child health information and services; and establishing sound technical and management approaches to support these services.

The program includes Government Reproductive Child Health (RCH) program staff, local leaders, and administrators of government health and development programs working as partners with a local community team. (2) Community members being actively involved in planning, implementation, and resource mobilization as they managed family planning, maternal and child health, and reproductive health program and serving on local management committees that oversaw service delivery in villages and urban slums guided by a locally designed work plan. (3) Local women participated directly in service delivery activities by serving as community volunteers to provided family planning, other health services and information about services directly to families. They also worked with government clinics and others, and made referrals for clinical RCH services. (4) The community helped finance service delivery by mobilizing cash and in-kind contributions from local resources.

Another component included introducing NGOs as intermediaries introduced to oversee implementation, work with communities, and provide technical assistance and other support. The NGOs provided training and support to the health committees (e.g. on project management and use of data), and through their own local activities and knowledge of the area, helped mobilize the community around health and adapt the activities of village health committees to the needs and capacities of the local population and health system. In order to strengthen

management skills of the partner NGOs and the communities, formal management training and technical assistance was provided[vii].

The 1850 community health volunteers were mostly female and largely illiterate. They were trained to deliver basic health-care information and services and then assigned responsibility of 50 households. They were key in organizing grassroots services through household visits, promoting health fairs (melas), and attracting clients to the services offered at mobile and satellite clinics.

The village based RCH committees are a part of India's program strategy and were important to the LIP model given they not only offer local support for the initiative but also provide a vital connection with local government. In Kolkata, the committees consisted of influential community members- male political, business, and social leaders[viii].

Community Action for Maternal Health Project

The **'Community Action for Maternal Health Project'** led by NGO Society for Health Alternatives (SAHAJ) between 2012-2015 was implemented in 45 villages with approximately 108,000 people in Gujarat. Key components of the intervention included a) raising awareness of maternal health entitlements, b) supporting community monitoring of services, and c) facilitating dialogue with health providers and other key stakeholders[ix]. Raising of awareness was done through focus group discussions and participatory methods with women's groups to elicit local understanding and preferences for safe delivery along with display of information, education and communication materials. Community monitoring included home visits to women who were 8 months pregnant as well as post-partum using a healthy mother tool (warli madi tool). Outreach of antenatal services at Village Health and Nutrition Day (VHND) through VHND tool was also monitored, and maternal death tracking was done to triangulate with government tracking. Thirdly, the dialogue with stakeholders helped identify gaps and develop report cards for functioning of Primary Health Centre (PHC). A color-coded system was developed to denote whether levels of service receipt were poor (red), average (yellow) or good (green). Over time changes in colour were found to be was highly motivating to community members and health providers. Report cards were initially share with local health authorities and medical officers, and an interest was expressed in receiving primary health center-wise report cards and discussed the results with staff[x].

Changes were seen in restarting of services (increasing the number of outreach clinics in hard to reach areas, initiating deliveries in a previously defunct facility), repairs that improved the quality of the service environment (fixing leaks and toilets), better relationships between community members and government providers (health trainings by government providers for women's collectives, invitation to NGO partners to attend block level maternal death review meetings), and addressing inappropriate practices (kick-backs between female community level providers and private providers, private hospital not providing services as per the public-private insurance scheme)[xixii] .

White Ribbon Alliance-India

In Odisha, an intervention aiming to improve accountability in Orissa, India focussed on the role of local women, intermediary groups, health providers, and elected politicians. **The White Ribbon Alliance-India** embarked in 2006 on a social accountability programme to address high maternal mortality and the inadequate implementation of maternal health programmes,

using three tools: maternal death audits via verbal autopsies, health facility checklists, and public hearings and rallies to bring women together with government officials and service providers to address grievances around maternal care.

The public hearings presented an opportunity for community mobilisation and a rare occasion for highly marginalised women to assert control through collective action. The public hearings are a forum for local women, the public, the media, and elected representatives to hold local health officials, health workers, health planners, and policy-makers accountable for implementing policies as designed so women can realise the health entitlements outlined through National Rural Health Mission's (NRHM) initiatives such as RCH-II, Janani Suraksha Yojana, and Janani Shishu Suraksha Karyakaram.

An evaluation found three drivers of success explaining how the public hearings translated into increased accountability- the generation of demand for rights and better services, the leverage of intermediaries to legitimise the demands of poor and marginalised women, and the sensitisation of leaders and health providers to women's needs[xiii].

1.2 Anaemia Management

Participatory Action Research in Maharashtra

Towards enhancing children and adolescent girls health, a **Participatory Action Research in Maharashtra** aimed to increase their heamoglobin level through provision of supplements and nutritional education. Engagement of community included community mobilization, motivation of villagers and healthcare providers and training of doots (local female community health workers). Community-based organizations consisting of 85 women's self-help groups, 20 Kishori Panchayat (adolescent girls' forums), 27 Kisan Vikas Manch (farmers' clubs), and 20 Village Coordination Committees (VCCs) (committees of representatives of the above-mentioned organizations) were formed to make a platform at the community level for actions. The VCCs were endorsed by the village Gram-panchayat for implementation and monitoring of the healthcare services at the village level. The intervention led to a drop in the prevalence of nutritional anemia from 73.8% to 54.6% among the adolescent girls and from 78.2% to 64.2% among the children[xiv].

1.3 HIV/AIDS

Ashodaya Samithi

Community ownership has long been used to tackle the HIV epidemic, finding a place within the country's National AIDS Control Program (NACP). For instance, a comprehensive Community-Led Structural Intervention, **Ashodaya Samithi** group led by 8000-plus female, male and transgender sex worker members tackled the epidemic in Karnataka, which accounted for 55% of all HIV infections in India.

The members promoted condom use, provide HIV testing and counseling, link HIV-positive sex workers to antiretroviral therapy centers so they can receive treatment, and volunteer in hospitals to ensure fellow sex workers receive adequate services and aren't discriminated

against. To expand services, a social enterprise approach was taken- a local restaurant originally funded by a World Bank Development Marketplace grant is run, as well as serviced apartments.

Profits go to support a community care home for HIV-positive sex workers. During phase III of India's National AIDS Control Program (NACP III), from 2007 to 2012, it was scaled up. The success has translated into training of sex worker groups from other countries, including Nepal, Bangladesh, Myanmar and Mozambique[xvxvi].

During the current pandemic, due to disruption of antiretroviral treatment was disrupted, Ashodaya adapted its HIV outreach programme to form an alternative, community-led system of distributing Antiretroviral Therapy (ART) at discreet, private sites. Further they used WhatsApp messages to distribute information on accessing government social benefits made available in response to the COVID-19 pandemic. They expanded their horizons to include advisory messages in WhatsApp groups to raise awareness, dispel myths and mitigate violence, and regular, discreet phone check-ins to follow up on the well-being of members. These activities present an important opportunity to consider more sustainable approaches to the health of marginalized populations that can enable community organizations to be better prepared to respond to other public health crises as they emerge[xvii].

Care and Support Centres

The National Strategic Plan for HIV/AIDS and STI 2017 – 2024[xviii] also recognises the importance of community engagement as a '"critical enabler" towards reduction of prevalence of HIV/AIDS. The engagement of diverse stakeholders including civil society and people living or affected with HIV, have all been identified as essential features of the Indian response to HIVAIDS over the last 30 years. The establishment of **Care and Support Centres** managed by the civil society and community based organisations is another success.

These centres provide support and linkages to various social sector schemes, Loss to Follow Up tracking, providing peer and psychosocial counselling, treatment literacy/adherence, home visits, stigma reduction, advocacy with other departments to increase access, partner testing, local resource mobilisation, and intensive case finding.

Around 1 million people living with HIV have been provided care and support services, 452,641 have been linked to various social welfare schemes and 267,901 Lost to Follow Ups have been tracked back into the system through 360 Care and Support Centres. The Targeted Intervention program of the NACP has evolved over 4 Phases and has been achieved through national, regional and state level consultations with multiple stake holders including community members and civil society organizations. For high risk groups such as truckers and migrant works, working with the communities have been key to harness the trucking community, associations, and volunteers among the migrants community respectively.

The harm reduction policy adopted by National Aids Control Organization (NACO) as a strategy for prevention of HIV/AIDS amongst Intravenous Drug Users in 2002 focusses on behavior change communication (BCC), among other strategies. One of the key aspects of the strategy include community participation in programme planning and implementation.[xix]

Avahan India HIV/AIDS Initiative

The **Avahan India HIV/AIDS Initiative** funded by Bill and Melinda Gates Foundation, started in 2003 and was rolled out in the states of Karnataka, Andhra Pradesh, Tamil Nadu, Maharashtra, Manipur and Nagaland in India.

During the first phase (2003–08) the goal of the program was to build and operate an HIV prevention program at scale for high-risk groups (HRGs). This was implemented through a "parallel" system of NGOs and community-based organizations (CBOs) that facilitated achievement of scale very rapidly. It offered a standardized package of services including outreach and behavior change communication, commodity distribution (condoms), linkages to care and treatment, clinical services for sexually transmitted infections (STI), community mobilization and creation of an enabling environment for HRGs through advocacy and crisis response.

Community engagement included components of program oversight by committees made up of community members, strong support to community groups, and community-led crisis-response mechanisms to respond to violence or harassment of community members. The Avahan framework ensured programmes would range from a 'for the community' to a 'by the community' programme, depending on the preparedness of the community. Some early data from Avahan have shown that the programme outcome is better, showing increased condom use and reductions in STI when the community is engaged.[xx] [xxi].

1.4 Kala Azar

The elimination programme in India for Kala-Azar is spearheaded by the National Vector Borne Disease Control Programme (NVBDCP). The strategy consists of an aspect of advocacy, communication and social mobilization for behavioural impact and inter-sectoral convergence among others.

Inadequate utilization of health services and lack of faith in public health systems can be addressed by intensive awareness campaigns with the involvement of communities and community health volunteers. The National Roadmap for Kala-azar Elimination 2014 stresses on a need for advocacy, communication and social mobilization through all existing methods (wall writing, hoardings, banner, pamphlets, radio jingles etc) as per local contexts[xxii].

An intervention carried out in 10 districts of Bihar and 4 districts in Jharkhand sought to implement a BCC intervention in using group and interpersonal communication, to improve knowledge, attitudes, and practices of communities, frontline health workers, and opinion leaders towards kala-Azar. The assessment found that households from intervention villages were more aware than those in control villages that indoor residual spraying is an effective control measure (82.3% vs. 41.7%, respectively; P<.001), and would encourage a patient to go to primary health centers for diagnosis and treatment (77.0% vs. 39.4%, respectively). The study stresses upon the role of key opinion leaders such as village heads, retired government employees, political representatives, social workers, and women's group leaders to address barriers such as low acceptance of IRS and lack of trust regarding the benefits[xxiii].

1.5 Malaria

The NVBDCP includes a three-pronged strategy: early diagnosis and prompt treatment, vector control and IEC/BCC with community participation for Malaria control[xxiv].

The National framework for Malaria 2016-2030 reiterates the same, laying down formation of community action groups for sensitization about malaria prevention, intensified control and elimination. These groups are meant to comprise of community volunteers such as NGO staff, teachers or local leaders[xxv].The framework also suggests training of mobile or migrant workers, military personnel, tribal or other population groups in malaria diagnosis and treatment, therein holistically involving communities in malaria prevention.

The framework heavily relies on community participation/community-based groups for vector control strategies (regular surveys to assess utilization of long-lasting insecticidal nets by community health volunteers), service delivery (collaboration with NGOs, community based organizations for reaching populations in hard-to-reach and conflict affected areas).

Standalone studies have utilised community-based mobilisation to improve care-seeking and preventive behaviour towards malaria mitigation. One study combined supportive supervision of community health workers with intensive community mobilization to demonstrate significant improvements in the reported utilization of bed nets (84.5% in arm A versus 78.6% in the control arm; $p < 0.001$), higher rates of treatment seeking from a community health worker (28%; $p = 0.005$ than in the control arm 19.2%)[xxvi]. Similarly, use of folk theatre to enhance health education awareness with regard to malaria prevention and treatment seeking in Karnataka led to a significant increase in knowledge and change in attitude about malaria and its control strategies, especially on bio-environmental measures ($p < 0.001$). Further, the local community actively co-operated and participated in releasing larvivorous fish, which subsequently resulted in a noteworthy reduction of malaria cases[xxvii].

1.6 Polio

Social Mobilization Network (SMNet)

India has been certified polio free since 2014. Within Uttar Pradesh (UP) and Bihar, the deployment of **Social Mobilization Network (SMNet)** was a major disruptor of the spread.

Its three-tiered structure mobilizes communities by spearheading civil society participation; and works at district, block and community levels. A multipronged approach using local religious leaders, community influencers, interpersonal communication, counseling, mothers' meetings, announcements from religious institutions and rallies targets resistance to polio immunization.

The success of the SMNet has been its ability to identify and convert resistant families into advocates for polio immunization. 98% of SMNet mobilizers are women who are deeply respected in the community. It was first established in UP in 2002 and then expanded to Bihar in 2005-06 with the objective of increasing oral polio vaccine uptake among children under 5 years of age in these states. The SMNet targeted families that refused immunization as well as families with lesser access to service such as mobile, migrant, and hard to reach families. The

SMNet thus gained shape as a cadre of mobilizers that could strategically reach out to resistant or left out families to ensure polio immunization.

Post mapping and identification of pockets of underserved and high-risk populations, selection of appropriate advocates was done based on negotiations and discussions with several implementing partners as well as beneficiaries. Being from the communities they served, the community mobilizer coordinators (CMCs) of the SMNet were responsible for 350-500 households, going house to house to engage families through interpersonal communication and counselling sessions - addressing myths and misconceptions and ensuring correct knowledge about polio.

They also mobilise families before every round to ensure that all children below 5 years get OPV through holding mothers' meetings and religious meetings to advocate for repeated polio immunization, coordinating temple and mosque announcements and conducting polio classes in schools, madrasas and other congregations.

The SMNet also reaches out to community assets to extend their footprint – with a reach of 31,000 community influencers to build trust and goodwill for the polio program while its 26,650 informers help notify movement of migrant communities[xxviii].

Children were used as mobilizers, forming into groups called ***Bulawwa tolies***. Children were seen as nonthreatening and themselves enthusiastic ambassadors of change—carrying positive vaccination messages through communities. They helped track small children, motivated their mothers, and, in many cases, even brought children to booths for the polio drops. Schoolchildren were used to hold rallies and parades a day before the round. Teachers also played a key role in mobilization since most booths were set up in schools, where teachers were put on duty as vaccinators. Many gave up their Sundays to work at booths and even supervised the preparation of a mid-day meal to feed children who came to the booth.

An independent assessment of SMNet in 2013 showcased its success in achieving its goals of increasing the total number of children immunized against polio and ensuring that those most at risk are protected. Between 2007 and 2015, resistant households declined 77% in Bihar and 86% in UP[xxix]. About 76% of the children less than five years of age in CMC areas of Uttar Pradesh were vaccinated at booths in every round, in comparison to this only 43% of the children vaccinated at booth in non-CMC areas[xxx].

Findings and analyses also suggested a high relevance of the network, SMNet design and interventions are aligned with community needs. The approach has been relevant to achieve the results of the polio eradication program by reducing resistance to vaccination and reaching the unreached in polio endemic states of UP and Bihar. The success of the network can be attributable to key strategies such as evidence-based communication planning and microplanning, development and maintenance of interpersonal communication skills for mobilization of individuals and groups, strong outreach and advocacy, systematic building of an effective partnership for communication and strong supervision, and accountability for action. The engagement of leadership at various levels with a focus on local leadership was a core strategy. The Panchayat Raj Institutions were involved in mobilizing their communities-building "polio gates," inaugurating booths/campaigns and ensuring proper visibility of materials. At a higher level, district and block officials were responsible for overseeing task

forces and evening meetings, ensuring corrective action to ensure continually improving, high-quality campaigns[xxxi].

1.7 Kidney Disease- STOP CKDu, Andhra Pradesh[xxxiixxxiii]

In January 2018, George Intitute along with TERI conducted a **STOP CKD** study in Uddanam region of Andhra Pradesh to understand and mitigate the effects of chronic kidney disease (CKD). By meeting with the District Medical and Health Officer and nodal officers responsible for public health delivery in Srikakulam district, an understanding was gained on community-based screening approaches and key areas were identified that reported high prevalence of CKD to inform the selection of the villages for the study area.

A detailed interaction was conducted with the frontline healthcare workers and the PHC medical officer to gather information on population size of the villages and health systems capacity in the area. Interactions with patients gleaned information about treatment status. Field visits within the 2 villages selected provided an understanding of farming practices, irrigation, socio- economic status, education and occupations.

Discussions were done around diet, drinking water sources, cultural habits relating to within family marriages, intake of recreational drugs/ alcohol, cooking fuel used, utensils for preparing and serving food. Community dialogues provided opportunity for members to voice concerns over water source and locally prepared alcohol as possible sources of health problems. Other issues which were expressed by care providers included inadequate fluid intake, use of over-the- counter drugs, especially pain-killers and pesticide exposures. A level of satisfaction was seen around dialysis treatment and awareness about kidney disease among the communities was high.

This formed a rich community element as a predesign phase of the study. Alongside, key stakeholders such as government officials provided insight into gaps with regard to supply and demand side issues in provision of treatment, such as need of awareness campaigns to focus on addressing the stigma associated with CKD, and abnormal serum creatine values as well as capacity building of doctors on diagnosis and management of kidney disease patients. Based on this feedback, interactive trainings were conducted with the medical officers on the early detection of kidney disease and management for preventing progression of those with early Chronic Disease. Within Uddhanam Mandals, village level awareness sessions in the community were conducted to gain perspective on chronic kidney disease risk factors, management, importance of regular check-ups and use of medicine.

Formation of village committee: These committee consists of one Auxiliary Nurse and Midwife (ANM), ASHA, Aganwadi teacher, village revenue officer, Govt. School teacher and a sadhikara mitra (Self Help Group (SHG) leader) towards concerted response to CKD and general health conditions.

The Andhra Pradesh Government with technical support from the George Institute for Global Health, India also established a Kidney Research Innovation and Patient Assistance Centre (KRIPA) at Palasa, Srikakulam District, Andhra Pradesh which would study the factors that contribute to the development and progression of kidney disease in the community, and set up a community-based surveillance and management program in the public sector to support to

people living with chronic kidney disease in the region. The centre also aims to undertake studies on the health needs of the community and suggest models of effective community care.[xxxiv]

1.8 Rogi Kalyan Samiti/Hospital Management Committee

Rogi Kalyan Samiti (RKS) is a community mobilization and participation initiative under the NHM. It is a patient welfare committee facilitating community members to participate and ensure the proper management and functioning of the public healthcare facilities. This committee, as a registered society, acts as a group of trustees for the hospitals to manage the affairs of the hospital. It consists of members from local Panchayati Raj Institutions (PRIs), NGOs, local elected representatives, leading members of society and officials from Government sector who are responsible for proper functioning and management of the hospital / Community Health Centre / First Referral Units.

RKS is free to prescribe, generate and use the funds with it as per its best judgement for smooth functioning and maintaining the quality of services. Participation of local staff along with representatives of local population has been embedded to improve accountability and ensure provision of services to all classes of the society[xxxv].

One main objective beyond strengthening infrastructure is serving as a consultative body to enable active citizen participation for the improvement of patient care and welfare in health facilities. They also seek out participation from charitable and religious institutions, community organisations, corporates for cleanliness and upkeep of the facilities, and facilitate participation and contribution from the community in cash/kind (drugs/ equipment/diet), labour including free professional services. There also exists a charter/guideline of RKS which includes a set of well-defined roles and responsibilities of each committee in order to make RKS fully operational in the state. This charter puts forth the communities right to information, access to healthcare, participation in decision making and right to a safe and health hospital environment among others. It states that patients have the right to participate in decision making regarding the course of their treatment, including seeking a second opinion on request [xxxvi].

An evaluation of the RKS in 12 facilities in Madhya Pradesh in 2004 noted that while the RKS does not have a sufficient user feedback mechanism to gauge whether user requirements have been prioritised in expenditure decisions, the model has led to faster obtainment of resources in the facilities. Level of participatory functioning varied across all facilities and seemed to be a function of prestige associated with the post[xxxvii].

Another evaluation in 2014 amongst one district hospital, Bhopal, one Community Health Centre and two Primary Health Centres with 30 members of RKS and 50 beneficiaries highlighted all the beneficiary's reporting improvement in the services and facilities available in the hospital during the last one year. At the same time, awareness of RKS was poor with only 32% beneficiaries aware as they were charged Rs 5/- in the name of RKS. Also, half of the beneficiaries had no knowledge of citizen's charter. It was found that there was little effort at the institution level to popularise the RKS as an innovation to improve the functioning of the hospital[xxxviii].

A third evaluation of RKS within district Pune in 2013 attempted to define 'functional Health Systems' with a focus on strategic issues concerning RKS operations. The study revealed that meetings and agenda were organized in democratic style in high performing Community Health Centers (CHCs) whereas the same were conducted in autocratic style at low performing CHCs. While in low performing CHCs committees were more concerned with purchasing basic material requirements, repairing and beautification, high performing CHCs set an agenda to addresses community health needs by the provision of medicine, drinking water facilities, and organization of outreach services[xxxix].

1.9 The Mitanin Programme

The **Mitanin Programme**, a government community health worker (CHW) programme, was started in Chhattisgarh State of India in 2002. The Mitanins are women volunteers whose role is to undertake family level outreach services, community-organization building and social mobilization on health and its determinants along with advocacy for improvement in the health system. There are nearly 60 000 Mitanins, all women, covering almost all the rural hamlets of the state. State Health Resource Centre facilitated the implementation of the programme[xl]. Lessons from this programme led to the formulation of a countrywide CHW programme called the ASHA Programme under the NRHM and all the Mitanins were subsequently recognized as ASHAs[xlixlii].

The Mitanin Programme started in Manendragarh in 2002 wherein the first step was for the block health officials to select the block co-ordinators. The block co-ordinators and the Auxiliary Nurse and Midwife (ANM) in turn selected women mobilizers who later became Mitanin trainers[xliii]. The mobilizers conducted meetings in the villages and facilitated selection of Mitanins in consultation with the village councils. Folk media was also used for social mobilization around the programme. In order to strengthen the Mitanin's work on nutrition issues, SHRC introduced a Nutrition Fellow in Durgkondal block to focus on nutrition issues, whereas in Manendragarh block, the Mitanin Programme was complemented by an intervention called the Koriya Initiative that was started around the same time by one of the collaborators of the Mitanin Programme. This initiative aimed to mobilize indigenous communities to fight for their rights.

A study conducted in 2014 aimed to document how and why the Mitanins were able to act on the social determinants of health, describing the catalysts and processes involved and the enabling programmatic and organizational factors. A qualitative comparative case study of successful action by Mitanin was conducted in two purposefully selected high achieving blocks in two districts of Chhattisgarh. One case focused on malnutrition and the other on gender-based violence. Action on social determinants involved raising awareness on rights, mobilizing women's collectives, revitalizing local political structures and social action targeting both the community and government service providers.

The Mitanins developed identities as agents of change and advocates for the community through these processes, both with respect to local cultural and gender norms and in ensuring accountability of service providers. The factors underpinning successful action on social determinants were identified as the significance of the original intent and vision of the programme, and how this was carried through into all aspects of programme design, the role

of the Mitanins and their identification with village women, ongoing training and support, and the relative autonomy of the programme. Providing health services to the community, especially to women and children played a critical part in securing the community's trust and confidence in the Mitanins, facilitating their work on social determinants[xliv].

Another quasi-experimental evaluation of a nutrition intervention in Chhattisgarh suggested that the Mitanin Programme was responsible for 4.22% and 5.64% annual average reductions in underweight and stunting, respectively[xlv].

1.10 Accredited Social Health Activist (ASHA)

The **ASHA** program was launched as the key component of communitisation under NRHM. The ASHA is a female community health worker selected by the community. She is trained to work in her own village/ward to improve the health status of the community by promoting improved health practices and behaviours, providing health services and securing people's access to health services as is feasible at the community level. The ASHA also anchors the community-based platforms created under the mission viz, Village Health Sanitation and Nutrition Committees (VHSNCs) in rural areas and Mahila Arogaya Samitis (MAS) in urban areas.

The program was first launched in rural areas of 18 high focus states1 and tribal areas of other states. It was later expanded to the entire country. Today the program exists in 35 states and Union Territories (except Goa) with nearly 9 Lakh ASHAs in all the rural and urban areas.[xlvi]

The ASHA program has been inspired by and gained from past experiences of community health worker programs implemented by the state and national governments and by several NGOs. Key program components that differentiate the ASHA program from previous efforts include mechanisms established for regular training, on the job mentoring support, provision of medicine and equipment kits and performance linked monetary and non-monetary incentives for ASHAs.

Systematic modular training efforts and dedicated cadre of support structures enable ASHAs to perform their three essential roles of a facilitator, health activist and community level service provider. The program has provision for 23 days of modular training in the first year, to be followed by minimum 15 days of supplementary training every year thereafter.

ASHAs are trained for a wide range of competencies such as essential maternal, newborn and child health services, reproductive health, prevention and management of communicable and noncommunicable diseases, mobilising communities for action on violence against women and reaching the unreached. They are also trained in newer areas across states, based on the local context and healthcare needs. They are provided with a medicine and equipment kit to enable them to perform their tasks effectively.

In order to provide a legal and administrative framework within which the ASHA is eligible and responsible for providing care for a range of illnesses and to ensure quality of services provided to the community, the process of ASHA certification has been initiated in the year 2014. As part of this process, all components of ASHAs training i.e, the curriculum, trainers, sites and ASHAs are certified by National Institute of Open Schooling.

At the community level, over the past twelve years, ASHAs have moved from promoting institutional delivery and immunisation to providing health education on a range of issues, home based care and active counselling for maternal care, childcare (normal and sick/low birth weight newborns), nutrition and family planning. They are also first point of contact for children with diarrhoea and pneumonia and are involved in community-based distribution of commodities such as contraceptives. More recently they are involved in community level risk assessments and health promotion for prevention and management of NCDs.

A set of supportive structures is woven around ASHAs, to facilitate their work and make them more effective as community health workers. At the National level, it is led by the Ministry of Health and Family Welfare (MoHFW)/ National Health Systems Resource Centre (NHSRC)with the National ASHA Mentoring Group providing the policy guidance and support. Within the State the program is supported at-state, district, block and sub-block level. Presently most of the states have well-established support structures for community processes. The ASHA facilitators, selected for a cluster of 10-20 ASHAs, form the ASHA training session most critical link as they provide direct on-the-job supervision and mentoring to the ASHAs. About 19 states have selected dedicated ASHA Facilitators while in remaining states Female Multi-Purpose Workers (MPW (F)) provide the mentoring support to ASHAs.

The ASHAs are "Honorary Volunteers", whose compensation package consists of performance linked payments for a set of predefined tasks. The payment package includes nationally approved incentives and state specific incentives introduced as per local context.

ASHAs today have become the face of the National Health Mission as they are the key drivers of most program initiatives at community level and contribute majorly in improving access to care. A realist evaluation of the ASHA program conducted across eighteen states reveals encouraging findings. 91 percent of service users opted for institutional deliveries and 74 percent of these cited ASHA as the main motivator. Of the 100 percent service users who received immunisation, 91 percent said that it was facilitated by ASHAs. About 57 percent of the respondents with a sick newborn sought ASHA's advice for care. In cases of diarrhoea and symptoms of ARI, 90 percent of the respondents reported that ASHAs helped them[xlvii].

For noncommunicable diseases, the Government of India launched the National Program for Cardiovascular Disease, Diabetes, Cancer and Stroke (NPCDCS) in 2010. NPCDCS was designed to provide comprehensive primary healthcare to communities through the primary health centres (PHCs). The programme aims to prevent and control common NCDs by increasing community awareness, facilitating early detection of undiagnosed cases, and linking the identified cases with the health system for follow-up and continuity of care.

An important component of the programme involves capacity building and training of the health workforce including the ASHAs to deliver these interventions. The role of ASHA as per guidelines include educating the community regarding the determinants of NCD's and various associated risk factors like unhealthy diet, physical inactivity, intake of Tobacco and Alcohol and Stress; Promoting a healthy life style; Assisting ANM/LHV in organizing camps/village health days on NCD themes, screening of people at high risk and advising patients to consult appropriate levels of health care system for diagnosis and treatment as well as arranging follow up visits[xlviii].

Though, studies have shown that there is still a gap in fully utilising ASHAs as a key strategy towards NCD risk prevention. This is mostly due to them not being recognised as part of the formal NPCDCS service delivery team, no remuneration for this work[xlix], and lesser time spent on discussing NCDs, attributable to lack of proper training, supervision, and support for transport[l].

1.11Chennai Urban Population Study (CUPS)[li]

The **CUPS study** conducted between 1996-2007 in Chennai aimed to increase physical activity through community empowerment in an attempt at primary prevention of non-communicable diseases.

Education regarding the benefits of physical activity was introduced to the residents of the colony. Individuals with diabetes and the community in general were taught about the beneficial effects of physical activity. Individual counseling was given to participants at high risk for diabetes. Mass awareness programmes included public lectures, video clippings, short skits emphasizing the importance of diabetes and physical activity and distribution of educational materials in the form of pamphlets. The residents were motivated to exercise every day by a social worker who regularly visited the colony. Weekly health education lectures were tailored to the cultural background, gender and age group of the community and focused on adopting healthier lifestyles and physical activity. 65-80% of the community actively participated in these lectures. Educational materials on diabetes, its risk factors, signs and symptoms, complications and lifestyle factors were prepared both in English and Tamil. Interactive sessions were conducted every two months, public lectures every three months and educational materials were distributed every six months.

The findings of the study pointed towards action taken due to enhanced awareness with regard to NCDs and risk mitigation strategies. Recognising the limitation of a lack of space for physical activity, a park was constructed in 2002 using funds raised by colony members.

In response to the awareness programmes, the colony residents constructed a unique public park with their own funds. There was a significant change in the pattern of physical activity. At baseline, only 14.2% of the residents did some form of exercise more than three times a week, which presently increased to 58.7%[$p<0.001$]. The number of participants who walked more than three times a week increased from 13.8% at baseline to 52.1% during follow-up [$p<0.001$], representing a 277% increase.

1.12 Kerala Diabetes Prevention Program

A cluster randomised controlled trial of a group-based lifestyle intervention among individuals at high-risk of developing type 2 diabetes mellitus (T2DM) was conducted in the state of Kerala.

The **Kerala Diabetes Prevention Program (K-DPP)** was a group-based peer-support lifestyle intervention aimed at reducing the risk of T2DM in high-risk individuals. The 12-month intervention program consisted of - a group-based peer-support program consisting of 15 sessions over a period of 12 months for high-risk individuals; peer leader (PL) training and

ongoing support for intervention delivery; diabetes education resource materials and strategies to stimulate broader community engagement.

The primary outcome was the incidence of T2DM at 24 months. Secondary aims included changes in clinical, biochemical, and behavioural risk factors known to increase diabetes risk, including weight, waist circumference, waist-to-hip ratio, systolic and diastolic blood pressure, body composition measures, plasma glucose, HbA1c, total cholesterol, LDL cholesterol, tobacco use, alcohol use, diet and physical activity at 24 months[lii].

The intervention participants received a 12-month intervention program consisting of 15 sessions, aimed at targeting and monitoring lifestyle behaviours. The first session was an introductory group session (lasted for 60–90 min). Two half-day diabetes prevention education sessions were delivered by experts in the field of diabetes, nutrition, and physical activity. Twelve group sessions (~ 60–90 min each) were held at local venues such as community centres, local reading rooms, community schools and peer leader's homes.[liii]

The peer support component was adapted from the US Peers-for-Progress program. During the inaugural session, each group identified and nominated peer leaders among themselves, based on their social credibility, willingness to lead the group and their acceptability to other group members. The K-DPP team delivered a 2-day training session for peer leaders before session 3 which took place after the first diabetes prevention education sessions given by experts. The peer leaders also received a 2-day refresher training after session 8. In order to support peer leaders for intervention delivery, a local resource person was nominated for each group, in this case ASHAs. The responsibilities of local resource persons included assisting peer leaders in organising the group sessions and community-based activities, following up with group participants and encouraging them to attend the group sessions and advocating for the program among local community-based organisations.

Each participant also received a Participant Handbook containing information on diabetes risk factors and its prevention and a Participant Workbook to guide them through group sessions with self-monitoring of lifestyle behaviours, goal setting and review and ongoing group support. The participants were also given a non-elastic measuring tape and taught to measure their waist circumference to assess the progress towards their weight reduction.

Peer leaders were provided with a Peer-leader Handbook which outlined the group sessions' objectives, along with activity guide and exercises to prepare them for conducting the sessions. In addition to measuring tapes, the peer leaders were also given measuring cups and spoons to assist them in educating the participants about the correct serving sizes for foods such as rice, oil, sugar and salt.

The group-based sessions were complemented by a range of community engagement strategies to reinforce the importance of adopting and maintaining healthy lifestyle behaviours learnt in the group sessions in the community. The community-based activities were organised by peer leaders with the support of local resource persons outside the peer-group sessions. As part of this strategy, individuals were encouraged to participate in various activities in the local neighbourhoods such as walking groups, kitchen garden training and yoga clubs.

After a median follow-up of 24 months, diabetes developed in 17.1% (79/463) of control participants and 14.9% (68/456) of intervention participants (relative risk [RR] 0.88, 95% CI 0.66–1.16, p = 0.36). At 24 months, compared with the control group, intervention participants

had a greater reduction in IDRS score (mean difference: −1.50 points, p = 0.022) and alcohol use (RR 0.77, p = 0.018) and a greater increase in fruit and vegetable intake (≥5 servings/day) (RR 1.83, p = 0.008) and physical functioning score of the HRQoL scale (mean difference: 3.9 score, p = 0.016).[liv]

1.13 Diabetes Management in Rural Gujarat[lv]

A 6-month community-based diabetes prevention and management program was done in rural Gujarat, India. A community-based participatory research (CBPR) method was used to plan and tailor the intervention by engaging trained community health workers as change agents to provide lifestyle education, serve as community advocates, and collect data from participants. To ensure CBPR method, the entire rural community was inducted into this partnership where the village elders, the research team, and the elected community health workers (CHWs) discussed and obtained a clear understanding of the purpose of the study, its usefulness to the community, and the anticipated outcomes.

Eight preplanning community meetings were conducted before launching the program, to build trust, confidence, and rapport with the stakeholders and academic partners. Community representatives identified chronic diseases, especially diabetes, as a major area of concern. Understanding the profile of the community helped to tailor scientific content and materials into appropriate intervention strategies. The elected block spokespersons were able to motivate and support villagers who were resistant to the acceptance of the program idea.

The project coordinator and the 16 CHWs were recruited from local areas and represented the target population's multireligious demographics. CHWs and the project coordinator underwent 4 weeks of structured training on an existing diabetes prevention and management curriculum. The training used instructive sessions, one-on-one mentored learning, and role-playing to impart knowledge on key diabetes prevention and management intervention strategies including basic nutrition and dietary modification with attention to fiber content, quality and quantity of fat and portion control, knowledge of diabetes and its risk factors and complications, lifestyle modifications for diabetes prevention, meditational breathing practices to help with stress and relaxation, physical activity improvement.

Ten face-to-face encounters (5 one-on-one and 5 group based) were provided to all respondents. Health education was tailored for sex, age, lifestyles, and socioeconomic differences. Lifestyle intervention included advice on healthy diet and regular physical activity. All participants received personalized advice about their risk for developing diabetes, and those with diabetes and prediabetes were provided education and counseling for blood glucose management by a certified diabetes educator in one-on-one sessions. For overweight/obese (27%) individuals, weight loss education was provided in group sessions. To demonstrate healthier dietary approaches, cooking competitions and model meals were used. Educational materials included handouts in Gujarati downloaded from National Diabetes Education Program.

Overall point prevalence of diabetes, prediabetes, obesity, and hypertension were 7.2%, 19.3%, 16.7%, and 28%, respectively, with significant differences between the low socioeconomic status (SES) participants (agricultural workers) and the high SES participants (business community) due to differing diet and activity levels. The intervention significantly reduced

blood glucose levels by 5.7 and 14.9 mg/dL for individuals with prediabetes and diabetes, respectively, and systolic and diastolic blood pressure by 8 mm Hg and 4 mm Hg, respectively, in the overall population. Knowledge of diabetes and cardiovascular disease improved by 50% in the high SES group and doubled in the low SES group; general and abdominal obesity also decreased by ≤ 1%. At 6 month follow up, lifestyle intervention significantly reduced fasting blood glucose levels by 1.3 mg/dL in general and normoglycemic individuals and by 6.02 mg/dL and 19.08 mg/dL among individuals with IFG and diabetes, respectively ($P < .001$; Table 4). Lifestyle intervention successfully lowered systolic and diastolic blood pressure by 7 mm Hg and 3 mm Hg, respectively, in both groups. There was a significant and meaningful improvement in the knowledge of diabetes and CVD risk factors in both groups (0.78 and 1.64 points, respectively; $P < .001$); more than 50% increase of knowledge in the high SES group, and awareness doubled among the lower SES group participants.

1.14 Ballabgarh NCD Prevention Project

A project was implemented in the urban areas of Ballabgarh block of district Faridabad, Haryana near New Delhi, India, in a population of ~145 000. The intervention project was facilitated by the Comprehensive Rural Health Services Project (CRHSP), a project run by the All India Institute of Medical Sciences, New Delhi, in collaboration with the State Government of Haryana.

The intervention model consisted of four major sets of activities namely: (i) individual empowerment; (ii) community empowerment; (iii) lobbying, advocacy and mediation; and finally (iv) reorientation of health services. The 'Healthy Settings' approach. At both the places, they formed a coalition of community-level partners called as 'Friends of City' was created which aimed for a 'Healthy Ballabgarh'. This was primarily a group of ~60 volunteers comprising of employed people, schoolteachers, small business men, housewives and social workers. A 'logo' was used as an identity to the IEC campaign. Health interventions were done through health camps organized through community volunteers. An NCD clinic was started at the local hospital to address this aspect. The medical records of this clinic show a good quality of NCD management. A tobacco cessation clinic is being initiated with the help of MoHFW. The referrals to the tertiary level for the patients followed the usual health system.[lvi]

Community meetings and school-based interventions were the main activities. Risk assessment camps in the community and at industrial sites were also used to a limited extent. Guidelines for Health Promoting Schools and Healthy Workplace were developed in consultation with concerned stakeholders in schools and industry. The schools and workplaces were sensitized and given them the guidelines, IEC materials, training etc. and left it to them to implement as found feasible[lvii].

The results of the preparatory phase showed that the communities recognized NCDs as a growing problem were able to link them to the changes in lifestyles and were ready to take action at individual and collective level to prevent these diseases. The change in measures of risky behaviours showed that the proportion of population consuming less than five servings of fruit and vegetables showed a decrease that was statistically significant. The proportion of people who reported having their blood sugar or blood pressure measured showed a significant increase pointing to a positive effect of risk assessment programmes[lviii].

1.15 SimCard Trial- Community Health Volunteers & Electronic Decision Support System app

The SimCard study was a yearlong cluster-randomized controlled trial conducted in 47 villages (27 in China and 20 in India). 2,086 'high cardiovascular risk' individuals (aged 40 years or older with self-reported history of coronary heart disease, stroke, diabetes, and/or measured systolic blood pressure ≥160 mmHg) were recruited. The key elements of the intervention were summarized as a '2+2' model, which consisted of two therapeutic lifestyle modifications (smoking cessation and salt reduction) and the appropriate prescription of two medications (blood pressure lowering agents and aspirin).

Participants in the intervention villages in Haryana were managed by CHWs through an Android-powered "app" on a monthly basis focusing on the two medication use and two lifestyle modifications. Since the CHWs cannot prescribe medication, they were supported by a partnership with licensed physicians in healthcare centers responsible for providing clinical guidance and prescribing medications.

The management program was delivered by trained CHWs in the intervention group on a monthly basis with the assistance of electronic decision support system (EDSS) in the form of an Android-based "app" installed on smartphones. It consisted of prompts regarding the patient's current lifestyle habits, blood pressure measurements, current medication use, previous medical history, new conditions, contraindications, and side effects. The EDSS had a desktop component for the use of physicians to approve the drugs as suggested by the smartphone-based EDSS for CHWs. CHWs were instructed to provide monthly follow-up visits for the high-risk participants under their management. These visits were conducted either in village clinics or another central place in the village or patient homes and included screening for new symptoms, diseases, and side effects since the last visit, measuring blood pressure, providing lifestyle counseling, and when appropriate, prescribing one or both medications. CHWs received refresher training every 3-4 months during the implementation of the intervention.

The primary outcome was the net difference between groups in the change in the proportion of patient-reported anti-hypertensive medication use from baseline to one-year follow-up. in India was 26.6%; both were highly statistically significant between the intervention and control groups.[lix]

1.16 Center for cArdio-metabolic Risk Reduction in South Asia (CARRS) Trial- Non Physician care coordinator [CC] and decision-support electronic health records [DS-EHR])

The **CARRS Trial** was a multi-component prospective, parallel randomized, controlled, open-label pragmatic trial. Patients with poorly-controlled type 2 diabetes attending ten outpatient diabetes clinics in India and Pakistan were randomized to a multicomponent care model – consisting of non-physician care coordinators (CC) and decision-support electronic health record software (DS-EHR)– or usual care in a 1:1 ratio. Participants included were aged ≥35

years with type 2 diabetes and poor cardio-metabolic profiles (glycated hemoglobin [HbA1c]≥8% and either: systolic Blood Pressure≥140mmHg and/or low-density lipoprotein cholesterol [LDLc]≥130mg/dl) who had attended the recruiting clinic for ≥3 months.

Intervention participants were supported by non-physician CCs, in addition to usual physicians. Selection criteria for CCs included: non-physicians with training in allied health fields (e.g., dietetics, social work); ≥six months healthcare experience; and good organizational and basic computing skills. CCs received intensive training with half-day refresher sessions at annual study meetings related to diabetes, barriers to treatment, supporting treatment changes, and motivational interviewing. CCs also had two teleconference sessions with an experienced endocrinologist to discuss common barriers and strategies to overcome them. CCs individualized patient follow-up based on patients' risk level and adherence. CC was responsible for following up with intervention patients at least every three months for setting up laboratory or clinic appointments and contacted patients telephonically at least once a month to discuss diabetes self-management, adherence to diet plans, exercise, tobacco cessation, medication use, self-monitoring of glucose (if taking insulin), and stress management. CCs had an access level in the DS-EHR to record their interactions with patients. To encourage responsive and appropriate treatment intensification by physicians, CCs were responsible for entering updated patient indicators into the DS-HER[lx].

Over 28 months, twice as many intervention as usual care participants achieved the primary outcome of HbA1c<7% AND either BP<130/80mmHg or LDLc<100mg/dl (18.2% vs. 8.7%; relative risk 2.24 [95% CI:1.71, 2.92]). Compared to usual care, intervention participants achieved larger reductions for HbA1c (−0.50%; −0.69,−0.32), SBP (−4.04mmHg; −5.85,−2.22), diastolic BP (−2.03mmHg; −3.00,−1.05), LDLc (−7.86mg/dl; −10.90,−4.81), and reported higher HRQL and treatment satisfaction[lxi].

Welfare Schemes

2.1 Health Insurance & other government schemes- Self-Employed Women's Association (SEWA) SEWA Shakti Kendras (SSK)

In 2015, the Self-Employed Women's Association (SEWA), an organization of close to 2 million women workers in India's informal economy, initiated community-based centres – **SEWA Shakti Kendras (SSK)**—to empower women workers to attain entitlements. Run by the Lok Swasthya SEWA Trust (LSST) and linked to SEWA's health cooperative, SSKs provide hands-on support to scheme beneficiaries through raising awareness, support in ensuring the correct documentation for registration and facilitating use.

SEWAs members and the communities it serves make up the poorest and most vulnerable of India's workers: women of the informal economy who typically earn low wages, with little to no effective social protection. The centres have helped to leverage and channel government health and social security services to the needs of ordinary working-class people in India, bridging the gap between the grassroots and the government. SSKs focus on utilisation of government schemes for health, nutrition and childcare in the state of Gujarat. The centres aim to improve programme delivery on the part of government officials and departments as well as promote integrated service provision. A key focus of their work is to improve utilisation of the Gujarat state health insurance scheme (Mukhyamantri Amrutam) and more recently, Pradhan Mantri-Jan Arogya Yojana. Staffed by local community health workers, the centres provide awareness, information and hand-holding to access schemes as well as linkages to primary health care to improve overall health security in an integrated approach[lxii].

Although not initiated by the government, the centres operate closely with the government through both cost-sharing and linkages. In rural areas, LSST has negotiated with the local government to set SKKs up in the village community centre. In urban areas space is normally rented, or a Centre might share space with government sponsored Integrated Child Development Scheme. The central location operates during convenient hours to meet informal workers' needs, which is important in ensuring the centres are successful. Importantly, the SSKs have become a meeting place for local government representatives and community members. Local elected leaders or village headmen commonly use SSKs to engage in community dialogue, in meetings facilitated by SEWA health workers.

The SSK model in Gujarat grew out of an experiment in partnership with the Delhi government initiated by SEWA in Delhi in 2007. SEWA Delhi implemented government-funded Gender Resource Centres to improve awareness and utilisation of government schemes through community-based, locally staffed centres with information and most importantly, hand-holding support for the poor to navigate government systems such as RSBY registration cards. A similar initiative has been implemented by SEWA in rural Madhya Pradesh amongst women workers. In Gujarat, LSST built on these experiences to initiate 18 urban and rural SSKs to focus on ensuring access to social security benefits, particularly health insurance and primary health services.

An evaluation of SSKs Gujarat by the Indian Institute of Public Health, Gandhinagar, indicated evidence for improved awareness and use of public entitlements amongst low-income

households for a range of public benefits, including insurance[lxiii]. Findings indicated four-fold improvements in awareness, as well as increases in utilisation, of both the Mukhyamantri Amrutam and Rashtriya Swasthya Bima Yojana schemes amongst the local community around both rural and urban SSKs.

2.2 Haqdarshak

Haqdarshak is a social enterprise working to make welfare schemes more accessible to citizens by creating a multi-state, multi-lingual, mobile technology platform that helps citizens discover, apply for, and benefit from, government and private schemes that they qualify for. It is pre-loaded with procedural details on close to 200 welfare scheme applications and documents/IDs of the state and federal governments. Community members can use the platform through a trained facilitator, or themselves, on payment of a small service fee, which makes it financially sustainable. The organisation provides training of field cadres as last-mile support agents who provide application support services to communities for a fee. They then use the Haqdarshak agent app for implementation[lxiv].

An impact evaluation study was done with KREA University, showcasing the role of Haqdarshak, in improving incomes of SHG women who are trained in its application for fee-based enrolment of community members in public welfare schemes in Chhattisgarh. The Haqdarshak model complements the capacity building requirement of the NRLM program by offering intense trainings to SHG women on engaging schemes/documents-related features on the app. The Haqdarshikas do not just acquire new information on welfare programs beyond what is already known via their SHG activities, but also continuously advance their knowledge and skills through learning-by-doing screenings and enrollments in their communities.

Haqdarshak MIS data on 2244 active women covering a 20-month period since August 2019, in-depth interviews with 30 women; and a baseline survey with 1267 women inform the findings. As of April 2021, the MIS database shows 67 percent of qualified women (n=2302) have used the app to enroll themselves and their families, as well as their neighbors in the communities into 139 welfare schemes and 18 scheme-related documents. Between August 2019 and April 2020, a Haqdarshika made an average of 117 welfare applications, and enrollment activities have generated a median income of Rs 1240 per month.[lxv]

Multidisciplinary Tools for community participation

3.1 Community scorecards

3.1.1 Case Study 1- Health in Andhra Pradesh[lxvi]

The Community Score Card (CSC) process is a powerful tool used to monitor services, empower citizens, and improve the accountability of service providers. The scoring exercises provide citizens the means and opportunity to analyse services such as health services or education based on their personal perceptions. Such collaboration between communities and their service providers can lead to better provision of services that can be sustained. These can be used across a variety of thematic areas- to assess public food distributions, agricultural extension services, health services, schools or even public wastewater schemes.[lxvii].

A pilot project under **the Andhra Pradesh Rural Poverty Reduction Project (APRPRP)**, was taken to apply community score card (CSC) to assess the performance of two primary health centers (PHCs) in two Mandals of Visakhapatnam District, Andhra Pradesh, in the context of primary health care service delivery in 2006. There were 3 phases of project delivery- in the first phase community resource persons (CRPs) were selected and the training program was designed and conducted. In the second phase the implementation was carried out through trained CRPs. All key activities involved in the score card process, such as input tracking, community assessment, self-evaluation by service providers, consolidation of score cards, and the interface meeting, were undertaken during this phase. During phase 3, post implementation activities such as preparation of action plans and dissemination workshops with key stakeholders such as the state and local governments, civil society organizations were conducted. The CRPs were selected community health workers, members of self-help groups, and community members who were communicative and acceptable to the community.

A total of 24 group discussions with men and women separately across 12 villages generated a cumulative total of 153 indicators. The community rated the various indicators on a scale of 0-100 to indicate their perception regarding the quality of service delivery. Qualitative views provided justification towards their choice and rating of indicators. The Community Score Cards generated at the community level were then consolidated to provide a holistic perspective on the issues affecting the community across different villages. This aggregation resulted in 11 indicators. On the supply side, a service provider self-evaluation generated total of 29 indicators were generated from two PHCs. These indicators were aggregated into seven broad categories for the purposes of analysis and comparison with the indicators generated during the community assessments.

Indicators included- Doctor's Hours/Availability; Staff Behaviour and Working Style; PHC Services; Transportation Services; PHC Infrastructure; Medicine Dispensing. Evaluation of the scores indicated systemic and support-level weaknesses for health care delivery at the primary level.

Issues were found related to the operating style of functionaries, including low scores in indicators such as staff behavior and working style, hours of operation/availability of doctor/staff, medicine dispensing point, poor accountability, and weak responsiveness.

Infrastructural issues further hampered service delivery. Low awareness amongst community members with regard to service entitlements, standards, or other government schemes adds to further issues in service delivery. Further, except for transportation facilities and doctor's availability in one village, there was a stark different in perceptions of the community and the service providers, with the former's scores lower than the latter.

The score card provided the opportunity to discern differences in indicators between villages, genders and the PHCs. The self-evaluations provided some explanations to the differences in perceptions between the users and service providers as well, leading to action plans that resulted in constructive problem solving. The pilot was successful in demonstrating how the CSC exercise can provide innovative solutions at a local level and reduce the gap between the community and service providers and increases satisfaction and quality of care.

The positive results led to the Society for Elimination of Rural Poverty (SERP), the APRPRP Project Management Unit, to scale up the CSC to all health Mandals, wherein proactive community participation enabled SERP to introduce several other community-managed health interventions, most of which have been now institutionalized through the issuance of operational guidelines by the Health Department of the Government of Andhra Pradesh.

3.1.2 Community Score Cards Case Study 2: Improving Panchayat Service Delivery in Maharashtra[lxviii]

A pilot project was undertaken by the Tata Institute of Social Sciences (TISS), Mumbai, in partnership with the World Bank-sponsored Jalswarajya Project (Maharashtra Rural WaterSupply Program). Tha community score card (CSC) methodology was applied to assess the performance of 14 Gram Panchayats in Satara District in four service sectors- Village Panchayat Services, water and sanitation, health, and education The pilot aimed at testing the efficacy of the Community Score Card as a tool to measure user satisfaction and improve service delivery. The Zilla Parishad, Satara, team was responsible for overall supervision, facilitation, village identification, and interdepartmental co-ordination, and for providing personnel to carry out the field exercise. TISS was responsible for capacity building, field exercise support, analysis, and documentation of the entire exercise.

Self-evaluation exercises and community assessment were followed by interface meetings between the community, service providers and district level administration officers. These meetings provided a space for discussions between the former two following which, action plans were drawn up to deal with highlighted issues. Most of the priority issues in all the four service sectors were identified during input tracking or focus group discussions. The community was concerned about issues such as lack of resources, staff functioning/behavior, optimal use of resources, convenience of services, information dissemination, and transparency across all sectors. In health specifically, the lack of facilities, staff availability (especially the female medical officers) and behavior, and transparency in medicine distribution were the key concerns. The service providers were more concerned about physical, financial, and human resources or the lack of community response/support during awareness generation activities.

A comparison of user and provider scores was done which revealed a stark difference in indicators dealing with transparency and behavioural issues but a nominal difference in indicators dealing with basic infrastructure, support services, and resources issues. Following this, the interface meetings resulted in solutions whose implementation was the responsibility

of either the Gram Panchayat or block/district level officials. For example, the community insisted that the school should send a proposal for conducting students' health checkups to the health department. In several villages, health committees agree to support health staff so that their performance could be improved. The interface meetings also highlighted community thoughts around dissemination of information about procedures, implementation processes, and financial management practices. People are aware of the constraints faced by service providers but not policy-level procedures to overcome these bottlenecks.

The CSC process led to feelings of user satisfaction but of empowerment given the community participated actively in service delivery management. On the whole the CSC exercise was effective in not only drawing up an action plan for the future but also reducing the gap between the service providers and the users, in turn leading to enhanced overall satisfaction levels.

Policy outcomes due to the CSC exercise included- (i) Revival of Village-Level Committees; (ii)Voluntary Disclosure of Information and Procedure Demystification; and, (iii) Performance Evaluation and Incentives.

Successful piloting led to scale up to 121 villages with the objective of achieving the Millennium Development Goals with regard to malnutrition and infant and maternal mortality. A second pilot in 41 villages showed encouraging results with respect to converge child health and nutrition outcomes. The percentage of normal grade children improved from 56 to 69 percent in Thosegar PHC and from 67 to 73 percent in Limb PHC between October 2006 to February 2007, while the percentage of normal grade children in Satara District improved from 59 to 66 percent between April 2006 to February 2007. The number of Grade 3 and 4 children (severely malnourished) in both PHCs was reduced from 7 to 0 between October 2006 to February 2007.The corresponding reduction in Grade 3 and 4 children in Satara District was from 399 to 58. 2.

3.2 ARISE Participatory Approaches

Accountability for Informal Urban Equity (ARISE) works closely with and is guided by vulnerable communities themselves including people living in informal settlements (slums) in Bangladesh, India, Kenya and Sierra Leone) who are often 'off the map'. ARISE collects data, and supports people by emphasizing on capacity building and giving importance to exercise their right to health. In India, ARISE members at The George Institute for Global Health work towards strengthening and safeguarding processes and to specifically advocate the translation into local languages of the Prevention of Sexual Harassment policy implemented by the Internal Complaints Committee, in order to enhance its reach among TGI's employees, associates, and collaborators[lxix].

ARISE also partnered with the **Society for Promotion of Area Resource Centres (SPARC),** an NGO based in Mumbai, and also works with two other community-based social movements - **National Slum Dwellers' Federation (NSDF)** and **Mahila Milan** (a network of women's savings collectives),to amplify voices of the urban poor in city development. In 2020, supported by ARISE, SPARC undertook a series of phone interviews with residents in living in relocation colonies and informal settlements across Mumbai in order to understand their perception regarding COVID-19 health crisis, Government and local response to the crisis, and experiences of lockdown. They offered direct nutritional support to 150 families with members

with serious health conditions, including tuberculosis (TB) who are severely affected by the COVID restrictions.

Another survey was conducted by SPARC and its federations with support from Mahila Milan involving over 4,000 families living in 13 locations in Mumbai informal settlements and relocation colonies. The survey inquired about co-morbidities in the wake of the pandemic, as well as food security and access to food.

Both activities led to an increased awareness among the federations regarding TB, which is a pressing issue for the informal settlement residents. Reflections from the survey, led federations to engage with District Tuberculosis Officers, municipal actors, and elected representatives to understand how they might support efforts to reduce the spread of TB and address the challenges faced by people living with TB.

ARISE has also contributed to increasing the capabilities of urban marginalised people to inclusively analyse and prioritise their health and wellbeing needs, and identify stakeholders to demand action. In February 2021, 12 women from four relocation colonies in Mumbai (three of which are also ARISE action sites) attended a training on introduction to TB arranged by MSF and delivered by an experienced and trained TB nurse. After this training, each location planned to take this information to the registered building committees, and then meet in three months' time. At that meeting, everyone will share feedback, plan next steps, and attend another refresher training from MSF to address any doubts emerging from local interactions, with support from experts[lxx].

A paper detailing the work of SPARC and its Alliance with the women's cooperatives (Mahila Milan) formed by pavement dwellers and the NSDF has shown how work in many different areas such as community-based savings and credit groups, pilot projects, housing construction, the development of toilet blocks and the management of resettlement can contribute to poverty reduction, as long as these are based on what communities can do for themselves and the communities retain control.

SPARC's early work with women pavement dwellers was to provide them a with space to meet and to discuss their problems. They sought an organizational form that invested knowledge with collectives of savings and credit groups formed by pavement and slum dwellers (Mahila Milan – "Women Together"). New strategies and tools were developed to bring them out of isolation, including: the pavement dwellers' enumeration (We the Invisible) that they undertook themselves; developing ways of dealing with common crises, including eviction, police harassment and obtaining water and ration cards (which gave them access to subsidized food). As one women's group developed an approach that worked, the strategy was spread through meetings and community exchanges. After exploring the constraints on obtaining a secure home, a housing strategy was developed starting with their own savings.

The Alliance's core activities include pooling savings by hundreds of community groups to finance a capital fund for crisis loans. As groups learn to manage this, so savings for housing can develop. There are now hundreds of thousands of urban poor with access to emergency loans, and more than 25,000 households who save for housing. Another core activity is House-building. "Shack-counting" done through community-initiated and managed surveys and maps, helped communities to identify their problems and develop their priorities. This also produced a visual representation of their situation which helped the development of physical

improvements and helped in the negotiations with external agencies. Community members learn how to develop their own homes – how to get land, to build, to keep costs down, to manage professionals, to develop new materials, to install infrastructure and to negotiate with government agencies. They develop designs through collective house modelling which usually includes developing full-scale models which are discussed through community exchanges. There are now over 3,500 houses built with permanent collective tenure and 5,000 borrowers.

To provide proper sanitation provisions for pavement and slum dwellers in Mumbai, the Alliance saw that they could work within a Municipal Corporation Slum Sanitation Programme and develop community-managed toilets. Building and managing shared toilets united communities and build their capacities and confidence as well as developing a relationship with the local authorities. The Alliance and the Railway Slum Dwellers' Federation in Mumbai also worked with the inhabitants of railway platforms to develop a resettlement programme in which people move voluntarily and get good quality housing in sites of their choice[lxxi].

The community exchanges build upon the logic of "doing is knowing" – and they may include concrete actions such as house-modelling. They develop continuously because they serve many ends, including: Drawing large numbers of people into the process of learning and teaching, especially women who previously were excluded and, over time, exposing more communities to innovation.; Supporting local sharing of experience, and reflection and analysis, enabling the urban poor to own the process of knowledge creation and to federate, developing collective vision and action.; Helping create strong, personalized bonds between communities who share common problems, presenting them with a wide range of options through which they can address their problems.; Creating grassroots organizations able to take up new possibilities if there is a change in policy. Growing numbers of organized communities also means more pressure for policy change.; Breaking down national boundaries. International links help stimulate new ideas and attract interest from local governments, creating space for negotiation[xL].

3.3 Participatory Action Research training with the Dalit Bahujan Resource Centre

The **Dalit Bahujan Resource Centre (DBRC)** is based in Guntur, Andhra Pradesh. It was established to work for the empowerment of the Dalit Bahujan communities with a special focus on women, children and workers in the informal sector. It's objective is to enable assertive interventions of Dalit Bahujan communities and mainstream them towards socio-economic empowerment.

In January 2020 a meeting was held between SPARC/SDI (Slum Dwellers International), the George Institute for Global Health, India and the Dalit Bahujan Resource Centre. The aim was to pilot test participatory action research tools used in ARISE. Methods included use of music, games, street plays, and a mapping exercise to enable learning and have as much of the discussion out in the open as we could. Each song was composed in simple, local language around social themes such as health, revolution, caste divides etc. Independent street plays touched upon issues of poor access to water and education among the marginalised residents and how it is possible to get access to them through collective negotiation.[lxxii].

DBRC works for promotion of livelihood, dignity and self-respect among Dalits, Adivasis, Waste Pickers and other informal workers. It facilitates uptake of schemes intended for the welfare and development of the Marginalized Communities; strengthens community leadership; acts as an interface between the Community and Government Departments; promotes discussion & Debate on Contemporary Socio-Economic Issues; Disseminates information through IEC material; engages with the Government to ensure policy changes in accordance with the community needs & aspirations and provides relief and rehabilitation[lxxiii].It works in 5 districts in Andhra Pradesh and 6 districts in Telanghana.

It has focused on **Empowering the Dalit Adivasi (EDA)** communities through the EDA Programme aimed to sensitize Dalits and Adivasis to access and utilize rights & entitlements available under SC ST Component (SC ST Sub-Plan) and also other welfare development schemes and programmes in both the states Andhra Pradesh and Telangana. They work towards resolving infrastructural and basic amenity issues such as water & sanitation, electricity in the identified 295 SC ST habitations, 301 angandwadis, 265 government schools, 53 government hostels. They also help facilitate SC/ST farmers in availing Govt. schemes from agriculture and allied departments like crop loans, seeds, fertilizers, tools, livestock, etc. Lastly, they help facilitating the identified 3000 SC ST households in availing housing sites / housing schemes[lxxiv]. To achieve the objective, the team of DBRC carry out awareness programmes, community meetings, constitute district budget monitoring teams, advocacy and lobbying, organize workshops and coordination meetings with the different stakeholders, and lastly, conduct interface meetings with different departments and communities[lxxv].

As per the Annual Reports 2018-2019, issues of basic amenities such as internal roads, drinking water, streetlights, side drains and grave yards were successfully addressed and resolved in 266 hamlets in Andhra Pradesh and Telangana. In 217 angandwadi centers, 226 government schools and 56 government hostel issues related to infrastructure facilities have been resolved. In, issues related to improving infrastructure facilities have been resolved.[xliv]

DBRC organized 6 interface meetings with the SC ST farmers and officials from Agriculture and allied departments. These meetings provided an opportunity for farmers to express challenges they face in availing the schemes and services and officials were able to provide clarifications of the same. Following this, 719 farmers were able to access agriculture and allied schemes worth Rs.3,20,11,185/-. 928 Women headed households received entitlements on homestead and new houses[xliv].

The **Green Workers Program** is an initiative of DBRC focusing on improving the living conditions of Waste Pickers and Sanitary Workers. To do so, DBRC aims to form a functional Co-operative with 1000 Waste Pickers. Apart from this, various activities carried out include consistent interaction with the Community; Regular Area Meetings; Awareness programs; Free medical camps; Campaigns on various issues; and Advocacy with different Government Departments. Motivational meetings have been organises with the waste pickers integrated into door to door collection in Guntur with around 200 waste pickers to sensitize them about Health Hazards they may face, cleanliness to be followed, Hygienic measures to be taken to be healthy. DBRC conducted a 15-day campaign on Rights and Entitlements for Safai Karamcharis in Guntur and Vijayawada. They were sensitized on their rights and entitlements; oriented about various government welfare schemes and programmes which they can avail from the government. DBRC has conducted these campaigns in 32 Areas and over 1200 target group

members were sensitized during this campaign. During these campaign issues of waste pickers were recorded and issues were taken to the notice of the Joint Collector, Commissioner. As Part of the Rights and Entitlements campaign, DBRC also organized grassroot level meetings with the Waste Pickers. Two interface meetings between the authorities of the Guntur Municipal Corporation and the Waste Pickers enabled the waste pickers to voice out their issues on their own and bring to the notice of the authorities. During the meetings waste pickers were also sensitized about the need be united and organized[lxxvi,xliv].

3.4 Community Based Monitoring (CBM)- Maharashtra

CBM is a form of public oversight where the rural communities that NRHM is intended to serve actively and regularly monitor the state of their local public health system as an input to improving the health services received by them. India's NRHM is making such accountability a reality through its community-based monitoring initiative. **SATHI** is the state nodal NGO responsible for facilitating the implementation of CBM in Maharashtra, which is one of the states included in the pilot phase of implementation of CBM, and the first in the country to include the CBM component of NRHM in its state Project Implementation Plan (PIP) in 2007. CBM is meant to compliment other components of the monitoring system, namely, information system (MIS) and the external evaluation surveys and audits[lxxvii].

CBM processes related to NRHM are organised at the village, primary health centre (PHC), block, district, and state levels. SATHI coordinates the CBM activities across districts in collaboration with the district and block nodal NGOs, working with the state health department. A monitoring committee at each level collates the findings from the level below, monitors the health system at its own level, and passes these results up to the next level two times a year. The PHC monitoring committee collects results from the village report cards, monitors services in the PHC, and passes village and PHC information up to the block level monitoring committee.

Some factors that contributed to successful implementation included pre-existing presence of grass roots people's organisations, community-based organisations (CBOs) and health advocacy NGOs with a strong community base operating in the state These existing relationships, nurtured through long-term association, made it easier for people's organisations, CBOs, NGOs and communities to work together to implement CBM. Second, Maharashtra has a history of action to demand community accountability of public health services, with strong support provided by CBOs across the state. Organisations had experience of holding jan sunwais on health rights. Lastly, the Maharashtra government's health department displayed a basic willingness to support monitoring and engage in dialogue with communities and CBOs. From the introduction of CBM in mid-2007, state-level officials have been attending key meetings, attempting to address complaint

In a pilot in Maharashtra, three rounds of data were collected by village health committee members in 225 villages. The first data gathered at the beginning of CBM in July-August 2008, the second round of data gathered in April 2009 and the third round gathered in October to December 2009. This indicated that the CBM program had an initial significant positive effect and continued on a positive trajectory into phase three. CBM is credited with improving healthcare delivery and causing attitudinal shifts among government health workers, especially

amongst the outreach functionaries, alongside raising awareness within communities regarding healthcare entitlements.

The various activities that led to successful CBM included filling Health Report Cards. At the core of CBM is the act of tracking, recording and reporting the state of public health services in villages, as experienced by the people themselves. Village health, water supply, nutrition and sanitation committees (VHCs) were formed, or, pre-existing ones were significantly expanded. Then, village health report cards and related tools for community-based data collection were developed and, in some situations, adapted and simplified.

The VHCs comprise of 10-15 members and in these meetings, meetings implementing organisations would introduce the idea of CBM and health rights to people in the villages. After the VHC was expanded, the members attended a one or two-day training session on CBM, conducted by the block coordinator and facilitators from the block nodal NGO or CBO. In the training sessions, the VHC members were informed about how the public health system is structured, health rights entitlements in NRHM, and how to fill in the village health report card. The training aimed to motivate and build capacity of the VHC to play a proactive role in monitoring village health services.

Once the VHC was established and trained, they have been involved in the process of filling up the village health report card, with active guidance from the nodal NGO/CBO. In the pilot phase, the block facilitator often played a key role in facilitating filling of report cards by the VHC members. Community members and block facilitators also fill out PHC and rural hospital report cards. They also conduct exit interviews with patients, asking them about indicators including the quality of service, behaviour of providers and whether they experienced any illegal charges or corruption. Indicators include maternal and child health services including immunisation, antenatal care and postnatal care; curative services at the village level; anganwadi services; availability of services and quality of care at PHC; utilisation of village untied fund; and adverse outcomes (denial of healthcare, maternal death, infant death).

Secondly, Jan Sunwais which are public hearings, attended by large numbers of local community members, People's organisations, NGOs, government officials and prominent persons from the region were conducted. At jan sunwais, people are invited to report their experiences of poor health services and denial of care, as well as findings included in the village health report cards. The authorities present are then expected to respond to these testimonies, stating how the problems will be addressed.

Under CBM in Maharashtra jan sunwais have been organised at the PHC level and district level and in a few places at the rural hospital level. In many places, jan sunwais were often the first opportunity that communities had to publicly share their views about the local health services. Jan sunwais were also often the first time that health officials were held accountable and expected to respond to the health-related demands of villagers. The report cards enhanced awareness of community rights and regular objective records of shortcomings led to people's sense of being wronged being given legitimacy. Also, conducting them at multiple levels led to increased accountability by government officials. The form and location of the jan sunwais also enabled their success. By involving media, public awareness was enhanced as well as amplifying demands for accountability.

CBM in Maharashtra showed remarkable effectiveness between rounds one and two, but is perhaps approaching a plateau in the third round. At the beginning of CBM, villages rated their health services "good" at an average rate of 48%. By round two, "good" ratings increased by 13 percentage points to 61% and by round three it increased by an additional 5 points to 66%. The average percentage of services rated "bad" by villages decreased from 25% to 16% to 14%. Immunisation improved by 21 percentage points from 69% "good" in round one to 90% "good" in round three. Anganwadi services and use of untied funds improved by 33% and 31% points, respectively, between rounds one and three. PHC health services improved by 42% points from 32% in the first round to 74% in round three.

3.5 Village Health Sanitation & Nutrition Committee

One of the key elements of the NRHM is the Village Health, Sanitation and Nutrition committee (VHSNC). The committee has been formed to take collective actions on issues related to health and its social determinants at the village level. They are particularly envisaged as being central to 'local level community action' under NRHM, which would develop to support the process of Decentralised Health Planning.

The committee is formed at the revenue village level and it should act as a sub-committee of the Gram Panchayat. It should have a minimum of 15 members which should comprise of elected member of the Panchayat who shall lead the committee, all those working for health and health related services should participate, community members/ beneficiaries and representation from all community sub-groups especially the vulnerable sections and hamlets/ habitations. ASHA residing in the village shall be the member secretary and convener of the committee.

The committee is meant to create awareness about nutritional issues and significance of nutrition, carry out surveys on nutritional status and nutritional deficiencies in the village especially among women and children, identify locally available food stuffs of high nutrient value as well as disseminate and promote best practices (traditional wisdom) through a process of community consultation. They also need to conduct an in-depth analysis of causes of malnutrition at the community and household levels, by involving the ANM, angandwadi worker, ASHA and Integrated Child Development Scheme Supervisors. They monitor and supervise Village Health and Nutrition Day to ensure that it is organized every month in the village with the active participation of the whole village. They facilitate detection and referral of malnourished children in the community to Nutritional Rehabilitation Centre, and supervise functioning of Anganwadi Centre in the village and facilitate its working in improving nutritional status of women and children. Most importantly, it acts as a grievances redressal forum on health and nutrition issues[lxxviii].

State and district level evaluations have highlighted low awareness among the members about role of the committee, community members about the committee and a focus on cleanliness activities[lxxixlxxx,lxxxi].

3.6 Citizens participation in budget making process (Odisha)[lxxxii]

The annual budget provides vital evidence of where a State sets its priorities, taking into account needs of the poor and marginalised people or not. In Odisha, civil society processes have been undertaken to make the budget participatory and pro-poor. In the past, budgetary trends in Odisha show a wide gap between the policy declarations and actual budgetary allocations and the amount of resources that actually reach the poor. An examination of the commitments of the Millennium Development Goals in the fields of health and education shows that, although nine percent of the Gross State Domestic Product (GSDP) was required, only four percent of the state's GSDP has been provided. A regional disparity is also noticed-budget is prepared on a departmental basis, not reflecting the priorities of regions and districts. There was a lack of formally assigned space in which civil society organisations could participate and communicate the needs at a grassroots level to the state administration.

In 2003, the **Centre for Youth and Social Development (CYSD)** (now the Odisha Budget and Accountability Centre) began its budget advocacy efforts to strengthen the citizen-led advocacy for a pro-poor budget. The strategy followed was to generate an advocacy dialogue with the policy makers on the issues of the state's policies and budget priorities. Alliances were formed with academic and research institutions, political parties, media houses, civil society forums, various people's movements and right based forums. Involving them in formulating demands on the budget making ensured that front line legislators who serve as catalysts for the budget are contacted continuously with research-based information. Regular bilateral discussions are held with legislators and media to enhance the state's quality of policy making.

To provide community feedback on the state budget of Odisha, community feedback is gathered by community radio and small group discussions at ground level. These community aspirations are consolidated in the form of district Charters of Demand at the district level that are endorsed by district budget watch groups. These watch groups were formed in six selected tribal districts of Odisha. They were given the means to track the budget at the district level and assemble the needs of the community in the District Charter of Demand. At the macro level, these demands are presented in the state pre-budget discussions for approval. The consolidated demands of the key budget priorities are presented to the state government for inclusion in the state's budget allocations.

Another intervention includes Pre-Budget Consultation as a platform where inputs from civil society organisations, media, academics and political activists can be heard. This process facilitates an engagement with the legislators, media and key budget makers of the state before the budget has been approved in the legislative assembly/parliament. The main objective is to involve all possible stakeholders and to facilitate a discussion with those who prepare the state's budget on different aspects of it, particularly the social sector allocations and spending.

These initiatives were effective in raising public awareness of the budgeting process and fostering the participation of citizens in it. During the state's budget preparations in August, some communities that listen to the Community Radio programme expressed a desire for specific budgetary allocations for textbooks, scholarships, and doctors for primary health centres. As a result of the submission of the peoples' Charter of Demand, there was an increase in the allocation of specific components of social sector. The allocation for free medicine was doubled at the state level with many changes to the mechanism for distribution of medicine to poor patients.

Synopsis and key takeaways

Review of the literature showcased examples of community engagement strategies across various domains and thematic areas. Community engagement studies were seen across various health and non-health sectors including reproductive, maternal, newborn, child health; HIV/AIDS; Infectious diseases; NCDs; health insurance schemes; city development; water, sanitation, and education.

Literature reveals that majority interventions highlighting community participation are limited to awareness generation and screening, using community health workers as an interface. Using CHWs does not truly involve the whole community, just a select number of people who are trained to provide basic services and generate awareness. Involvement needs to go beyond CHWs to include community based organisations, youth volunteers, women's groups and CSOs.

Some interventions have focused on meaningful engagement and participatory research methods. Few successful large scale initiatives exist such as interventions put in place for HIV and Polio which have successful embedded community engagement and allowed people with lived experience and the larger community to take accountability of their health

Most studies on community engagement within the NCD space mainly focused on screening and increasing awareness towards NCD risk mitigation through IEC materials, counselling, mass media. Even Accredited Social Health Activist (ASHA) involvement in NCD prevention and treatment is low, by virtue of excess workload and lack of incentives. There are very few examples of community centric research- wherein communities are actually embedded in research design such as StopCKDu or participatory mechanisms to manage diabetes.

The way forward for truly embedding community engagement within NCD programmes and interventions would involve meaningfully involving those living with NCDs. HIV and Polio programmes have an action plan delineated to bring in CSOs and community engagement and highlighting how they are critical enablers for success. These can be used as good practices to model community engagement within NCDs. A bottom-up approach is necessary, with two-way communication and feedback to promote participation and inclusion. There is a need to involve stakeholders beyond CHW, including people living with NCDs, CBOs, CSOs and youth.

Annexure

Interventions included in the literature review.

Intervention	Mechanism for Community Engagement	Thematic Area
HEALTH		
Ekjut cluster-randomised controlled trial	WG, AG	RMNH
India Local Initiatives Program Model	PR, Committees, CV	RMNCH
Participatory Action Research in Maharashtra	WG, Committees	Anemia
Community Action for Maternal Health	WG, AG, CBM, SC	MH
White Ribbon Alliance Intervention	Public Hearings	MH
Ashodaya Samithi	CAG, AG	HIV/AIDS
Avahan	Committees, CAB, G	HIV/AIDS
National Vector Borne Disease Control Programme (NVBDCP)	AG	Kala Azar
NVBDCP	AG, CV	Malaria
Social Mobilization Network (SMNet)	CAG, AG, CV	Polio
STOP CKDu	PR, Committees	Chronic Kidney Disease
Rogi Kalyan Samiti/Hospital Management Committee	Committees, AG	Health Service Delivery
Mitanin Programme	CHW, AG	Overall Health (Focus RMNCH)
Accredited Social Health Activist (ASHA)	CHW, AG	Overall Health (Focus RMNCH)
CUPS study	AG	NCD risk factors
Kerala Diabetes Prevention Program (K-DPP)	AG, peer supporter, coordinator	Diabetes

Diabetes prevention and management	PR, CHW, AG, Coordinator	Diabetes
Ballabgarh NCD Prevention Project	CAG, AG	NCD & risk factors
SimCard study	CHW,AG	NCD & risk factors
CARRS Trial	AG, Facilitator	Diabetes
BEYOND HEALTH		
SEWA SSKs	WG, AG	Linkages to schemes
Haqdarshak	Facilitators, AG	Government schemes- health and non health
Andhra Pradesh Rural Poverty Reduction Project (APRPRP)	SC, PR	PHC Monitoring
Maharashtra Rural Water Supply Program	SC, Committees, PR	Village Panchayat Services, water and sanitation, health, and education
ARISE Participatory Approaches	PR, WG, AG,	Poverty reduction through strengthening resettlement areas, Health
Dalit Bahujan Resource Centre (DBRC)	AG, PR	Livelihood, scheme linkages, water, sanitation, infrastructure development
CBM in Maharashtra	CBM, Committees, SC, Public Hearing,	Overall Health, Nutrition, sanitation, education
Village Health , Sanitation and Nutrition committee	Committees, AG, grievance addressal	Health, Nutrition, sanitation
Odisha Budget and Accountability Centre	PR, AG, CAG	State budget development

WG- Women's Groups CBM- Community Based Monitoring AG- Awareness Generation CV- Community Volunteers PR- Participatory Research SC- Score Card CAG- Community Action Groups (Lived experience) CHW- Community Health Worker

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