Advancing Environmental Health Science Research and Translation in India through Community Based Participatory Research (CBPR) Workshop

February 26th -28th, 2019

Organised by:

Participatory Research in Asia (PRIA), India and

College of Public Health, University of Iowa, USA

Supported by:

Indo-U.S. Science and Technology Forum (IUSSTF) and

US National Institute of Environmental Health Sciences

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Preface

A three day workshop was organised by the Participatory Research in Asia (PRIA), India and College of Public Health, University of Iowa, USA from February 26th – 28th, 2019 on Advancing Environmental Health Science Research and Translation in India through Community Based Participatory Research (CBPR) with generous support from the Indo-US Science and Technology Forum (IUSSTF) and the US National Institute of Environmental Health Sciences/National Institutes of Health. The workshop aimed to deepen understanding of CBPR methodology and its contributions in the field of environmental health research and its application in India. The conference also served as an opportunity to encourage the use of CBPR methods in the field of environmental health and identify potential partnerships amongst Indian and US professionals.

The three days of workshop encompassed plenary sessions on: impact of use of pesticides on the health of farmers and their families, impact of air pollution (both ambient and household) and impact of disasters like floods and cyclones/ hurricanes on community environmental health.

Day one was dedicated to introducing the workshop by giving an overview of environmental health (both global and Indian perspectives), history, methodology and impact of CBPR, followed by sharing of case studies on health impacts of pesticides. Day two saw the sharing of case studies on environmental disasters – floods, hurricanes, drought – and air pollution. The sessions marked with a balance between Indian and US scholars sharing their research findings, methodological considerations and process details through case studies, visualisation and reading material links. Each session was followed by an open house which incorporated insights from the group. Specially crafted sessions using group discussion methodology were used to deliberate on community engagement, use of methods, ethical considerations, partnership development, use of PRA tools, community participation in data collection and analysis, knowledge mobilisation and dissemination through public interface and stakeholder engagement were also discussed. Day three focused on mapping out the next steps by holding group discussions around three themes: Air Pollution, Environmental

Disasters and Pesticide Exposure followed by a panel discussion on citizens' engagement in environmental health research at the American Centre.

The workshop marked a significant opportunity for academicians, practitioners, government officials and civil society actors to be part of a discourse and galvanize support in addressing the challenges posed due to disasters, air pollution or the use of pesticides in the community. The group was in consensus that a collaborative action by means of Indo–US partnership can open pathways for exchange of knowledge to evolve methods, technology and tools to address the current challenges in the field of environmental health in the country impacting all aspects of human development.

Day 1: February 26, 2019

Plenary Session: Welcome and Overview of the Conference, Its Objectives and Design – An Introduction of Participants

9.30 am – 10.00 am

Speakers

- **Dr. Rajesh Tandon, Founder & President, Participatory Research in Asia, New Delhi, India**
- **Dr. Edith A. Parker, Dean, University of Iowa College of Public Health, Iowa City, USA**
- **Dr. Banalata Sen, Independent Researcher & Consultant, PRIA, New Delhi, India**
- **Dr. Kaustuv Kanti Bandyopadhyay, Director, PRIA, New Delhi, India**

Dr. Banalata Sen – Shared that it was a dream to organise the workshop and they have been working with PRIA team since a long time. She also shared a personal narrative about her visit to one of the NGO sites in Dehradun (North India) where the community engagement into the initiative as limited though the publications were phenomenal, which made her realise the need for pondering further on the need to work with communities to find solutions which are sustainable. The situation also highlights that there is more need to have investment in community based research in the field of environment health.

Dr Rajesh Tandon: Welcomed everyone to the special occasion. He briefed about PRIA's journey which started in 1982 and how in the nineties PRIA got engaged into the field of environmental health while working with the trade unions on the issue of silicosis. For the past few years PRIA has been looking back to its work on silicosis. Two years back the Supreme Court came through with the judgement addressing the hazards of siliceous and a framework for compensation to the workers. It was a restless effort through constant capacity building – education and advocacy through different stakeholders which made it

possible to have a collective efforts and demand from the workers to hold the employers accountable. Thus, the community based participatory efforts have contributed to the field of occupational health in the country.

Dr. Edith A Parker while addressing the participants shared that though she and many of her colleagues are working on environmental health and the use of CBPR in the USA there is a lot to learn from the colleagues in India. She also thanked everyone especially colleagues who have been helping to launch this workshop.

Dr. Bandyopadhyay: Introduced the participants with the agenda elaborated the session layout and set the context for the sessions.

Dr. Tandon: Emphasised on interaction and participation during the session and the workshop per se. Based on his experience as a facilitator he suggested that the group should keep on changing sitting place in order to have diversity of interaction, by including people from different background to the table and not ghettoise with the same group or kind of people will help knowing everyone in the group by the end of three days.

The group members introduced each other and proceeded with the session.

Plenary Session I: History, Methodology and Impacts of Community Based Participatory Research (CBPR)

10.00 am – 11.00 am **Speakers:**

Dr. Gwen W. Collman, Director, Division of Extramural Research and Training, National Institute of Environmental Health Sciences/NIH, Durham, USA

Dr. Banalata Sen, Independent Researcher & Consultant, PRIA New Delhi, India

Moderator:

Dr. Kamalesh Sarkar, Director, National Institute of Occupational Health, Ahmedabad, India

Dr Gwen W. Collman: There is a strong need to bring research to action to contribute to the betterment of Environmental Health. Dr. Collman started with addressing the question "what is our environment?" She shared that at the National Institute of Environmental Health, they considered that whatever is chemical, physical and biological constitutes the environment. She also stated there is a direct connect between nutrition and impact through exposures. There is a high potential that if one is nourished well, they might not be impacted to the extent as to the one who is undernourished.

She shared that chemicals stay for a long time in human body and impacts in multiple ways. One can be exposed to pollutants while we eat, breathe, and touch. There are many components to measure exposures like GPS technology, etc. Exposures do have physical, economic and social impact and result into shared vulnerability. People live in places they have no regulatory laws and thus are not protected.

She further asserted that there is a dire need to share information with the community and scientist should do so for the communities to learn and protect their environmental health.

If a foetus is impacted it has a long term impact on the health of the individual. If women can be saved or protected during the pregnancy window there is a high probability to save the child born from exposures and contribute to their long term health

Research has indicated that air pollution is connected to autism and long term exposure can lead to many disease areas and impact long term health of individuals.

Participatory Action Research can be a powerful tool to engage with the communities, report back and build capacities in the community to deal the problem.

Community is the core to the idea of bringing any change in people's life. Thus, it's essential to include the community since the inception of the research idea. There is need to bring the scientific research out of the shelf so that the collective action can be geared to save and protect communities from the harmful impact of exposures.

Participatory Action Research thus, should have the focus on reporting back to the communities, they need to know and there is need to build on their capacity with information to work for the well-being.

As part of our work we share information with the community through community based methods, e.g. we engaged with the community members to identify their needs and also suggest locations to install air quality monitors. The project is evolved based on the feedback form the community members.

Climate change is a grave challenge impacting communities at large thus, projects are encouraged which work in partnership with the communities. For example the chemical exposure stand project in New York, where the installations were put up after discussions with the community.

One of the projects she referred to was the project in Bangladesh where environmental health was integrated with the school curriculum as part of the education process to generate awareness and encourage participation of the school kids. The process took the discourse on environmental health to a new level of preventive care and helped in finding ways to work towards it.

The second speaker of the session **Dr. Banalata Sen** shared the following as part of her presentation.

Environmental Health in India from what is wrong to what is strong:

Ms. Sen started the presentation by displaying an image from the Chipko movement in 1973 against deforestation and went on to give numerous examples including that of the Bishnoi movement as evidences of peoples will for nature conservation. She went on to add, "The state of the environmental pollution is so grim and visible that we don't have to go elsewhere for example – take the case of Delhi - we can feel the effect of pollution. India has further scaled down to 177th position out of 180 countries ranked globally on the pollution scale. Though, it takes a long time for the exposures to surface and create health impact, it's also observed that the impact evidence varies based on the exposure. "

"The State is focused on improving the reproductive health outcomes by propagating institutional delivery of pregnant mothers, etc. but till the issues of environmental health are not addressed, it will be difficult to achieve desired health outcomes."

Currently there are two key government programs focusing on environment health.

Pradhan Mantari Ujjawala Yojna: which focuses on providing LPG connection to the BPL families 60 million connections are already provided this is a big initiative to address the household pollution. Currently there is a study ongoing to look at the Children's exposure to air pollution. There are few flaws identified in the scheme where the household received the cylinder connection but does not have the resources to get the refill.

Affordability is a major constrain in the sustainability of these initiatives. The communities are also trying to address these problems; there are generational barriers thus, knowing about the health is unable to bring behavioural changes.

The government is making efforts in form of launching programs and schemes to address household air pollution like the Smokeless village program is an initiative to promote LPG, to address household air pollution but has not seen much success.

She further suggested that through there have been efforts made by the state but many gaps have been identified, so the significant question is how to address the gaps.

She also shared that there are instances of both good and bad practices for e.g. the first biometric study conducted in Hyderabad revealed more than 40 % levels of pesticides were

found in the food served at outlets as compared to the US. At the same time there are instances like Sikkim which is the first bioorganic state in the country. Thus, there is a need to also study the good practices and know for example how the Sikkim model is going to impact health.

To bring a lasting impact on the environmental health, it is important to understand the farmer's perspective which required some kind of environmental, psychological study.

She also emphasised the need for collective action and shared that collectivization of community members can help to address the issue of pesticides, which the distressed farmers agree has harmful impact to health but they don't have many alternatives.

The other program is **Swachh Bharat Abhiyan (Swachh Bharat Mission)**: The research needs to look at whether it has worked and not much research has been done to look at the community based research on environmental and health impacts of the program.

CBPR constitutes an important space in any environmental health research considering that the stakeholder engagement is the core component which defines success of any community based initiative. She also emphasised on the need to include stakeholders like lawyers who could understand the legal paradigm of environmental health projects and can help deliver them. Due to lack of research and evidence on health effects of the environmental exposures in India the issue needs more attention. Research and action (intervention) cannot be sequential it has to be simultaneously done. As far as the IRB is concerned taking data from the communities and not reporting back to the communities is highly unethical, thus, it is important to reach out to the communities."

Sustainable behavioural changes take time. All individuals have the agency. She shared that one should also focus and reflect on what are the projects yielding positive results and why for taking the efforts forward.

The house was opened for Discussion and Questions answers from the audience.

Question: The speaker has pointed to the household air pollution though the major problem is due to pollution at workplace, the speakers have to also look at the developmental model which has been adopted over years and how it is impacting the environmental health. Also

sanitation is not a new issue it has been realised in 1957 when the refugee crisis was at its peak in Delhi and had required to build sanitation facilities.

Answer: There is a lot of literature available which suggest the impact of exposures on human body and organs and variation in exposure can impact people differently. There are more people dying due to cardio vascular diseases there is need to have regulations but the issue is o non-compliant. There is need for regulators to address the problems created. It is a multidisciplinary issue and needs political will to address.

The toilet movement has been there for long problems are there and we can help with theory – knowledge transformation.

Health and equity are important aspects it is observed that it's not necessary that exposure is where the source is, but disbursal is a concern and we need be conscious. Policy dissemination is important to bring changes.

Question – Have you quantified the food consumed by the mothers as part of the research?

Answer – We have not done it, we know it does contribute and a lot of exposure is coming from the environment which constitutes their food, we did another study on organic food and have identified that the food has a deep connection though there are many factors that impact.

Question – How much time it takes to remove pesticides to remove from soil

Answer – Don't know

Cumin and grapes takes a long time, which is an area to look at.

Question: Poison control centre – what are available options?

Answer: We don't have answer. There is one in Ahmedabad they do clinical management and reference centre.

The issue flagged by panel members is very important for the farming community – especially farmers – we need to challenge the fundamentals farmers are considered to be beneficiaries there is a problem – CBR is not just research but also an extension to it leading

to community mobilization to bring change, we need to challenge the institutions and longitudinal researchers can help to contribute further to it.

11.00 AM – 11.30 AM : Tea Break

Plenary Session II: Overview of Environmental Health Research: Global and Indian Perspective

11.30 am – 01.00 pm **Speakers:**

Dr. Rajesh Tandon – History and Practice of CBPR in India

Dr. Edith Parker – Application of CBPR on Environmental Health Research in the US

Moderator:

Mr. Ravi Agarwal, Director, Toxic Link, New Delhi, India

Dr. Kaustuv introduced Mr. Ravi Agrawal to moderate the session and speakers – Dr Tandon (Founder President of and Dr. Edith Parker (Dean University of Lowa College of Public Health.) It was also briefed to the panel that the presentation is 20 minutes each and then there is open house for question and answers.

Environmental Health falls into two area is an issue that kits many issues but still lacks the policy focus. Who suffers the most is a question that is not addressed the most … the agriculture women, labours, mining workers et are the people exposed the most and not addressed. There are political issues in data – there is no desire to create data.

We did a research on pesticides took us to court we beat them but at the cost of resources, community is seen as a political tool and CBR is seen with great anxiety. It takes like a political campaigning to make environmental health on agenda.

The kind of scale that policy demands is impossible to do. What data really mean and what social context means are critical questions? Like there is a protest for waste incubators – there is no data so the trade-off does not exist.

Unfortunately the leverages are missing there is complete lack of having environmental health in the forefront of policy discourse.

Dr Tandon:

Dr. Tandon shared the journey of PRIA, he emphasised on the central issue of who owns the knowledge which dates back to the historical analysis of a hierarchal society where Brahmins had control over knowledge. Subaltern voices of the oppressed reflected in the teachings of reformers like Guru Nanak, Kabir, Tagore, Gandhi, etc.

In the 1960s the Agriculture Research Institutes were among the few institutions to incorporate some elements of community based research as part of their extension work, where the students have some degree of engagement with the farmers because the research focused on including the farmer groups as respondents, some students use to make efforts of further informing the farmers about the findings.

Action Research which emphasises on building research based on action finds its mention in the management literature. During the 1975 the phraseology of participatory research emerged. The phenomenon is widely used in the field of adult learning and research.

In Asia PRIA was the first organisation to initiate participatory research in the field of health, forest rights, land rights and occupational health.

Women's rights movements were using community based practice methodologies to address problems. In the early 90s the International organisations used the term PRA. Social scientist hesitatingly agreed that the participatory methods and finding made sense.

Gradually the government adopted the community based participatory methods as part of its programs for e.g. – participatory planning and evaluation which helped to enhance public engagement to developmental programs in form of social audit. Community engagement was supported by professionally trained workers. Knowledge for change programs were initiated in academic institutions with the goal to create spaces for building change.

Appreciating community Knowledge and building partnership with the communities resulted in creating trust. The process often takes long and a lot of hard work. The fundamental question is that does one believe that people with degrees are not the only

ones who has knowledge but knowledge can also be with people who do not have degrees. if one is willing to listen and value people's knowledge they are also open and willing to learn from you.

There are various models of CBPR incorporating cognitive approach and action research models. Contextualising, analysing needs and community management is the key element of the process. The researcher should share the findings through means which are accessible to the community like songs, street theatre, exhibitions, etc. When one builds stakeholder partnership, one needs to keep in mind how one can share knowledge in contextual ways.

There is need to hold seminar for training young researchers. There is need to learn to listen. There is an acute need to create a broader perspective for the young researchers who have an objective position but lack world view and sensitisation about field realities.

Dr. Edith Parker

Dr. Edith initiated with sharing about their research in the USA. She shared that there were many concerns with the traditional research that have prompted this initiative. It was observed that there is a dire need to emphasis on the community engagement. The focus is to enhance patient participation in the field of research even the National Institute of Public Health is doing so. CBPR contribution in research processes has been significant in identifying the research topic and research questions, designing the study protocols and methods, data analysis and interpretation in partnership with the community.

The project undertaken by the College of Public Health was on Community Action against Asthma (Detroit) is partnership between the community and the academic community. It has been very fortunate for the project to receive funding for the community based partnership which has not been the conventional practice in the funding sector.

The standard regulations are not appropriate for thus the project focused on identifying the environmental causes of Asthma for children as their priority. University researchers identified a team to work in partnership to conduct the research which resulted in 13 years of partnership with 6 separate research projects and also few policy changes.

Community was engaged while designing the study protocols, based on which the methods for the community actions against Asthama were evolved. The community opted for techniques like *Toxic tours* which were designed and lead by the community based organisations that disseminated information on exposures in the community.

During the data collection phase community members were the data collectors and were also the research staff. It was the community members who decided how to use air filters. The researchers along with the community members presented paper in a conference. Community and academics co-authored publications. The project had community engagement during all the phases, a direct feedback from the community has helped paw way leading to policy changes.

There is a dichotomy between community members and researchers. When the researcher goes to the community many inter linked issues surface along with the issues related to health, thus the researcher conducts a dialogue with the community on what issues are to be approached first and how funding can be secured. Conversations with the community should focus on sharing the areas for research which can bring benefits for the community. Honest conversations while having focus on the research can be building blocks for working with the community.

Question: Do you see academic institutional changes happening to promote community academic partnership, and if so what is the status.

Answer: there are two ends of difficulty – training of researchers in the field of CBPR is a challenge. In universities where there is a stream of funding which necessitate community research where there is a partnership for e.g. ICSSR use to promote partnerships. But Academic Performance Index (API) scores don't include it. Dr. Tandon shared that he has been working with the UGC to build in community partnership as a mandatory area of the teaching and research at the university

Question: How do we draw attention of the Policy makers to the issue of community based research and partnerships in projects?

Answer: Dr. Tandon shared that we have tried to hold dialogue with the national and state actors and universities some and have motivated them to incorporate CBPR some have

aliened and some have not. The bottlenecks with implementation process are grave. Thus, we can start with the motivated district and state level institutions. We can work on how existing policy, rules and laws can be implemented.

The important thing for the researchers is to speak in the language the community speaks. Communication is a major barrier. Finding intermediary organisation can help meditate relationship with the community and take the research forward. It is essential to have partnership between the world of academic and community to take the research to action. Chipko movement was a great example. There are times when the gatekeepers like the union might exploit the labours both ways and might not always be in the best interest of the labours. The community is still caught in the hierarchies of caste, class and religion, etc. thus, there is a need to build partnership which is a time taking process.

Question:

Last two decades there is a decline in the use of CBPR, there are researchers who are using participatory approach have also named it like – Social Audit, etc. Academic and Community Partnership is possible but there seems to be political reluctance in opting for the community based participatory methods. So what do you see as the future of CBPR?

Answer: Dr Tandon replied sharing that he is aware about the current situation and thus, he is not insisting on using a particular phraseology. It is important to note that in different context the CBPR methodology has gained different momentum and contributed to various disciplines; like in the US it has been used in the field of management Psychology in Latin America it has been used in the most radical movements for action research. Thus, Participatory Research and Action traces a long history and the impetus on action research in development sector by Robert Chambers has driven its way. It is us who have abandoned the methods in the race to engage in heavy data crunching exercises without contextualising the findings.

In countries like Canada where universities – community partnership is encouraged the project funding is the most competitive bidding.

For participatory research it is also essential to have contextual frameworks instead of the hegemony of a particular framework from a particular region. For example what is the South African framework for research? Thus, the need to root research to the local context is paramount. Funding stream as partnership research should be local and contextual.

Question: We use CBOs or intermediary organisations to implement our projects, we have noticed that there is a heavy reliance on funding and there are contractors and subcontractors for project implementation, how do we address the context gaps created by the donor driven projects.

Answer: Dr Edith replied that we use to invite the Community outreach workers to our meetings and most of them were high school educated, they use to sit in a corner and not engage, it was a wakeup call for us and we learnt that we need to listen to the volunteers and not just the steering committee members.

Dr. Tandon shared that researchers these days go to distant places and do research to new locations, social processes do matter and positionality of the researcher matters to understand the world of the community members. There can be multiple perspectives of the field reality which requires time, effort, money which seems to be not available. Thus, it is important to pay attention to building community relations and engage in social processes, which needs time.

Question – How to use CBPR for sanitation campaign? There are implementation issues in the Swacchh Bharat, how to address them?

Answer: Dr. Tandon shared that there are instances where Participation word has been as much abused in the name of transformation which in real sense does not contribute to the communities. The community loses interest if the knowledge generated is not used for their good. The knowledge should bring change. Thus, it's important to have field processes geared to address community needs and interest than only developmental programs can work and yield success.

Question: In Tamil Nadu which is frequented by disasters, most of the funding agencies work through intermediary agencies to implement projects where at times community members want to know why the research is happening and what are the objectives, at times

the funding agency does not disclose the findings and there is a conflict how to address it so that it becomes part of the research requirements.

Answer: Firstly, There is need to have community as partners, short term research cannot be termed as CBPR.

Question: Environmental health is less recognised in the country how to create the ecosystem to facilitate it? Also even if the participation is high in the community processes, there is a hesitation in community to ask questions from the state how to address it?

Answer: One of the ways to address the issue is to encourage universities to take initiative for community engagement and propelling CBPR in environmental health. University has resources allocate them for research it. The university should have obligation to partner with the community to share knowledge, build alternative structures to bring relevance to their research.

01.00 pm – 02.00 pm Lunch

Plenary Session III: India and US Case Studies on Health Impacts of Pesticides

02.00 pm – 03:00 pm ***Speakers:***

- ***Dr. Nanda Kishore Kannuri, Associate Professor, Indian Institute of Public Health, Hyderabad, India***
- ***Dr. Kim Harley, Associate Director for Health Effects, Center for Environmental Research and Children's Health, University of California, Berkeley, USA***

Moderator:

- ***Dr. D Manavalan, Executive Director, Action for Food Production, New Delhi, India***

Dr. Nanda K.Kannuri – Thanked PRIA for the invitation. In 1998, he attended a workshop with Robert Chambers on engaging with the community which was his first exposure to participatory methods.

Some of the tools that he has used in the past ten years including transect walks, in-depth interviews, etc. have been very helpful. Using Community based methods and continuous interaction with the community the responses changed over a period of time. He worked on farmer suicides, gender, victims of exposure, Perceptions on safety etc.

He began by saying, "Extensive use of chemical fertilizers has resulted in toxic landscapes. Farmer have been using the toxic chemicals for a long time, interestingly the farmers are aware about the harmful impact of the pesticides but they do feel where individual effort

will lead , there are constrains on both sides at the community level and at policy paradigm."

"There is a gender dimension to protection and care while using the pesticides; types of pesticides used are cotton is one of the highly chemical dependent crops more pesticides are used.

There are products where chemicals are highly used and they are part of our life in household consumption both at household level and farming. Some of the exposure of the health is gender – exposure and activity are gender segregated. Women load it and men use it. Health is not a priority the priority is to earn a livelihood. The communities are concerned for earning livelihood. The research in Palakkad have shown the children born with the issues like mental retardation and other diseases and the child care has been a liability for the family where there is no compensation and support.

There is a myth that the young girl children can quickly pluck cotton seeds which has are exposed to the idea of sex in the young age and unwanted pregnancy are high…. Break down of family land there is need for more hands to work.

Building trust is a continuous challenge and engaging young girls and parents for building rapport and trust for a year has been of great effort. Positionality as researcher was quite an issue and it took time to build relations with the community. "

"We prepared questions and went. When we asked the girls do you want to study they said, "What will we do after studying even if we do, we will still be working here, our concern is not education. We want to get married and be happy. We need to have money to support our families." Health was not a priority for them but money was, as it gave them freedom and to power to make decisions. Education as liberation - It demands us to be more accountable to the communities from our end rather than, the CBR processes helped to bring down partner violence in the region. The findings of the research were shared and community was happy to know that someone came back to them with some findings as not many people did it, someone even framed and kept it, even though they could not read and write, as they had lost their son to pesticide exposure."

Challenges in studying the pesticides exposure –

"The land is so toxic that there is no way to do farming without pesticides. The chronic exposure or health impact is not able to motivate community due to lack of alternatives like safety exposure, alternative means of farming. So there are challenges of researcher going to the field for interdisciplinary researchers. Uses of methodologies – body mapping – chemicals are not in picture as there is a low perception of the threat as we anticipated. Used drawing as a mean to probe deeper into what they feel like – some girls found it good to work in the field as it helps they to be away from household chores, but they also represented that there were times when drunk men would follow them."

Dr. Kim – Pesticides and Children's Health: The CHAMACOS study

Dr. Kim initiated the presentation by sharing CBPR experience while doing a longitudinal research study in USA. The study helped us to draw a map which depicts the areas with highest pesticide use in the Salina valley – the salad bowl of the nation. The name of the project is - Center for the Health Assessment of Mothers and Children of Salina. The objective of the research is to observe how pesticides impact the health of the children and how can they contribute to the improvement of their lives.

"What we did was a longitudinal study – enrolled them they have been followed them for last 18 years. We do a three hour test – interviews, samples of biologicals, etc. All our staff is from the community for the community. Which is why, when the project is over, we want to share the findings of the study with the community first."

"Community partners were made a part of the advisory board; we also brought the industry representatives on board. It was difficult as most of them were suing each other and the meeting were the only ground where they were coming together. The project was created with the intention of community outreach being the core obligation of the researchers."

"We organised community meetings and made it interesting with food, music and interactions. We determine pesticide exposure in 5 ways. Home inspections, interviews, dust samples maps and bio markers. We shared the results with the community. One of the questions which was of concern to us was does these result are related to the health

mothers and children. The sample results during pregnancy and child growth exposure that there is a direct connect between pollution and mental growth. “

“It’s what is happening to the mother while she is pregnant, which is impacting the children. Health and development is dependent on a range of factors – poverty, social background – high family adversities were more impacted due to high exposure and were subjected to triple jeopardy to the consequences of exposure to pesticides.”

“We realised that farm education was important as most of the farmers were not aware of the time and usage of pesticides though they were concern about their family health. We tried to find ways to address it by providing them hand gloves, laundry service and field based education to the farmers. The gloves observation helped us to find that the use helped lower the exposure. “

“We developed and piloted curriculum for the farmworkers and their families which helped in community reach out. Seminars were conducted with the children to send the message to the community regarding the research work. Youth councils were initiated which not just gives advisory support but is a great opportunity to create the next generation of health workers form the community. The youth council members are the children who were part of the study since they were born and are now young adults in the community and have become members of the youth council. We used the coloured wrist band – as passive tool for identifying exposure. It was identified that clean home and door mates helped to reduce exposure.”

“Radio as a communication media helped a lot to reach out to the farmers. It was observed that the farmers were using radio for music and thus it became a tool to do advocacy. The teenagers from the community are also doing news and songs to generate awareness on the radio. They also use community mural as a medium for communicating and generating awareness with the community.”

03.00 pm – 03:30 pm Tea Break

Group Discussions

Objective

- Partnership development
- Building trusting relationships
- Listening and valuing local knowledge
- Framing research questions
- Negotiating MoUs and protocol agreements for research project

Methodology:

The participants were divided into three small groups for deliberating on different components of the process geared towards building partnership with the community. The objective was to hold a focused discussion with the participants and lead to experiential learning about the CBPR in the field of environmental health in specific and working with the community at large in general.

Group 1: Co-Facilitators – Professor Doug Brugge and Dr. Banalata Sen

Rapporteurs: Ms. Shashi Shikha and Ms. Carolyn Poutasse

Partnership development; building trusting relationships; listening and valuing local knowledge, framing research questions; negotiating MoUs and protocol agreements for research project

In our research work what kind of partnerships do we require?

Partnership is a very challenging issue and often misunderstood as contractual relationship. Partnership in community mobilisation is transformative work as it is long term.

The institutions should approach the community through a CBO as an intermediary organisation. In case there is an absence of such an organisation, then the community should not be approached. If there is a transactional relationship of the institution with the community then it won't work.

For instance, while doing research on agriculture waste burning in Punjab two types of organisations was chosen for partnership. A CBO which works with farmers along with a Hyderabad based organisation which has been influencing agricultural policies. The CBO is already doing work and the research project further added onto their existing work with the objective that this kind of project becomes sustainable. In another example for working on the issue of arsenic in Bihar, a CBO called Paridhi was partnered with. This organisation has been working in the community for the past 30 years and will continue to be there for the next 30 years or more. The programme was done in collaboration with them such that local people will be interested in this issue as well as the CBO will continue to keep working on this concern as it impacts the people for whom the organisation is working. The community members themselves can partner with the researching group. For instance in the US, the farmers are also a part of the research committee apart from NGOs.

For substantive collaborative research tripartite arrangement between research institutions, intermediary organisations and a CBO such as farmer's collective operating at a community level is essential. This collaboration should not be a token transactional arrangement but each organisation should have a stake in the process. So, there is a need to move from transactional approach in partnership to transformative practice as this partnership will lead

to social mobilisation. The research done in this manner will create ownership of the data amongst the stakeholders and benefit each partner in this synergistic approach.

When a researcher enters a community the latter should be able to have a hope in the former. For e.g. When Gandhi went to Champaran, Bihar to talk to the indigo farmers, a hope was created. This hope lied in being listened to. He collected 4000 testimonies and categorised them into 120 types of exploitative practices that were being inflicted upon these farmers. If the community does not find our engagement with them meaningful they will not invest.

Partnership with the government as the local stakeholder is essential such that community development becomes the agenda of the state and the process continues even when the donor funds have ceased. However, partnering with government has its own challenges.

Often the community doesn't approach the researcher and ask them whether the research is going to solve a problem. This is because the research has assumed a very alienated position by using language, terminologies not commonly used by the community. The research should have the capacity to incorporate local language and lexicon used to describe certain things.

The relationship between researcher and community is usually unequal but we should attempt to make it equal. The professional researcher has to come down and build trust and equality. Researcher's responsibility is to share the power and learning. Real point of research is that it enhances the research as bidirectional and beneficial for everybody.
Participation is not a banking relationship. In any kind of partnership, there is bound to be tension but we need to establish a system to deal with the dynamics of this tension. In US there are communities that are continued to be studied which make them jaded and angry. In India also there are such hotspots especially the areas around HEIs without giving anything back to the community. CBOS consider research as a waste of time. Hence, it is essential that as a researcher we give back to the community.
Listening and valuing local knowledge

What people in the community say must be critically analysed by the community themselves. For instance if they say,' we are illiterate therefore we are poor.' The researcher needs to facilitate the discussion such that people determine the reasons for their condition.

Sometimes it is essential to believe what the community is saying without rationalising it into logic of science or objectivity. For instance, in Jadugoda, the mountain of Uranium was being protected in the name of the God and fear from the divine. Till 1000 years they protected it. Scientists took out uranium which has exposed the entire committee with harmful radiations impairing them for generations. Hence, we as researchers must value their local knowledge and not dismiss it as 'superstition'. We must analyse properly and with caution.

Framing research questions

There is a tension in framing research questions along with the communities. In scientific inquiry there is a limitation but there is possibility of answering few questions. Researchers need to be sensitive and flexible to address the needs of the community.

CBPR is time consuming. To hold dialogues with the community, the researchers need to be adept with facilitation skills. Most of the HEIs, government organisations and mega research outfits do not know how to even sit with the community and elicit responses from them.

Additionally, the community suffers from fear and anxiety in dealing with sensitive issues for research. On the other hand, the expectation from the research is also exaggerated.

For e.g. a research on exposure of chemicals may lead to closing down of a factory. Researchers do not have answers to these kinds of events or responses.

In yet another example, in a village in Bhuj in Gujarat, a number of trucks would carry the sea salt to the factories. On the way the salt would fall down from the truck making the soil alkaline along the 20 km stretch. When, a research was attempted to be conducted regarding testing the soil and advocating for change in the route of the trucks, none of the members in the village came forward to cooperate with the process. This was because at least one member from each household in the village worked in the salt factory.

At the same time there are other examples. For instance, previously certain land areas were marked as dump sites for MSW in Delhi. With these dump sites being overloaded, when new sites are specified, the villagers resist and do not allow that to happen. Since people have adequate knowledge, these lands are not given out by the villagers and the authorities face a lot of resistance. So the more the community knows and gets empowered they can take charge of their situation.

Framing research question calls for more intimate relationship with the community. While RQ can be initiated by the researcher there should be consensus between the community and the researcher.

The research should consciously look into where the sufferings are. It should be able to identify and address issues and mobilise the community to ameliorate the problems.

The problems are also with the ways in which researches are funded by the government in India. Research funding in India is limited. Quality and output of research is not maintained.

Group 2: Co-Facilitators: Dr. Praveen Kumarand Ms. Sunanda Reddy

Rapporteurs: Mr. Shubhayan Sengupta and Prof. Edith Parker

Highlights of the discussion are as follows:

Who all are our partners?

Everyone in our group agreed that the main issue was that occupational health diseases were not diagnosed. Since they were not diagnosed, workers in a lot of places were not aware of the health problems they were facing and the detrimental effect it was causing to their personal health. A lot of those in attendance expressed a desire to partner with social security organizations and engage with government associations to solve the problem. But with that being said, they also admitted that they had some concerns regarding the relationship between non-government organizations, the public and governmental institutions.

The theme of trust, dominated the discussion, and was identified as the main point of contention by the group. For example, how does one partner with local government organizations? Local government organizations are an influential part of any grassroots movement, since they collect information and data of their constituents. However, this information is only sent forward to health departments, and not shared with public or private organizations. Such actions tend to alienate the public and the researchers, creating space for doubt and mistrust. This information should be shared and distributed, if not with the public then at least with researchers (who lie between government and the public) who can study and then disseminate this information in an easy-to-understand format to the public.

With this context, it begged the question:

What could be the strategies which could foster financing and trust?

- Getting partners who the government trusts
- Most of the time, it might be better to collaborate with local government rather than involving other NGOs. Local government are more comfortable working with the community directly rather than NGOs working with the community

One of the strategies with respect to partnership development is that there is an increase in the chances if the government works with the community and then partners with NGOs who facilitate this relationship between the govt. and the community.

<u>Building a trusting relationship with stakeholders</u>

If the government has to increase access to services, there is no problem, as they look to work with researchers to solve the problem. But if there is a power bargain with political undertones, than the chances of building trust decreases. One of the members gave the example of Oregon state where corporates signed a backdoor deal with the government to clean the land less but when the situation escalated, they employed researchers not NGOs to help out, since researchers were expected to be “apolitical” and “would not raise too much fuss”.

Ownership of the issue was also identified as a major problem when building trust with the community. A lot of the group members had noticed through their work that, on most occasions, nobody wanted to take responsibility, however little regarding the issue. This creates problems such as a lack of community participation because for a lot of the stakeholders, their rationale is that they stand to lose a lot more than they gain should they help out with conducting research. One of the members gave the example of working with laborers who suffered a lot from silicosis due to the nature of their work. A lot of the workers expressed the fear that if they demanded better work conditions, they would just be fired and replaced, since the job demand was far greater than job supply.

The group members also identified, by citing their work done in the field, that there were a lot of differences within the community as well. Some people were willing to help but others did not even want to see the researchers face. For example, One of the researchers once asked this lady who was not participating in the study, as to the reason behind her voluntary exclusion. She said that it was because the tribal community the lady came from was forcibly removed from the forest and since then, the community refuses to engage with anybody with "research or govt." affiliations.

In conclusion, the group members agreed that it was important to take into considerations the various power dynamics among a community since they were not homogenous. There is often a conflict in interest between private interests and public good. Most communities that organizations work with are more concerned with what gets the food to their table rather than the greater public good.

<u>Listening and valuing local knowledge</u>

A large portion of the debate revolved around discussing the importance of the question: Who owns the data that is obtained from the community? One of the American group members gave the example of certain Native American tribes which **own** stories they discuss which means that they cannot be published by the researcher, in theory. But researchers tended to overlook such "traditions" and go ahead and publish their stories anyway. This is because there is little to no value placed by researchers on the local knowledge that they interacted with.

All of the group members agreed that It was very important to value and listen to the local communities and to discuss the issue of sharing with the community, so that the knowledge can be shared and disseminated.

However, there are occasions when tradition supersedes such sharing and communities may get offended if their local traditions are shared to the rest of the world by the researcher. Or they may resist changes to their lifestyles because of tradition. So what does a researcher do in this instance?

It was at the point, that due to time constraints the group was forced to move on to the next question for discussion, but they agreed that the question of, where researchers draw the line between doing what is good for the community and valuing what the local knowledge which, while being harmful are the traditions that the community has followed for years, is an important one and should be in the minds of every researcher.

Framing research questions

How do we frame research questions which are both digestible for the policy makers as well as the community being studied? This question has been troubling researchers for years, and after considerable experience in the field, the group members had encountered some ways to go around the issue.

One of the members underlined the importance of asking the “right question” because if you didn’t ask the right question, you will not the answers you are looking for. He recommended that questions must be posed by personalizing the problem to the community. For example, asking workers whether they need to have a bath after working their shift is a good way to make the community (and the researcher) realize that they interact with a lot of dust as part of their occupation.

One of the members provided the description of an approach called Group model building, where one would sit with different sections of the community and understand mental models among the community from an individual point of view which would then be aggregated to formulate a collective model. To employ this model, one would have to not go with a research question but with a general reference point, and then ask the various stakeholders of the community information around the reference point. It is also important

to ask the community representative / village head about their opinion as well, since it helps incorporate their perspective as well.

After deliberating over the various discussion points, the group decided that it was best to consolidate the lessons learned and understood under one overarching common question, for the sake of simplicity. The question they decided was:

What should we do to strengthen the voices from the field and build trusting relationships with all of the stakeholders involved?

- First step is to listen
- Combine community voices and expert opinions
- Training bureaucracy to listen to the people
- Publish results as soon as possible so that it can be discussed and improved upon
- De-jargonise research articles which alienates the local community

Group 3: Co- Facilitators: Dr.Upasana Gosh and Dr. Yogesh

Rapporteurs: Dr. Nicole Novak and Ms. Aarti Upadhyay

The group discussion was focused on the following components:

- Partnership development
- Building trusting relationships
- Listening and valuing local knowledge
- Framing research questions
- Negotiating MoUs and Protocol agreements for research project.

Dr. Yogesh initiated the discussion by posing the question on – "What are the current practices in partnership development in the community?"

Dr. Nanda Kishore Kannuri (Associate Professor, Indian Institute of Public Health) – "Entry in the community defines your success; the CBPR methodologies are of great help. During my field experience the CBPR helped a lot to engage with the women and men to build trust

and engage with the communities. To engage with the gate keepers has been a critical element of the process."

Dr. Upasona – "Building trust is a crucial aspect, what works in one context does not work in other context. In my experience of work in Sundarbans – as a researcher when I visited the men were not ready to talk to me but women were ready to talk to me. It took time to build trust and it somehow percolated to the men relatives / families and helped to build trust.

First of all we need to give time and sometimes too ethnographical and anthropological – not to have a hypothesis in mind, before designing the project build relationship with the community. "

Dr. Ashok: "In my experience in the field of rural development, we need to hold communication with the community members and communicate to them, the mutual interest which can be met through the study. We convinced them and shared the report / findings with them. E.g. we work with communities for arsenic levels and need blood samples – we communicate, convene them and share findings. We form a community, take the mukhiya (head of the community) in confidence and then execute the project; we have at least one to three members knowing local language. You need to have gender balance if there is a requirement to interview the female members of the community.

If the community knows and is convinced by the purpose, the team co-operates and go to great lengths to help the research team."

Dr. Tiwari – "I agree that there is an objective aspect to the process, with our work in occupational health we realised if there is compensation attached to it. The level of participation is high. We are working with Bhopal gas victims where we are only to monitor the activities and there is not much to contribute to the community, there is not much cooperation. There is a lot of resistance from the industry; that is a special challenge where we have to go to the factory inspector who communicates to them that this is a government commissioned study which helps them to support the activity."

Dr. Ashok –" In most of the projects we keep stakeholders meeting one initial, one mid-term and one final where we share the findings with the stakeholders, we also keep meetings in the community and disseminate the findings. We offer the structures are

handed over to the community we tell them if they wish to handle the project they can take ownership. Most of the places the assent is maintained by the communities."

Dr. Nicole: "There is a lot of fear on documentation among the community members. "

Dr. Suresh: "Many experiments done in the field, where people come and go and the community does not know what we have done with the data. "

"We had put chargers at two to three places in prominent community spaces, we could tie up with few CSR companies, building a relationship is important. As our intervention was there we wanted to also look at other areas like health, etc. we organised health camps …. To connect to the community, there were many models.

The company making the cook stoves are getting subsidies from the ministry of renewal resources but the benefit was not coming to the community so we made a model of how to bring the benefits to the community. We made an office in the community so that we could build the intensive methods for the study. The local volunteers were trained and they become the face of the study. It was a complete story board where roles and responsibilities can't be allocated; so, never promise anything which you cannot deliver, where you don't just block your way but also others who will come in future. The cook stove designed to put understanding the local requirements is important, should be designed with the community."

Dr. Nicole: "Local knowledge – like dipping okra in rat poison, people know that it's harmful there is a local knowledge ---- they believe that as consumers and know that we as researchers can be catalyst to the change in knowledge,"

Dr. Nand Kishore: "We can't be devil's advocate and tell them what to do."

Dr. Tiwari: "We were working with the ship breaking company – there is a single size glove for whom it fits they use it, and for the ones it does not, they leave it. When we want to provide occupational health services, the local knowledge is very helpful as we have scarcity of resources and it helps us to prioritise the resources."

Dr. Ashok: "The regulatory bodies play an important role, no hospital in Bihar were following the bioregulation. Because no one says anything to them they don't pay heed to it."

Dr. Tiwari: "Child protection issues – we worked with the child labourers – everyone said that the parents are forcing their children to work as they need more hands to earn a livelihood. So the ILO rules say that put the child to school and put the child into non arduous work in evening."

Dr. Tiwari: "When we worked with the Agra shoe makers the industry uses chemicals and the children have even suffered Neuro -behavioural issues."

Dr. Nand Kishore – "The education has been the de-skilling impact after 10 years the children were not fit for agriculture and thus there was a burden for sending the children to schools."

Dr. Ashok: "There are barriers in the mono disciplinary research, there is a need to have a multidisciplinary effort, there is no dearth of technology and there is a need to build social component of the project and integrate it with social realities. I have a social scientist in each project and it helps. The study process becomes more relevant."

Dr. Tiwari: "Don't highlight the question where you do not have answers for it, as it can create panic in the community and can create more problems, thus, it's important to provide some solutions."

Dr. Yogesh – "We work on the research only if it's needed by the people. Health assembly, sometimes we come up with problems which community does not think at that time as problems but at times they acknowledge them to be solutions."

Dr. Nand Kishore – "The knowledge of researchers will be challenged and we need to be open to accept challenges and make amendments."

Dr. Suresh: "People do literature review – we use triangular approach – we do quick pilot in the community and make changes, sometimes things are not at all relevant to that particular area, we do brainstorm and it's a quick brainstorm with the community.

Gathering the data – sometimes we present the data in graphs – social scientist tell us how to present the data.

Inherent unreality – people were not ready to accept that there is something like vulnerability –

If the community is not aware, we help build those components in the interview questions it helps to build the research it helps to reach the community with information. "

Mr. Gupta – "We keep our questions broad so that we can have more community participation."

Dr. Yogesh: "Exploratory research – it can be very open and for testing results you don't have many choices –"

Dr Ashok: "A pilot helps – the questionnaire looks well but might need changes if you go to another place a round of testing helps"

Dr. Suresh: "If the people executing the research are not trained it helps – based on your objective of the research – if you wish to have some information form community there is need for interviews to be open-ended"

Dr Ashok – "Got two responses for household income – husband and wife have responded differently."

DAY 2: February 27, 2019

Plenary Session I: India and US Case Studies on Environmental Disaster – Floods and Hurricanes

09.00 am – 10.30 am **Speakers:**

Dr. Upasona Ghosh, Senior Lecturer, Indian Institute of Public Health, Bhubaneswar, India

Dr. Diana Rohlman, Assistant Research Professor, Oregon State University College of Public Health and Human Sciences, Corvallis, USA

Dr. Jill Johnston, Assistant Professor, University of Southern California Keck School of Medicine, Los Angeles, USA

Moderator:

Mr. Binoy Acharya, Executive Director, UNNATI, Ahmedabad, India

Mr. Binoy Acharya began the discussion by talking about the major shift in understanding regarding disaster governance in India and the world. He mentioned how the world was moving from a disaster management perspective to a risk reduction perspective. The difference being that disaster management was an activity done in the aftermath of a disaster whereas risk reduction was more to do with the prevention of the disaster in the first place and was a 365 day a year activity as opposed to a one time intervention. Over a thousand people died due to Hurricane Katrina, but in 2018, during Cyclone Titli, only one or two people died. This is because of better preparedness.

Disaster governance has now acquired a lot of importance due to this, and begins at the community level. Those who work at the community level are also more familiar with disaster prevention, which increases the relationship between governance and disaster prevention. But this comes with a down-side as the government is also more responsible for preventing disasters from escalating, for example, as we saw in the Kerala floods, 34 out of 35 dams were released by the government during the monsoon season, exacerbating the effect of heavy rains across the region.

Dr. Upasona Ghosh

The first speaker was Dr. Upasona Ghosh who was presenting on the following topic: how climate impacts child health: Case study from the Sundarbans

She began her presentation by giving a little context behind understanding the issue. The Sundarbans is the largest mangrove delta which India shares with Bangladesh. It is a hub of diversity. It has also always been a hub of geo-social marginalisation due to the migrant workers who shift near the Sundarbans. There is a lot of climactic turbulence along with child illness and malnutrition. The latter exists because healthcare facilities in the region are very poorly maintained, since it was not possible for a doctor to stay on an island with no electricity.

Sundarbans is a climate change hotspot experiencing consistent sea level rise and high rate of soil erosion

What is the relationship between climate change and child health in the Sundarbans?

Short-term impact

- More water-borne diseases
- Crop loss
- Demolished shelters

Long term impact

- Declining fish catch
- Land loss
- Changing food system and displacement
- Fragmented knowledge on climate change among stakeholders

Dr. Ghosh expressed her concern about how local policy makers did not know much about climate change, choosing instead to advocate more for infrastructural change rather than

social change, plus there is reluctance among them to interact with scientists and researchers to solve the issue among other bureaucratic issues such as red-tapism

Techniques used

Ethnography for 8 years (Which included Participatory social network analysis)

- Vulnerability analysis
- Food choice exercise
- Climate-hazard ranking and seasonal calendar
- Photo voice

What is a photo-voice?

-A visual action research tech by Caroline Wang

-Enables representation of communities' collective voice, as they are asked to take pictures of their daily lives and the issues they face during it. The visual nature of a photograph makes the viewer understand not just the perspective of the local community but also the hidden contexts that dominate the issue afflicting the community.

-Enables communication and allows the members to engage with decision makers (with more power due to the graphical nature of the photographs) through a dialogue for social action.

Dr. Ghosh used this approach with 79 participants, gave them cameras and they took the pictures, after having been instructed about how to use a camera. She noticed that a lot of the images the community took were that of male migration (male members going across to major cities in West Bengal for employment) and the various adaptive strategies the community used to work around the challenges they faced in their daily life. There were also some hidden determinants, which included elements of their life which they were not able to capture through photographs.

These included:

- Non-functional public health
- Generational gap between mother and daughter in law
- Domestic violence

The findings from the study helped bring about the following changes:

- Concrete roads
- Sending across health facilitators
- Breaking the stereotype (women were now taking photographs which was interpreted by the community as a "man's job")
- Opportunity to dialogue with local decision makers
- Developing leadership skills

This study was not without some challenges however. Dr. Ghosh outlined them as follows:

- Geographical hurdles
  Sundarbans is in a very remote part of India with little to no network connectivity or access to electricity
- Political bias and bureaucratic hassles
  The local administrators tended to look after what served their interests first, with the needs of the community coming in afterwards.
- No equal representation of voices
- Issue of time commitment
- Bias of community gatekeepers

Dr. Diana Rohlman

The next presentation was given by Dr. Diana Rohlman who presented her study which was based on understanding the environmental impact and rise in air pollution due to Hurricane Harvey. The study was primarily conducted by Rohlman Laboratories with the primary intention of helping the community by giving back to the community, information in a language they use and understand. The primary method of data collection was through

Silicon bands which the members of the community were required to wear. These bands would analyse the surrounding air for over a thousand contaminants and micro-particles and collect information on which ones were present in the air. These bands would be worn by the community members and would analyse the air as the community members go through their daily routines.

Methodology used for the study

- Establish partnerships with the local community
- Based on this, tools were identified to conduct the research in the best manner possible so that the study could illicit the necessary questions
- Returning research findings to the community

Dr. Rohlman also outlined some challenges surrounding disaster research all over the world:

- Timing: There is little to no way to identify when a disaster can happen, and the intensity of the disaster when it does happen
- Ethical approval to conduct study can take upto 6 months

She also outlined some of the questions that arose when creating the study design:

- How would the participants be identified? Through Random recruitment? Or would a more targeted study be required?
- What will be the research focus? How will the research question be communicated to the community

Context of the Study

Hurricane Harvey led to around fifty inches of rainfall in four days, causing more than a 100 billion dollar worth of damages, making it the costliest cyclone since Hurricane Katrina. It also led to a lot of unintended releases in the air such as toxic waste sites which were flooded, polluting the air and water in the state of Texas. The local community, alarmed by the sudden drop in the quality of the air partnered with community groups and academics,

who in turn, contacted Oregon University, since they didn't have the technical knowhow to understand the scale of the issue as well as the various nuances surrounding it.

The demands of the community were as follows:

- Study the impact caused by flooding of Toxic Waste sites
- Understand the rise in Air pollution
- The information should be made accessible to the local community

As environmental research tended to be rather technical, making it harder to grasp for people with a layman's understanding, Dr. Rohlman explained the need to formulate a research question and a community question, where one was asked to the community to understand the impact and exposure (DId the hurricane increase exposure to pollution?) with the research question being what they actually wanted to find, with regards to chemical exposures.

The study was also helped by the formation of a Disaster Ethics Approval Committee, which was put in place to allow for an immediate response to studying disasters, and to bypass the various time-related hassles surrounding a typical ethics approval.

The Disaster Ethics Approval Committee helped by:

- Allowing for immediate response so that work can be done
- When Hurricane Harvey struck, researchers were able to begin their study within 3 weeks
- Helping in the creation of pre-approved surveys and use of wristbands which reduce the amount of time taken to get approval

Data collection was done between September, 2017 (when Harvey struck) and December, 2018 to understand deterioration in air quality and the measure the degree of change

Dr. Jill Johnston

The last presentation of the session was by Dr. Jill Johnston who presented on "Drought, dust and health in California", where she spoke in detail about the study she had conducted, analysing air pollution caused by dust in California.

The main source of air pollution in the region was due to the large amounts of dust in the air, caused by the receding rainfall, increasing construction as well as high amounts of water recession. Water recession is an especially important issue as the local water body, called the Salton Sea has considerably receded over the past few years, leading to a lot of environmental upheaval in the region. Water politics in California also played a factor as a lot of water tended to be redirected from the rural areas to the urban areas, leading to 40-80 tons more of dust in the air in these areas, besides increasing tendencies in the region to fall into a state of drought.

With this issue in mind, the Children's AIRE study was established to work with the local community, to understand the state of respiratory health in Southern California with a focus on the impact of the air on the children themselves.

The approach focussed on two things:

- Collect air samples and train comm. to collect dust samples with the community through community air-monitoring kits
- Raise awareness in the community by developing partnerships with schools and community centres

After establishing a dialogue with the community the following health concerns among children came to light. Children in the area had reported an increase in the number of cases of:

- Asthma (One in four children had asthma)
- Cough
- Wheezing
- Allergies

Since this project was initiated recently, Dr. Johnston was not able to share any of the data received. However, she was able to outline a few of the steps that the study would incorporate going forward:

- Assess lung health to look at changes over time
- Use simple infographics to explain impact to the community

Key takeaways

- Importance of health concerns of the community, especially when it comes to the health of their children
- Importance of partnering with schools to facilitate change in the younger generations
- Reporting back to the community is helpful as it makes communities feel a part of the change that they are making around them.

Question and Answers:

Question: It is difficult to assess what exactly is the cause behind respiratory diseases. How do you differentiate and distinguish what is causing the health risk?

Response (Dr. Johnston) – We currently do not have the answer but want to look into it. By following the children over a period of time, we can find out what is aggravating it and then hope to reach somewhere near the cause.

Question: Wristbands are helpful… but when disasters happen, what/how do you monitor it?

Response (Dr. Rohlman): Community can tell us more about areas they're concerned about, like in Houston; they had industrial areas so that was a concern. And we also knew what kind of chemicals is present in those areas. What we are able to do is take their concerns and compare them to our list of chemical groupings and go back to the community to discuss it with them. When we do record data facts, we specifically mention which are the

main concerns of the community and when we have results, we go back to the community for the specific feedback

Audience: How do chemicals impact the health of the community?
Response (Dr. Rohlman): The community had certain health concerns that they were worried about and for many of the toxic waste sites were next to day care facilities. NIH has set up a Disaster Response Research and we use a survey tool called CASPER where we were able to ask questions regarding specific issues by sampling the chemicals people are exposed to and then 1 year later we did another such survey and tried to bring in comparative co-related possible causalities.

Audience: Do you have any suggestions that you would do to make participation of the community post disaster more inclusive?
Response (Dr. Ghosh): The lesson learnt is that you design your study to allow sufficient time to those participants whose voices are needed and according to their daily routine/work schedule so that they won't feel left out and constant rapport building and facilitation.

Audience: How is it that you ensure that the children are motivated? Do they have anxieties? Any other ethical concerns?

Response (Dr. Johnston): So far we've only done surveys with kids that they took back to their parents, had classroom discussions and received a bag of school supplies if they returned back the survey. So that worked well as a motivation. Moving forward I think we'll figure out more strategies through the pilot phase but my colleagues have been working with over 12,000 kids for years now and we hope to replicate those strategies because they worked very well for us and the children.

Group Discussion

Group 1: Co- Facilitators: Jill Johnston and Ritu Nanda

Rapporteurs: Ms Nilanjana Bhattacharjee and Ms Carolyn Poutasse

- Conduct research – ethical and institutional review of community engaged data collections.
- Arts based Methods
- PRA Tools
- Joint Analysis of Data with the community.

Dr. Jill Johnston started the discussion by asking how to determine research design in a collaborative way and defining if one wants to take qualitative/ quantitative approaches. What ate principles one should think about while developing such designs?

Dr. Tandon: "There are hierarchies in all cultures; we have a particular difficulty that the lingo of research is American or British English and depending on where you studied. The lingo framework of everyday life has nothing to do that. That's where you need people to mediate that conversation. If the community is organized enough then it can reach out through intermediaries. On the issue of affluence water and soil, there are many examples of local panchayat leaders/ community leaders asking somebody to ASK someone else. It's a Oregon- Texas kind of situation. There exists a physical and social difference.

So in the organized community, one of the main reasons for land alienation was not displacement but in cement factory areas, loss of productivity was the reason. And they knew productivity is going down but didn't know WHY. The trade unions said, let's find out and asked someone to do a research on it and they would thus reach out to professional technical experts who may support it. But there's also the problem that public institutions have not been open to the idea of receiving requests from a community group. We were involved in Bhopal disaster and two days later we brought land, soil samples, leaves, etc. samples but we could not get it tested in Delhi. The testing labs were all public and there weren't enough private/non-profit institutions that would test it. We couldn't get any

sample from post mortem as that was declared as official secrets. TATA institute was asked to conduct research on how much was people's health impacted to determine level of compensation. Despite my advice, they went there with police escort with guns. What data will you get then?! There is a pressure on public research institutions in India, who are funded by government, and they periodically conduct their own research on effluents/when they see a story—but when the results come in the pressure is to keep it a secret. Various vested interests come in. The real challenge is how do we build alliances through intermediaries? So we can invite these professionals to come do workshops with community people to demystify the concepts and would also gather data in the process –mutual learning. Then they can take up more systematic research. So the need for alliances is primal. "

Dr. Jagdish: "There is a high incidence of cancer in our area. And when we say we can do some research, they are scared, and they can't cooperate. Because we say we need names, how many people are suffering now/died in the past/medical papers, people get worried about the information being traced back to them and thus withdraw. "

Dr. Johnston: "Any examples of how you'd involve communities as a part of the design process and collecting data etc. and not just the after ends of a project?"

Dr. Suresh: "So for example, if we are explaining about lung cancer to the brother/sister of the affected individual, they are willing to help. But it is doubtful if the benefits or results of such information or deliberation go back to the society?"

Dr. Sen: "But isn't that the prerogative of the researcher? To involve people? If I am doing a lung cancer research, I'm doing it and getting data from them but isn't it on me to at least go back and give back to the community? It is the ethics of the individual researcher to address that. It's our responsibility to disrupt that system."

Dr. Tandon: "What you're talking about, it is a research culture and training – both. Lots of people may be interested in ethical ways, but in health research the ethics is based on patient model but it doesn't have the rule of taking the findings back. That's a high level of awareness. But before awareness, the researcher needs to ask the community of they

would like the results of the research or any other information back. If the researcher doesn't have the capacity to present data in a way that the community understands, the researcher runs away because he feels inadequate. So the part of the problem is research capacity and methodology. "

Mudita: "Most often, when we go to the field, most communities do not have the kind of awareness to declare their expectations regarding the research analysis. Their common expectation is not that you come back and give the analysed data, but that the researcher must have come with some government schemes that the community can access."

Ritu: "The term 'participation' itself – who decides the research? Who undertakes it? My dream is that communities collect their own data and they own it. "

Dr. Johnston w.r.t US – "We've developed low cost air monitoring sensors that we can loan to communities who can analyse what they're being exposed to. Another e.g.: training communities to understand how to collect soil samples and analyse that to get results immediately. Community presents the problem and we work together to figure out what we can do, and sometimes it's a proper project and sometimes it's just providing data.

Dr. Tandon: "There's a very strong educational role. Even in the beginning. People may come in with a problem but the researcher can explain to them bits of the problem that he/she already knows. This is not accounted for often or paid for. For those communities you've to spend time to demystify concepts. The educational function for researcher in PR is critical."

Dr. Jagdish: "We had a project where we needed time of a worker to be able to collect samples of things they are exposed to. The worker would end up earning less, so he was expecting compensation. And our researchers said no that's biased, and I tried to negotiate. These questions came often and I was of the opinion that we were expecting his cooperation and when we want his time, we must pay him for his time. That wouldn't make the study biased."

Kamlesh: "Suppose you engage a person for a day and give him one day's income + transport money, that's not bribe. That's a fair thing to do."

Dr. Tandon: "What is the system in US?"

Dr. Johnston: "For compensation? It's regulated by the university IRB. I'm not allowed to give people cash; I've to give them a gift card/ some kind of gift in kind."

Dr. Tandon: "In some of the indigenous communities like western Canada, you should read their protocols. They have very strong ones. And they specify very clearly about the compensation etc. because they are very well organized as communities and nobody can engage with them unless it's agreed by the organized community together."

Dr. Sen: "There are requirements needed for systemic change. Institutes can host a CBPR workshop, especially if conducted by the government; it will generate a lot of positive results."

Dr. Johnston: There are community engagement course in universities where you can't conduct a research but translate a research with the community, which has been very helpful. This helps building trust and the language within the community to take some things they observe to then translate them into research.

Dr. Tandon: "Main thing is building relations of trust, which is the basis of any and all steps of the research process. In any community there are layers of power relations, and it's important to go and interact to understand those layers which are not obvious from the surface."

Group 2: Co-Facilitators: Kim Harley and Pratibha Ganesan

Rapporteurs: Edith Parker and Pooja Pandey

Discussion Questions:

Imagine a potential community-research partnership to study environmental health in your community and/or your area of research.

- What could be some effective strategies for research and community partners to collaborate in all stages of the research process? For example, how could community partners and researchers work together to establish the
- Research design: How would you discuss possible research designs with community partners and researchers? How would you make decisions about whether to use quantitative and/or qualitative methods, cross-sectional or longitudinal study designs?
- Development of data collection protocol: How would community partners and researchers work together to develop data collection instruments and tools? What strengths would each group bring to this part of the process?
- Data collection process: How would community partners and researchers work together to collect data? What strengths would each group bring to this part of the process?
- Data analysis: How would community partners and researchers work together to analyze data? What strengths would each group bring to this part of the process?

Highlights of the Discussion

The **first** question garnered great amount of interest amongst all the group members. Sharing their own institutional experiences of ethics review committees, the members flagged the concern of inclusion of community members in the sample. Who should be a part of the sample and who shouldn't is also an important component of research ethics. Making different types of consent forms for different purposes was also proposed. Deliberations on what constitutes of '*informed consent*' was also done. When asked if the community is involved at the designing stage of the consent form, most of the members answered in negative. Consent was also said to be a clear communication of ideas and terminologies to the community member and was said to be a challenging process. Dr. Tiwari mentioned that institutionally they ensure to include a *layman or and outside member* in their ethics review committee at ICMR but that person is not necessarily a community member on whom the proposed research is being directed at.

The major thread of contestation that emerged was in the nature of PR process which is slow and self-evolving as opposed to ethics guidelines and consent form which is often pre-

signed and pre-determined. There is seldom any institutional provision for changing consent and ethics guidelines during the course of the research. As a response, Dr. Diana said that these provisions need to be pushed back to IRB and asking the institutions to incorporate these ongoing changes. They at least do it as a practice in their research lab.

Another major issue in ethics was that of confidentiality and anonymity, especially in settings where social and cultural networks are small. A very interesting example of a research was cited where the research objective was to find the major sources of combustion in the village and one of the major sources of combustion was lighting candles. Such a clear cut data in a small village setting made it very easy for the villagers to guess the identity of the person, who was a religious woman having the habit of lighting candles at all hours as a part of her religious chores. As an alternative, the members discussed the possibility of devising two types of reporting: one individual and the other general. Another example of the challenges of anonymity was given by Dr. Tiwari where research was being conducted on particular kinds of medical experiments. Since there were merely 3 hospitals which undertake such medical experiments, it was an easy guess for everyone to identify the names of the hospitals once the research work was out. Another example by Pratibha Ganeshan pointed towards the clash of interests and power while dealing with the ethics question. Drawing from her work on solid waste management in Kerala, she said that she wanted to share back her findings with the communities and the local authorities. The local authorities however were not interested in this proposition and did not permit her to share the findings.

Next was the question of whom to approach to get the consent? And the uncertainty of getting the consent from the community members is another challenge. Telling the Indian case, Prof. Jagdish narrated that more often than not the community members are willing to give you their oral consent but are very reluctant to a written/signed consent.

Moving towards the **second** question of community engaged data collection, it was said that local community based organizations can be of great assistance in that regard. Cases where CBOs helped in developing data collection methods, field testing and data analysing were shared by Dr. Kim as successful examples of CBPR. It was also pointed out that the community members, in a lot of cases, give the onus to the researchers to formulate data

collection methods as they don't have the time and interest in this part of the process. In that case, it was proposed that the researcher must first communicate the purpose of the research to the communities. If they approve and show interest, then the researchers with the help of CBOs and interested community members can formulate data collection methods. Some members also pointed to the entry level challenges in data collection, to which a possible approach of taking into confidence influential community members/govt. officials first can be useful.

Binoy Acharya cited his earlier work experiences to substantiate this point where he first organized discussion meetings with local authorities and explained them the research purpose after which the rest of the process became a fairly smooth endeavour. This also led to the possible challenges of power dynamics, especially between the communities and the state authorities. The only key in that case is the job of careful negotiations between the researcher and other stakeholders. There are also possible chances of conflict with law, industries, government etc. which needs to be taken into account beforehand. Lastly, the suggestion to have multiple processes of data collection mechanism was echoed in the group. Using Focused Group Discussions before developing the questionnaires was also suggested.

On the **third** discussion pointer, it was unanimously felt that certain methods like Photo-Voice, video documentation etc. cannot be imposed on the communities unless they are comfortable with it. The example of Swacchh Bharat Mission and its initiative of posting photos of people indulging in open defecation were discussed. In one of the incidents, this intrusive means of imposition led to a death of a person in Rajasthan who dissented against the practices of posting embarrassing pictures of women openly defecating in the fields. As a researcher, it becomes one's personal responsibility to not intrude into the personal lives and space of the communities. At the same time, it is also a desired practice to provide remuneration and jobs to the community members who are assisting in the research project.

On the **fourth** discussion pointer of data analysis, the members expressed the difficulty of involving the communities at the stage of data analysis. It was felt that people will take more interest only in issues which is of priority to them. There were also some

apprehensions about the community's ability of analysing the data in traditional ways. Use of art based methods like theatre; music etc. could be one of the ways out. A lot of times, the community members are interested in asking the questions but not necessarily be involved in the process of analysis. It thus becomes very important to re-imagine the very definition of data analysis. *Data Interpretation* was proposed as a more suitable alternative to data analysis. Lastly, it emerged that the communities is interested in knowing something but if their existing perceptions is skewed or poor, then the analysis of data and moreover their involvement in the process becomes a tricky task to undertake.

Group 3: Co- Facilitators: Dr. Nicole Novak and Mr. Jagdananada

Rapporteurs: Ms Shashi Shikha and Dr. Gwen Collman

Conducting research – ethical and institutional review of community engaged data collections; Arts based methods, PRA tools, Joint analysis of data with community

Designing Research

The group member shared an experience from the Nepal earthquake in 2015, which saw an influx of NGOs. So the government said that only doctors and organisations working on public health would be allowed and not the institutions that carried out assessments. It took 10 months to get an ethical review approval for mental health such as fear, anxiety and stress. International review board takes time. It gets difficult to get clearance and community should decide what they want.

There is a need to have involvement of community at different stages. Is the community part of the ethical review? This is a pertinent question as they do not know neither are they informed

In the US, the community reviews the material along with IRB. The tribal societies gave their own rules and regulations. There are town-hall meetings to approve the process of researcher's engagement.

When we go to the community, it is ideal to sit with the people. We can identify stakeholders who then interact with the community to develop acceptance of the research programme or design. So the community helps in providing data and informs the design.
It's not common to find community proactively engaging in the research.

We must have a review by the community. At best, the researcher can inform the community of what is going to be done. The community doesn't really know how to approve.
What could be some of the ways to intervene in the community?
Ethics is related to RCT which is related to public health which leads to challenges.
Having context expertise is important.
Key informants were engaged in IRB throughout. People feel more comfortable to share than hide. So ethics also has different perspective and it is difficult to get a conclusive understanding of ethics.
Department of public health of Nepal was in charge but they were giving permissions to the universities. Taking IRB permission is difficult.so, it's useful to have pre-approval from the community and the institutions.
IRBs are required to have context. Are there guidelines to review CBPR proposal? If not, this can be included.

IULD has ethical committee and the process is efficient. People, who apply, get approvals in 2-3 months. As it conducts operational research of existing health records, in the last 7-8 years it has slowly evolved the mixed method approach.
In clinical trials, there is a concept of community advisory groups to have better understanding of community and inform researchers what the community wants and articulate the science back into the community.
Develop and empower TB patients by discussing the challenges and taking the results at the national level.
In TB, there is a patient charter which has rights and responsibilities if these patients but how is this impacting these patients in various areas?
Diseases such as TB are also associated with social stigma. Participatory network analysis can help to understand social support of TB patients. Ethnographic studies were rejected

with the IRB, which is why the project team added a vulnerability index and photo voice recording. The group members also discussed on issues with taking photo of a person. One needs their consent and people are not ready to accept, as they think they are taking photos of their neighbours and practicing ethical practice is difficult.

Social Network Analysis: Why we are mapping social networks is difficult for the communities to understand. Rapport building is easier when one explains their position and women get enthusiastic to share their story.

Time is important and people were given the choice of methods. In 2011 ethnography was the main method but slowly it has evolved. Participatory research in SNA is different from SNA as the latter is highly quantitative.

Association with MHADA-

A study of rehabilitated buildings was conducted to see what the implications on health are. Some indicators that were included comprised of relapse and death rates.

It was found that first two floors never received any light. So a mixed method study was conducted. Data of district TB programme was taken as a case and control group. The case was the sandwiched buildings while the control was the building which had lights on all sides to elicit burdens and pressures of TB.

The investigations were camouflaged by activities such as women empowerment initiatives. Government resists these investigations because they have provided these buildings. Stigma around TB was addressed through street plays.

We assume that if we have knowledge then we won't practice the stigma but knowledge is often not practiced. Even doctors and professionals know that TB can relapse. In these cases, awareness also does not help.

There are other causes of TB such as use of kerosene, wood fuels that impact environment and causes TB.

To study architectural patterns and public health, inter-sectoral research needs to open up.

Community advisory board-does it change the research? For clinical trials it's important that social, emotional support is given out to patients and families. To raise network to support children and these must be integrated into the research design.

Developing data collection Protocols

The questionnaires need to be adapted to local cultural contexts and not copied as a standards format. The Framework of implementation is also a science. Thus, cognitive response testing. 4-5 community members are administered the questionnaire and it is seen how they respond and researchers understand. Accordingly the questions are adjusted.
There is a need to start from the problems of the community rather than questionnaires. To work with field supervisors and not get stuck to standardised tools.

It is important that the researchers should not go with a predetermined question, mixed method approach.

When we translate the question sometimes the essence is lost and does not fit the local cultural context. E.g. USAID food security question where it was asked how many meals a day?
This was an offensive question to many people. There should be a conversation before questioning begins. Research design should include these components as well.
Concepts of translation such as wheezing or depression-in Chinese it is just very sad. So one needs to be aware of the linguistic aspect as well.

Assessing well-being of girl child is an essential aspect. How do we contextualise the question.so mapping tools were used drawing was used as a method such that it opened up conversation on well-being to be integrated into larger tool.

Environment exposure through CBPR
Simplified methods to measure air pollution colour of water. Different environment indicators that are simplified must be identified, so as to motivate participation where science could be seen as an opportunity. This is a huge issue of the methodology and hence we need to bring community on board as researchers themselves.

Data Collection and Analysis

It is essential to understand mental model of the community collection of data and analysis. Underlined socio economic behaviour is caused in nature around a reference mode. Community members volunteer the causal factors are explained. So community members engage in analysis. Meaning of data, visualising data, science design and methodology to be made simple and how it impacts their life.

Community takes ownership of the data and takes it to local regulatory board. After super cyclone in Orissa, a number of schemes was launched by the government. So monitoring to see how long it takes a particular package to reach households. There were lots of dialogues happening with the government. People were excited to report back. Government was keen to listen.

Plenary Session II: India and US Case Studies on Air Pollution (Ambient and Household)

01.30 pm – 03.00 pm **Speakers:**

Dr. Anand Krishnan, Professor, All India Institute of Medical Sciences, New Delhi, India

Dr. Doug Brugge, Professor, Tufts University School of Medicine, Boston, USA

Dr. Praveen Kumar, Assistant Professor, Boston College School of Social Work, Massachusetts, USA

Moderator:

Mr. Dunu Roy, Director, Hazard Centre, New Delhi, India

This was an all-men panel and the conversation was initiated by the moderator. Every speaker was given 20 minutes each to make the presentation which was followed by a joint Q&A session with the participants.

Dr. Tiwari set the context by stating that it is established that Air Pollution is one of prominent causes of morbidity and mortality in not just India but all over the world. It doesn't just result in respiratory toxicology by several other kinds of toxicology too. He went on to saying that environmental health has often been symbolized with Green initiatives. While these are important factors in absorbing emissions, but we also have to curb emissions. Community Based Participatory Research (CBPR) can be a very effective means in the case of Air Pollution.

The moderator then opened the floor to the panellists.

1. **Dr. Anand Krishnan, Professor, AIIMS, New Delhi, India**

   The presentation was titled as '*Community Based Participatory Approach for outdoor Air Pollution in India-Lessons and Way Forward'.* Dr. Krishnan started with his challenge of locating any comprehensive CBPR work in the Indian context on outdoor air pollution. Admitting to the fact that CBPR is still not an integral part of

the public health studies in India, he highlighted the lack of Case Studies on the related topic.

He further said that Air Pollution is evidently visible in India. Even though visible, we don't know how bad the condition is. This becomes further complicated with the government rejecting claims of pressing issues of Air Pollution in India. In addition, it is not very easy to put numbers & figures to Air pollution, it is methodologically very challenging. There is an increased media interest in the issue but the coverage of the issue is more problem oriented than solutions. It is everyone's problem but there are bifurcations of onus and responsibilities into different categories like state vs. center; rural vs. urban; development vs. environment and so on. There is a need to question what the appropriate model of development is. He stated that there have been several instances where the communities have participated in top-down interventions such as *Odd-Even scheme*, *Diwali cracker ban* etc. which displays a sense of concern by the community but there is a lacking know-how of what to do about the situation. He cited two examples: SIPCOT Area Community Environment Monitor and The SAFAR (System of Air Quality and Weather Forecasting and Research) android Application which is a project of Ministry of Earth Sciences, Govt. of India. About the SIPCOT community environment monitor, he commented that the initiative took a more confrontational approach and also opted for legal approach which witnessed weak enforcement issues. He then stressed on the need of more involvement of academicians including researchers who can facilitate information sharing on the issues of Environmental health. Commenting on the SAFAR App, he applauded the initiative but apprehended any ensuing community action as its result.

As closing remarks, Dr. Krishnan commented that the conceptual framework of CBPR in Air Pollution issue is not well probed. The concern of Air Pollution is relatively recent and CBPR should start finding space in such discussions. CBPR isn't yet entrenched in the Indian public health study and practice more so because the issue of pollution cannot be tackled with community participation. He proposed that CBPR models be adopted by community as well as academics. A more collaborative and

consensual approach needs to be adopted as opposed to a conflicting and confrontational approach. Adequate attention also needs to be given to technical solution for they will aid the participation of the people.

2. **Dr. Doug Brugge, Professor, Tufts University School of Medicine, Boston, USA**

Drawing from the earlier presentation, Dr. Doug said that in the USA, air pollution is lower but public participation much higher. Starting with the technical explanation of what Air Pollution is, Dr. Doug went on to talk about his recent projects under CAFEH (Community Assessment of Freeway Exposure and Health Study) Project of Tuft University. Having the commitment of community engagement, capacity building, rigorous science and policy-practice, several projects under CAFEH were insisted by the community. It was the community engagement which further helped in translating the efforts to policy much faster. All these projects involve participation of multiple stakeholders including faculty, students, community members; Community based organizations (CBOs), city & regional level agency staff any several others. This active community engagement is complimented with a presence of an active Advisory board. As a practice, these projects recruit, train and hire community based field teams. Some of their research studies have been done in as many as six languages. One of the Project's initiatives, **New Mobile Lab** doubles up as a recreational/science lab and undertakes huge data collection exercise amongst the communities. There are also practices of door to door recruitment of people, over 700 community members have been recruited by far.

Talking about Ultrafine particles, Dr. Doug mentioned about the growing evidence on association of ultrafine particle exposure and health issues including blood pressure and C-reactive protein (CRP). This is particularly higher in communities residing near highways. CAFEH has undertaken multiple projects to research upon and mitigate the risks for these communities The Project have also produced research papers with co-authorship of the community members. For a much wider and easier dissemination, a simple fact sheet summary of the research works has been given back to the communities for knowledge and action. One of the factors which really aid their work is their receptivity to media and their stress on making media

presentations simple and universal. He attributes the success of this CBPR model to support from several partners and funders.

Lastly, Dr. Doug then mentioned briefly about several projects like *Clean Air Project, Boston Puerto Rican Health Study, Near-Highway Pollution-From research to action, New Mobile Lab* and several others. The details of all these projects are available here: https://sites.tufts.edu/cafeh/

3. **Dr. Praveen Kumar, Assistant Professor, Boston College School of Social work, Massachusetts, USA**

The presentation was titled as '*Uptake of Clean Cooking Fuels in Rural India: Behavioral Underpinnings'*

Taking his recent project as case study, Dr. Kumar started with the descriptive details of his ongoing study which was directed at understanding the practices of clean cooking in India. Traditional methods of cooking using biomass fuel are a major source of household air pollution with major impacts on the health of women and children in rural areas. The present study aimed at understanding the scientific frameworks of cooking fuel and its relation to air pollution and also to evaluate the relative influence of gender networks on LPG adoption in BPL households in selected districts. The study used the framework on *Participatory social network analysis*. Being participatory in nature, the researcher collaborated with the community members in collecting as well as analyzing the data and henceforth envisioning possible actions. One of the major observations was that *Homophily* was a major but invisible barrier to LPG adoption. Dr. Kumar gave several anecdotal examples from the communities to elucidate this. The study also monitored their stove use patterns through scientific monitoring systems installed in the kitchens of the community members. Several Participatory Rural Appraisal (PRA) exercises were undertaking in the course of the study to understand the behaviors of the community. As a result, several factors emerged as an answer to these patterns of cooking gas usage. On analysis of the data, one of the women from the community proposed 3As i.e. Affordability, Accessibility and Awareness as the answer to the behavioral

underpinnings of clean cooking fuel usage. Dr. Kumar and the team incorporated this concept in their research work with due acknowledgement to the community member who proposed it.

Lastly, summing up Dr. Kumar's overall takeaways from the research project were stressing on the need of local awareness; he also stressed on the need of unpacking social, economic, cultural network sub-systems while doing CBPR and lastly the importance of using scientific methods while undertaking research with the community. He also commented on the importance of easy language of dissemination, and use of Participatory tools like PRA to strengthen the analysis of research.

Closing Comments and Q&A

The closing comments by the panellists and moderators re-emphasized the lack of CBPR case studies around Air Pollution in India. It was said that the progress around the efforts on mitigating Air Pollution is rather slow paced in India. Media can be deployed as an important stakeholder here. The reasons why these efforts are not taking off as anticipated could also be because of acceptability and not just accessibility.

Questions and Answers

Question: How can we introduce CBPR methodologies to the training and practice of public health professionals in India?

Response (Dr. Krishnan): CBPR as a part of medical school curriculum is a far –fetched expectation. There is some scope in the discipline of Community Medicine but still the process is difficult majorly because Community medicine in India is mostly service oriented and not always research oriented and hardly community oriented.

Dr. Doug: CBPR in health existed marginally in America before. It took time to evolve and flourish. Hopefully, it will evolve in India too.

Edith: It takes champions to undertake CBPR research. There needs to be equal push by funding agencies too.

Dr. Krishnan: The National Clean Air Program is a good example. More than 100 civil societies have worked together for this. Everybody came under one umbrella and then focused on their respective national, regional and local goals. Many of the CSOs are working in different areas but somehow the focus has moved to Delhi. It's a part of a well-thought design. But the mode of work here is more demonstrative rather than research oriented.

Group Discussion

- Public Engagement
- Knowledge mobilization and dissemination of research findings to different stakeholders

Group I: Co-facilitators: Diana Rohlman & Ritu Sogani

Rapporteurs: Pradeepta Nayak & Carolyn Poutasse

Meaning of Public Engagement (in research)**:**

The discussion started with a difficulty in defining what public engagement is. All the participants (except Dr. Rajesh Tandon who joined the group later) admitted that they were not sure as to what public engagement was.

One group member suggested that they check the meaning in Google. However, the co-facilitators tried to explore the meaning by asking each of the participants. As all the members confirmed that they did not know the meaning, they decided see the definition of public engagement in Google. Still there was confusion, till Dr. Tandon joined the group, and explained the concept with clarity.

Public engagement is multi-faceted. There are lots of terms that people use while describing public engagement. These include citizen science, participatory arts, patient-involvement,

collaborative research, lifelong learning, partners engagement, outreach and community engagement

While Engagement is a two-way process, involving interaction and listening, with the goal of generating mutual benefit, 'public engagement' is used to describe the many ways in which the activity and benefits of higher education and research can be shared with the public for mutual benefit.

The National Coordinating Centre for Public Engagement (NCCPE) has chosen to define public engagement broadly, to encompass the many and varied ways university staff and students engage with others outside the institution. There is a whole family of different types of engagement, for instance 'civic' or 'community' engagement, which are part of the same family.

Public engagement (PE), particularly in the UK, has been described "the involvement of specialists listening to, developing their understanding of, and interacting with, non-specialists".

PE has different meanings and context.
While the meaning of public engagement is vague, community engagement is more specific. Community engagement is about engaging beneficiary communities who are the primary stakeholders. Community engagement as a phrase is better than public engagement in this context.

How to do community engagement [CE]:

Strategy for communicating the research findings by scientific community in beneficiary communities
There are different approaches and methods of CE for different locations, projects, and different kinds of audience.
Before going public with the findings, share it with participants, and validate the findings.

Facts + Face approach: Decide what message you have, and who should disseminate, who can do it effectively. Data is necessary but scientists should also have requisite training on how to share with the media. Language of articulation is important. The language of the scientific community may be difficult to understand, and therefore, it should be simplified.
Sharing materials should be interesting and easy to understand. Using pictures, infographics are important; hire graphic designers to do it who can represent the entire research study through two pictures.

Do not use jargons, technical terms, in written or verbal communication. Do the local language translation wherever necessary. Communication through small group participants and village level meetings is a significant medium. Sitting down with the community, listening to them, understanding them, and speaking in people's language are the key to communication.

Communities can better be engaged through simple examples, and stories open up a space where they community people can come and share

Organise exhibitions and knowledge fairs attended by multi-stakeholders: In these fairs, communities get exposed to different kinds of knowledge. Moreover, different communities can share their own knowledge, tradition and practices. While NGOs are facilitators, communities are actors in these fairs. Different communities not only connect with each other, they also get connected to the scientific communities, media, academia, government and research organisations. It is a good place to learn from each other, and disseminate scientific information.

Community members and researcher should work with each other. Community-research partnership is important for dissemination of information.
When community members make their presentations, it should actually be joint presentations. Researchers, experts and other stakeholders should also present. For example, during a presentation on a health project, doctors should be present

An important process of information dissemination is to take community actors to other stakeholders. It depends on their literacy levels.

Community actors are important. They should be present when specialists/scientists make a presentation. Community perspective /voice add value to this equation. The journals of scientific community should be co-authored. However, academic institutions have research grants which usually do not have a provision for the travel and other logistics for the community participants to attend and contribute to conferences.

Funding support for community partners should be a component in the grant proposal.

Strategies can be evolved for the groups, the ones which participate and the ones which do not. Use of mainstream media (e.g. newspapers, TV, Radio), and social media, local media, folk media, and vernacular outlets is popular and can be used.

Examples of community engagement [CE]:

Before building a check dam in a particular location, the authorities and NGO partners engaged with the community, listened to their views, on issues and solutions, which helped in implementing a better plan.

A participant from ICMR said, “In India, we go back to the community, and share the findings so that they understand it. For policy advocacy; we send it to ICMR which then sends it to the Ministry of Health.”

A change in the risky behavior of sex workers community was brought through a community based approach. For this the researchers collected data, prepared report, went back to the community for validation of data, disseminated the findings through lectures, meetings, and small group discussions. They used visits and verbal methods to inform the target group on healthy and unhealthy practices. a longitudinal process of dissemination helped in behavior change.

A community in Gujarat was successfully engaged on cropping patterns by sharing the success stories and practices from other states.
When a not-so-easy idea was communicated to a community in Rajasthan in terms which the people understood easily; they took it to their leaders demanding for their use and implementation.

In USA, community engagement has influenced the people to do things in a better way. The collaborator in community engagement has included CBOs, students, city and regional agency staff. Many advisory boards have consisted of community members, and community based field team.

How to get the results out to the audience?

The approach for policy makers should be different. It is important to contact and communicate differently to policy makers at different levels. Policymaking could be influenced through convening, workshops, printouts, and presentations.

For policy makers, they should be sending papers, meeting in conferences, meeting personally, and verbally discussing the findings. However, the approach should vary according the context, though each approach has its own strength. It is also necessary to go to the policy makers directly if the situation so demands.

One should meet the policymakers face to face. They have no time to read your reports/papers/letters. During a meeting with the policy members, one should start the meeting by having a community member tell her/his story. Then open your laptop, and make the presentation. Do leave behind the printout.

Approach for political policymakers should be different from non-political policy makers//bureaucrats. A political policymaker would like to cut ribbons, while a bureaucrat could be informed and influenced differently.

There was an opinion that before going to state level officials, one should go to block officials, then district officials/district collector.

For effecting a change in the cropping patterns in a village in Rajasthan, an agency went to the district collector who gave the permission to go ahead. With the collector's permission, the community agreed to the proposal. The BDO also offered support. The intervention started in one village, then the neighboring village, more villages, in the entire block and then the district.

Group 2: Facilitators: Edith Parker and Chandrashekhar Joglekar

Rapporteurs: Pooja Pandey and Bono Sen

Discussion Questions

Imagine a potential community-research partnership to study environmental health in your community and/or your area of research.

- What could be some effective strategies for research and community partners to collaborate in disseminating research findings?
- How could researchers and community partners work together to identify potential audiences for dissemination? What might be some good audiences beyond research publications?
- How could community members contribute to all dissemination activities, including publications and conference presentations?
- How could a community-researcher partnership contribute to dissemination to policymakers and other stakeholders to address the health problems of the community and efforts around policy change?

Discussion Pointers:

The discussion within the group started by understanding what Public Engagement could mean. It was felt that engagement can happen at so many levels. To elucidate, Binoy Acharya gave the example of the RTI Act in India and the public advocacy behind it. He explained that the movement caught public imagination and witnessed tremendous engagement. On similar lines, there was the example of the Clean Air campaign where the youth in Delhi took charge of the problem and did tremendous mobilization around the issue of Air Pollution. The insistence was on the fact that excluded people should be included in the dissemination activities. A possible and useful method of doing it is through public hearing *(jan-sunvayi*) which involves asking stakeholders about their view point and then mobilizing them as per their need. As a response, it was told that in USA it is possible to make the communities testify but not necessarily mobilize.

It was further discussed that stakeholders vary according to the nature of research. Context of research is thus of great importance. It is also equally important to decentralize powers when we are dealing with the dissemination process. Examples were given wherein the community representatives were brought to national/international forums by the researchers and given inclusive, platforms to voice their opinions. This adds a face to the data and makes it more humane. It was then said that in addition to national avenues, it is equally important to tap local avenues of knowledge dissemination including media, social media and other similar platforms.

An interesting comment was made by Dr. Kim stating that scientists don't like to talk to the reporters and vice versa. Training needs to be given to the scientists on how to talk to media personnel. This then led to the discussion around the Indian media which has fallen into the tendency of sensationalizing the facts and projecting a distorted work and message. A need for *Dissemination Guidelines* was strongly felt. Thereon, it was proposed to evolve a standard practice of sharing the results first with the communities and primary stakeholders before the world outside. In this case, community partners/organizations play a crucial role as they are connected to the communities and equally to other stakeholders in the process.

It was discussed that information can be curated differently for different categories of audience/stakeholders. In addition, rather than simply decentralizing the disseminating process to community partners and other field based actors, the researchers must

themselves also be a part of disseminating information to people. Attempts should be made to include non-participating communities too. Lastly, in case where the research results are against the interests of communities and stat actors, particular caution needs to be taken by the researchers in passing that information further. Constituting an Advisory committee, if possible can be a plausible solution.

Group 3: Co- Facilitators: Dr. Gwen W. Collman and Dr Anand

Rapporteurs: Dr. Nicole and Ms Aarti Upadhyay

The discussion started with Dr. Nanda Kishore Kannuri (Associate Professor , Indian Institute of Public Health , Hyderabad, India) – "How does one share and disseminate information with the community members?"

Dr. Doug Brugge (Tufts University School of Medicine, Boston, USA): "Engaging with a communication expert is one way. What comes out in the press is not what we want to communicate so we oversee what we communicate."

Dr. Anand Krishnan – "Challenge is that if you prepare a good press release than they copy paste and if there are some shortcomings then they use their mind and it messes up"

Dr. Yogesh (Search, Gadchiroli) – "We go a step further and make the news article and give the press. "

Dr. Gwen W. Collman: "At times the study groups are not too sure what to share, in CBPR you are obligated to share and disseminate information."

Dr. Nanda Kishore Kannuri: Dissemination of findings is essential.

Dr. Gwen W. Collman – "It depends on the kind of CBPR exercise you are doing like if you are on a trial then there is a way to present the data to the audiences in the community. What is your experience with media on reporting the air pollution in Delhi?

Dr. Anand – "There has been a positive experience so far they are advocating and raising voice and pulling the government."

Dr. Collman – "Is it evidence based?"

Dr. Anand: "The evidence based research is not there."

Dr Yogesh – "The common person's perception is that the problem of air pollution is a larger problem and is not them to do so."

Dr. Collman: "That is because the reporting in media is more from political point of view."

Dr. Yogesh: "The culture of engaging with science and the role of science as problem solver is contested. The need for science to solve problems is not there."

Dr. Collman: "Are there more studies and papers based on the scientific perception? Are the government policy makers helping with government funding for these researchers?"

Dr Anand: "In past years there is an increase in research on air pollution. There have been few areas where there is dedicated funding for the air pollution."

Dr. Collman – "Sustained community funding are the areas which helps to problem solving and engaging communities."

Dr Yogesh: "Community do not think the problems can be solved or addressed by the scientist in the country; the perception is that it will be politicians or government. The community of scientists has limited power. "

Dr Anand: "In India its rare thing to have the access to the politicians"

Dr. Parveen: "Articulate in the way they understand, not advised to bypass the power corridors. One does not have to reach to the CM for everything"

Dr. Yogesh: "There is a difference of issues – It's important to strategize at what level you work, strategy for communication should be clear – the finds – evidence helps. It's not the data but stories move action in India."

Dr. Yogesh – "Issues of distrust is paramount – e.g. Tobacco users will not disclose unless there is trust and relationship."

Dr Karuna – "We don't face the difficulty because the community goes through the entire process we brief the community for the entire period. E.g. TB - diabetic bidirectional study -

there was a clear connection between TB and diabetes and then there was an advocacy with policy makers which brought the order to screen all TB patients with diabetes. There is a policy on board but the implementation is a problem.

Dr Anand – "Are there are platforms in India or do we need to create that people can leverage to engage with all stakeholders. It's difficult. Every researcher has to make their own way to it?"

Dr. Yogesh: "There are no platforms."

Dr Anand: "You need communication expert. This is so costly we generally don't budget it."

Dr Karuna: "We make it part of the process and budgets."

Dr Anand: if it is an international partner it's easy, but if it is national it's a bit difficult."

Dr. Gwen W. Collman: "The group has people with expertise and internal partners can be communicated through. Community partners can help it."

Dr Berg: "There is a person, who is part of my team and it's not difficult."

Dr. Collman: "If we value the partnership, co-learning process and learning – the community is invited for the talk both sets the voices which are credibility required."

Ms. Aarti – "There are instances where the academics have given co-authorship to community members. "

Ms. Shashi: "Is co-authorship for publishing possible and if so how?"

Dr. Gwen W. Collman: "Research can't be done without standardization – there were people from the community to publish and few academicians worked with the community members and came up with co-authored papers, the pace has to be created and it's possible."

Dr. Karuna – "Advocacy at the political level has to be devised – e.g. tuberculosis advocacy with MP MLAs through a cricket match."

Day 3: February 28, 2019

Dr Tandon shared a few words on the National Science Day which is celebrated in the honour of Dr C.V. Raman. There are two important components of Science Education – Citizens and Science and Citizen's Science.

We had a number of popular science movements in the country. Popular science movements are a part of our history and it's interesting that today is science day and we are going to discuss on taking forward our collaborations and discuss ways to address.

Dr Bandyopadhyay briefed the group on the schedule for the day and logistical announcements. Announcement is about – not carrying laptop, phones are allowed but no storage devices.

The session started with Ms Caroline's presentation –

Disaster: Hurricane Harvey, Texas

Silicone Wristband – it's made of silicone porous material; it's worn as a bracelet. They are not able to detect bacterial, virus but 1530 chemicals can be detected.

There are a number of chemicals in the wrist band which can make things complicated so the procurement has to be cautious. When we use the band we don't use airlock band – we use sealed bangs label them, strip off all background material. The bands are disinfected completely before distribution. Silicone wristbands demonstrate Individual and temporal variability: Even though the two wrist band data is not the same there are similar trends in terms of exposure is identified.

The wrist band can be applied to a lot of different topics and occupations. The group members requested for sharing the papers published for people to refer further.

Workshop Exercise: Mapping out Next Steps for A CBPR Environmental Research Proposal

09.00 am – 10.30 am: Guided exercise: First steps of developing a CBPR research project.

Participants will be divided into three exposure groups (Air Pollution, Environmental Disasters, and Pesticide Exposure) and will develop ideas for a collaborative research project using principles of CBPR discussed on Day 1 and Day 2.

- What are potential CBPR environmental health research topics that you/your agency could conduct?
- How would you identify your community partners?
- How would you listen to your community partners?
- What would you and your organization need, within India or externally, to make this research possible?
- How could this research be useful to promote healthy environments?

Group 1: Air Pollution

Facilitators: Dr. Anand Krishnan and Dr. Doug Brugge

Rapporteurs: Ms. Aarti Upadhyay

The broader purpose of this discussion is to have conversation to take the collaboration.

Dr. Anand – "Are we looking at Indo US partnerships or domestic partnerships among us?"

Dr Tandon "Yes it is both. Currently we are looking at the partnerships at domestic level and with the US institutions. "

Dr Edith – "US-India collaboration on research"

Dr. Anand- "There is ICMR sponsored US – India – environment collaborations where the general model is India takes care of the Indian collaborators responsibility and US for their collaborators."

Dr Edith – "Any projects to promote CBPR practices? NIHS will be very much interested"

Dr. Anand – "Do we see this as a possibility to take funding for CBPR?"

Dr Tandon- "The reason we were interested was that that it was an opportunity to promote CBPR in the health and environment and mainstreams CBPR methodology in at least one or two areas of environmental health. It does not aim to restrict the partners to this table."

Dr. Sarkar: "If the group is interested, ways can be devised to build in the component of CBPR."

Dr. Berg – "We are working with colleagues in Chennai , one of the ways to address is that instead of building a new project we can build on the existing projects and partnerships."

Dr. Praveen – "There is a demand in the ambient and household air pollution – we have partnerships in western and southern geographies. We can impress upon them and build CBPR component and strengthen it."

Dr Anand: "To leverage existing projects and funding and add CBPR component, we should go for scale, especially in Indian context. Take a look at institutions in this room and outside the room, and build a good proposal. Look for different partners who are able to contribute to the process."

Dr Tandon – "I like the idea you are proposing – if you really want to start CBPR, we need to start from the beginning. If the design and the methodology is set, than it will bring tension. There is need to put a lot of effort needed to build partnerships to bring change, the process is a bit different than just having the need to create new knowledge. Instead, we are trying to bring about change and transformation."

Dr Anand – "We have largely three kinds of air pollution – rural, urban and composite. What would we like to see?"

Dr. Anand – "The US partners can bring the participator methods of monitoring and other methodologies while addressing the Air Pollution."

Dr Berg: "Industry – there are many pollutants but I propose to focus on 2.5"

Dr Anand – "Let's not decide and work with the community to narrow down on the focus."

Dr Praveen – "The urban areas will give the opportunity to study both ambient and household air pollution together --- Do we have the bandwidth to look at new innovations as part of the CBPR work in these projects?"

Dr Tandon – "In order to demonstrate the CBPR methodology in India, we need to find ways to export the methodology to other parts of the country to expose them so that they can also learn. Doing is where innovations happen.

There are many methods and facets to CBPR – there is also a digital and technological means to it, as we heard over the period of two days."

Dr Berg – "I really don't get what you mean by working through communities – where most of them don't have pollution or even health as priority."

Dr Tandon – "Let me share that like Dr Ghosh and his team –in Muzaffarpur, where we also work, we work with all stakeholders to bring them around the table and involve them to build partnerships to begin with. It will take a set of activities to build the necessary environment and then initiate the actual research."

Dr Bern – "I am not sure about how many of us in the room have the capacity to provide them elementary schooling on the environment."

Dr Tandon – "There is no need to give them – the members from the community are more than intelligent enough and they can be engaged into the conversation. See if there are groups who want to work on livelihoods and take them along so that they don't create livelihoods which are detrimental to the cause."

Dr Berg – "Most of the people are not aware about the impact of air pollution and health --- there is a need for education so that the community is more aware".

Dr Tandon – "Educational work goes hand in hand with the research work it happens simultaneously and it does not happen later on. The preventive health education for example is not a priority with forget about middle class but also the so call upper class there is a need for education."

Dr Berg – "So there are two ways to go about it – first, to look at epidemiology and second to look at peoples knowledge, behaviour … I am not proposing one or the other, but to seek suggestions."

Dr Anand – "Both are needed."

Ms. Ritu – "We use a patient-centred approach for diabetes. What we have learnt from the experience is that education is important but is not enough time is being spent in building ownership in the community.

Dr. Tandon – "One of the challenges to work on a CBPR proposal is that there are initial resources required to build the proposal there – we will need proposal development grants to hold consultations for the development phase where the stakeholder discussions can be geared."

Dr. Anand – "There is a need for a platform – it is more important to develop platforms at both community and academic level to hold a conversation for working on environmental health. Once the platform is reasonably mature, we can attempt embedding new issues to it."

Dr. Tandon – "There is a need to ask questions, to document it. In the domain of environmental health, the use of this methodology has been less, whereas other sectors the methodology is greatly established.

Dr. Anand – What do you think will be measures of the success and demonstrate success? For e.g. decreasing 2.5 particles

Dr Berg – Too Ambitious

Dr. Anand that's what I am mentioning than how do we go about.

Dr Parveen – "In our study in Rajasthan, we used CBPR methods to encourage and involve community members and women to help them move completely from smoke based chullahs to smokeless stoves. Work with the local self- governance has been also very helpful to take the agenda forward."

Dr Tandon – "CBPR has three outcomes – awareness – community changes, knowledge generation

Regarding 2.5 particles, we need to work at a large level of stakeholders. To demonstrate the results we need to work on different geographies, so we can have a modest approach and work on to bring change in the communities to demonstrate the use of methodologies. In the process we can reach out to different stakeholders, who can be included in the process and co-learning can happen."

Dr Karuna – "Air pollution is important but if we can include occupational health also into it. There are very little policy structure in place and workers have no voice in the companies, is there an opportunity where CBPR methodology can be used to empower the workers to reduce exposure and impact their health positively?

Dr Edith – "There are many tangible outcomes research that one can refer to."

Dr Tandon – "In occupational health, research has been happening since 1980s, but in the field of air pollution it has not."

Dr. Jill Johnston – "Personal and political strategies can be evolved from CBPR methods where community works collects and owns data."

Dr. Berg: "Maybe, the partnership goal is not just to reduce the particles or air pollution but to also establish the role of CBPR in the research arena of environmental health at all levels of governance. The other point is that there is a role of funding mechanism but there are smaller stepping stones – grants to start work for larger investments. May be the group can deliberate and use this platform as a stepping stone and build something larger?"

Dr Yogesh – "We start with a problem and work on it, there are number of deaths due to chronic diseases and that's how I am here –to understand how we can work on environmental health. We are looking at how we can make a difference, even a small one is useful to start with."

Dr Sarkar – "We need to also find solutions, doing only CBPR will not solve the problems; we will need resources and solutions to implement them. E.g. silicosis – if detected at early

stages can be reversed but later it can't be. So CBPR is a part of it but there is need to have solutions for the community."

Dr Yogesh – "We can come up with the success stories where community action made changes – this initiative can build on it."

Dr Tandon – Bring in institutions like ICMR etc. on board and build up on CBPR. It does not have to be either or NIHS can have a project of its own and build CBPR into it. The other idea is to work on two three places and demonstrate the CBPR methodology. For research institute we need to define new knowledge is important.

Dr Tandon – "Most of the major funds for research is addressing reproductive health, not air pollution."

Group 2: Environmental Disasters

Co- Facilitators: Dr. Upasana Gosh and Dr. Diana Rohlman

Rapporteurs: Ms Nillanjana Bhattacharjee and Ms Carolyn Poutasse

Discussion questions:

- *What are potential CBPR environmental health research topics that you/your agency could conduct?*
- *How would you identify your community partners?*
- *How would you listen to your community partners?*
- *What would you and your organization need, within India or externally, to make this research possible?*
- *How could this research be useful to promote healthy environments?*

Many settlements are located in the vicinity of landfill sites in a city. In instances when there is a case of fire in these sites, the toxic smoke pollutes the settlements nearby as well as the

vicinity of the city. In case of floods the leachate from the landfill sites pollutes the drinking water. Hence, what could be some of the ways of working with people living near the landfill site on the issue of water contamination and air pollution?

In India, at present, post-disaster damage assessment takes into consideration impact on assets, health, livelihoods, local economy etc. however, no assessment is carried on the impact of disaster on the environment. In the post flood times, although interventions are carried out on issues of WASH, assuming it to be a problem, no attempts are made to understand the nature of the problem from the perspective of the community.

There is a need to understand the history of a place and the experience of people over time with respect to a problem. For instance in Chennai when the floods happened, it was very unusual and when people tried to find out the reason, it was ascertained that the city's solid waste was being dumped on a wetland in the city. The wetland is historically connected to multiple areas but over a period of time, it got blocked. Hence, it is important to know what the community thinks about the issue from their past experiences.

During floods, heavy rains or cyclones, the upper layer of soil is eroded. What could be some of the ways in which farmers can be capacitated to cope with land erosion through self-assessment of their farmlands? Post disaster, the assessments can't be delayed and the responses have to be quick. For this, the community needs to be involved during implementation of the project. Accountability of the government needs to be reinforced to understand whether government aid is reaching the community.

<u>Engaging community in a research project</u>

- The community needs to be involved in assessing water contamination or toxicity after houses are burnt. It is possible for the leadership from the community to take lead in water testing through the facilitation of researchers or NGOs. Having an intermediary to research with the community is also an option.
- Baseline mapping post disaster need to involve the community to identify waste sites etc. It is recommended that the community and the researcher together set up the agenda. Scientific literature can inform this agenda.

- Temporary shelters distributed during post disaster should be designed with community inputs.
- Making communities resilient in pre disaster period, so the processes such as water testing are in place. To facilitate a multi stakeholder dialogue, commitment is mobilised from each and plans will emerge from there.

How does one bring expertise or connect with scientists and experts in doing CBPR?

It's important for the government officials to build rapport with the community. People in the centre and the state do not have any idea of CBPR. So, in India we need to work together to do a pilot on CBPR so that in future we can get connected to experts and national level institutes to do a good pilot.

This could include doing baseline studies, impact assessments by involving communities etc. It is important to identify community members with interest and bring in technical experts.

<u>Promote healthy environment</u>

What is required for health facility to be climate resilient needs to be communicated? Community needs to start demanding health facilities. There are gaps in provision of health providers.

In Indian health system, parameters are unrealistic. There is a need for the community and the researcher to sit together, have a dialogue to know of the behaviour change to confront disasters in future.

Community have done lots of emergency planning such as evacuation. Public education, school awareness and testing different communication strategy

Caregivers and people create huge debris in the post disaster phase. Therefore ways and means to dispose this debris need to be found.

Research Project: During floods, pesticides and fertilisers need to be stored in a particular manner. For instance in Kashmir, a number of shops had fertilisers for apple production. There are no protocols on how these chemicals can be stored during flood situation.

- Mapping of places of chemical outflow must be undertaken.
- Protocols to be followed by the shops during floods.
- Spreading awareness of community and awareness of government on chemical effluence.
- Map areas of high contamination.
- Understanding disaster risks.

While government is committed to do this, community should also understand this.

Elements of the ways in which to go forward to undertake new CBPR projects in small locations and we need to learn about it. To create a platform to pilot and create a model.

To improve and implement elements of CBPR in existing protocols, projects, institutions and national level institutes such as ICMR and ICAR.

Specific capacity building programmes such as master class jointly on use of CBPR in EH issues. It may be worth considering that we need to create a mechanism where small funds are available for partnership funds.

Group 3: Pesticides Exposure

Co- Facilitators: Dr. Nand Kishore Kannuri and Dr. Kim Harley

Rapporteurs: Mr. Shubhayan Sengupta and Ms. Bonolata Sen

The group spoke in great detail about the Indian farmer crisis and the various linkages to use of pesticides. Since there were some individuals in the group who did not have much information on this link, the group began the discussion by setting the current context among farmers in India:

The group came to the conclusion that:

- Pesticide use had become extremely pervasive, almost “mandatory” for growing crops. The amount of pesticides used could be noticed in their immediate surroundings as household foodstuffs such as flour would be stored in empty pesticide cans.
- Groundwater had become very contaminated due to heavy pesticide use
- A lot of these effects are a consequence of the Green Revolution in India
- Farmers in India seem to be in a straitjacket, as they know the problem but don’t have a solution.
- Lack of state and policy support for farmers to explore alternative measures other than pesticides

This is happening because farmer suicides are an economic and livelihood issue, but is treated by researchers as one or the other, rather than as an intersection of the two factors.

The group now began to identify the possible areas for further inquiry:

- Utilise existing mechanisms like soil health cards which make the farmer understand the consequences of pesticide use as well as documents the amount of pesticide used
- Farmers know it is harmful but not why it is harmful. Efforts must be made by researchers to make the farmers understand the impact caused by pesticide use.
- Organic certification is not enforced
- Need to educate farmer and consumer (through a behavioural change intervention)
- What is the meaning of “Organic” according to consumers, farmers and government?

One of the group members proposed an interesting solution to the dilemma encountered by researchers when convincing farmers to switch over from chemical pesticides and fertilisers. According to her, farmers (in Gujarat where she hails from) tended to get alienated by talk of the benefits of organic food as opposed to inorganically grown food. In her opinion, it was much more beneficial to talk to the farmers about pesticides by talking to them about it

through the perspective of “soil health” as opposed to “organic-inorganic”, which in their eyes, seems like argument based on privilege.

What would you need to make to make this research possible?

- Access to good scientific facilities (biomonitoring, sample drawing etc)
- Research Grants

What will help in making behavioural change successful?

- Bio monitoring (to help support policy change)
- Make farmers aware of what they are consuming
- Understand various aesthetics of food and how it influences consumer choice (Consumers buy what “looks good”)
- Integrated approach is necessary (anthropologists, scientists etc. need to come together)
- Make the landowners aware of the damage being done to their land (eg: show toxic exposure through the dust in their house)
- Must work towards a gradual reduction of pesticide use and move towards organic farming rather than asking the farmer to immediately stop pesticide usage. Farmers would be more eager with this approach as it will not immediately jeopardise their source of income.

The group spoke about the need to create a model for a change which can be applied and then scaled. After a lot of deliberation, they identified the following step-by-step process:

- Identify a community with the right conditions to saturate all of the research. It doesn’t need to cover all problems.
- Create farmer co-operatives to work with these issues
- Include a neurological approach

  Find proof for ill-effects of pesticide use. Even though pesticides have been proven to be harmful to the human body, there is still considerable doubt among Indian farmers and public about the ill-effects of pesticides. As one group member noted, organic food is still treated as a foodstuff consumed only by the elite which has given rise to schools of thought which argue that studies confirming the harms of

pesticide use have not been conducted with Indian people, therefore opening the results up for what is absolutory and allegations. By conducting a conclusive study analysing Indians specifically, there will be indisputable proof, thus forcing the Indian consumer and the farmer to believe it

- Include grass-root organisations in the planning (academics + field workers + researchers)
- Have 2 pilot models, one local and one at a national level, which will make the project scalable as well as ease the implement ability of the recommendations.

Post group discussion

Panel Members: Dr Edith A Parjer, Dr Rajesh Tandon, Dr. Gwen W. Collman, Dr. Rajnarayan R. Tiwari and Dr. Kamlesh Sarkar

Dr. Tandon – "We designed the session to identify the next steps broadly looking at the emerging ideas and look at the ideas and discuss on how we can take these ideas forward."

Dr Sarkar – "It was a good experience for the last three days in terms of stay, food and discussions. CBPR methodologies are also used in our projects but after discussing the approach in the conference, we have identified the broader issues and components of concern which can be addressed. Just like there is a need for a larger discussion on the issues like – air pollution, pesticides, arsenic, silicosis contamination, etc. there is need to use CBPR methods. There is also a need to work on the areas like impact of pollution on the unorganised sector. The CBPR approach can be used to raise their awareness and can help the policy makers to detect the problems in early stages to address them. We hope when we go back we think of the issues and in future the improvement happens."

Dr. Tandon – "We are confident it will happen, we need to build the capacity of young researchers where there is a need to build on the methodologies and also contributed to the betterment of the community. "

Dr Tiwari – "In operational research, we do a lot of quantitative and qualitative research and I was inquisitive about what will the workshop bring in – we are not doing community empowerment as part of the qualitative research which has been the additional factor of the CBPR approach.

Science for the people and people for the science has been the motto today and we need to build on it. There has been collaboration in the past but there is a need to build knowledge and capacities so that we can join efforts to work on CBPR in the field of environment health in India. The colleagues from USA can be of help. With respect to the pesticides everything boils down to economy. Even if you curl down all components like farming etc., the community don't have health as a priority and there is need to work around we need to address the issue of wealth also with health.

We don't have the data to fix priority; there is a need for quantitative research. There is a need to work in the field of occupational health in the county, the workers doing feel that there is no need to address health; CBPR is a need to engage and empower the workers. Make them aware.

In the field of disaster management – our people need more support, CBPR can be of great help to support people in crisis.

Thus, there are many areas CBPR can be used, it was an eye opening workshop, we learned a lot in the field of the pesticides we can definitely use it. We are a new institute and we have the opportunity to mould our scientists to use new methods and contribute to the communities."

Dr. Gwen – "The last few days have been a source of positive energy , I suppose all members in the group felt connected to the subject and got an opportunity to talk about what they are concerned about.

Learning and growing in the field of environmental health and recognising the new methods and knowledge in the field of CBPR as well as in the area of public health – environmental health.

"We run programs on public health and support a large network. We are open to assistance and can help reach out. The partnership we have with the public health institute, we do a lot of publication – newsletter, there is need to take the network global. We have organised virtual conferences, podcasts and webinars. We would like to share stories of your network and share stories – which is part of our commitment to the field of public health and understanding the role of environment here in India. "

Dr Edith: "It has been a wonderful learning experience and I thank everyone for contributing their knowledge and expertise and taking out time to be part of the conference. For me the learning and take always has been that there are parallel streams of practice – CBPR in India and USA and there may be instances that we might have moved further on the spectrum to take CBPR to the field o environment and health, there is a buzz to build communities of knowledge and build on the experience in the field of environmental health, health or CBPR approach thus there are ideas to build on the energy and build the platform."

Dr Tandon – "I would like to take it further from two of the esteemed colleagues - Dr. Anand Krishnan and Dr Ashok Ghosh who also echoed what Dr Tiwari and Dr Sarkar shared – that inclusion of CBPR is important in the field of environmental health, not at the cost of other issues but incorporate these ideas – to build on citizens science, take few areas in the country – cities and build on few areas at the community level, institutional and build up the CBPR capacities. This is a way forward to take forward the CBPR methodologies and take it forward in few cities and also learn from it, the method and tools can be adapted. The idea of building a platform, where learning can be shared and scaled up through strengthening partnership and collaboration.. Using our understanding o the CBPR methodology and including it in the existing mechanism and work on – in this context the institutional models can be used to propel the use of CBPR methods.

There is an appeal from both Dr. Tiwari and Dr Sarkar, who represent the research institutes on how the protocol and procedures and institutional frameworks can be evolved to include CBPR. Dr Gwen can also help to share learning how NIEH can help evolve institutional frameworks and funding.

The second area is to work jointly to work to find opportunities for capacity building and momentum for co-learning.

We need to create a mechanism to have small partnership projects before larger projects can be evolved. Small pockets of partnership funds can be evolved where a meaningful, mutually beneficial successful partnership can be evolved. I have been sharing these based on the experience with the global work we have done and this step helps to evolve ground and critical work which helps to go a long way.

We at times rush to propose a research design which does not go long way. We should find ways to find seed funding to evolve ways to being possibilities for building projects to get rooted and flower.

I want to thank all of you, the Indo – US colleagues, please share the movement of the CBPR to the global level. I also want to take the opportunity to thank all our colleagues who have been facilitating, reporting, cooking and taking photographs. Thank you."

Know Your Exposures, Know Their Impacts Citizen Engagement in Environmental Health Research

3 PM to 5 PM – Venue – American Centre, New Delhi

Background

With rapid economic growth, agricultural-to-industrial and rural-to-urban transitions and inadequate and weak regulatory mechanisms, India faces many environmental challenges, which are affecting the health and quality of life of its population. Improving environmental health research and its translation to practice in India is essential to not only address the environmental health burden of disease, but also to meet India's SDG targets. Given the scope and urgency of India's environmental health challenges, there is a need to generate local knowledge in diverse contexts of India to inform local practical actions and decision-making.

Experience shows traditional investigator-led academic research methods are not sufficient. Addressing environmental challenges requires engaging citizens in understanding the causes and co-creating solutions through *Community Based Participatory Research (CBPR)*. Community-Based Participatory Research (CBPR) is a collaborative approach that involves all stakeholders in the process of undertaking research. It recognizes the unique strengths that each brings, aims to combine knowledge with action to achieve social change to improve outcomes that, in this case, will strive to eliminate environmental and health disparities.

On 28 February 2019, citizens and researchers came together at the American Centre in New Delhi to discuss how CBPR can contribute to creating a safe, clean, and healthy environment, and how citizens can contribute to such efforts. The event titled, "Know Your Exposures, Know Their Impacts: Citizen Engagement in Environmental Health Research" was jointly hosted by the U.S. Department of Health and Human Services (HHS), the U.S. National Institute of Environmental Health Sciences (NIEHS), the University of Iowa College of Public Health and Participatory Research in Asia (PRIA), India. The event was also an occasion for participatory researchers from India and USA to share their experiences in promoting CBPR in Environmental Health Research arising from a three day workshop,

'*Advancing Environmental Health Science Research and Translation in India through Community Based Participatory Research (CBPR)*'. One of the takeaways of the workshop was to highlight the benefits of CBPR for environmental health, and the public event at the American Centre was beneficial in doing this.

Mr. Conrad Turner, Cultural Affairs Officer, US Embassy, New Delhi

"Know Your Exposures, Know Their Impacts" was centered around a panel discussion comprising CBPR practitioners and researchers. **Mr. Conrad Turner**, Cultural Affairs Officer, US Embassy, New Delhi welcomed the panelists and participants. The discussion was moderated by **Dr. Preetha Rajaraman**, HHS Health Attaché to India and Regional Representative to South Asia.

The panelists were:

Dr. Gwen Collman, Director - Division of Extramural Research and Training, National Institute of Environmental Health Sciences (NIEHS), U.S. National Institutes of Health (NIH), HHS, USA

Dr. Rajesh Tandon, Founder-President, Participatory Research in Asia (PRIA), India

Dr. Edith Parker, Dean, University of Iowa College of Public Health, USA

Mr. Jagdish Patel, Director, Peoples Training and Research Centre, India

Ms. Jyoti Pande Lavakare, President & Co-Founder, Care For Air, India

Participants

The event was attended by academicians, students, researchers and practitioners from civil society organizations (CSOs) universities and think tanks across disciplines including medicine and law.

Highlights of the Discussion

The discussion was opened by Preetha Rajaraman as she invited the panelists to comment on **how grave or big the problem of environmental health is, since its impact is felt across the globe**.

Gwen Collman pointed out that air and water know no boundaries and environmental pollution caused in one location can have consequences in a different location. Efforts to address environmental health therefore need to be interdependent, collaborative and convergent. The issue of environmental health is a problem of the people as much as it is a problem for science to investigate. It is imperative to take the science out from the labs, demystify environmental research and put findings and solutions into the hands of the community.

Rajesh Tandon informed that impact of environmental health issues in India arising out of use of pesticides and air pollution have existed since the Bhopal gas tragedy of 1984. While the consequences of environmental disasters are increasing faster, there is still a very low level of awareness and even lower response to such concerns. Hence, there is a need to think of ways in which people can be engaged in research related to environmental health.

Edith Parker suggested that they have been fortunate enough to receive funding from NHS to create a platform for demonstrating CBPR practices in the field of environmental research. In the absence of such mechanisms it is difficult even for enthusiastic researchers to contribute in doing research in participatory way with the communities and hoped that USA and India would be able to foster partnerships to initiate and support this kind of research.

Jagdish Patel elucidated that environmental health includes environment at work where we are exposed to several pollutants. It includes our exposures on the roads, on factory shop

floors, within mines, and outside and inside our homes (which are often workplaces for informal sector workers). It is important to recognize that impact on health of the working population also impacts the economy of a nation. There are no laws to monitor workplace environment. At present, in India, when a new set of chemical products are launched, such as paints, varnishes etc., there is hardly any research on their potential hazards. There is a need to formalize the research in these areas and inform the users or consumers before they begin to use these products and chemicals. The issue of nano-particles present in ambient air is another problem that needs solutions.

Jyoti Pande shared that air pollution has to date largely been seen as a problem of Delhi but now we know that it is a problem across the world. Air pollution does not just affect our respiratory organs but affects all the organs of the body through infection in the blood. For long, the problem of air pollution in India has been seen as a problem of the elite but actually it affects the poor and the middle class even more. Elites can access air purifiers but workers on the roads such as auto rickshaw drivers are impacted the most. Rising air pollution leads to high mortality; however, awareness of the consequences of air pollution among the general population is very low. Unless the experts of air pollution bring out their research in the public domain, use the results to inform and empower communities on their harmful effects, till then we will not see any change in our efforts to tackle air pollution.

L-R: Preetha Rajaraman; Gwen Collman; Rajesh Tandon; Edith Parker; Jagdish Paten; Jyoti Pande Lavakre

Using Community Based Research in Environmental Health Research

Preetha Rajaraman requested the panelists to comment on the significance of using CBPR in environmental health research.

Rajesh Tandon pointed out that CBPR has been practiced widely in many disciplines across India over the last 40 years, such as in land rights, water and sanitation, livelihoods, maternal health, but has not been applied much on the emerging issue of environmental health. The world of science in environmental health remains aloof of the real world problems related to air pollution, pesticide use and environmental disasters in India. The discipline does not involve the community in framing the research question and investigating the reality together.

Gwen Collman shared that in the past 15 years, NIEHS in the US has promoted CBPR in environmental health research, opening up various avenues for scientific researchers to engage with community mobilization and awareness. However, they acknowledge much more needs to be done. The US experience teaches us that 4 to 5 pilots in different cities involving multiple stakeholders is necessary to build adequate evidence for the relevance and impact of CBPR. Knowledge production and action need to be linked to awareness in the community and their ownership of the generated knowledge.

Jagdish Patel further informed that in India, it is a challenge to get the poor and marginalized to talk about and get involved in environmental issues. In the occupational health domain, for example, practitioners have often experienced that workers are reluctant to speak of their occupational health problems as they are scared of losing jobs and livelihood. Occupational health diseases such as silicosis, asbestosis and byssinosis are still prevalent today, but even trade unions do not consider occupational health as a priority. Those working in the unorganized sector remain unaware of workplace occupational health hazards. Dust and pollution impact the health of street vendors, for example. It not only affects neighborhoods and the environment within homes, it can have other grave consequences. Parents die early, leaving orphaned children; women are deserted or left alone to bear the economic burden because their husbands are suffering from occupational health problems. There is no political will to work on the issue of

occupational health, leaving the poor and marginalized vulnerable as they have no choice but to continue working in unhealthy work spaces.

Jyoti Pande reiterated that any change, however, would begin from awareness and from recognizing that our environment affects us every day, with impact over a long period of time. Hence, awareness programs should be linked to issues of public health and complemented with the hope of bringing socially responsible behavioral change on a mass scale. For this, there is need to build capacities of various institutions and encourage funding partnerships for the use of CBPR.

Methods of CBPR in Environmental Health Research and Affecting Policy Change

Preetha Rajaraman further requested the panelists to describe few models of CBPR and how it impacts the policy change.

Gwen Collman of NIEHS shared that there are a number of existing community air monitoring systems throughout California to provide data for and to support community specific actions. These existing community air monitoring systems utilize a variety of air monitoring approaches and technologies to address community-specific air quality concerns. Air monitoring within communities is often a collaborative process and can be led by community members, community groups, and/or state and local air quality agencies. Community air monitoring data uses can range from providing localized air quality

information that may help an individual make decisions to reduce their personal exposure to informing local mitigation and regulatory authorities.

In one example she shared, a community concluded that the existing monitors were not adequate. With the help of an advocacy organization, community members went to air pollution experts. They started mapping the level of air pollution in their neighborhood and used the data to educate and inform each other. This led them to identify days when air pollution high in their neighborhood. Schools in that district were involved. A system of flags was devised. A red flag communicated to the community that young children would not go outdoors for recess on that day. Thus, technical experts and the community came together not only to raise awareness but also act to reduce their exposures to air pollution.

Edith Parker shared her experience where the scientific research done in partnership with community led to building self-confidence, trust and leadership amongst the people which was crucial in bringing about policy level changes. Though these successes were not many but this engagement was able to demonstrate how community can take leadership and decisions for their own future in a way that contributes to sustainability of the project.

Rajesh Tandon of PRIA shared that in India a number of brick kiln factories operate where workers live on the site, often with their families, in temporary hutments. These families move from one construction site to another. Some years ago, PRIA engaged with an environment group already working with brick kiln workers in the vicinity of Delhi. The workers reported suffering from breathing problems. When they went to health clinics and consulted the doctor, they were diagnosed with asthma, but the prescribed medicines brought no relief. PRIA partnered with National Institute of Occupational Health and got 100 workers tested for silicosis as a result of being exposed to dust for a prolonged time. 70% of those who were tested were diagnosed with silicosis. A workshop was conducted with community leaders where the workers were informed of their actual disease as a result of their occupation. The data of the tests was shared with them, and the workers discussed what action they could take to mitigate the impact. A dialogue was held with local health inspectors and brick kiln supervisors. The workers presented their data to the health officials and employers. They were then sent to ESI hospitals to get the relevant treatment and compensation for their disease. The workers and environmental groups also got together to

campaign for provision of adequate residential facilities further way from the work site as well as crèches for their children. Many years later, the Supreme Court of India recognized health as a basic human right. Prior to this, a number of studies reports on silicosis remained on the shelves of NIOH without any action. However, when this data and knowledge was used to mobilize workers, an action for change was possible.

Jagdish Patel from PTRC shared that a number of occupational health diseases were diagnosed and informed to workers working in cotton mills through such initiatives. Byssinosis is a lung disease resulting from prolonged inhalation of cotton fibers. However, workers did not know about this. The doctors who examined these patients also did not know how to diagnosis byssinosis. The ESI Act had no provision for compensation for this disease either. PTRC organized meetings with the workers to inform and educate them about the disease. NIOH and trade unions started locating workers and directing them to ESI for compensation. In Baroda, a 70-year-old glass factory kept diagnosing workers with tuberculosis (TB), even though they were suffering from silicosis as a result of being exposed to glass dust. The workers were made aware, which led to a campaign to advocate for adequate compensation for the disease. After many years, the Gujarat high court ruled that if a person is suffering from silicosis he/she must be considered to have 100 % disability.

Q&A session

A student asking question to the panellists

The panel discussion raised some interesting questions from the audience. Students asked suggestions from the panelists on how youth can be empowered on the issue of environment within campuses. The current system of education in India teaches environmental science in the classroom with no learning about the issues affecting populations in the real world. Rajesh Tandon, as UNESCO Co-Chair in Community Based Research, shared his experiences in advocating for community university engagement to make higher education more socially responsible. Jyoti Pande affirmed that youth can be empowered when they begin to ask relevant questions, have peer wide discussions and get involved with their immediate surroundings on an everyday basis.

An audience member highlighted how it was important to make special efforts to include the knowledge and voice of women in CBPR. The journey to undertake meaningful CBPR is long. Hence, combinations of techniques have to be used to engage the community, and especially women.

On how to initiate action by the community after awareness has been generated, Jyoti Pande Lavakare answered that media reports, newspaper articles and public discussions bring confidence amongst the people or the community that are affected. While many laws and acts are available in India, enforcement is riddled with challenges and implementation

more often than not is weak. This needs to change and involving the community in monitoring and implementing solutions is necessary.

Conrad Turner, Cultural Affairs Officer, US Embassy, New Delhi said, engaged research requires research projects to weave in advocacy, social mobilization and activism at the planning and strategy phase.

In conclusion, each panelist shared a key takeaway for the audience.

Workplace environments have affects beyond the workspace and the impact of occupational health needs to be looked at from a wider perspective, said Jagdish Patel

CBPR calls for partnerships and to make research rigorous, partnerships are crucial. The workshop has shown many potential avenues for building partnership between the US and India, said Edith Parker.

Information and awareness are the keys to initiate action for change. The more we know about our environment the better we would feel equipped to do something about it, said Gwen Collman.

Rajesh Tandon urged every member of the audience to become “active, engaged citizens”. We usually behave either as voters, consumers or beneficiaries. For every question related to capacity and funding for doing engaged research in the area of environmental health in India there is a law, research body and funding institution. It is time we began to ask questions and make our ministries, departments and research institutions accountable for the research they conduct.

Finally, Jyoti Pande emphasized that the challenge of environmental health needs collaboration with the community as well as other stakeholders. We all must do our bit in raising awareness and advocacy and engage our friends, family, peers and neighbors to get involved in CBPR for environmental health.