

A witness seminar titled

‘Tracing the historical trajectory of community engagement in TB related public health interventions in India’

By FORUM FOR MEDICAL ETHICS SOCIETY ([FMES](#))

Under the aegis of

A Collaborative Project on Community Engagement in Implementation Research in India

[Eco-researchTM](#) (Engagement of Communities in research in Tuberculosis and Mental Health)

supported by WHO-TDR

Thursday, October 21, 2021 | 10:00 am - 2:00 pm

Opening remarks on the thematics	Indicative discussion points with focus on role and extent of engagement with/involvement of communities in TB Program development, implementation and evaluation in India
FMES team	<ul style="list-style-type: none">Welcome and introductionIntroduction to the theme of the witness seminar and the relevance
<p>Theme 1: TB program and its evolution in India 10:15 am - 12:00 noon</p> <p>Moderated by Dr Anant Bhan</p> <p>Note to the witnesses: Invited witnesses to present brief remark for about 10-12 mins each. This will be followed by open discussion drawing upon the thematic points highlighted by the speakers. The themes enlisted are indicative only and to provide a framework for opening the conversation. Speakers are welcome to choose related themes</p>	
Dr Debabar Banerji (10:15 am – 10: 40 am)	<ul style="list-style-type: none">A critical reflection on the evolution of the National Tuberculosis Program (NTP) over the past few decades: Conceptualization and overall vision, involvement of communities and integration of patients’ perspectives, if any, during planning and implementation of the NTP historically
Dr Rohit Sarin (10:40 am – 10: 50 am)	<ul style="list-style-type: none">Evolution of TB therapy in India from conventional chemotherapy to short-course chemotherapy, therapy for MDR-TB. A clinician’s perspective on patient-centered care in India.
Dr KS Sachdeva (10:50 am – 11:00 am)	<ul style="list-style-type: none">The process of formulation of the National Strategic Plan for TB elimination in India, the revised diagnostic and treatment guidelines.The Joint Monitoring Mission.Perspectives on more broad-based development of policies and

	programs, and involvement of patients and communities
Dr VK Chadda (11:00 am – 11:10 am)	<ul style="list-style-type: none"> ✚ Founding and evolution of the work of National Institutes in the National TB program. Responsibilities and challenges. Engagement and role of patients and communities.
Moderated discussion on Theme 1 11:10 am – 12:00 noon	
Break 12:00 noon – 12:10 pm	
Theme 2: TB program and its social context 12:10 pm - 2:00 pm	
Moderated by Dr Sunil Kaul	
Dr Thelma Narayan (12:10 pm – 12:20 pm)	<ul style="list-style-type: none"> ✚ Social Paradigm of TB ✚ Social understanding of non-adherence Life for a TB survivor; TB from a gender perspective, treatment of Women with TB
Dr Beena Thomas (12:20 pm – 12:30 pm)	<ul style="list-style-type: none"> ✚ TB in Tribal communities and care of TB in indigenous populations, stigma; ✚ TB care for indigenous populations ✚ Inclusion of perspectives from tribal communities in TB programs
Ms Blessina Kumar (12:30 pm – 12:40 pm)	<ul style="list-style-type: none"> ✚ Patient advocacy and patient centered treatment, ✚ Perspectives and expectations from TB patients and survivors ✚ Role of advocacy in enabling patient and survivor perspectives to be centre-staged
Dr Muniyandi Malaisamy (12:40 pm – 12:50 pm)	<ul style="list-style-type: none"> ✚ Socioeconomic impact of Tuberculosis ✚ Impact on patients and communities
Dr Nerges Mistry (12:50 pm – 01:00 pm)	<ul style="list-style-type: none"> ✚ Research in TB in India: Indigenous research in development of newer anti-tubercular drugs in India; ✚ Pharmaco-pathology and therapeutic balance in TB care; how to minimize OOP expenditure; ✚ Rural Vs Urban TB and TB care
Ms Leena Menghaney (01:00 pm – 01:10 pm)	<ul style="list-style-type: none"> ✚ Right based approach to TB care; ✚ The campaign of HIV –TB communities for access to care for HIV and MDR-TB treatment
Moderated discussion on Theme 2 01:10 pm – 01:45 pm	
Closing remarks and way forward 01:45 pm – 02:00 pm	

Annexures:

1. Annex 1: Bio sketches of participants
2. Annex 2: Concept note
3. Annex 3: A brief note on ‘witness seminar’ approach

Annex 1

BIOSKETCHES OF PARTICIPANTS

1. Dr Anurag Bhargava

Dr Anurag Bhargava is physician and epidemiologist is currently a Professor in the Department of Medicine, at Yenepoya Medical College in Mangalore, Karnataka, India, and Adjunct Professor in the Department of Medicine at McGill University. He is an advisory group member of the following technical groups: the SAGE –IVD (WHO Geneva); STAG-TB (WHO SEAR), the Indo-US REPORT-India consortium, and the National Technical Working Group on TB and Comorbidities of the National TB Elimination Programme.

He has three decades of experience in delivery of healthcare at all levels of care in India, including a decade spent as one of the founders of a large community health programme and rural hospital in rural central India. His research interests are in the field of tuberculosis, nutrition, acute febrile illnesses, and non-communicable diseases. He has led the development of 2 national guidelines and co-authored a third. He has led research which established undernutrition in adults in India as the major driver of the TB epidemic in India and undernutrition as a major reversible risk factor for mortality in patients with TB. His epidemiologic analysis of the historic Papworth socio-medical experiment in TB control (1918-43) showed that TB incidence in a high-risk group could be reduced by more than 80% with social interventions including adequate nutrition. He is currently leading the largest field-based cluster randomised trial of nutritional support in TB affected households (the RATIONS study in eastern India) which aims at reducing TB incidence in household contacts and improving outcomes in patients.

<https://www.linkedin.com/in/anurag-bhargava-095a705b/>

2. Dr Beena Thomas

Completed her Masters in Social work and PhD from Madras University. She is trained in behavioural aspects of HIV/AIDS as part of Fogarty post-doctoral AIDS international training program. She has been dealing with psychosocial issues around TB and HIV, services include counselling, strategies to improve patient compliance, working with families, rehabilitation of patients and documentation. She has expertise in HIV and stigma; Community engagement relevant to TB, counselling, evolving strategies to improve patient compliance, working with families, rehabilitation of patients and documentation.

3. Ms Blessina Kumar

Health activist with background in Health systems management and community health. She is the co-founder of Global Coalition of TB activists (GCTA) and has extensive experience of working with varied marginalised communities in India and internally displaced populations in Sudan. Experienced in working with TB patient communities in Cambodia, Indonesia and India. She is passionate about ensuring policies reflect and are informed by the affected communities and the ground realities and advocates strongly for policy change at Global Regional and National level.

4. Dr Debabar Banerji

Completed his MBBS in Calcutta in 1953, Masters in Anthropology from Cornell University in 1963. He served as Medical officer, Indian Trade Agency in Western Tibet between 1956-57, Demonstrator Physiology at AIIMS, Delhi 1957-58 and MO at Himachal Pradesh. He retired as a Professor from Jawaharlal Nehru University Center of Social Medicine and Community Health. Has been listed as noteworthy community physician and educator by Marquis Who's Who. He has authored several papers and critiques on the Public health care system in India and of the WHO. Has several years of hand on experience of the health programs and policies in India.

5. Dr Kuldeep Singh Sachdeva

He has graduated from Maulana Azad college and trained in TB and chest diseases from the VP Chest Institute at the University of Delhi. He served as ADDG in Central TB division, MoHFW, has experience in drug procurement, logistics management and TB program. He was the Nodal officer for: (1) Drug Resistant TB (2) Laboratory (Quality, Scale up) (3) Operations Research (4) TB-HIV Collaborative activities (5) TB - Diabetes Collaborative activities (6) Donor Coordination (Global Fund, World Bank, UNITAID, USAID) (7) Paediatric TB (8) Procurement (9) Health System Strengthening. He was the resource person for capacity building in rational use of drugs, procurement, and logistics management.

6. Dr Leena Menghaney

Leena Menghaney is a lawyer, and the Global IP Advisor with the Access Campaign in Medecins Sans Frontieres/Doctors Without Borders. She works with other experts and in partnership with patient groups and civil society to increase access to affordable vaccines, medicines, and tests in low and middle-income countries for diseases like HIV, drug-resistant TB, Hepatitis, cancer, and COVID-19.

7. Dr Madhavi Bhargava

Dr Madhavi Bhargava, Assistant Professor in the Department of Community Medicine, Yenepoya Medical College; Deputy Head, Center for Nutrition Studies, Yenepoya (Deemed to be University), Mangalore, Karnataka, India.

After having worked as a full-time surgeon and clinician in tribal areas of Chhattisgarh for more than 10 years, she got trained in research at McGill University, Himalayan Institute of Medical Sciences, and St John's Research Institute. Her work focuses on primary care, public health in low resource settings and social determinants of health. Of the social determinants, nutrition and its intersection with communicable diseases like tuberculosis is the major work she is currently involved. She is Co-PI for a large ICMR supported cluster randomized trial, the RATIONS trial in Jharkhand, has also analyzed national level data sets of adolescents to identify important nutrition problems such as stunting, thinness, and tuberculosis in them. Using operational research approach she investigated the preparedness in primary care for nutritional assessment, screening disease severity and risk stratification for TB. Maternal diet and nutrition are other areas of work. She has collaborations with UNICEF, NIN, NIRT, Karnataka State TB Task Force, and the Lady Irwin College, New Delhi. She is Academic Editor for PLoS One, PLOS Global Public Health and Associate Editor for Heliyon.

8. Dr Muniyandi Malaisamy

He serves as Scientist 'D' & HOD, Department of Health Economics, ICMR-National Institute for Research in Tuberculosis (NIRT), Chennai. He is an expert in Health Economics. He completed his PhD in 2005 from the International Institute for Population Sciences, Mumbai. He has been involved in diverse socio-economic, behavioural and epidemiological research and intervention projects in the context of improving population health. He has contributed as a principal investigator and co-investigator in various research projects. He is also coordinator for Regional Resource Centre for Health Technology Assessment in India (HTAIn) at ICMR-NIRT, Chennai. He has made significant scientific contributions in work organizations in terms of documentation and dissemination of research findings. He has 95 research papers published in reputed indexed peer reviewed journals with high impact factor.

9. Dr Nerges Mistry

She is the Director and Trustee of The Foundation for Medical Research, Mumbai and The Foundation for Research in Community Health, Pune. A microbiologist and immunologist by training from the University of Mumbai and The University of Birmingham, U.K. Dr Mistry's work encompasses infectious diseases with a recent focus on the molecular epidemiology of multidrug resistance tuberculosis and the mechanisms of acquisition of rapid drug resistance in tuberculosis and its public health implications. The Foundation for Medical Research (FMR) was contributor of over 7500 TB strains for Whole Genome Sequencing (WGS) led by the University of Oxford to better diagnostic sensitivity of DR-TB.

Her recent work in Mumbai based on her basic findings impinge on establishment of infection control measures in TB facilities and supplementation of knowledge on TB transmission Dr Mistry was also engaged in a Gates Foundation sponsored study on Pathways to Care of TB patients in Mumbai and Patna which served as a pointer for intervention approaches with private providers in vulnerable areas of both cities. She was an active member of the Mumbai Alliance Against Tuberculosis and participated in a number of advocacy measures for TB patients in Mumbai.

Dr Nerges Mistry and her team recently developed a mask-based aerosol capture method for COVID-19 to understand viral transmission and are currently engaged in (i) designing cost-effective measures of pooled sampling for community screening; (ii) concurrent single sample testing for TB and COVID; (iii) Use of Sars COVID genomics to explore virus pathogenesis. Dr Mistry has over 105 publications in peer-reviewed journals and has been a principal investigator of over 50 major projects. She serves as an Expert on the Global Coalition Against Tuberculosis (GCAT) and is an Advisor to the TB Private-Public Mix Learning Network (TB PPM LN) and also a member of the National Technical Expert Group (NTEG) on Diagnosis of TB under National Tuberculosis Elimination Program (NTEP).

10. Dr Rohit Sarin

He is the Advisor and had been the Director of NITRD and has experience of over three decades. He has been the recipient of Karun Styblo Public Health Prize in 2017. A medical graduate with specialized training in tuberculosis. He is a post-graduate teacher for DNB Students of Respiratory Diseases and is a National Trainer for Revised National TB Control Programme (RNTCP). He worked as WHO National Consultant

for over three years and was instrumental in framing and pilot testing of the RNTCP at the Central TB Division, Ministry of Health. He was deputed as a temporary advisor of WHO from time to time on various aspects of Tuberculosis Programme and its Control in the South-East Asian Region. He was the SAARC Trainer for MDR-TB and DOTS Plus.

11. Dr Sunil Kaul

A Public health doctor graduated from AFMC, Pune and currently the Managing Trustee of the ant, an NGO based in rural Bodoland in Assam. He is the founding trustee of this organisation. His areas of interests have been Malaria, Tuberculosis, Maternal and Child Health, Mental Health and more importantly the social determinants of health. He completed his Master's in Public Health (in Developing countries) from the London School of Hygiene and Tropical Medicine. He had also served as the State Advisor to the National Commission for Protection of Child Rights and as Advisor to the Commissioners appointed by the Supreme Court on the Right to Food PIL. Sunil has more than 10 years of experience as an army medical officer and 27 years of experience in the Development sector.

12. Dr Thelma Narayan

She is the Secretary of SOCHARA and is a figure well known amongst the Public Health fraternity. She has graduated from the St John's medical college of Bangalore and has her post-graduation in Epidemiology. She was awarded PhD by the London school of Hygiene and Tropical Medicine in 1998 for the Study of policy process and implementation of the NTP, India. She has served as the Director of SOCHARA and School of Public Health Equity and Action (SOPHEA). She is the member of the Advisory Group on Community Action for Health of the National Health Mission. She has written extensively on Tuberculosis, its bio-social implications and the social paradigm associated to diseases. She has to her credit a large number of reports, publications and papers. She has worked closely with the Government in conception of National mental health programme.

13. Dr Vineet K Chadda

He is currently the Advisor in the Public Health at National Tuberculosis Institute (NTI), Bangalore. He has worked in multiple positions at the NTI and has operational and programmatic expertise with TB control. He was the Consultant for TB from WHO in countries of Indonesia, Korea and Bhutan. He has provided technical assistance to TB Unit, WHO, South East Asia Regional Office in preparing the Annual TB Report titled 'TB Control in South East Asia Region, 2010'. HE was involved in comprehensive TB epidemiological assessments in Timor Leste and Bhutan in 2013 and 2014 correspondingly. He has technical expertise on the functioning of District TB centers and implementation of TB programme for more than three decades.

Organizing team at FMES

- 1. Dr Anant Bhan**
- 2. Dr Parimala S**
- 3. Dr Sharanya S**

4. **Dr Sunita Sheel Bandewar**

Annex 2

CONCEPT NOTE

Theme

The historical trajectory of Community Engagement (CE) in TB related public health interventions in India.

Introduction

A witness seminar is a specialized group oral history recollection strategy, deployed to better understand the ‘what and how’ of the evolution of important events in the past. The key witnesses who had witnessed or had first-hand experience of making the event happen or had been part of the process or have researched in-depth on this subject, including those who have been critically impacted by the event, are invited to discuss and recollect on the circumstances which unfolded and contributed to the events.

Witness Seminar is thus a novel tool suitable to track down history of significant events, through moderated discussions and debates with those adept and having lived experience and knowledge with regards to the theme.

As part of FMES’s new project funded by WHO-TDR titled “ *A collaborative research initiative cataloguing key community engagement practices embedded in Implementation Research Public Health Projects Involving Disadvantaged (rural/indigenous) Communities in India*”, we plan to conduct a Witness Seminar focused on exploring “the historical trajectory of community participation in TB related public health interventions in India”.

We are convening this witness seminar to understand the perceptions and understanding of key drivers, facilitators and challenges of incorporating community engagement approaches and perspectives in the evolution of the TB program in India.

This is important as the involvement of communities (the lay public) in public health interventions, through their intersections with the planning, process of roll-out, decision making, service delivery is a key factor in ensuring that the communities feel involved, supported and engaged in such programs. In the TB space, from a health system perspective, this might also influence retention/attrition in the program.

This is also in line with the vision of the clarion call of “Health for All” (WHO, 1978) where health has been positioned as not just being an outcome of medical interventions, but also linked to social, economic, cultural and political determinants.

CE is a twin concept with diverse notions of its two constituent components- community and engagement. Community is a broad and fluid concept. Individuals are always members of multiple communities, with views and perspectives that may have competing interests, potentially shifting over time with changing priorities. It remains complex to define the concept of ‘community’ and therefore the concept of ‘community engagement’ (Lavery, 2018; Wilkinson et al., 2017). The concept of community and stakeholder engagement (CSE) has evolved to be more comprehensive in terms of constituencies of engagement. It covers a broad spectrum of key players and stakeholders relevant to the enterprise of health research. CE is justified both to protect the trial participants and to preserve the integrity of the science.

Rationale:

The importance of community engagement was recognized early in the TB program as early as the late 1950s when National Institutes for TB were established in India, and were mandated to evolve policies based on public health principles and community based strategies. This was in line with the vision of

developing TB treatment pathways which were integrated with primary health care approaches, and delivery of general health services.

However, over time, concerns have been raised that the TB program became more focused on a biomedical model of case finding, case holding and action on defaulters, though this was often enabled through mechanisms to involve communities to support treatment adherence through initiatives like DOTS.

TB continues to remain a public health problem with immense complexity and public health concern even in recent times. India continues to have the highest TB case burden globally. Despite the advances in research and development of impactful policies, there have been concerns raised on the shortfalls and inadequacies of the TB program in achieving its objectives. To identify the gaps in the implementation of TB control strategies, Implementation science is useful. It helps to recognise the barriers and help to overcome them to obtain effective outcomes and reduction in the impact of TB on the community.

We hope to better understand how the involvement of and engagement with communities was conceptualized and operationalized, including omissions, any gaps between intent and implementation of these concepts. We would also like to trace how community engagement as a core concept intersected with the historical evolution of the TB program in India to the present date.

Key Witnesses

We intend to invite experts having extensive knowledge and experience in the theme. Preferably, the participants should have witnessed the development of events or had firsthand experience in the development of the TB program, and/or were impacted by it. Their role and contributions are crucial to the conduct of the witness seminar.

Witness Seminar conduct and schedule.

We are conducting the witness seminar on 21st October 2021, keeping in mind the convenience and availability of the participants. The witness seminar will be held over 4 hours, with a break in between. The witness seminar will be conducted online via Zoom platform.

The witness seminar sessions would be moderated discussions, guided by key questions and prompts of significant milestones occurring in the past. This being an open discussion we expect to navigate through key themes around community engagement in TB related Public health interventions research and implementation.

To avoid technical hassles during the seminar, we propose to dry run one to one with the seminar participants in advance, by joining 15 minutes ahead of the session, to check on the internet bandwidth and other technical issues.

We intend to record the sessions, lest, any valuable data isn't missed out and also expect to bring out the verbatim transcripts and reports pertaining to the discussion, on consent from the participants. Any important documents and objects relevant to the theme, shared by the participants, will be carefully archived by FMES, and will also be part of the analysis.

Expected outcome

The expected outcome of using this fairly novel technique of Witness seminar is to unveil insights and significant developments which led to the unfolding of TB curative and preventive interventions in India. We will come out with academic outputs from the witness seminar in the form of a seminar report and/or academic publications.

About the Organizer

[FMES](#) is a non-profit organization registered as a society under the Societies Registration Act. The Forum for Medical Ethics Society (FMES) was founded by a group of Mumbai-based medical practitioners in 1989. The primary agenda of this group was to highlight issues in medical ethics and generate discussions around them. FMES was registered as a Trust and Society in 1995. FMES is also the publisher of the [*Indian Journal of Medical Ethics*](#) .

FMES is the organizer of this seminar and more information about the organization and the project can be obtained [here](#).

Annex 3
A BRIEF NOTE ON ‘WITNESS SEMINAR’ APPROACH
By Dr Parimala S, FMES

Parimala S, Program Assistant, FMES

Witness seminar is a specialised form of [oral history](#) taking. The name ‘Witness Seminar’ has been coined by the [Institute of Contemporary British History](#) (now, the *Centre for Contemporary British History*), and the full list of all the Witness Seminars conducted is available [here](#). It basically involves collection of oral history to help historians and social scientists to track complex events and those which are missed out during the journey of large scale social and medical developments.

A Witness Seminar brings together individuals involved in a particular set of significant events associated with the treatment of a medical condition to describe its background and to discuss, debate, or disagree with their peers’ recollections (Snow, 2013; Reynolds, 2004). This novel technique is popular among British researchers, mainly to help track the history of biomedical advances and policies. Witness Seminar is an innovative qualitative research technique not often practised in low- and middle-income countries (LMICs) (Jones EM, 2013). The aspects of contemporary history, many of which have yet to be recognised or used as historical sources, are discussed here.

Much of the medical science literature is available in fragments, concealing the relevant processes by which scientific medicines were developed. Many scientists state that scientific literature may be misrepresenting the thoughts and processes which gave rise to a particular innovation. Structured in rigid formats, most scientific literature, forbid the expression of known facts. Historians are now turning towards traditional techniques of oral history documentation to supplement, or extend their existing records and create new resources. Existence of the sources of contemporary medical history has encouraged the arrangement of Witness Seminars so as to record the recollection of the events from these sources. The main purpose of these is to gather the testimonials from eminent people, to explore facts that may have been omitted in the process of official documentation.

Witness Seminar is appropriate for data generation and filling the gaps in knowledge of significant events. It brings together a group of eminent people to reminisce and discuss their first-hand experience about the event. These discussions are recorded, transcribed, and made available publicly, with the permission of the participants. Once the topic is finalised and the academic advisers identified, participants are invited and a flexible outline for the meeting is planned. At times the meetings have to be called off if the key participants are unavailable. Some other issues may include incomplete recall, repetition of old tales, or candid reporting of history by the participants.

After finalising the research questions and incorporating feasible inputs from the invited participants, the actual discussion takes place. The discussion is recorded and transcribed, and the unedited version is immediately sent to the participants to check their contributions. They are also asked to provide their brief biography. The agenda being preset and when discussions are led by the Chair (Jones, 2016) (Jones EM, 2013), certain conceptual and empirical dimensions missed out earlier can be explored. The tentative plan is flexible where in a few participants are invited to discuss certain themes; the Chairman usually creates the ground for such discussions. The editors turn the unedited transcripts to readable formats by incorporating participants’ corrections and any additional points. Bibliography and biographical details are usually provided as footnotes, and the final script is sent to every contributor. They are required to sign a legal document for assigning the copyrights of the final script to the host organisation. Any additional evidential material or correspondences received are protected and archived.

The strengths of Witness Seminar, in specific instances, outweigh pragmatic concerns by providing valuable insights on the interpersonal dynamics, intellectual and cultural differences, and individual motivations influencing the event. The group activity may not be expected to bring about consensus though it may aspire to generate perfect collective memory, exposing areas of dissent or concordance. No representativeness to historical narratives needs to be attributed – which can be a benefit. The Witness Seminar transcripts provide deeper insights into the participants’ ideologies and theoretical assumptions, revealing their perceptions as ‘bearers of culture’.

For our WHO-TDR approved project, we intend to conduct a similar Witness Seminar focussing on patients’ involvement in public health implementation, by specifically emphasising the TB care initiatives. This being a new concept had been earlier employed by CEHAT in their study on corporatisation of private healthcare in the State of Maharashtra (Marathe et al., 2020). Adopting from some of their steps in conducting Witness Seminars, we are trying to concretise the potential participants, contextually relevant opportunities and challenges, and attempt to solve some of these challenges. By not limiting these seminars to recent history, we intend to explore how peoples’ involvement in public health has changed over time, and the way active community participation in control TB interventions have been perceived (Thomas et al., 2021).

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