

A witness seminar titled

**Community engagement and Patient-centered care in TB related public health interventions in India: perspectives of survivors, champions and community-based organizations**

By FORUM FOR MEDICAL ETHICS SOCIETY (**FMES**) and  
Health, Ethics and Law Institute (HEaL Institute) of 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

The UNICEF/UNDP/World Bank/WHO Special Programme for Research and  
Training in Tropical Diseases (TDR)  
[Grant Number: P21-00344]

**Saturday, December 18, 2021 | 1430 – 1800 Hrs**



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<b>Opening remarks on the thematics</b>	<b>Indicative discussion points with focus on role and extent of engagement with/involvement of communities in TB Program development, implementation and evaluation in India</b>
FMES WHO Project team	 Welcome and  Introduction to the theme of the witness seminar and the relevance
<p style="text-align: center;"><b>1435-1625 Hrs  </b></p> <p style="text-align: center;"><b>Theme 1: TB prevention and care in India: Voices from the ground</b></p> <p style="text-align: center;"><b>Moderated by Dr Anant Bhan &amp; Dr Sunita Sheel</b></p> <p><b>Note to the <i>witnesses</i>:</b> Invited witnesses to present brief remark for about 8-10 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 drawing upon their own experiences on the ground</p> <p style="text-align: center;"><b>Structure: 8-10 mins introductory remarks by witnesses followed by open discussion for about 30 mins seeking comments and additional inputs from the house</b></p>	

Mrs Rupa Kumari	<ul style="list-style-type: none"> <li>✚ Narrative drawing upon your own lived experiences of having TB before marriage, bearing the social stigma associated with TB and your coping mechanism and support system if any</li> <li>✚ Your views on what needs to be changed in National TB program in India and how can it be done, and how can survivors be part of this.</li> </ul>
Ms Nandita Venkatesan	<ul style="list-style-type: none"> <li>✚ Narrative drawing upon your own lived experiences: Access to and quality of TB care, side effects of TB drugs and accountability of the government towards persons with TB, rehabilitation in post TB care, and relapse of TB</li> <li>✚ Your views of intersectionality and/or any advantages you may have had given your location in terms of schooling/education, being based in urban centers, and an edge that is offered by being in better economic position</li> <li>✚ MDR-TB and the support available for these individuals</li> </ul>
Ms Mridula Das	<ul style="list-style-type: none"> <li>✚ Narratives drawing on your own lived experience with TB and if there are any specificities of your experiences that either provided you better opportunities or posed unique challenges as user of TB care program (eg: consuming Anti Tubercular Treatment (ATT) and out of pocket (OOP) expenditure for TB care)</li> <li>✚ Best practices, and gaps in the engagement with the TB program in her opinion.</li> </ul>
Mr Ganesh Acharya	<ul style="list-style-type: none"> <li>✚ Insights from working closely with patients and raising issues at national and international level about access to expensive TB drugs, patents related matters focusing on role of patients, their families and people at large</li> <li>✚ Experiences as a TB patient and survivors advocate during the ongoing pandemic and disruptions it caused to TB care</li> <li>✚ Your thoughts on ability of the campaign and advocacy to avert distressing situations such the one caused by the pandemic or others, opportunities and challenges</li> <li>✚ Intersection with the TB program and does it support and involve survivors</li> </ul>
Ms Prabha Mahesh	<ul style="list-style-type: none"> <li>✚ psycho social counselling to TB patients: how important and who is best placed to do this? Role of peer support mechanisms</li> <li>✚ Networking of TB patients- has this been organic, why has it picked up in the last few years? Does the program support it?</li> </ul>
<b>Moderated discussion on Theme 1   1525 - 1600 Hrs</b>	
<b>Break   1600 – 1610 Hrs</b>	
<b>1610-1800 hrs   Theme 2: Programmatic, Legal and Policy Engagement</b>	
<b>Moderated by Dr Sunita Sheel and Dr Amita Pitre</b>	
<b>1610 – 1640 Hrs</b>	
<b>Insights from working in different states, especially the ones from the Eastern and North-Eastern regions: Assam, Odisha and Sikkim</b>	
<b>Structure: 10 mins talks by witnesses</b>	
Mr Prashanth Sharma	<ul style="list-style-type: none"> <li>✚ Experiences of working in Sikkim with focus on engagement with the state government for TB diagnostics and care options</li> <li>✚ Locating your TB advocacy efforts in your engagement with marginalized communities for basic health care as TB survivor and</li> </ul>

	<p>advocate for TB patients and survivors</p> <ul style="list-style-type: none"> <li>Your take on role of community engagement in the coming times in TB prevention and care program, and how it can be achieved and integrated in the program and policies</li> </ul>
Ms Bijayalaxmi Rautaray	<ul style="list-style-type: none"> <li>Experiences working in Odisha and difference it makes of having been closely involved in national networks and movement such as Jan Swasthya Abhiyan, and the National Coalition for Reproductive Health and Safe Abortion</li> <li>Opportunities and threats from your experiences of employing a humanistic approach to safeguard rights of persons with drug resistant TB</li> </ul>
Mr Khageshwar Kumar	<ul style="list-style-type: none"> <li>Experiences and insights from your work as part of the TB Elimination network in Jharkhand</li> <li>Quality TB care in the public health system</li> <li>Role of survivors and champions in highlighting and responding to these issues</li> </ul>
<p><b>1640-1710 Hrs</b></p> <p><b>Insights from intersectoral and intersectional engagement at programmatic, legal and policy level</b></p> <p><b>Structure: 10 mins talks by witnesses followed by open discussion for about 45 mins seeking comments and additional inputs from the house on Themes 1 and 2</b></p>	
Dr Chapal Mehra	<ul style="list-style-type: none"> <li>Insights from multi-stakeholder engagement in recent times with focus on rights-based approach in TB care, and developing gender specific TB guidelines;</li> <li>Shedding light on the spaces for communities, patients and patient advocates in these efforts drawing upon your experiences; where are the gaps? How can these be addressed?</li> </ul>
Ms Veena Johari	<ul style="list-style-type: none"> <li>Insights from working in the legal spaces to help persons with TB and survivors, and their families towards health justice, especially in cases of iatrogenic adverse outcomes and/or adverse outcomes due to delayed diagnosis of TB or non-availability of drugs;</li> <li>Using the experience of legal interventions and advocacy on making TB treatment affordable, especially much costlier Anti Tubercular Treatment (ATT) in multi-Drug Resistant (MDR) and Extensively drug-resistant (XDR) tuberculosis, what can we do to make the state accountable?</li> <li>How can we enable survivors and TB champions to be able to better advocate for their rights and needs?</li> </ul>
Ms Anupama Srinivasan	<ul style="list-style-type: none"> <li>Experiences of working with the government and also with survivors and champions at different level drawing upon your long-standing association with Resource Group for Education and Advocacy for Community Health (REACH), and background of working in gender, and disability spaces, and supporting work in TB at a national level in India</li> <li>Some of the key learnings with focus on engagement with communities and other key stakeholders towards influencing programs and policies; and more importantly implementation of these on the ground – has it made any difference on the ground</li> </ul>
<p><b>Moderated discussion on Theme 1 and 2   1710 - 1755 Hrs</b></p>	
<p><b>Closing remarks   1755 – 1800 Hrs</b></p>	

## **Annexure 1: Bio-sketches of Witnesses**

**A witness seminar titled**

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### **1. Dr Amita Pitre**

Completed her Master’s in Public health (M.Sc. Health Sciences) from Emory University. She completed her Fulbright fellowship from the same, in June 2017. She currently is the Lead specialist in Gender at Oxfam, India (an Oxfam International confederate) and has more than 20 years of experience in gender health, Gender based violence (GBV) and equality.

She has a PhD in Women's Studies at the Tata Institute of Social Sciences in Mumbai, India. Her research looks at how systemic gender, class, and caste discrimination operate within society, and is directed at making recommendations for policy change. Prior to Oxfam, she worked has worked with TISS and UNFPA (United Nations Population Fund). She has worked with the Ministry of Health and Family Welfare to develop a framework for a gender-responsive tuberculosis programme, which has been adopted. Recently she was involved to look into judgements and trial court data in rape cases, to understand how medical evidence is used in adjudication of cases. She is also interested in looking at how women's bodies are constructed in the process of the trial and how meaning is made of medical evidence. Currently, she serves on the Managing Committee, FMES.

### **2. Ms Anupama Srinivasan**

Assistant Director at REACH (Resource Group for Education and Advocacy for Community Health), has been in the organisation for more than 10years now. Prior to this she has worked at Prajnaya in Gender Violence Research and Information Task force (GRIT), Internews Network and Leonard Cheshire Disability in various positions. A Journalist with an MA in International Relations and Development studies and Masters in Public Health in London school of Hygiene and Tropical Medicine, she is interested in Gender issues in health, specifically in TB space

### **3. Ms Bijayalaxmi Rautaray**

Based in Bhubaneswar, Orissa she is the Secretary of SAHAYOG, an NGO which works in advocacy for TB patients’ treatment. Having completed double masters in Arts and Social work, she has been associated with Sahayog since it’s inception in 2011. With a rich experience of about 2 decades, in academic and development She has 20 yrs of experience in Academic, and developmental field. A very practical and value driven social developmental practitioner has strong faith on common people’s strength. She is the Secretary of Sahayog, a voluntary organization based in Bhubaneswar, Odisha. The organisation focuses in advocacy for TB patients’ care and treatment, supporting needy TB patients to continue and complete their treatment in TB patient support initiative (TPSI), maternal, child and adolescent health, child right and education. She is the co-convenor of “Voice of Patient Forum” which has been working / advocating for rights of patients and especially for people affected with tuberculosis. She is also the steering committee member of a national coalition for reproductive health and safe abortion. She is also a core team member of

Jan Swasthya Abhiyan, Odisha. She has been working in TB patient care and advocacy in focusing on right based care and humanistic approach of drug resistant TB patient.

#### **4. Mr Chapal Mehra**

With an MSc in International health Mr Mehra works in the space of patient advocacy and has authored a book on [Voices of MDR-TB](#).

#### **5. Mr Ganesh Acharya**

A TB survivor living with HIV for the past 23 years. Having survived TB and facing a number of access barriers, he started engaging with other patients to provide them requisite support. As a patient advocate, Ganesh interacts with a number of patients, including DR-TB patients who face a range of challenges in the city of Mumbai such as accessing new DR-TB drugs and government mandated nutritional support. Mumbai in India is a hotbed of DR-TB and experience of patients of treatment roll-out in the city is crucial in understanding barriers and urban settings across the country. He has been a leading voice in the media and other forums bringing concerns of TB patients to fore.

Ganesh has worked with Mumbai HIV/MDR-TB project of Médecins sans Frontières for 10 years. Currently he is a member of many organisations working on TB which includes Global Coalition of TB Activists (GCTA), community-based organisation Sanjeevani, Mumbai Aids forum, Mumbai TB collective, Touched by TB, a national coalition of TB affected community members and regional coordination focal point of FAC (Fight against Aids India). Engaged in HIV/AIDS Act movement, the movement to strike down Section 377, Access to HIV/TB/Hepatitis C medicines Campaigns, organised protests and silent Dharna on HIV/TB drugs shortages and stock outs. Participate Rally against EU-India FTA- European Union's attempts to push India to increase its intellectual property (IP) protection and enforcement standards through the on-going free trade agreement (FTA) negotiations. Mobilise civil society organisations in Mumbai Aids Forum and India CSOs. Ganesh filed 7 patent opposition for essential medicine as Treatment access campaign and global access to treatment.

#### **6. Mr Khageshwar Kumar**

25 year from Giridh, Jharkhand living with parents, grandparents and younger sibling was diagnosed of TB early when he was 11 years old. He completed higher secondary in 2015 and presently pursues BA. After completion of ATT he was given training as TB champion by REACH; after which he started working with Catholic Health Association of India as Community Volunteer. In 2019, TB Elimination from Jharkhand Network, was initiated for TB survivors, wherein he serves as treasurer and is currently working with ICMR-NIRT as Field Investigator in RATIONS Study project at Jharkhand.

He wants to save lives of TB patients and fight for their rights.

#### **7. Ms Mridula Das**

TB survivor from Baksa district of Assam. Completed her Bachelors in Assamese in 2017. She was diagnosed of Abdominal TB in 2019 for which she took treatment at Guwahati Medical College and its teaching hospital. She was put on 99 DOTS but as it had few adverse effects of dizziness, unable to work in her, she was given alternate AT drugs which she had to purchase herself. Now she has completed her Masters and has cleared Upper Primary Teachers examinations in Assam.

#### **8. Ms Nandita Venkateshan**

A journalist, TEDx speaker, classical dancer, two-time intestinal tuberculosis survivor and patient-rights advocate. She lost over 90 per cent of her hearing at 24, due to a rare after-effect of a TB injection. Her eight-year battle with TB began in 2007, and she suffered a life-threatening reinfection in 2013. Determined to fight back, she gave dance performances without hearing, and recently returned to work with the Economic Times. She has been awarded the prestigious ICICI Advantage Women Award, the Rotary India's Vocational Excellence Award and the REACH Media Award.

She has addressed prominent national and international forums including the 2018 United National General Assembly in New York. She also co-founded Bolo Didi, a sisterhood of TB survivors who counsel people affected by TB. Her advocacy resulted in her being named by The Lancet as 'A Voice of Hope for TB Survivors'. She holds a Bachelor's in Mass Media from University of Mumbai and PGDip in Broadcast Journalism from Indian Institute of Mass Communication. She completed Masters in Public policy(MPP) from Oxford university with a distinction in 2021 and currently is a Chevening- Weidenfeld Hoffmann Scholar.

## **9. Ms Prabha Mahesh**

Masters in Social work from University of Mumbai, is largely experienced in counselling, mentoring and relationship management. Well versed in multiple languages Ms Prabha has varied skill set in needs assessment, solution recommendation, development, and implementation of training programs. Her key areas of work are socially responsible public welfare and healthcare. Currently she is the Project Director at ALERT india and has been with the organisation for more than 17 years now. She also has a Certificate in Theme Centered Interventions, Counselling psychology from TISS.

## **10. Mr Prashanth Sharma**

A TB survivor and community representative working with marginalised groups, hailing from Sikkim. He is an activist advocating for their right to access to health, social, legal services.

Having lost his father due to TB, his mother and sister also are champions like him, have bravely fought against TB. He has unfortunately experienced the plight, stigma and discrimination meted on TB patients and contacts. He adds of having witnessed many people giving upon life due to lack of human resource, basic diagnostics, substandard medicine, painful injection, institutional stigma, poor psychosocial support from the public health system; by hanging themselves.

He advocates with State and National agencies for better TB diagnostic, medicines, psychosocial support and also providing peer support, care and counselling to the people with TB. During the C19 pandemic I was calling many people under TB treatment, delivering TB medicines, managing travel passes, providing necessary mask, sensitizer, gloves etc.

In the current pandemic he wrote to CM, Sikkim requesting additional care to TB patients and program. He believes, without the robust and active community engagement/participation and empowerment on the ground we can't make any impact in TB care. He has actively participated in state, national and international conference and workshops on equal partnership with different organisation and agencies to access to better medicine, diagnostic, support, care and wellbeing of the people with TB

## **11. Mrs Rupa Kumari**

27 year old TB champion from Bokaro district, Jharkhand. She has faced TB in 2018 before her marriage and encountered the stigma of TB. She is now with her family husband, mother-in-law, father-in-law and three sisters-in-law. She has completed MA(Honors) in Hindi from IGNOU in 2019 my treatment by taking TB medicine from government hospital and after winning the battle with TB, I got from REACH institution. Received training to work as a TB champion and for 06 months I have worked under mentorship program to provide psychosocial support to people with TB, advocacy on TB and organize social awareness programs for TB eradication. In August 2019, ICMR's RATIONS Study project from NIRT also got an opportunity to work as a field investigator for 02 years. Today, I feel very happy and proud in myself that I am able to help the people who are going through such a difficult journey and help them in every possible way. This is nothing less than a link to success for me.

## **12. Veena Johari**

An advocate in Mumbai, she is the Proprietor of Courtyard Attorneys, a legal consultancy firm that works on public interest issues for the marginalised and the poor, and carries out research on the law and policy, with special reference to healthcare. She has substantial experience in drafting, filing and appearing in various courts for the legal rights of the marginalised and disadvantaged populations, especially people living with HIV, drug users, sex workers, the

LGBT community, women, children, and the poor. She has also advised on surrogacy law, clinical trials, and has filed pre-grant oppositions against patents on pharmaceutical drugs. She has collaborated with other groups in conducting seminars, workshops and meetings to disseminate information about rights and the law. She has done research and written papers relating to HIV and rights, the criminalization of HIV, sexual and reproductive health, and women and inheritance; and jointly developed a training manual for drug users and the law. Have been an advisor to social researchers on issues relating to drug related clinical trials, especially to the United Nations Development Programme, the International Development Law Organization, the Cancer Patients' Aid Association, Sama Resource Group for Women and Health and the International Development Law Organization.

## Witness Seminar on

# Community engagement and Patient-centered care in TB related public health interventions in India: perspectives of survivors, champions and community-based organizations

### A concept note

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#### Introduction

As part of [FMES's 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 (WS)<sup>1</sup> 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 of TB survivors, activists and advocates, impacted community members to understand history of, as well as enablers and challenges of incorporating community and stakeholder engagement (CSE) or community engagement (CE) approaches and patient centered interventions in TB care 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 and in turn overall outcomes of public health programs.

This is also in line with the vision of the clarion call of "Health for All" (WHO, 1978) and the Declaration of Asthana (DoA) (WHO, 2018) where health has been positioned as not just being an outcome of medical interventions, but also linked to social, economic, cultural and political determinants. Ensuring this transition from the conventional public health methods to comprehensive, sustainable, feasible community-oriented strategies has to be the prime focus of policy makers, researchers and implementation partners globally. Public health should be based on community support.

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. CSE is justified both to protect the trial participants and to preserve the integrity of the science.

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<sup>1</sup> 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 adepts and having lived experience and knowledge with regards to the theme.



## **Rationale of community and stakeholder engagement in the Indian TB program**

The importance of CSE 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. The current emphasis in TB care globally is on UHC, patient centered care and quality of care. Gaps and delays in access to TB care and diagnostics influence the long chain cascade of care; ranging from access to health care facility, diagnosed as a TB patient, adherence and completion of treatment and leading a recurrence free life. Involving patients, survivors and communities and understanding their unmet needs should be an essential component of the provision of quality care.

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 understand the position of patients, their involvement during the whole process of design, conceptualization, policy formulation, implementation and revision of the TB program in India.

### **Key Witnesses**

We intend to invite TB patients, survivors, activists and advocates of patient centered care in India. Preferably, the participants should have been part of the development of events or had firsthand experience in the development/revision 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.**

Tentatively we plan to hold the seminar on 11<sup>th</sup> December 2021, keeping in mind the convenience and availability of the participants. Considering the availability of all the witnesses, we plan to hold the witness seminar in the first half of the day, for 4-5 hours, with breaks. 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 CSE in TB related public health interventions research and implementation.

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 the proposed witness seminar is to get deeper insights into perspectives of TB patients, survivors in relation to CSE in the TB program and to

reflect on addressing the gaps in development and delivery of comprehensive, patient centered quality TB care. We will come out with academic outputs from this 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](#).

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