



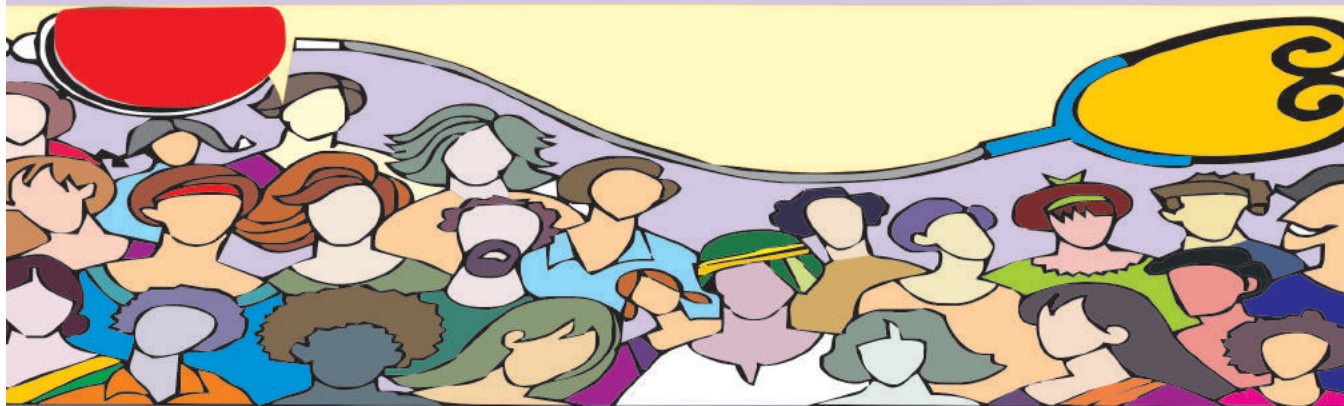
Proceedings Report of

A Witness Seminar on

Community engagement and patient-centred care in TB-Related public health interventions in India: perspectives of survivors, champions and community-based organisations

Held on Saturday, December 18, 2021

Co-organised by
HEaL Institute, FMES; and
CNS, YDU



Supported by

The UNICEF/UNDP/World Bank/
WHO Special Programme for Research and
Training in Tropical Diseases (TDR)

[Grant Number: P21-00344]



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Health, Ethics and Law Institute for Training, Research and Advocacy
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Under the aegis of the project titled

A collaborative research initiative cataloguing key community engagement practices embedded in Implementation Research Public Health Projects Involving Disadvantaged (rural/indigenous) Communities in India

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Abbreviations

AIDS: Acquired Immunodeficiency Syndrome

ANM: Auxiliary Nurse Midwife

ART: Anti Retroviral Treatment

ASHA: Accredited Social Health Activist

ATT: Anti Tubercular Treatment

CAF: Community Accountability Framework

CBNAAT: Cartridge Based Nucleic Acid Amplification Test

COVID-19: Corona Virus Disease-19 or SARS-CoV-2

CSO: Civil Society Organisation

DOTS: Directly Observed Treatment Short course/Direct and Supportive Supervision

DRTB: Drug-Resistant Tuberculosis

HIV: Human Immunodeficiency Virus

ICDS: Integrated Child Development Services

ICMR: Indian Council of Medical Research

JSA: Jan Swasthya Abhiyan

MDRTB: Multidrug-Resistant Tuberculosis

MoHFW: Ministry of Health and Family Welfare

MSF: Médecins Sans Frontières/ Doctors without Borders

NHM: National Health Mission

NIRT: National Institute of Research in Tuberculosis

NiTi Aayog: National Institute for Transforming India

NPY: Nikshay Poshan Yojana

NTEP: National Tuberculosis Elimination Programme

PIP: Programme Implementation Plan

PPSA: Patient Provider Support Agency

RATIONS: Reduced Activation of Tuberculosis by Improvement of Nutritional Status

REACH: Resource Group for Education and Advocacy for Community Health

SATB: Survivors Against Tuberculosis

SEARO: South-East Asia Regional Office

TB: Tuberculosis

TEJ: TB Elimination from Jharkhand network

TPSI: TB Patient Support Initiative

WHO: World Health Organization

XDR TB: Extensively Drug -Resistant Tuberculosis

PREAMBLE

We are pleased to bring this report on the proceedings of the witness seminar titled, **‘Community engagement and patient-centred care in TB-related public health interventions in India: perspectives of survivors, champions and community-based organisations’**, one of the series of two witness seminars. We — Health, Ethics, and Law Institute (HEaL Institute) — a programmatic platform of the Forum for Medical Ethics Society (FMES), and the Center for Nutrition Studies, Yenepoya (Deemed to be University) (CNS-YUD) co-hosted this witness seminar on Saturday, December 18, 2021.

This witness seminar was organised under the aegis of a project titled, ‘A collaborative research initiative cataloguing key community engagement (CE) practices embedded in Implementation Research Public Health Projects Involving Disadvantaged (rural/indigenous) Communities in India (Eco-researchTM)¹’, hosted at the HEaL Institute, FMES and is supported by the UNICEF/UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases (TDR).

Briefly, ‘witness seminar’ is a specialised form of oral history taking. Underlying assumption is that it would help historians, social scientists and other similar professionals to track and document journey of complex and large-scale health programmes, policies, biomedical discovery programmes or any such matters of one’s interest. One of the interests or motivations behind organising a witness seminar is also to capture any missed-out perspectives and/or milestones in the existing documentation. In India, it is an emerging approach to exploring longstanding journey of complex health care system, public health programmes or other thematics of relevance to peoples’ well-being.

Ours is one such attempt in the interfacing space of tuberculosis programmes in India, community and stakeholders engagement (CSE), and implementation science. The seminar was aimed at better understanding how the involvement of and engagement with communities was conceptualised and operationalised, including omissions, any gaps between intent and implementation of these concepts over the period in independent India.

We locate the theme of the seminar within the context defined:

- a. By the overall mandate of the WHO-TDR’s call for application titled, ‘Identification of good practices in engaging communities in research for implementation and in social innovation in health in low- and middle-income countries’, the aforesaid project secured the WHO-TDR support. One of the

¹Eco-researchTM stands for Engagement of Communities in research in Tuberculosis and Mental Health, a short title of the said FMES project.

domains for extending support is implementation research on infectious diseases of poverty aimed at health improvements. The goals and objectives of this call have been woven around the need to document good CE practices in research and social innovation in the LMIC context. Given the fact that the call was put out during the ongoing pandemic, it also aimed at getting insights into CE practices during the public health emergencies in the context of implementation research;

- b. Flowing from this mandate of the call, a witness seminar was proposed in the FMES project that would attempt to capture the role of communities, patients, and other key stakeholders in shaping public health programmes in India from a historical perspective; and
- c. Lastly, by the thematic focus on tuberculosis of the study namely RATIONS² (Reducing Activation of Tuberculosis by Improvement of Nutritional Status), one of the two sites for the FMES project. RATIONS, a cluster randomised trial, is aimed at responding to tuberculosis (TB) in India by exploring the extent of nutritional support made for reduction in TB activation³. The FMES project is looking into CE-CSE practices and other aspects of communication strategies employed in the RATIONS project, their role in RATIONS' implementation, and other related matters that contribute to understanding the role of CSE in implementation research involving marginalised and vulnerable disadvantaged communities.

The existing scholarship in health research, including clinical trials and experimental research in public health intervention, demonstrates increasing recognition of the salience of CSE on two grounds. One, it is being increasingly recognised as one of the key research ethics obligations of researchers towards participating communities and individuals; and two, it is one of the contributing factors enhancing the quality of research. Community engagement is justified and supported both to protect trial participants and to preserve the integrity of the science. Similarly, by drawing upon this scholarship, the role of CSE in implementation science is being recognised, amongst others, towards ensuring better implementation and outcomes of public health programmes which in turn are expected to contribute to improving peoples' well-being. Implementation research now treats CE as an ethical obligation⁴.

²Bhargava, A., Bhargava, M., Velayutham, B., Thiruvengadam, K., Watson, B., Kulkarni, B., Singh, M., Dayal, R., Pathak, R. R., Mitra, A., Rade, K., & Sachdeva, K. (2021). The RATIONS (Reducing activation of tuberculosis by improvement of nutritional status) study: A cluster randomised trial of nutritional support (Food rations) to reduce TB incidence in household contacts of patients with microbiologically confirmed pulmonary tuberculosis in communities with a high prevalence of undernutrition, Jharkhand, India. *BMJ Open*, 11(5), e047210. <https://doi.org/10.1136/bmjopen-2020-047210>

³RATIONS is implementation research hosted at the CNS, YDU, Mangalore, Karnataka, India.

⁴World Health Organization, TDR (2019). Ethics in implementation research: Facilitator's guide. Available from: <https://apps.who.int/iris/bitstream/handle/10665/325608/9789241515375-eng.pdf?ua=1> Cited 2021, Feb 11.

History of TB has been traced back to millions of years^{5,6,7}; discovery of the Mycobacterium tuberculosis that causes TB is traced to the 19th century⁸; and discoveries in the area of biomedical interventions, especially starting from BCG in 1921⁹ followed by other medicinal interventions such as streptomycin in 1943¹⁰, para-amino salicylic acid (PAS), and isoniazid (INH). And yet, TB continues to remain a public health concern with millions suffering from the disease and dying, both of which are avoidable. It is specially concerning in India. For example, the Lancet Commission on TB (2019)¹¹ notes that India is one amongst the eight countries which together account for two-thirds of all new cases worldwide.

We were honoured to have on board, speakers, that is, witnesses, from India's premium National institutes that have been deeply engaged with TB research, programme designing and implementation since post-independence as well as other key players from non-government organisations and the civil society. Witnesses, being from diverse disciplines have brought diverse perspectives on TB programmes to the table and have worked in different regions of India. In terms of chronology of the TB programme evolution in India, in the larger global context, witnesses came from different phases of TB programme and/or have witnessed different facets of the Indian TB programme. All of this together helped trace the trajectory of the engagement with communities and other relevant stakeholder, and outcomes of evolving versions of the India's TB programmes from the point of view of communities, patients, and their families.

We note the availability of documentation of histories of premium TB institutes in India which reflects evolution of TB programme in India, its role in shaping TB programme globally, and deeper engagement of UN agencies with India. However,

⁵Hershkovitz, I., Donoghue, H. D., Minnikin, D. E., May, H., Lee, O. Y., Feldman, M., Galili, E., Spigelman, M., Rothschild, B. M., & Bar-Gal, G. K. (2015). Tuberculosis origin: The Neolithic scenario. *Tuberculosis (Edinburgh, Scotland)*, 95 Suppl 1, S122–S126. <https://doi.org/10.1016/j.tube.2015.02.021>.

⁶Daniel T. M. (2006). The history of tuberculosis. *Respiratory medicine*, 100(11), 1862–1870. <https://doi.org/10.1016/j.rmed.2006.08.006>

⁷Raviglione M. C. (2003). The TB epidemic from 1992 to 2002. *ScienceDirect*, 83(1-3), 4–14. doi:10.1016/s1472-9792(02)00071-9

⁸Daniel T. M. (2006). The history of tuberculosis. *Respiratory medicine*, 100(11), 1862–1870. <https://doi.org/10.1016/j.rmed.2006.08.006>

⁹Sakula A. (1983). BCG: Who were Calmette and Gue'rin? *Thorax*; 38:806–12.; Daniel T. M. (2005). Leon Charles Albert Calmette and BCG vaccine. *The international journal of tuberculosis and lung disease : the official journal of the International Union against Tuberculosis and Lung Disease*, 9(9), 944–945.

¹⁰Amrith, S. (2004). In search of a 'magic bullet'for tuberculosis: South India and beyond, 1955–1965. *Social History of Medicine*, 17(1), 113-130.

¹¹Reid, M. J., Arinaminpathy, N., Bloom, A., Bloom, B. R., Boehme, C., Chaisson, R., ... & Goosby, E. P. (2019). Building a tuberculosis-free world: The Lancet Commission on tuberculosis. *The Lancet*, 393(10178), 1331-1384.

this, to the best of our knowledge, is the first of its kind witness seminar providing insights into India's TB programme centre-staging communities, patients and their families by experts having extensive knowledge and experience in this arena. We hope that the peer communities cutting across disciplines and thematics within the broader health spaces would find these proceedings relevant.

WITNESSES



Amita Pitre Amita is Masters in Public health (M.Sc. Health Sciences) from Emory University and has completed her Fulbright fellowship from the same University in June 2017. She is currently the Lead specialist in Gender at Oxfam, India (an Oxfam International Confederated) 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 (TISS)¹ 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 with TISS and United Nations Population Fund (UNFPA)². She has worked with the Ministry of Health and Family Welfare (MoHFW) to develop a framework for a gender-responsive tuberculosis programme, which has been adopted. Recently, she was involved to look into judgments 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.



Anupama Srinivasan Anupama, Assistant Director at Resource Group for Education and Advocacy for Community Health (REACH)³, has been in the organisation for more than 10 years now. Prior to this, she has worked at Prajnaya, Gender Violence Research and Information Task force (GRIT)⁴, Internews Network and Leonard Cheshire Disability in various positions. A Journalist with an MA in International Relations and Development Studies and a

Master in Public Health from London School of Hygiene & Tropical Medicine, she is interested in gender issues in health, specifically in TB space.

¹<https://tiss.edu/>

²<https://www.unfpa.org/>

³<https://www.reachtbnetwork.org/>

⁴<http://retro.prajnya.in/grit.htm>



Bijayalaxmi Rautaray Based in Bhubaneswar, Odisha. Bijayalaxmi is the Secretary of Sahayog⁵, an NGO which works in advocacy for TB patients' treatment. Having completed a double masters in Arts and Social work, she has been associated with Sahayog since its inception in 2011. She has 20 years of experience in the academic and development sector. 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 organisation 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-convener of "Voice of Patient Forum" which has been working / advocating for the rights of patients and especially for people affected by 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 (JSA), Odisha. She has been working in TB patient care and advocacy in focusing on right-based care and humanistic approach of drug resistant TB patients.



Chapal Mehra A public health specialist and Director at Pi Consulting, Chapal has an MSc in International health. He works in patient advocacy and has authored a book titled 'Voices from TB'⁶. He has worked in different roles, to mention a few as Editor with McGraw Hill in 1999-2000, Development Editor at Oxford University Press from 2000-02, Managing Editor with Sage Publications from 2002-06 and Acquisition Manager with Penguin. Later on, as part of

his MSc, he was engaged as a Public Service Leadership Scholar from 2007-09 at New York University (NYU). In health, he worked as an independent consultant with Gates Foundation funded project on Human Immunodeficiency Virus - Acquired Immunodeficiency Syndrome (HIV-AIDS) and then as Senior Director at Global Health Strategies for about 4 years.

⁵<http://sahayogodisha.org/profile.php>

⁶This a collection of patient stories documented by Chapal Mehra. It speaks of stigma & emotional toll of TB disease. These are stories of those who have survived the curable but contagious disease from their point of view. A collection of patient stories from across the country, the book is meant to highlight the experiences of the biggest stakeholders in the fight against TB - the patients' themselves. More on this available from: TB is like a monster eating people alive, says TB activist (dnaindia.com); Voices of Tuberculosis - breaking stereotypes | Business Standard News (business-standard.com)



Ganesh Acharya Ganesh is 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 Drug Resistant-Tuberculosis (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 is a hot-bed 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 the concerns of TB patients to the fore.

Ganesh has worked with the Mumbai HIV/MDR-TB project of Médecins Sans Frontières (MSF)⁷ 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 FAA (Fight Against AIDS India). Engaged in HIV/AIDS Act movement, de-criminalised 377 movement, Access to HIV/TB/Hepatitis C medicines Campaigns, organised protests and silent dharna on HIV/TB drugs shortages and stock outs. Participated in the rally against European Union (EU)-India Free Trade Agreement (FTA)- EU's attempts to push India to increase its intellectual property (IP) protection and enforcement standards through the ongoing FTA negotiations. He works to mobilise civil society organisations in the Mumbai AIDS Forum and Indian Civil Society Organisations (CSOs). Ganesh filed seven patent oppositions for essential medicines as treatment access campaign and global access to treatment.



Khageshwar Kumar Twenty-five year old Khageshwar from Giridh, Jharkhand lives with his parents, grandparents and younger sibling. He was diagnosed with TB when he was 11 years old. He completed higher secondary in 2015 and is currently pursuing a BA. After completion of Anti Tubercular Treatment (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 (TEJ)⁸ Network, was initiated

⁷<https://www.msf.org/tuberculosis>

⁸<http://www.reachtbnetwork.org/wp-content/uploads/2020/01/Call-to-Action-for-a-TB-free-Jharkhand.pdf>

for TB survivors, wherein he serves as treasurer and is currently working with Indian Council of Medical Research-National Institute of Research in Tuberculosis (ICMR-NIRT) as Field Investigator in RATIONS study project at Jharkhand. He wants to save the lives of TB patients and fight for their rights.



Mridula Das Mridula is a TB survivor from Baksa district of Assam. She completed her Bachelors in Assamese in 2017; was diagnosed with Abdominal TB in 2019 for which she took treatment at Guwahati Medical College and Hospital. She was put on 99DOTS⁹ (Directly Observed Treatment Short Course) but as it had a few adverse effects such as dizziness, she was given alternate AT drugs which she had to purchase herself. She has now completed her Masters and has cleared upper primary teachers' examinations in Assam.



Nandita Venkatesan Nandita is a journalist, TEDx speaker, classical dancer, two-time intestinal tuberculosis survivor and patient-rights advocate. She lost over 90% hearing at 24, due to a rare after-effect of a TB injection. Her eight-year long battle with TB began in 2007, and she suffered a life-threatening re-infection 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 Nations 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 a PGDip in Broadcast Journalism from Indian Institute of Mass Communication. She completed a Masters in Public Policy (MPP) from Oxford University with a distinction in 2021 and currently is a Chevening – Weidenfeld-Hoffmann Scholar.

⁹The RNTCP has been using 99DOTS, an IT enabled 'pill-in-hand' adherence monitoring system for all DSTB patients on daily regimen. [from:<https://tbcindia.gov.in/WriteReadData/l892s/030920201430Module6140120CTD.PDF>]



Prabha Mahesh Prabha did her masters in social work from the University of Mumbai, and is largely experienced in counselling, mentoring and relationship management. Well versed in multiple languages, she has a varied skill set in needs assessment, solution recommendation, development, and implementation of training programmes. Her key areas of work are socially responsible public welfare and healthcare. Currently she is the Project Director at ALERT India¹⁰ and has been with the organisation for more than 17 years now. She also has a Certificate in Theme Centred Interventions, Counselling Psychology from TISS.



Prashanth Sharma Prashanth is a TB survivor and community representative working with marginalised groups, hailing from Sikkim. He is an activist advocating for their right to access health, social, legal services. Prashanth lost even his father due to TB. But he and his family have bravely fought this fight against TB. He has unfortunately experienced the plight, stigma and discrimination meted on TB patients and contacts. He has witnessed many people giving up on life by hanging themselves due to lack of human resource, basic diagnostics, substandard medicine, painful injection, institutional stigma, poor psychosocial support from the public health system.

He advocates with State and National agencies for better TB diagnostic, medicines, psychosocial support, and also provides peer support, care and counselling to the people with TB. During the coronavirus disease, 2019 (COVID-19) pandemic, he was calling up TB patients to check upon their health and to help them out, delivering TB medicines, managing travel passes, providing necessary mask, sanitizer, and gloves. During the pandemic, he also wrote to the CM of Sikkim requesting additional care for TB patients and support for TB programme. He believes, without robust and active community engagement/participation and empowerment on the ground, we cannot make any impact on TB care. He has actively participated in state, national and international conferences and workshops on equal partnership with different organisations and agencies to access to better medicine, diagnostic, support, care and wellbeing of the people with TB.

¹⁰<https://alertindia.org/about-us/our-team/>



Rupa Kumari Rupa is a 27-year-old TB champion from Bokaro district, Jharkhand. She 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 (Honours) in Hindi from the Indira Gandhi National Open University (IGNOU) in 2019. She took her treatment from a government hospital, and after winning the battle with TB, she received training from REACH to work as a TB champion. For six months, she worked under the mentorship programme to provide psychosocial support to people with TB, advocacy on TB and organise social awareness programmes for TB eradication. In August 2019, under the ICMR's RATIONS Study project from NIRT, she also got an opportunity to work as a field investigator for two years. Today, she feels very happy and proud of herself that she was 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 her.



Adv. 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 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 criminalisation of HIV, sexual and reproductive health, and women and inheritance, and jointly developed a training manual for drug users and the law. She has been an advisor to social researchers on issues relating to drug related clinical trials, especially to the United Nations Development Programme (UNDP), the International Development Law Organization (IDLO), the Cancer Patients Aid Association (CPAA) and Sama Resource Group for Women and Health.

ORGANISERS



Dr Sunita Sheel Bandewar Sunita Bandewar has training in Anthropology (PhD, University of Pune) and Bioethics (MHSc, University of Toronto). Her engagement with health as a field of enquiry over these past 30 years is primarily via empirical research in health and allied thematics, training, and advocacy in the areas of women and health, global health, public policy, and bioethics. Currently she holds the office of Secretary General, the Managing Committee, Forum for Medical Ethics Society (FMES),

Mumbai, serves on the core editorial board of the Indian Journal of Medical Ethics; and serves as Director, Health, Ethics and Law Institute, a programmatic platform of FMES. She is one of the founding trustees of Vidhayak Trust, Pune.



Dr Anant Bhan A medical graduate with a master's (MHSc) in Bioethics from the University of Toronto in Canada. He is a researcher in global health, health policy and bioethics with over 20 years of experience and numerous publications to his name. Anant Bhan is currently one of the leading voices on issues related to medical ethics and social justice in India. He is also the immediate past president of the International Association of Bioethics (2017-19), serves as an Adjunct (Visiting)

Professor, Yenepoya (deemed to be University), and is a member of several committees, and serves as Principal Investigator/Site-Principal Investigator for Sangath, a leading health research organisation for its Bhopal hub.

LinkedIn: <https://in.linkedin.com/in/anant-bhan-53233b11>

Twitter: @AnantBhan



Dr Anurag Bhargava Dr Anurag Bhargava is a physician and epidemiologist, and 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, Montreal, Canada. 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 Programme¹¹.

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.



Dr Madhavi Bhargava Dr Madhavi Bhargava, Associate Professor in the Department of Community Medicine, Yenepoya Medical College, and Deputy Head, Center for Nutrition Studies, Yenepoya (Deemed to be University)¹², 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 randomised trial, the RATIONS (Reduced Activation of Tuberculosis by Improvement of Nutritional Status) trial in Jharkhand, and has also analysed 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 (United Nations Children's Fund),

¹¹In 2020 the RNTCP was renamed the National Treatment Elimination Programme (NTEP) to emphasize the aim of the Government of India to eliminate TB in India by 2025. [from: <https://tbfacts.org/rntcp/>]

¹²<https://www.yenepoya.edu.in/academics/centers/center-nutrition-studies>

NIN (National Institute for Nutrition), NIRT (National Institute for Research in Tuberculosis), 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.



Dr Parimala S Dr Parimala S has graduated in allied systems of medicine and has a post-graduate degree in public health. She is specialised in Epidemiology and is experienced for about a decade now, in various roles of different public health projects. She is currently a doctoral candidate working in the area of public health policy and allied system of medicine. She has obtained training and mentorship in public policy and leadership by senior state health administrators. She is an accident survivor and is extremely passionate about public health research. Currently she serves as a COVID-19 marshal and is volunteering with Step one and Yumetta foundation. <https://www.linkedin.com/in/pari-eshwar-500b8a147/>



Dr Sharanya Sreekumar Dr Sharanya S is Public Health Dentist and earned a Postgraduate Diploma in Bioethics and Medical Ethics (PGDBEME) from Yenepoya University of Mangalore. She has completed certificate programme in epidemiology and Biostatistics from Manipal University. She has also completed her training on Qualitative Research methods and analysis at Schizophrenia Research Foundation (SCARF), Chennai. She is currently a clinician and researcher in the field of public health and Bioethics. <https://www.linkedin.com/in/sharanya-sreekumar-3a35b0157/>



Mr Mahendra Shinde, Finance and Admin In-charge Mahendra is post graduate in commerce, with a Diploma in Financial Management and Government Diploma in Co-operation and Accountancy. He is certified GST practitioner and has worked on documentation, taxation and statutory compliances from a project point of view.



Mr Vijay Sawant, Admin and Website Manager Vijay has vast experience in library administration. He has completed his Bachelors in Library Science and has in-depth knowledge of various library software, open sources and website management. He has previously worked with the Centre for Enquiry into Health

and Allied Trust for over 24 years.



Georgiaria Fernandes Ria is qualified Computer Engineer who is now into scientific editing. After working for 12 years in different job roles, Ria has joined FMES-IJME team as an Editorial Coordinator. Her most recent job was in a similar position for 2 years at the Indian Journal of Cancer.

Proceedings of witness seminar

SESSION 1

TB PREVENTION AND CARE IN INDIA: VOICES FROM THE GROUND

PROCEEDINGS OF WITNESS SEMINAR

SESSION 1 | TB PREVENTION AND CARE IN INDIA: VOICES FROM THE GROUND

Moderator: Anant Bhan

Anant Bhan: I welcome all to this witness seminar. In the first panel we have included Rupa, Nandita, Mridula, Ganesh and Prabha to bring to the table the survivors' perspective, and we hope to hear also their own personal narratives of having lived with TB. As we are all into activism and as it has been said in the feminist movement that the "personal is political", sharing personal experiences is relevant here. In the first session, let's hear more on what have been your own experiences within the space of the TB programme. We would like to know the intersection of the programme with patients in terms of engagement and how involved with the programme have you felt as a survivor and as a champion. We invite you to speak on stigma drawing upon your personal experience, and your views on integration of the perspectives of survivors and champions and the items which have to be revised in the programme.

Rupa Kumari | Experiences of TB before marriage and bearing with social stigma

Rupa Kumari: Thank you, Sir. When I was infected with TB, I had been pursuing MA studies. I had to face a lot of challenges due to the disease. I faced difficulty to go to college, to meet my friends. Then, I suffered from immense fear of stigma. I couldn't even confide with anybody as to how I felt. I couldn't even take help from my family members due to the fear of the disease. I lacked the knowledge and awareness of how TB could be treated and prevented from spreading. I was facing a lot of difficulties then.

Anant Bhan: While you speak, we would also like to know if the programme, that is, the health system supported you during the stigma you faced, whether you received the expected support from the health system, and if not, how did you address this?

Rupa Kumari: Yes sir, I received support from the health system. But there was a delay in seeking care from the government Anti-Tubercular Treatment (ATT) centre as I first visited a private hospital where I was not subjected to any sputum examination. But an X-ray was taken in which I was told that I am negative of TB. I visited the private clinic again where they gave some medicines for 15 days. I took the medications for 2-3 months but my symptoms of blood in sputum and loss of

appetite did not improve. Then I decided to seek care at the government hospital, where I was diagnosed of having DR-TB.

The STS (Senior TB supervisor) and staff at the centre supported me. I suffered from haemoptysis/blood vomits while taking the anti-TB medications. I feared what was wrong and consulted STS. Later, I went to a private hospital where I was treated for vomiting, loss of appetite and generalised weakness for about two months along with the ATT drugs from a government health facility. The STS reassured me that TB wasn't a deadly disease and that with continued medications it can be cured effectively. I completed six months of treatment, and when I joined Resource Group for Education and Advocacy for Community Health (REACH)¹³, I received good response and training which helped me overcome all the fear pertaining to TB. Having overcome the fear, I decided that I wouldn't hide about my illness, will be open about it, and to the possible extent, help other patients. Once I was cured, I shared my experience with TB patients and have continued working for and with them.

Anant Bhan: Thank you, Rupa. It was nice to know you received support from the programme and you have been involved in activism as a TB champion with REACH, supporting other patients as well. Please help us know what are your expectations in making TB programme better, specifically in supporting the patients through their TB treatment and post-treatment period due to the impact of possible side effects and mental stress caused by the disease.

Rupa Kumari: Yes sir, the government run ICDS (Integrated Child Development Services)¹⁴ programme is beneficial to pregnant women and children with respect to their nutrition and health. There is hardly any awareness and information regarding this programme amongst the people, especially in the tribal population. This programme helps to address specific concerns of pregnancy, the changes happening in pregnant women and to address their lowered immunity issues. This would help in preventing infections like TB in pregnant women and the new born infants.

I think in India, specifically in tribal areas, there is lack of information and people

¹³An acronym for Resource Group for Education and Advocacy for Community Health, REACH was established in 1999 in response to the rolling out of the Revised National TB Control Programme (RNTCP) in Tamil Nadu. Managed by an executive committee, REACH has been a key partner and leader in the fight against TB.

Our mandate is broad and includes support, care and treatment for TB patients as well as research, advocacy, public education and communication. We work with a range of partners including the RNTCP, local government officials, private hospitals, community-based providers and private practitioners among others.

¹⁴Integrated Child Development Services (ICDS) Scheme is one of the flagship programmes of the Government of India and represents one of the world's largest and unique programmes for early childhood care and development. It is the foremost symbol of the country's commitment to its children and nursing mothers, as a response to the challenge of providing pre-school non-formal education on one hand and breaking the vicious cycle of malnutrition, morbidity, reduced learning capacity and mortality on the other. The beneficiaries under the Scheme are children in the age group of 0-6 years, pregnant women and lactating mothers.

are unaware of TB, how it spreads, and controlling this infection. I feel as TB champions, who have suffered and fought this battle of TB, we are better placed to guide and convince other patients like us to take treatment, comply with medications and face the situation.

Anant Bhan: Thank you, Rupa. You have mentioned very rightly about the ICDS, Anganwadi system through which information can be shared and spread awareness regarding TB, which may help them take necessary precautions. This would also help pregnant women to keep themselves and their yet to be born babies free from infection. Thank you, Rupa. We will connect with you again during the open discussion.

I would like to invite Nandita Venkatesan to share her perspectives regarding access to TB care reflecting on the component of quality in TB care. For someone like you who has suffered DR-TB twice and undergone multiple side-effects of TB, we invite you to share your perspectives on access to TB care; was there adequate information specifically when dealing with DR-TB on potential anticipated side effects, what to look out for so that early intervention is possible and whether there was an intersection with the programme? We would like to know your thoughts on whether there was true engagement and how you faced this issue; now as a TB champion, how important are these issues according to you.

Nandita Venkatesan| Access to quality TB care and coping mechanisms to deal with adverse effects of Anti-tubercular drugs

Nandita Venkatesan: Thank you, Dr Anant, for inviting me to this platform. I am glad to be here to participate in this conversation. Before I begin with my journey of MDR-TB, I want to share a recent message I received from a 25-year-old lady with 90% hearing loss in her right ear and 60% in the left. It is unfortunately shocking to come across such instances, despite my own experience of hearing loss 8 years ago. It is also shocking because now with the government claiming at every platform about the availability of newer and better drugs and yet this girl from a metropolitan city suffered these sequelae. I am totally disappointed and disheartened that even after so many years, the improvement in TB care has not been up to the mark and people continue to suffer in the absence of a quality TB programme.

In response to the brief given to me by the organisers, I would like to briefly narrate my story regarding having lived with MDR-TB, relapse, side-effects, and a range of related matters. I have suffered twice from tuberculosis. The first time, way back in 2007, it was an intestinal TB infection during my college days. During those days, intestinal TB was rare. As a result, diagnosis was much delayed in my case. Initially, my intestinal TB infection was diagnosed as malaria, later as jaundice, and as a viral fever caused by rain. It was only after ruling out all of these infections that they said that I was having TB in my intestine. As you all know,

during that period in 2007, the TB treatment regimen was for a longer duration for almost about 15 months, as opposed to the current shorter course regimens of 7 to 8 months. I feel happy that now, people can get rid of TB within a shorter time span of about 7 to 8 months. However, I had to take it for 15 long months!

Later in 2013, I had a relapse, and with this re-infection, I had to stay hospitalised for a longer duration. I had to undergo many abdominal surgeries, about 6-7 of them, to save my life. This wasn't the end of it, and I suffered sudden unforeseen hearing loss due to injection of kanamycin¹⁵ which is widely used in ATT. Now where ever I go to speak at various different fora, I have repeatedly stated this bitter fact that the hospital-stay for longer period of time due to TB is only one part of the story. The sadder part is the transformation in my life caused by hearing loss! For anyone to suffer all of a sudden, without any warning or indication, hearing loss is something that is incomparable to any other aspects of TB care and side-effects of TB drugs. I used to feel angry and frustrated with the fact that I had to go through all this with no fault of mine in this whole journey.

However, now, more than anger I feel sad that from 2013 to 2021, it's been 8 long years, and yet the awareness about autonomy of TB patients in TB care treatment, and the responsibility of treating teams to inform them well about side-effects and every other aspect of the proposed TB treatment continues to be absent in TB care. The problem lies in the fact that many clinicians and government programme managers try to infantilise TB patients, that is, forcing their own opinions on patients and expecting patients to accept those opinions. They do not take into account the fact that the other party or stakeholder, that is, TB patients are well educated and informed enough to decide what is good for their health. There isn't any need to treat the patients as some ignorant kid who do not understand anything. Doctors should share relevant information with their patients including the possible side effects and that the patients need to watch out for these possible side effects. Patients should not be treated as kids, which has been my observation all throughout my own TB care journey.

I feel there is much information asymmetry between TB treatment and care providers and TB patients, that is, doctors have much technical information with them and patients have much less or no information in certain instances. In my opinion, a balance between these two constituencies is very important and I think, community engagement can play a major role in responding to this information asymmetry. One of the ways to respond to this information asymmetry is to involve communities at every step of programme development and implementation. This is where I feel a witness seminar like this one is important. Such seminars and opportunities/platforms for us to speak, show that patients'

¹⁵Kanamycin is bactericidal in nature and a strong anti-TB drug. Administered through IV/IM routes only. Common side effects are hearing loss(ototoxicity), nephrotoxicity and vestibular toxicity.

voices and survivors' perspectives are valued. The opportunity to speak in such platforms reflects on the initiative to put forth patients' voices and that we are listened to. This is a concrete evidence-based way to move forward.

To reiterate, I would like to say, patients shouldn't be infantilised, they need to be treated as equal partners when it comes to sharing information about TB prevention and treatment. Here, I would like to completely acknowledge the privilege of being from the metropolitan city of Mumbai, my parents being well-educated and belonging to upper caste and that I could get TB care at private hospitals. Nevertheless, I would like to state that I could get the care only at a very high cost which led to my family having to suffer long term financial repercussions and consequences.

Now, when I come across the information on COVID-19 and its long-term effects, which already exists for TB. We do have long-term chronic sequelae of TB treatment which has not been acknowledged the way long-COVID-19 is being discussed and paid attention to. I hope there exists a term of 'long TB' like 'long COVID'. So much of the discussion happening over COVID-19 and its long-term ill effects, why didn't these occur for TB and other neglected diseases as they are for long COVID¹⁶. In my opinion the COVID-19 scenario is similar and built upon what happened in TB.

Anant Bhan: Thank you, Nandita. I agree that those who are aware of TB would be aware that it leaves behind a lot of health, social and financial vestiges. It is surprisingly sad that long-term chronic effects of TB are not spoken about much, unlike long COVID-19 discussions which are taking place now. It is noteworthy that Nandita had to go through these challenges while completing TB treatment despite her privilege of being from an urban city, and we also heard her acknowledging the privilege of being from a well-educated family with means and resources. I remember we two co-authored a blog piece titled, "Nothing about us, without us: when critical medical decisions are made, patients must have a seat at the table"¹⁷. I would like to request you to elaborate a little more on your long-standing experience of advocating for TB patients' rights and also your experience of having spoken at the United Nations' Annual General Assembly (UNGA) and other fora, and your thoughts on how important are survivors' perspectives to be centre-staged within the TB Control Programme.

Nandita Venkatesan: I concur with the issue about community engagement which though exists for many years now, we haven't made much progress in this front. However, organisations like REACH, and yours (FMES), and other similar ones; and we also have individuals such as, Drs Anant, Madhavi and Anurag and

¹⁶WHO/2019-nCoV/Post_COVID-19_condition/Clinical_case_definition/2021.1

¹⁷Available from: Nothing about us, without us: When critical medical decisions are made, patients must have a seat at the table (indiatimes.com)

other public health professionals who are cognisant of the need to integrate communities and their voices in the TB programme. The government intervention at a policy level of creating TB Champions' forums at district and State level is a positive step forward. However, much more needs to be done to disseminate the already existing information about TB. I still get calls for help from patients from different parts of India. It makes us aware that TB programme system continues to be an unorganised and haphazard one with much inequity and information asymmetry between patients and the health care system or TB programme system, as I earlier referred to. There is a need for a systematic integrated approach to bringing the entire community of survivors together so that nobody is missed out.

I would dare say here that a change of mind-set of public health and government officials regarding treating patients as an important stakeholder and as one who should be considered and consulted with while deciding on their health is required. I have observed during meetings with state level TB officers, on a few occasions where officials tried to restrict the survivors/patients to speak only on certain issues of TB. This stems from government officials' sheer belief that they are much knowledgeable in the space of TB compared to patients. This makes me angry and I wish to rebuke such officials highlighting the fact that I am equally literate on this, especially having a degree from the University of Oxford now, and having lived with MDR-TB, am equally aware of this subject as you are. On many such contexts, there is need for systematic engagement with communities.

Very importantly, incentivisation of the time of TB survivors as champions needs to be considered; especially those with MDR-TB have their own needs and families to look after with priorities to make a living. Hence, incentivisation of their time for and involvement in the TB prevention and care programme is very critical. I think, participation of TB survivors having to bear heavy TB treatment costs, is possible only by incentivising their time and efforts.

Anant Bhan: Thank you Nandita, very well said that lived experiences are as valued as any other experience and expertise, and also about the need of incentivising their time and expertise with honorarium. Thank you for sharing.

We now request Mridula to share her perspectives on how her engagement or interactions with the TB programme have been, especially as you have been a TB survivor yourself and are from the state of Assam, we would like to know your lived experience. Though they say everything is free in TB care, we are aware that medications cost money, not everything is free and this being a chronic disease drains much of patients' money. Please share your experience on this and also on how the programme can involve TB survivors more, and what might be the hindrances in this.

Mridula Das | TB care in Assam and unique challenges faced during TB treatment

Mridula Das: Namaste, Sir. In 2019, when I was at hostel doing my master studies, I faced a lot of difficulty in pursuing studies due to fever and sudden weight loss. I was examined and after doing a lot of tests, I was diagnosed with abdominal TB. They put me on ATT of 99DOTS¹⁸, which I took for about a month. During this period, I suffered from severe vomiting, dizziness and excess fatigue. Then, I again went to the doctor and he re-examined, changed the medications, which were available at the pharmacy. I took the newer drug for about 6 months to find my symptoms reducing but had to continue it for longer duration as the prescribed one was of lower strength than 99DOTS, which is a stronger medicine and may be that is the reason I couldn't tolerate it.

I completed nine months of treatment with the drugs purchased from pharmacy. On re-visiting the doctor, the CT scan showed that the coverage of TB infections had reduced but it wasn't completely cured. So, I had to continue the same medications for yet another nine months. At the end of eighteen months, a repeat CT scan showed persisting TB infection in the abdomen. I continued the treatment, and at the end of 26 months, I was completely cured and the doctor asked me to stop the medications.

During the treatment, I used to get fever many times, had vomiting and dizziness. I had to discontinue my studies for a year, and resumed it when my health condition improved largely. I completed a Master's course and a Diploma in Elementary Education (D.El.Ed) during my treatment.

Anant Bhan: Mridulaji, you shared your TB experience of having gone through the TB treatment over a period of 26 months. During this long treatment period did you face any challenges like spending for your treatment, travelling to the treatment centre? And did the programme support you enough?

Mridula Das: No, I used to buy the medicines from the pharmacy and could access as they were affordable. Earlier I was given 99DOTS, the power of which was high and didn't suit me. So, I was put on low powered medicines which I could afford as well. But if anyone like me is diagnosed with TB, I feel it is better that the government health system provides them with free lower power drugs and that patients need not have to spend from their pocket for TB medicines.

Anant Bhan: How was your relationship with the programme staff? Did they support you through your treatment and what did you like about this, and

¹⁸99DOTS is a low-cost approach for tracking adherence using a combination of paper packaging and low-end mobile phones. the WHO has endorsed a set of digital adherence technologies, including 99DOTS. World Health Organization. 2018. Handbook for the use of digital technologies to support tuberculosis medication adherence. Available from: <https://www.who.int/publications/i/item/9789241513456>.

according to you, which aspects can be improved?

Mridula Das: I took treatment at Guwahati Medical College and Hospital (GMCH). Doctors there were good and supported me. They were close to me and treated me respectfully. They provided me with diet plans and talked about what should be eaten and what should not be. During my entire treatment period of 26 months, I faced no issues and the health system's response was good.

Anant Bhan: Good to know you got support from the health system. Do let us know if Accredited Social Health Activists (ASHAs) or Auxiliary Nurse Midwife (ANMs) from the health system visited you in the community?

Mridula Das: None from the health system used to visit me at the home. I used to go directly to GMCH, though it was far from my house. I would visit the doctor myself and in-between the hospital visits I would get blood tests to know my haemoglobin level and used to get other examinations done to know the status of disease spread to the liver and kidney once in about two months. I did not get any help from anybody in the system for these diagnostics.

Anant Bhan: According to you, on which aspects should the programme concentrate so that patients can be helped more?

Mridula Das: TB is a disease which can be cured with treatment and patients who are on the 99DOTS regimen get cured. The TB programme has no problem. People should be aware of TB disease, how this disease spreads and how it can be controlled. When I got TB, I was worried whether I will be cured of this disease, what will happen to me. But the doctor kept assuring me that this is just a disease which can be cured with treatment and regular medications. So, the programme and treatment were just good enough.

Anant Bhan: You mentioned that TB drugs are very powerful. Why do you think so and what impact did it have on your health?

Mridula Das: Everybody's health is individualised, and in my case, I had abdominal TB. Due to this, I lost a lot of weight and was reduced to 29 kgs and my haemoglobin became 4.5 gm. Hence, couldn't tolerate the heavy TB medications. If all would get lower power TB drugs at ATT centres, it would be good.

Anant Bhan: If you could access to TB care close to your place, at a nearby PHC/CHC/SC¹⁹, would that be better?

Mridula Das: Near my house there isn't any medical facility, such as, PHCs, CHCs or SCs where I could get treatment. The medical college is very far from my place but I used to go there for medical care.

Anant Bhan: Thank you so much for sharing, Mridula. Anurag, I see your hand

¹⁹<http://nhm.gov.in/index1.php?lang=1&level=2&sublinkid=971&lid=154>

raised. We will have one round of interventions from everyone and then we will open it up for discussion.

Anurag Bhargav: I had a comment on what Mridula mentioned. But I can take it up during open discussion.

Anant Bhan: I now invite Mr Ganesh Acharya, a Tuberculosis-Human Immunodeficiency Virus (TB-HIV) survivor, an active advocate at national and international level having spoken on access and patent issues. I would like you to share your perspectives on the importance of activism and advocacy in TB space; to speak on disruptions in care during the COVID-19 pandemic and your responses on the same and to share the significance of campaigns in improving TB care.

Ganesh Acharya | Access to expensive TB drugs and intersection of TB programme

Ganesh Acharya: Thanks to the organisers for providing me with the platform and organising this witness seminar. I too have survived TB twice. TB is not a new disease; anybody can develop TB and earlier speakers have shared their experiences on the same. I would like to start by sharing two of my very recent experiences, concerning expensive drugs and patents. During the second lock down of COVID-19 pandemic, somewhere around July 2021, a 13-year-old girl, from rural Maharashtra, Raigad district, was diagnosed with extensively drug resistant TB (XDR-TB). Her mother was told to take her to Mumbai as there wasn't any medical college or hospital in Raigad district. We all can imagine what happens when a woman from a rural and tribal area visits a metropolitan city like Mumbai.

The young girl stayed at the hospital for almost a month and the poor mother would travel to her village once a week. She was not aware of our network of TB champions who support TB patients. She only knew that her child had XDR-TB and she required medications. The patient was referred to a peripheral hospital as she wasn't taken up for treatment by the medical college directly. Therefore, she went to the J J Hospital where she was put on kanamycin. She couldn't be put on bedaquiline as she was less than 18 years and delamanid wasn't available. After about a month when the child started losing her hearing, she was put on an alternate regimen of amikacin. The mother and the family of the young girl approached us only in September 2021. It is left to one's own imagination about what they might have suffered during those 4 months from the time they came to Mumbai until they approached us.

Even after four months since this young girl was put on treatment for her XDR-TB in Mumbai, the new drug delamanid wasn't available for them. In the past 50 years, very little is spent on research on TB and TB drugs and hardly any new

drugs have come to the market. Despairingly, these new drugs are also patented and under the monopoly of certain pharmaceutical companies. The cost of these drugs is dictated by a few pharma companies who have established a monopoly over their productions for many years. Thus, the cost of these drugs continues to remain high and the government cannot purchase them for the sake of poor patients, who are deprived of newer and better treatment.

As Nandita mentioned during her discussion post in 2018, TB patients are not supposed to receive older injectable forms of medicines. This has been emphasised by the TB programme itself at various forums. Despite these guidelines from the Government, the child was given two doses of injections. She did not receive the new oral drug of delamanid even after four months between July and September 2021. Finally, we tried through another NGO and tried to put her on an alternate oral regimen of delamanid. The child was then able to return to her village after 5 months. It is regretful and hard to imagine as to how much the child and her family from rural area must have suffered during this whole journey from diagnosis to receiving oral drugs.

This makes it evident on the criticality of the availability of drugs. It also shows how little an individual patient's dignity and respect is valued in the health care system when it comes to access to treatment. Patients are mostly seen by the system from the point of view of a specific TB bacterial strain for diagnosis and treatment purposes and rarely treated as a fellow human being. We as activists also focus more on access to treatment for the sake of saving the patient's lives. The value or respect of a person/patient depends on the outlook of society towards TB patients. A change in this attitude of the society has not happened over the century, at least in the TB space.

The second example which I would like to share is of a 23-year-old woman whose brother approached me through Facebook. She was the only breadwinner in her family taking care of her mother-in-law and her young child of one and a half year old. Her husband being an alcoholic was not taking any responsibility to support the family. She lived in Mumbai and has all the tertiary hospitals, such as, the Hinduja hospital, the J J hospital within the periphery of 2 to 5 km. She was diagnosed with TB infection in her brain at a private facility mentioning that 95% of the infection was XDR-TB and the rest 5% was drug sensitive TB. The diagnosis of TB struck the woman and her brother with fear and that she had to entrust her very young child with her mother-in-law and run for treatment. Up until the last week, she still wasn't examined for pulmonary/chest TB nor was a lumbar puncture (LP) carried out for her at the private facility where she is seeking treatment from. Despite being in Mumbai, she could not access proper diagnosis and treatment in a timely manner even in today's times.

Like Nandita mentioned, during the pandemic, facilities were made available for all and anyone with COVID-19. However, such an approach making sure equitable

access to TB patients has not happened in the TB space. Government has to take heed about making facilities equitably accessible and available to all. In rural areas, even today, we don't have medical colleges. We are equally responsible for this inequitable distribution of health care. During COVID-19 all our diagnostic tools like Cartridge-Based Nucleic Acid Amplification Test (CBNAAT) and GeneXpert which helps in diagnosing Pulmonary TB and MDR-TB within short span of time were shifted from TB programme. We still don't have adequate health facilities and testing for TB is also lesser than in earlier times. I agree COVID-19 is a pandemic and may continue for some time to come, but the infrastructure and essential items of one programme cannot be diverted to other, at the cost of the existing programmes, such as the TB programme.

If we speak of person-centric care, I think, patients should be centre-staged in healthcare service delivery, and they should be playing a crucial role in testing, diagnostics and treatment guidelines. We as TB survivors and TB patients should be considered as important players in TB prevention programmes and activities and not be viewed just as individuals with TB infection and causing spread of the disease. For instance, if I am sick and the system doesn't invest in treating my illness, or doesn't bother to know what is wrong with me or diagnose and treat me, then it is not acceptable. Along with biomedical facilities, psychosocial and economic facilities have to be provided for better health outcomes.

In this regard, I would like to mention one more point that TB services still do not include counselling care for patients. Earlier speaker, Rupa Kumari, mentioned that the Anganwadi system under ICDS has to be strengthened and a similar system has been there even for TB, but the way TB programme is there and how the disease occurs, we do not have designated counsellors who can speak and coordinate for the patients. The roles and responsibilities of any designated person is not clearly defined. There aren't designated counsellors to look into the psychological wellbeing of TB patients. As mentioned by the earlier speakers, an MDR-TB patient suffers from a lot of mental stress due to the long-drawn illness. I would also like to mention that within this system some are more vulnerable. For example, a TB patient from a Dalit community might be more vulnerable. They suffer perpetually of discrimination in society and may be facing such discrimination in the health care system and possibly heightened negativity if they are diagnosed for TB infection. We know that they are discriminated both generally and also in the health care system in the TB space, but we require more evidence for the latter. Thank you.

Anant Bhan: Thank you, Ganesh, for sharing your personal experience of supporting other patients. I wanted to know from you, having involved in activism in both the spaces of HIV and TB, you might have come across many common things between the two programmes. What according to you are some of the differences in the HIV programme with regards to advocacy and activism? Such

differences may be regarding patients' perspectives or involvement of champions or community engagement or similar sort of aspects? Are these kinds of things missing from the TB programme?

Ganesh Acharya: Exactly, Dr Anant. I have recently accepted a new role in the HIV movement as a regional coordinator of the Fight AIDS Coalition (FAC) for the Asia-Pacific region as part of the Civil Society Organisations (CSOs) where the WHO changed the terminology of Acquired Immunodeficiency Syndrome (AIDS) to Advanced HIV disease.

I would like to thank REACH and other organisations who helped in coining the terminology of champions in TB programme. Earlier, TB patients did not exist for the programme. I think HIV programme is one of the successful public health programmes of India which is globally recognised. The reason for this success is the fact that it invested in bringing to the forefront the HIV community. The HIV community was and continues to be in the forefront of all aspects of the HIV programme including, HIV testing, linking, navigating through the system, treatment, and responding to the stigma. HIV programme has been successful because technical groups are also supported by the HIV-affected community. We find HIV community representatives in the HIV programme at every level — from policy making to the work at ground level; from Anti-Retroviral Therapy (ART) centres to National AIDS Control Organization (NACO) technical resource level meetings. HIV-affected communities run the programme themselves. TB programme has to learn from the best practices of the HIV programme. Amongst the HIV infected, almost 8-10% get affected with TB. Therefore, there is need to utilise the existing facilities for TB champions rather than developing something new. In TB spaces, we have champions. But how long can we encourage them separately and how do we sustain their participation? Because there is already so much invested in the HIV programme, and that 8 to 10% are HIV-TB affected, integrating these HIV-TB champions with the TB programme champions is more cost-efficient and may also be efforts-efficient.

I would like to share data recently put out by the WHO-SEARO office. It suggests that the total number of HIV-TB patients in India taking treatment at ART centres is 16 lakhs. Out of these, about 35% have CD4 count below 200 and hence, are at risk of getting activated for TB. Therefore, with so many TB patients from HIV community itself, it seems logical that TB champions and HIV champions work together as a single constituency and it would be very beneficial as well as cost and time efficient.

Anant Bhan: Thank you, Ganesh, for sharing your perspectives. Now, I call upon Prabha Mahesh to share her experience. You have been involved in counselling care for TB patients and survivors; and have been actively working with them. In your perspective what is the importance of psychosocial counselling for TB

patients and survivors? Does peer support have a role to play? If yes, in what way? Are we able to work with TB patients and provide them peer support and what do you think are the gaps in the TB programme on this front, and what are your thoughts on how these could be addressed?

Prabha Mahesh | Psychosocial counselling and networks of TB patients and survivors

Prabha Mahesh: Thank you and a very good afternoon. It is always overwhelming to see our fellow champions together in such spaces. Platforms like this rejuvenate and we all gather new strength and energy. Before I even talk about the psychosocial aspect of tuberculosis, I would like to begin by sharing my lived experiences with TB like my other friends have shared their own today. To me, these lived experiences are of critical importance to the TB programme. When talking of TB, people tend to emphasise its clinical aspects. But I feel that TB is far beyond just about its clinical dimensions and they tend to over medicalise the disease.

I have been a TB survivor and have been working in this space for more than two decades and have reached out to 60,000 TB patients. So, here I wear a hat of a TB advocate and I am the Project Director at the organisation, Alert India. We are into disease control programmes, and have done some pioneering work in the area of supporting leprosy patients. I have been leading the TB control programme in Mumbai, Maharashtra and also in other states. I am a board member and founder of the organisation called Touched by TB²⁰, which is a national coalition of TB survivors. I am sharing some of these details as it is relevant to my experience which I would like to share.

If we speak of counselling, one of the questions is: who might be the best person to counsel TB patients? The doctors don't bother to inform their patients. For example, in my case during the investigation of my health concerns then, medical advice for going for a TB diagnostic came only in the last. Like Nandita rightly said often it is the last thing that strikes anybody (doctors) to advise patients to get a TB test done. When I went with a lump in my lymph node and was suspected and tested for carcinoma and other possible diagnoses, I had a one-year-old child. All these diagnostics that I had to undergo as advised by doctors and developments during that journey of getting through diagnostics only pushed me into depression.

Finally, by the time I was diagnosed with TB, I had lost a lot of time. I had to also undergo a major surgery and the mental trauma of hospitalisation and separation

²⁰REACH | 'Touched by TB' – the coalition of TB people in India formed (reachtbnetwork.org); <https://twitter.com/tbtouched?lang=en>

from the family added the unnecessary baggage of guilt and suffering which could have been avoided. This entire process of going through a series of diagnostics was started by my doctor who did not effectively counsel me. I was diagnosed with Extra Pulmonary Tuberculosis (EPTB) which doesn't spread. I was not properly counselled about the non-contagious nature of the type of TB I have had after I was diagnosed with it. As a result, I suffered from guilt and anxiety for a period of a few months between the TB diagnosis and the point at which I was told that it was non-infectious thinking that I must have been spreading the infection over the period of one and half years when various diagnostics were being done. This was the scenario 10 years ago and I have known many women patients who suffered from a similar guilt that I did. This has been a major part of the counselling care I provide, that is, making people understand that EPTB isn't contagious. This simple message is one of the key points in counselling as it helps address much of their emotional trauma.

Anupama and all other stalwarts, my colleagues and survivors are here, and many of them would agree that stigma begins even before the treatment begins. For example, just two days back I got a phone call from a person whose MDR-TB was just confirmed. But he was unwilling to go for treatment. He expressed his fear to me saying that he would be sent to the Sewri Hospital²¹ and that he was afraid of going there. He felt that once he got admitted there, he wouldn't come back alive. On that day late at night, I spent half an hour counselling this person and explaining him the diagnosis, what are the next potential steps and processes in the TB treatment, and spent the next 20 minutes counselling his family on what would be the next course of action.

This patient was from an interior area in Mumbai and it was good that they contacted me. To me, this was the usual access to care issue as he had only one private provider in his vicinity and the government local PHC was very far. Fortunately, I had a former colleague who had also lived with TB in the past living in that area. He agreed to make a home visit to this person the next morning and try to help him and his family out. Such kind of help is possible with this kind of networks of TB survivors. However, given the scale of TB occurrence in a country like India, there will be number of people being diagnosed with TB and number of deaths happening of TB patients every minute even now while we are discussing this matter.

We are now in 2021 and when I entered this TB space about two decades ago, people used to see the Sewri Hospital in Mumbai as a place of no return. It is extremely unfortunate that if this feeling still persists in the people, then it is high

²¹<https://www.dnaindia.com/mumbai/report-500-beds-down-sewri-tb-hospital-braces-for-rise-in-patients-this-monsoon-2229455>

time that an attitudinal change regarding TB disease is required. We as advocates, and having survived the battle with TB, have to ensure that the stigma attached to TB disease and the fear stemming from such stigma in the minds of people is addressed. I am sharing these details and stories to highlight that my response to such situations is shaped by my lived experiences with TB.

In yet another case, a Category II^{22,23} patient refused to take medications, saying it was even difficult to swallow them. She was from a slum area called Suryanagar in Vikhroli, a Mumbai suburb, which had a DOTS centre. I tried convincing her but, she actually spat the tablets on my face retorting, nor was I aware of the extent she was suffering. Until then, I never had the guts to share with anybody openly that I also was a TB survivor due to the stigma attached to the TB disease.

In this regard, it is noteworthy that HIV networks are different and way better than the TB networks as Ganesh mentioned earlier. HIV networks have gone way ahead of their TB counterparts. Today HIV people come out and say openly at many platforms and forums that they have survived HIV. I have mentored about 2500 TB patients and am well cognisant of how much time it takes me to speak, convince, understand them. Then they come out and declare that they also were TB patients earlier. In reality, it takes much longer time to declare the TB status than HIV status of a person. When this woman spat her TB medicines on my face, that was a turning point which made me into an advocate from a TB survivor and a worker. Now when I think back, I ask myself as to why I had to wait for such an incident to happen, to even disclose my being a TB survivor and turning into an advocate for the rights of TB patients and survivors. Today there are more TB patients at grassroot levels, who may feel that counselling is taking place, but what is thought of as counselling is mere communication. But there isn't any treatment literacy that takes place as part of this communication. It is important that counselling care begins with treatment literacy.

I was conducting training for my team of Sputum Collection and Transport (SCT) agents who mentioned that their curriculum included how the patient has to expel the sputum, how it has to be collected and transported. I replied that it is not all that is there in the curriculum and that we need to know beyond that. Even a person's readiness to come out and get diagnosed is a big thing in the TB space. Many are not ready to get tested and diagnosed because they fear if they are tested positive what to do. A similar thing happened during COVID-19 as well,

²²<https://tbfacts.org/treatment-category/>

²³Treatment category is an historical term from the earlier days of drug treatment for TB. For many years the WHO defined four treatment categories for TB. (WHO, 1997). Category I was for new smear positive patients with pulmonary TB.; Category II was for sputum smear positive patients who have relapsed, who have treatment failure or who are receiving treatment after treatment interruption.; Category III was for new smear negative pulmonary TB patients (other than those in Category I), and patients with new less severe forms of extra pulmonary TB.; and Category IV was for chronic cases who are still sputum positive after supervised re-treatment.

many were not ready to get RT-PCR test done since they feared of the consequence of getting tested positive.

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It is true that earlier the TB programme didn't even have a designated role of a counsellor as Ganesh said. But now we have designated positions for counselling professionals embedded in the TB programme. Again, often communication is confused with counselling. Unfortunately, these personnel who serve as counsellors on the programme do not get properly trained or don't have enough spaces within the TB programme for quality capacity building. I have been a witness myself of such capacity building programmes and I have provided my recommendations and feedback on how these can be improved. According to me, these capacity building programmes are just to check or tick a box sort of activity. The government provides funds which must be utilised for training. Training is provided until the funds are exhausted and these training often are just namesake exercises. No one is bothered about evaluating these training interventions or to know what has been the impact of these training. There is no full-fledged or 360-degree capacity building that takes place in the TB programme.

We along with Maharashtra District TB Control (DTC) Society, under the Patient Provider Support Agency (PPSA)²⁴ programme roped in the TB survivors, and trained them to provide them opportunities and help strengthen the TB programme. We need to invest in their training and capacity building because we have the information available and they have the lived experiences, which is a much-required combination for contributing to making the TB programme more

²⁴PATH. Patient Provider Support Agency: A toolkit to implement Patient Provider Support Agency in your region. Available from: PPSA_Toolkit_89YDt8C.pdf (azureedge.net)

²⁵Saksham, Tata Institute of Social Sciences (TISS).: "Saksham (which means "making capable") is a project of the TISS funded by the Global Fund since 2008 to support the Ministry of Health and Family Welfare in its fight against HIV and TB. Saksham has shaped the Psychosocial support program for HIV and TB in the country. Globally, Saksham is the only programme managed by a public national academic institution under the Global Fund. Currently Saksham has three major grants in the area of HIV & TB counselling, capacity building and community engagement.". "**Saksham Pravaah**: Using the learnings accrued from the engagement with the HIV/AIDS epidemic, in 2015 **Saksham Pravaah** introduced psychosocial counselling for TB in government's TB control program in 4 states viz Maharashtra, including Mumbai, Gujarat, Karnataka, Rajasthan and has demonstrated the need for moving beyond the "bio-medical", "disease control" approach and addressing social determinants of TB.". [From: About | Saksham, Tata Institute of Social Sciences - Field Action Project (tiss.edu)]

effective. All they need is more knowledge and skills to augment refinement in or strengthening their understanding of the complexities of the issues enabling them to be better equipped to help other TB patients and impart the training as well. This is important but unfortunately it is not happening.

We have Saksham Pravaah²⁵ counselling for MDR-TB. Generally speaking, all such projects are sponsored or funded which function for 3 to 5 years after which they aren't sustainable. We trained a fleet of TB survivors under this project and they were pretty good. The DR-TB Centres where MDR-TB patients are counselled are not up to the mark and these trained TB survivors supported them. Since that the project's funding would end, there is no way we can continue this support. Sustainability is a big issue for such projects and they need to be sustained for a longer duration. These projects cannot just be dependent on funds but instead need to translate them into long-term programmes.

Earlier, there used to be 'family-member DOTS' programme along with community DOTS. The family-member DOTS initiative used to identify members of a patient's family as DOTS provider and they expected to follow the DOTS norms. Family members used to be reimbursed for their services. We had engaged all the private providers through this scheme. I have been implementing PPSA in Mumbai. When we engage private providers, they get reimbursed, and incentivised. So, such similar policies have to be implemented. We do have policies like NGO forums and TB forums. We have to ensure that the people who are speaking here are the representatives of TB patients or have lived experiences and/or have witnessed suffering at the grassroots so that they can relate better with the TB patients as counsellors or DOTS providers.

In many NGOs, we have many people who are accessible; in fact, I was very happy when Nandita said she was approached and reached out by TB patients. Why do these patients reach out to us? This is because REACH and other organisations have worked hard on developing apps for TB patients; they have a hotline which serves as a lifeline! People are working on this but that has to be modelled up. What kind of support rendered to such organisations? We are truly happy that TB patients approach us and others connect us to TB patients. These were doctors, or other stakeholders including even the people/staff at my grocery store who contacted me saying that they knew TB patients and they wanted me to connect with them and help them out. We need to be available and accessible to all those in need but this have to be more systematic and organised.

I would now like to briefly mention regarding the other issue of what happened to TB care during the COVID-19 pandemic. As many of my friends here and Ganesh have shared, we are falling short of supplies needed for TB diagnostics, such as cartridges used for CBNAAT. Also, doctors are facing difficulties in ensuring that diagnostics are carried out as per the standard protocol during the pandemic. For example, recently and prior to the pandemic, they have been using the progressive

advanced TB diagnostics in the TB programme. However, in the face of short supplies of the materials required for such advanced TB diagnostics, they had to fall back on the older diagnostic methods, such as Acid Fast Bacilli (AFB) sputum microscopy. Neither patients if they earlier had undergone CBNAAT diagnostics nor doctors are happy with these older diagnostics. Programmes are planned and implemented but they need to be effective and prepared to face any unforeseen disasters. Furthermore, the projections or targets have to be realistic. We being cognisant of the fact that there are still TB deaths happening and therefore to meet the target of controlling TB by 2025 seems too challenging. This makes it obvious that the investments and the efforts for TB need to be substantial and accelerated.

During COVID-19, we made optimum use of digital technology and social media. We created WhatsApp group of active TB patients and the cured patients became buddies who provided them the counselling for treatment adherence. We sent reminders to patients helping them to comply with treatment regimens. We made extensive use of social media where cured TB patients have come forward and they have been sensitised to support TB patients who are still on treatment. Similarly, we have made small groups or associations of TB patients for instance, patient support meetings. Now that the mobility restrictions are getting relaxed, we tried small group in-person meetings with these PTB support groups. The point I would like to emphasise here is that the cured patients can be best counsellors for the active TB patients. I have heard in many Focus Group Discussions (FGDs) that stigma can be self-induced amongst patients or within their family, and that it has not escaped even those who are well educated and those who are from doctors' families, and those with understanding of modern science of illness like TB. In these group interactions, I have heard many patients sharing the fact that there are instances when patients are not disclosing even with their family their TB status and the fact that they are on TB medication. There are people who do not want to take the support of their spouse. How demeaning and depressing is this fact and imagine the kind of counselling efforts this would require for creating awareness amongst family members of TB patients. These kinds of experiences demonstrate that the stigma that exists in the family is concerning.

The other point I want to strongly emphasise on this platform is that there are many parallel groups functioning for TB patients, such as the TB survivors' group. When many of these small groups are working in parallel there is the risk of dilution of intentions, goals and objectives, and there might be a risk of shifting the focus. I feel that all these groups need to work in close collaboration. Even in the HIV space, there are multiple groups and there are differences in their opinions and intentions. Today, Ganesh would agree with me on this; if somewhere a mishap happens to a single HIV person all the groups will come together and fight unitedly for the cause. This is the kind of unity I would like to

see in the TB space.

Last week when I was in Delhi, I learnt one Trans person/gender (TG) was murdered in one particular area and the whole of the TG community came together that night and shared their experiences in the morning about the kind of advocacy they were involved in. We may have different thought processes, but there is need for all the TB survivors, champions, and advocates to come together as one organisation or entity and this is the need of the hour.

Anant Bhan: Thank you so much. One of the key messages coming out of this seminar is that the community has to come together to support each other. Due to lack of understanding about the disease and pervasive stigma, the families of the patients need support mechanisms and counselling, as they are also involved with the patients. How do you think this can be addressed and what are the best practices? Are you seeing family involvement happen in any way?

Prabha Mahesh: Yes, it all begins with the family. All of us survivors here, along with my friends who spoke earlier would agree, family support is important. Of all the patients I have seen, the kind of emotional scar on the minds of these patients, the trauma that they suffer from because they have not been accepted by their families or have been thrown out of their families is immense. Family is the first group into which we are born and we know that we don't choose families to be born in. One of the most important things is to counsel the family members. The family members have to be made responsible during the entire journey of treatment adherence, and ensuring that post TB treatment patients are taken care of. Families face a number of problems stemming from stereotypes that exist in our society. For example, families getting worried and anxious about getting their girl married who is suffering from MDR-TB, who may carry scars on the body, or her skin might have been affected due to TB and TB medications, and any other side effects of the TB treatment. Families ask many questions on these fronts. As they are bothered by so many concerns, some are real and some imaginary. Hence, extending counselling to create awareness amongst families is very important.

We have micro communities, where we have identified community spokesperson or leaders who can influence family members of a TB patient and ensure that attitude change takes place. We have identified such spokespersons in the community who is responsible for anything and everything in the community. Stigma is that thing which cannot be warded off and it requires lot of efforts and time to get rid of or responded to. A lot of interventions are needed for a TB patient to cure the disease. This requires family support and involvement. Cured TB patients/survivors play a very important role there and we have experienced success in it by involving TB champions. Also, in community mobilisation and of course, as the influential person in the community and private providers, the doctor can contribute significantly and bring in an attitude change in the

community.

Anant Bhan: Thank you so much, Prabha, for very useful set of comments and contributions. I will now open it up for discussion. I know a lot of interactive chat discussion also happening.

Anurag, you had a question or comment?

Anurag Bhargav: I am not sure where to begin, but we should understand that there are multiple levels of inequity and different ways of examining diseases based on where they occur and who is affected. So, TB is a classic case of where the patient perspective was neglected by the medical community or international medical community, whatever you may say. For instance, in the treatment guidelines, the terms that was used earlier was 'case finding' and chemotherapy and the term 'patient' was not even mentioned. The underlying assumption was that the diagnosis has to be made, the patient needs to be given certain drugs, and one just has to ensure that the patient takes those drugs, and that everything will be fine. Another significant issue is that all the policies have been usually formulated by people in higher income countries who often lacked practical experience of working with TB patients in countries like India, and listening to them.

I will illustrate this dimension with an example which was of concern to us. It relates to the dosages of TB drugs which were divided into two categories earlier: one for patients who weighed less than 50 kilograms (kgs) and another for patients who weighed more than 50 kgs. In Chhattisgarh, while running a TB treatment service in a non-profit organisation, I encountered a patient from a tribal area who was severely underweight (around 28 kgs) who was given the same drug dose as would be given to a person with 49 kgs. As mentioned above, we had only two categories of patients — those who weighed less than 50 kgs and those more than 50 kgs — to determine the dosages with the corresponding regimen formulated by WHO and followed by India's TB programme. She developed seizures as a result of the over dosage of isoniazid and fell into the fire and suffered about 30% burns. She came to our centre. Thus, these very frail and thin people were not able to tolerate this dosage, and they would vomit, they would feel very weak. And there was no way to deal with this adverse effect because no education was provided to the people about it or those supervising their treatment. The treating doctors themselves were not registering these adverse effects failing to capture patients' voices.

The TB research centre at Chennai had pointed out in a publication in 1986 that patients with TB in India had a higher frequency of adverse effects because the dosages meant for higher weight in the west were used without adjustment in lower weight patients with TB in India. Yet the RNTCP treatment guidelines in 1997 recommended the same dosages in adults irrespective of body weight. This

was changed later in 2005 with a separate category for patients who weighed less than 30 kgs. With the kind of experiences I have had in my own practice, I had to explain this issue to the National TB programme, and therefore the need for the TB programme to modify the dosage of TB drugs according to weight range in our context. We also raised this issue in a technical paper in 2008. Now, India's TB programme finally has dosages that are more appropriate for patients of different weight categories in the Indian context. These examples from the ground demonstrate that we have consistently ignored our own patients at all levels, haven't listened to them or catered to their needs. Instead, we are being driven by policies which aren't responsive to what is happening on the ground.

Whenever a drug regimen is developed in the west there is a lot of work undertaken on its impact on the 'quality of life' of patients who receive these regimens. This takes into account the patient's experience with regard to adverse effects and related aspects. But in India, where is the data on adverse effects on patients who are under drug therapy? These adverse effects go unrecorded and the pharmacovigilance mechanisms are weak. So, if somebody is developing deafness, or somebody is developing neuropathy, or somebody is developing hepatitis, there is no system of recording, auditing and feeding these back into the programme.

The other point I would like to make is about how the emergence of HIV impacted TB care in India and elsewhere. I must not be disrespectful of the HIV community and the people advocating for the rights of persons with HIV. But the fact that HIV struck the west before it struck India really altered the whole perception of the HIV disease. Tuberculosis programmes in India were struggling for a few crores at the time but funding for HIV came flooding in which didn't match the scale of the problem at the time. However, what stood out in the HIV case were patients' voices giving rise to patients' networks. This was because they were very vocal, they had a lot of international backing, and there were celebrities who came out sharing publicly their HIV positive status saying, "I'm HIV positive". No such thing happened with TB except for example, in India one leading actor came out saying that he had TB and possibly it was EPTB. So, there has been a differential approach to HIV and TB, the latter being a poor man's disease, occurring in the Third World. Until HIV struck, everything was okay with TB in India.

The India's TB programme in 1981 was allocated only INR 20,000,000/- (two crores) for two million patients when patients were dying in hundreds of thousands. A follow up study of patients treated in the 1980s showed that nearly 30% of patients treated in the programme were dead after two and a half years, and an equal number remained infectious. In other words, the programme was performing very poorly but nobody really bothered. That's one thing, but there's also another kind of problem and that is the policies never actually reflected the situation on the ground including experiences and perspectives of patients and

communities. It's time that when policies are made at the level of the WHO and at national level, like the RNTCP, communities should have an active role in defining how these policies will translate into things useful for patients. Unless that is done, we will always be trying to limit the damage after it has occurred.

The second issue is when we're talking about TB, and I've worked with patients with TB in the past 30 years. I feel, however, that what we need the most is a strong public health system not just for TB but for all other diseases. This is because even with the finest TB drugs available in the world, they will not be available to patients without an adequate public health system. Also, this health system must be capable of addressing the major problems people currently face regarding availability of TB care facilities at a place which is close to where the patients live. These problems include not only TB but diabetes, mental health issues, etc. Who is going to counsel TB patients and those with diabetes? Similarly, for mental health patients, counselling care and its operational facets need to be thought through.

With our current health care system, we cannot have separate counsellors for different health conditions, such as TB, MDR-TB, diabetes, HIV positive, and a range of other illnesses. We want a health care system which addresses all major health issues and a system of counselling and follow up which can be delivered by primary health centre staff and adopted well for patients' communities with different health concerns.

In this regard, I would like to share the approach we adopted a decade ago when we were doing a TB programme in the rural area and medical graduates were participating in that programme. We had trained a group of medical professionals to develop skills and attitudes to listen to their patients for half an hour. We had developed an information booklet in Hindi. This was given to all patients diagnosed with TB before we would do a counselling session with them like Nandita, Mridula and Prabha said. The vast majority of patients are ignorant about simple things such as diet, treatment regimens, and the spread of infection with TB. First, we must find out what TB patients know about the disease and educate them. While counselling is essential for the patients and is a matter of importance, simple education should be provided to them, as well. Therefore, I would suggest that before we start contacting counsellors; let's become more efficient patient listeners and health educators to enable us to enhance health literacy amongst patients. We should also aim to make services socially accountable and allow patients to demand it. If these elements are not integrated into the TB programme or into the health system, we will keep making the same mistakes.

²⁶Datta, M., Radhamani, M. P., Selvaraj, R., Paramasivan, C. N., Gopalan, B. N., Sudeendra, C. R., & Prabhakar, R. (1993). Critical assessment of smear-positive pulmonary tuberculosis patients after chemotherapy under the district tuberculosis programme. *Tubercle and lung disease : the official journal of the International Union against Tuberculosis and Lung Disease*, 74(3), 180–186. [https://doi.org/10.1016/0962-8479\(93\)90008-L](https://doi.org/10.1016/0962-8479(93)90008-L)

For years, I have been telling those in the TB programme of the Joint Monitoring Mission (JMM) about a patients' charter. It will be a tokenism if we are not monitoring its implementation. For example, if there is no grievance redressal mechanism within the TB programme, where will patients go if they don't get medicine and/or if they faced discrimination in the TB programme? It is important that grievance redressal be built in TB programmes.

I would also like to share one more thing which I found useful. It covers all the points that have been discussed so far in the conversations today. We published a paper²⁷ which refers to eight steps, making a more pro-poor and effective health services in the TB programme. These eight aspects are: ensuring accessibility to TB care, availability of human resources, nutrition, financial, psychosocial support, avoiding stigma and discrimination and lastly the functional mechanisms relating social accountability as a rights-based TB programme. We must integrate all these aspects into a TB programme that is rights-based so that the treatment is given according to the patient's wishes and not as per the whims of the person providing the care. We should talk to the patient and respond appropriately. There should be a patient charter and grievance redressal mechanism for the patient. As Prabha mentioned, we have to be proactive and speak up otherwise they might use us as a tokenism. We are patients' groups and can effectively take part in the programme. What has been promised to patients by the TB programme must be delivered to them without fail.

I'm sorry if I took more time. But I would like to highlight that there is one more problem relating to bedaquiline and its compulsory licensing. If this was a drug for COVID-19 or HIV, we would have been able to produce all the drugs. But why are TB drugs still hanging in the balance? There are enough safeguards in the TRIPS agreement that allow to issue a compulsory license if a particular health condition or disease stands at a scale to be treated as a public health emergency. Issuance of such a compulsory licence enables us to produce/manufacture these drugs/medicines in India. However, in the case of TB, since we do not have compulsory licensing, this particular drug bedaquiline remains very expensive. As a consequence, we procure only limited quantities of bedaquiline leading patients to continue to be deprived of oral drugs and are kept on toxic drugs. I think, this is a very specific issue here where patient organisations have to articulate this more strongly in addition to what is being done on this front.

I would say that while people are working in TB space, let us all join hands with patients suffering from other health conditions such as diabetes who are demanding access to affordable and patient-friendly insulin. It is important that

²⁷Bhargava, A., Bhargava, M., & Juneja, A. (2021). Social determinants of tuberculosis: context, framework, and the way forward to ending TB in India. *Expert review of respiratory medicine*, 15(7), 867–883. <https://doi.org/10.1080/17476348.2021.1832469>

the voices of patients with different health conditions are merged to strengthen patients' networks. This will help mutual reinforcing of issues of concern, accountability related matters could be fore-fronted and policies could be made by keeping clearly the patients' perspectives in mind.

On a related note, it is very funny that if we write a letter article for consideration for any international peer reviewed journal, they come back asking if and how a patient group was involved in the formulation of the article. But no policy can clearly say that it has been ratified by a patient group or patient organisations. This just shows the reality of TB patients in India. In a paper on the cascade of TB care it has been pointed that out of nearly 2.5 million TB patients in India, 30% have not been able to access TB tests and there are further drops along with a cascade. As a result, the number of TB patients cured in a sustained manner is a small number of those who develop TB in India. Therefore, subsequent care cascade is dropping. One third of rural patients are not able to access care in time. So, these are all very concerning issues in the TB space.

Thank you so much and I really appreciate all those who spoke and I really think we can take these things beyond this discussion.

Anant Bhan: Thanks, Anurag, for sharing and also for the slide. In the interest of time, we will now move on to the next panel. So, Sunita and Amita over to you.

Proceedings of Witness Seminar
SESSION 2 | SEGMENT 1 |
PROGRAMMATIC, LEGAL AND POLICY
ENGAGEMENT
Moderator: Sunita Sheel

Session 2 | Segment 1

Programmatic, legal and policy engagement

Moderator: Sunita Sheel

Sunita Sheel: Welcome back again. It was very humbling to hear everyone, especially those who have been survivors and who have had difficult times, for a longer period of time and at different ages. This is not my space as such, and therefore, I found the experiences and the presentations shared so far very insightful. I think that perceptiveness that comes from one's lived experience has its own strength and lends it unique power, one may say. With that introductory note, I like to start the Session-2. We have two segments in this session, and Amita and I will be moderating these segments.

Amita has worked in these spaces of TB in the past and she also had a chance to engage with some of you via her work in a programme supported by REACH. Building on this work, she had an opportunity to work with the Government of India in developing gender sensitive guidelines for TB care.

We invite Prashantji to share his experiences to start this segment. Prashantji, you are from Sikkim and have been a TB survivor and you have mentioned in your bio-sketch that unfortunately you lost your father due to TB. We will find it useful if you speak specifically on two things and your experience regarding those: one, your experience in TB space during the COVID-19 period, and two, I know that you had done a great deal of advocacy relating TB care and access to TB medicines in your own state. You can also speak about any other matters related to TB drawing upon your work and experiences of working in Sikkim. Prashantji, over to you.

Prashant Sharma | Experience of TB advocacy in Sikkim, TB in drug users

Prashant Sharma: Thank you, I am Prashant. I am a member of an organisation called the Sikkim Drug Users' Forum (SDUF). This organisation works for the health and rights of the people who use drugs in the state. The use of drugs is a criminal offence and due to the fear of arrest these people tend to run or hide from the communities which makes it difficult for them to access public health services. There are a good number of people who use drugs in the state. Many approach us and we work for them.

But I've not had a good experience with advocacy in TB from the beginning, and it's the only disease in which I've had a great deal of experience. After listening to some of the speakers like Anurag, I would like to know how often we talk about tuberculosis-like diseases with reference to the North-Eastern region of India. I

have very little experience of being part of such conversations such as this witness seminar where doctors or experts from various places come together and discuss about TB. To me, it is rare and I think this is a very good start.

To begin with, I would like to start on a very positive note which is that it is great to know that an organisation, such as, FMES, the host of this witness seminar, wants to hear the voices of communities. I never had the experience of an organisation reaching out to me and asking me, “Prashant, what are your problems as a TB survivor and TB patients champion, and if you consider sharing with us”. I also do not know whether an organisation comes to my state of Sikkim, and works in the area of TB disease prevention and care. Congratulations again to the organisation and to the team, which is leading this initiative.

I would like to start by briefly describing my work and that of my organisation, and our role in TB prevention and care. We are basically activists not so much into service delivery. We formed the organisation called Hepatitis Coalition of Sikkim (HepCoS), primarily to bring forth the voices and to highlight the challenges and issues they face. Our organisation, therefore, is not geared towards service delivery. Instead, we try to give visibility to the issues being faced by TB survivors, patients, and their families. For example, we organise a press release or a press conference to portray the ground realities.

I come from a very interesting state. I don't know how many of you have been able to travel to my state - Sikkim. We are a landlocked state and we share an international border with three countries - China, Bhutan and Nepal. Our only way to reach the mainland is Siliguri and there is no other way to travel to other parts of the country or to other countries. The geographical landscape of Sikkim involving a hilly terrain, makes it difficult to access the health care services, provided at the health centres which are usually far off from residences and hence time consuming and inexpensive to make frequent visits.

Coming to the issues regarding the TB programme, I support the view expressed by the other speaker that data sometimes do not reflect the true picture and we have often seen this sort of thing in the TB arena. In India, we have the highest reported suicide cases. It has been observed that many TB patients also commit suicide, which is not reflected or finds mention in the TB programme. I know a number of TB patients who have committed suicide, especially those under MDR-TB treatment and also have heard through other sources of such incidences elsewhere. Yet there is no counselling, regular monitoring or peer-based support provided to patients of MDR-TB.

In this regard, whenever we try to contact the State or District TB cell, they have been unwelcoming, very much unwelcoming to respond to this matter. Not only that, they act as if we are intruding in their space and intend to cause trouble. This was one of the triggers for us to start advocacy and undertaking activities for the

same. We learnt that our TB programme was not working as they are expected to. We, therefore, started our TB advocacy in 2014-2015, if I remember it correctly. Since then, to date, it has been more than 5 years. During this period about four nodal officers have already been changed and we can imagine how frequently officers are being changed and doctors are being transferred from one posting to the other. These sorts of things have made the TB Programme rather dysfunctional.

Furthermore, and closer to the ground, we have witnessed different types of challenges. We have also learnt about stigma and discrimination with reference to TB in my state. I don't know what might be the case elsewhere in India regarding stigma and discrimination experienced by TB patients. Initially, I had presumed that TB patients experience stigma and discrimination, mostly in communities and in society at large. However, later I realised that there is more stigma attached to healthcare institutions providing TB care to the extent that those patients don't wish to visit District Tuberculosis Cell (DTC) and hospitals.

In this regard, I would like to share a story briefly. A few years back, a state nodal officer invited us to join their DTC and wanted us to work for them. As I told you earlier, we are not a service-oriented organisation. We are activists and interested in giving visibility to the issue at hand, and when necessary, filing court cases seeking justice for TB patients and their families. We agreed to work with them, even though it was challenging for us. As part of this work, we started visiting DTC twice a week and we started engaging with patients to know the challenges and difficulties they were facing, and how they could respond and help improve the situation for them. As we continued working with the DTC, we began to realise that there were so many challenges and diverse needs, including nutritional support, counselling care, adequate medicines, availability of diagnostics, needs regarding other medicines. This opportunity of working with the DTC is one of the reasons for us to get more interested in the TB programme.

Additionally, my own experiences regarding TB care of my own family have been bad. In my family, myself, both my parents and my sister all have had TB. My father couldn't make it, but the rest three of us could overcome it somehow. My father was an alcoholic and he possibly damaged his organs or his body because of heavy drinking. Upon his getting diagnosed with MDR-TB, I believe, the doctor immediately put him on TB medication. Although I am not a medical person, I think something went wrong and my father died because of TB medications which were started immediately after diagnosis. I think he could not tolerate or bear those medicines that were given to him resulting in his passing away.

I would like to share yet another similar experience with one of my uncles. He was a cancer patient and he was undergoing chemotherapy. During this cancer treatment, his doctor suspected some sort of hole in his lungs. He, therefore, was transferred to the DTC and he was diagnosed for MDR-TB. So, they decided to

initiate the TB treatment immediately. Once TB treatment was initiated, he started losing his weight and lost so much that he decided to stop TB drugs after 5 months. And he started to recover! I don't know what happened, but he healed quite quickly, he was awake, he could eat, and he was able to do everything. Therefore, I realised that something was going wrong while putting people immediately on TB treatment. I also have a few other experiences, too. I have seen a lot of people who are suffering from this disease. We often see this particular advertisement with Amitabh Bachchan featuring in it, and we have also seen the Prime Minister of India says that TB is preventable, treatable and curable. But from my own experiences, it doesn't seem to be the case, it still kills people!

Another very interesting thing is that if you read the recent NiTi Aayog²⁸ report, my state ranks the first under the category of the population size of five hundred lakhs with regards to development, that is, we are the best state in the country on the 'development' index. We need to note that my state's population is only about seven lakhs. Therefore, if someone dies in my state it means something is very serious. Also, 60% of our population are employed under the government indicating we are well equipped in terms of human resource. And yet, we are losing lives.

The organisers had also requested me to share experiences, challenges and insights of working with TB patients during the COVID-19 times. I think, during the COVID-19 pandemic, we were the first ones to write a letter to the government nodal officer expressing our support for the TB programme and that we wanted to know how the government would be going about diagnosing and providing drugs to TB patients. They told us that they had stock-outs and they would soon be receiving medicines and that they were well equipped to run the TB programme during the COVID-19. However, when the lockdown was extended, we received complaints from many people regarding disruptions in TB medicine supply. I remember that a person, who was on MDR treatment and was also a drug user, called me one day to say that his doctor had told him, "DTC won't be able to deliver medicine in his area." He continued saying when he asked the doctor what to do without MDR medicines, the doctor responded, "It is ok not to take medicine for two days and after 2 days you can start the medicine". As a result, people from a very remote location had to rent a vehicle and pay a huge amount of money to reach the DTC to collect their dosages.

The majority of people we know do not have rations and do not have money either and it is just INR 500/- (per month) for nutritional support from the Government! I am not sure whether the government really means to support TB patients. I have a feeling that it is doing it for the sake of doing it and is not with an intention to

²⁸National Institution for Transforming India, better known as NITI Aayog, was formed via a resolution of the Union Cabinet on 1 January 2015. [from: Overview | NITI Aayog]

care for the patients. Therefore, we started delivering medicines and ration to people who are in need although we didn't receive funds from anyone. As an organisation, we collect funds ourselves and then we support communities in need with small funds. In this manner, we have been able to help more than 50 TB patients. We have made efforts for engaging with the chief minister and other ministers in the health department on TB. Sometimes they respond and it seems like they wish to do something. However, many a times they forget about us and we have to keep reminding them. Furthermore, it is a bit exhausting sometimes, but we decided to follow this path and will continue to do so.

Another interesting thing in my context is that those of us who are working in the area of TB and with TB patients along with drug users to help them, are highly stigmatised and discriminated against, and are poorly understood by communities. The TB programme in our state is so bizarre, it does not specify what kind of work it does as Ganesh mentioned earlier. The state's HIV programme, however, is better organised and implemented. Hence, I am unclear as to how we can make the TB programme more robust and will draw upon learnings from the HIV programme. On the point regarding monitoring of the TB programme, I agree with Dr Anurag who said that if communities are not involved in TB programme monitoring as part of the system, then most likely the data won't reflect accurately the situation on the ground. For example, the place I come from has institutions deeply stigmatised in addition to the stigma or discrimination that individuals experience based on their being poor. Therefore, there are many things to look into when it comes to making the TB programme work.

Sunita Sheel: Thank you so much, Prashantji. We have very different kind of narrative coming from Sikkim and it seems that there a lot of things for us to know and we can hope to do that during discussion time. Now, I would like to call upon Bijayalaxmi and you come from Odisha. You have been engaged with Jan Swasthya Abhiyan (JSA) and also work with other national networks. If you could narrate some of your work and experience working with these national networks in the country, it would be very good. Bijayalaxmiji, over to you please.

Bijayalaxmi Rautaray | Safe guarding the rights of TB patients in Odisha

Bijayalaxmi Rautaray: Thanks for giving me the opportunity to share my thoughts. I wanted to share my experience with TB patients since 2011. I began

²⁹Mr Tushar Kanti Ray has over 27 years of experience in public health, social development, poverty alleviation, institutional and organisational development in Asia and Africa. Mr. Ray has carried out a number of assignments such as planning and implementation of TB control programme based on DOTS strategy in India. He also served as National Advisor to the Danida Assisted National TB Control Programme in India. Mr. Ray served as Technical Officer to WHO in Bhutan and Myanmar. He has served as a Country representative in Nigeria. He has extensively worked in 30 countries with more than 8 International NGOs.

working in the TB space because my mentor, Dr Tushar Kanthi Ray²⁹, was an expert in the field and knew a great deal about TB. He advised me to try to work in the TB area and that I would enjoy working in this space. So, I started my work in the TB space. Initially, I was not working jointly with JSA or with the Common health forum. When I was working with JSA, it was about access to medicine but I was not working in TB space. There was no discussion about the issues of TB Programmes at JSA during those times and when I was in-charge of releasing citizen report cards. During that year, we saw people attending the government programme on World TB Day and we distributed citizen report cards to participants, panellists and media to know the missing patients. There were a lot of untreated patients back during those times and we talked a lot about it during this seminar. We then started working on the issues in TB care at Sahayog, my organisation. We could then understand the condition of a lot of TB patients. We as Sahayog engaged in a great deal of advocacy, and when we worked with TB patients, we were able to understand their extremely challenging situations.

At JSA, I served as a core team member. We collaborated with JSA and Voice of Patient's forum and would call thousands of TB patients as well as other patients for meetings and inform the higher-ups in JSA on issues with the TB programmes and in the meetings mostly focused on TB medicine. We then assessed the need for medicine in each area and evaluated where patients would get medicine. We used to discuss the missing patients on the list as time went by and it kept growing. Furthermore, we also collaborate with similar programmes or networks where we talk about things like women with TB symptoms and how their lives were changed when they were diagnosed with the disease.

A major problem in Odisha is access to drugs and there is always a stock-out issue with TB medicines. Once there was caprimycin stock-out. We informed JSA immediately and yet caprimycin stock-out lasted for two months. Another time, we received expired medicine and someone had consumed those leading a death. We have been always taking up these issues to the TB Network. Our discussions are not like those between a CSO and other networks, but instead, we are raising these issues through the JSA to TB forum. Sometimes people ask me for guidance. They ask me, "Bijayalaxmi, why is that there so many problems with the TB programme in Odisha?" So, I thought of working with several networks so that I could get more insights and become more knowledgeable about issues on the ground with TB programmes in Odisha.

There are some other issues I would like to talk about beyond the brief given to me by the organisers and questions asked by the host. One of the things that no one pays attention to is the treatment regimen of TB patients, whether they are taking medicine correctly or not while they are enrolled in the vertical TB programme. In short, I feel the vertical TB programme lacks both a holistic and comprehensive approach, and this is where the problems begin. When we

consider frontline workers, such as ASHAs who are not getting paid the incentives for their work within the vertical TB programme but they get paid while working with other vertical programmes such as Maternal and Child Health Programmes. ASHA workers had mentioned to us that they had worked for a lot of TB patients but were still not getting paid. They were asking as to why they should be working for the TB programme. When we discuss these issues with Senior Treatment Supervisors (STSs) and District TB cells, they cite the need for an interface stating that otherwise, the programme would not be successful. When we discuss issues in the TB programme with ANMs, they said that it was not their work to look for TB patients and that they didn't know how many TB patients might be there in their respective areas. If these kinds of problems are not addressed, then how can we stop TB?

Let me share a recent experience, highlighting the extensive problems TB patients are confronted with. Two days ago, I got a call from a woman; she is about 25 years old. She was diagnosed with bone TB and she was talking about her problems that she is facing including, stigma she is subjected to in her community. The government doesn't know how much these people are suffering. In this particular case, since she has TB, she is unable to walk, and she gets treatment from a government hospital without any help. She has her old mother, who rests under a banyan tree, eats food and sleeps there, and looks after her weak daughter. There are a lot of patients of this type. What support government extends to such TB patients?

I have observed that these things are not mentioned in official TB reports. The TB caseload here in Odisha is very high and we have patients with many types of TB infection, including brain TB, and gastrointestinal TB. However, there is no discussion regarding these patients with these different types of TB diseases? What support is available to them? Occasionally, patients with co-morbidity will take medicines for a while and then they stop without notice and eventually, they die from all these factors. I would like to share another instance, which disappointed me. One of the TB patients that I knew had successfully completed the TB treatment and became well. However, after some time, this person died. I feel that this could have been averted if there had been a systematic follow-up which is not happening anywhere. In the absence of accurate follow up, how could we conclude that TB is curable?

We feel that patients are not healthy, and patients say they are troubled by TB disease. But once the patient has been treated for TB and has completed the regimen, there should be support for these patients in the government system. Our personal experience was that we had met a few doctors who believed that even if TB disease is cured, the symptoms may remain and the patient can re-infect. But we cannot prolong the medication because they may end up with Drug Resistant-TB. Government provides INR 500/- to TB patients but they don't get

the money on time. Doctors think that patients are receiving money for TB disease, but the fact is that they are not getting access to medicine which is very important. Additionally, there is no sufficient budgetary allocation for the TB programme which suggests that the government neglects TB patients, although the government claims that they do a lot for the TB programme. We need discussion on this question as why TB patients are neglected in all aspects.

During COVID-19 times, all CBNAAT machines were taken for COVID-19 testing. As a result, these machines were not available for TB testing. Between March 2021 and October 2021, no CBNAAT testing for DR-TB was provided for any TB patients, which potentially can lead to more deaths of such patients. Obviously, I'm not referring to death. My point is that the system needs to be more robust in this regard. Because if timely testing is not done, it may lead, at least in certain cases, to patients losing life or will die if the tests are not provided on time and their lives may become more difficult. I feel that if we are not giving sufficient attention and importance to these critical matters, then how can we expect to control TB transmission, and who will be held responsible for these gaps in the programme and its fatal consequences to patients?

The nutrition problems in TB patients are largely unknown. We are working in the drug access area, but we also discuss nutrition issues in the TB programme. We had raised this issue to the higher ups in the TB programme and appealed that the TB Programme should extend nutrition support. They acknowledged that another group of people/community also needed nutritional support for TB patients. They have said that they plan to create a single window system and they plan to provide ancillary medicine for the overall health of patients along with TB medicine. But this has not yet happened. Another thing is that with the help of Amita we have helped to develop a DR-TB care centre in Cuttack where we provided volunteers as treatment support assistants. She had donated INR 24,000/- to Sahayog and had said that we could utilise this for TB patients. Those funds helped us to support the work at this centre for 6 months. This suggests that if resources and support are available, we could help a lot of TB patients and it will also help to run the TB programme more smoothly. In all the other health programmes there are support staffs and I wonder as to why there are no support staffs in DR-TB centres.

As part of a research project carried out in 2015, we had worked with DR-TB patients. We were aware of the weakness of the system and we looked through a lot of interruptions in the treatment of these patients. It is important to know the reasons behind DR-TB patients not complying with their regimens and to know the problems they might be facing? I would like to share my experience relating to a DR-TB patient. She was not taking her medicine properly and it seems the doctor didn't try to explore the reasons for the same and to know if the patient might have been facing any problems. Instead, the doctor informed the police station directly and said that if this person works anywhere, the police should arrest him.

The police also filed the case against the said patient. Would such doctors think about the condition of such patients and what might be the implications of such threatening behaviour by treating doctors? It amounts to doing injustice to such patients. It is true that it is the doctor's responsibility to reduce the spread of TB infection, but we also have to view these people as ordinary persons who don't have support from anyone. Nobody is making attempts to look at TB patients from a humanistic perspective. As a consequence of such absurd behaviour of treating clinicians, many such DR-TB patients with co-morbidity tend to die after a year or so.

On April 7, 2018, bedaquiline was launched for the first time in Odisha. It was an outcome of the advocacy efforts by Banty Sethi³⁰. That day we from Sahayog were conducting a programme, "Together we can END TB", when a mother suffering from DR-TB attended the programme. She was a cancer patient and had completed TB treatment. But clinically she still had symptoms and could hardly walk. She said, "They are carrying me as I am not able to walk. It seems that my treatment is over, but I continue to feel that I have problems. Even now I have a cough and feel suffocated, which is not due to my old age or co-morbid condition. And yet TB diagnostics indicate that I am TB negative. I am not admitted to ICUs as they think I may be infected with TB, nor does the TB ward accommodate me as I am diagnostically negative. I have come here to request you to do something that I would get treatment and can live." The doctor in the government hospital told he couldn't give her the ICU as she still presented symptoms of TB. He advised her to seek care at a private hospital. She was admitted at Vivekananda Hospital in Bhubaneswar after paying INR 22,000/-. She was on a ventilator at night, and in the morning she passed away. This experience led the TB advocates and Sahayog to appeal for creating some sort of "buffer wards", where treatment and ventilator support could be available for patients like this. We regret that even after our struggle for getting her to access hospital care, we lost her in the end.

In another case, a TB patient had repeatedly begged everybody for medications, but nobody bothered to check his condition. Later, we got to know that he was a DR-TB patient and died without access to medicine during that crucial period. If we don't discuss about all these things, then how can we say that we are considering TB patients as humans?

Whether it is XDR-TB or MDR-TB, TB patients are all alone and the government has to assist the needy. In Nikshay Poshan Yojana (NPY³¹) there is nothing. We

³⁰BantySethi is a well-known name for his advocacy work relating to access to and availability of bedaquiline. His efforts enabled the state of Odisha to access and make available bedaquiline, rather quickly. We – Sahayog - uploaded his video suffering from TB on March 13, 2018 and medicine reached Odisha on March 21, 2018. Seven patients along with Banty received bedaquiline on April 7, 2018 on the World Health Day. (Further telephonic communication with Bijayalaxmi Rautaray).

³¹<https://tbcindia.gov.in/index1.php?lang=1&level=1&sublinkid=5275&lid=3385>

need to inform all TB patients that diagnosis by Culture Drug Susceptibility Testing is extremely important in addition to CBNAAT. This helps to know the type of TB infection, which determines the treatment regimen.

A lot of changes have taken place in the TB field during the period between 2011 and 2021. For example, in the past, TB patients experienced much neglect and stigma including in the health care system. For example, hospital staff used to tell TB patients to stay at a certain distance which I have witnessed myself. Over these past ten years, a lot of changes in such a situation have taken place, patients are now treated with more respect and we would like to see more reforms since this is not enough.

It is essential to make patients aware of the TB disease in order for it to be truly cured. In 2015, the majority didn't know about DR-TB, but now that they know a bit more. We need to continue educating TB patients and the general population about the disease like we educated the public about COVID-19. The government needs to develop such a mechanism enabling everyone to be better aware about the different types of TB, ways in which TB is spread and necessary precautions which are to be taken.

According to Programmatic Management of Drug Resistant TB (PMDT) Guidelines 2012, the government is expected to reimburse cost of travel to the hospital when a patient and caretaker visit to a DR-TB centre. There is no explanation for this failure or gaps in the TB programme. Earlier, we used to follow up patients and during those times they were able to get these reimbursements which are not the case now. If government is not providing these kinds of support to these patients, then how can these patients go to the hospital for their treatment? In this regard, I would like to share an experience of an old woman who lived in a joint family and she was not able to tell anyone in the family about her disease. She said that if she could get money from the government, then she was able to go to the hospital in Cuttack to continue her treatment. But she didn't get the money. In such a situation, the chances that she would transmit the disease to other family members increases multi-fold. As you can imagine, it is challenging to keep a distance from other family members and wear masks because doing so would make her family members suspicious about her health status. This case example suggests the TB programme needs to have some arrangement that would enable to take care of such patients who may need to stay away from their families.

Another thing I would like to mention here is about pyridoxine (Vitamin B6) medicine that should be necessarily supplied to TB patients. In private hospitals, they are giving this vitamin to TB patients as part of treatment. So, patients are thinking that TB care in private hospitals is good. These are not included in the TB regimen in the government run TB programme. It is unreasonable that vitamins are not included in the TB regimen as part of the government TB programme. These vitamins are rather expensive if patients have to purchase them on their

own.

Another problem is that doctors from the private hospitals change TB regimens without having the knowledge about the type of TB infections, XDR or DR-TB that their patients are suffering from. I have seen people die from such an unethical approach to TB treatment in the private health care system. In the public health care system, there is a treatment committee for DR-TB and XDR-TB patients. We need to ensure that the doctors practicing in private hospitals are taking advice from these committees to prevent unnecessary deaths of TB patients. Collaborative efforts are necessary in these areas because ultimately TB patients suffer.

Although as an organisation we are working to help TB patients, we do not have sufficient funds to do so. I am sure we can help a lot of TB patients if the government or someone else can provide us funds to pursue this work. It is difficult to find this kind of funding. Whenever funding was available, we helped patients to travel from their place to health care facilities under the TB Patient Support Initiative (TPSI) programme of Sahayog. As part of our efforts, we had set up STOP TB WhatsApp group with government people included in the group. We used to share all problems regarding TB patients. It did help us to resolve some of the problems. It is sometimes harder to help people when we don't have sufficient money, but we are continuing to work in this field despite the challenges.

Thanks a lot, Nandita, you have helped us a lot, and there are some others too who are helping us. I would like to mention here that persons who are working passionately in the TB space need to be aware that there are people on the ground, they are TB survivors, but these survivors are not coming forward and leading the effort for eradicating the disease. The question is: Why are these people not coming and working with us? One of the reasons might be because as Nandita said we need to support these people. They cannot do this voluntarily without any financial support/honorarium. TB patients and survivors should be compensated for their contributions to the TB programme because they should be able to continue working in this field. These were some of the thoughts in my mind to share with you all. Thank you so much for this opportunity.

Sunita Sheel: Thank you so much, Bijayalaxmi. Your insights were very helpful to us and I like to ask certain questions in which I shall park them to be taken up during discussion time. Now, I would like to call upon Khageshwar Kumar and you are from Jharkhand. You have been working jointly with RATIONS, are involved in TB elimination network in Jharkhand and you also work with REACH. You mention in your bio-sketch that you had TB when you were much younger. I would like to invite you to speak for the next 10 minutes about the issues you faced as a youngster with TB and your experiences of working with these different networks and initiatives; it will be helpful. Khageshwar, over to you please.

Khageshwar Kumar | Experiences of surviving TB and supporting patients in Jharkhand

Khageshwar Kumar: Thank you, organisers for giving me this opportunity. I am Khageshwar Kumar from Jharkhand. I was diagnosed with TB while studying in 6th standard in 2007. After I had survived TB, I started working for other TB patients. I could earn a lot of experience and came to know about issues of TB disease by working with a lot of TB patients. Therefore, I learned that there are many TB patients in need of assistance and benefit. Now, we have connections with a number of organisations which help us to support these patients to meet their needs as much as possible.

First, I like to start by sharing a lot of issues regarding the sputum test that I experienced or witnessed during my work on the ground. When a patient is referred for a sputum test based on symptoms, s/he has to wait for at least 3 to 4 days to receive the result. Later, if it is positive, the patient is referred for further testing, such as CBNAAT or other tests. During this time, while waiting for the results of the tests, the patient is not under treatment and there are greater chances of the infection to spread to their contacts. Another problem that I have seen is that when patients visit the out-patient department (OPD) with symptoms of TB, they are unable to communicate to doctors about their problem comprehensively which might be due to some kind of fear in their minds. This leads to misdiagnosis by the physician. This indicates that the relationship between patient and physician should be improved so that diagnosis of TB disease is accurate.

Yet another problem is that there is a huge difference in the TB medications provided by the government sector and the private sector. From my observation, government-provided medications are usually of higher strength, though some may have side effects, resulting in patients avoiding them. Many patients shift to private hospitals for medications where, different dosage medications are provided. The lower dosage drugs usually require long duration treatments and sometimes patients don't get cured completely and there is also a risk of non-compliance due to longer durations. I have also observed that in certain cases, patients were complying with the prescribed regimens for TB and yet were not getting cured. There is only one country and one programme, but different medicines for the same disease. I think, this is one of the contributing factors of MDR cases in the country and it continues to rise. Hence, standardisation of the drug regimen across government and private health care should be made mandatory.

Then, there is a language issue. For example, English is not understood well everywhere. There are some places where people understand the local language better. In such situations, TB survivors from that area should come forward, the TB programme should educate them, and in turn they can educate people in their

respective areas. Thus, we can reduce the spread of TB infection to a family or a community. If this is not adopted, then patients in that area will not continue with TB treatment, increasing the chances of TB cases and death.

I would like to share a recent incident. Last month I got a call from a woman and she was on DOTS. When her medication ran out, she was unable to travel to the hospital and she was unable to call them as her mobile balance was low and connectivity range was limited. So, I think technology also should be improved, and it should reach rural areas. In addition, I would like to suggest that if there is a court in the country for handling all the problems that the citizens have, and likewise there should be a court or any other set up where patients can go and tell them about their issues, and they should be able to act independently to respond to those concerns. As a result, many of the problems among TB patients could be resolved.

When the patient is under tuberculosis treatment and when the intensive care phase is over, they have to do further testing to know if they need to continue the treatment. However, most people do not come for such testing because they live in remote areas and it is difficult for them to reach the testing centre. Even when CP (Continuous Phase in TB treatment) is completed, patients are expected to check their TB status. But sputum test or CBNAAT test cannot be done for these same reasons. To encourage these patients to do their testing in a timely manner, the government should provide incentives.

Then, if you are able to print the NI-KSHAY³² help line number in the treatment card it will be very helpful. Because the Central TB helpline number is actively working but patient cannot use this properly. So, printing the NI-KSHAY helpline number on the treatment card will be a good transition and more TB officials will be able to hear the problems that patients face in the community. Thank you so much.

Sunita Sheel: Thank you so much, Khageshwarji. After this there is another segment and I like to call upon Amita Pitre to moderate it. I also like to request all speakers to please keep your presentations to 8 or 10 minutes so that we can have more time for discussion. With this, I hand over the moderation to Amita. Thank you.

³²NI-KSHAY-(Ni=End, Kshay=TB) is the web enabled patient management system for TB control under the National Tuberculosis Elimination Programme (NTEP). It is developed and maintained by the Central TB Division (CTD), Ministry of Health and Family Welfare, Government of India, in collaboration with the National Informatics Centre (NIC), and the World Health Organization Country office for India. [from Nikshay]

PROCEEDINGS OF WITNESS SEMINAR
SESSION 2 | SEGMENT 2 |
TB Prevention and Care in India: INSIGHTS
FROM INTERSECTORAL AND
INTERSECTIONAL ENGAGEMENT IN
PROGRAMMATIC, LEGAL, AND POLICY
ENGAGEMENT
Moderator: Amita Pitre

Proceedings of witness seminar

Session 2 | Segment 2

TB prevention and care in India: Insights from intersectoral and intersectional engagement in programmatic, legal, and policy engagement

Moderator: Amita Pitre

Amita Pitre: Thank you, organisers, for giving me this opportunity. We have three speakers/witnesses to share their perspectives and experiences in this closing segment of the witness seminar today. They are: Dr Chapal Mehra, Advocate Veena Johari, and Ms Anupama Srinivasan from REACH. You may speak in whatever language you are comfortable with.

The discussion so far has been very interesting and the views expressed so far by witnesses are enriching. I have worked with some of you in the past. And yet I didn't appreciate sufficiently enough the width, breadth and depth of these perspectives then; for example, Bijayalaxmi sharing the insights into painful stories of patients seeking TB care. Despite being a medical doctor and a public health professional, I realise that we have little exposure to the realities of TB affected people, though TB is a very old and highly prevalent disease in India. We have not prioritised understanding and addressing TB in the way we should have. We did this for HIV, we had educated people on HIV but we didn't do much in case of TB. During my visit to the district TB centre for my own research work in TB spaces, I felt that there is a lot to improve in TB care in India. The TB programme is still mostly focused on treatment, and in the initial years of the TB programme, the emphasis was only on the aspect of reducing transmission and it was all about germs. They were not concerned, for example, about patients who are cured to know if they were safe and healthy with no long-term adverse effects of TB medicines or any other related issues. I realised then that our vertical programmes are fully focused on the TB treatment and nothing much beyond it.

I would like to invite Dr Chapal Mehra to speak from this perspective, drawing upon his experiences. It will complement the discussion we have had so far if you could focus on the issues relating to intersectoral co-ordination. For example, alcohol is one of the prime reasons for noncompliance with TB treatment and there is a need for us to work across sectors to be able to respond to such issues and to be able to integrate different experiences from each of these sectors. It will be helpful if you can talk from this perspective and share your experience working across sectors, and your thoughts on the way forward. Over to you, Dr Chapal Mehra.

Chapal Mehra | Right's based approach in TB care and advocacy

Chapal Mehra: Thank you, Amita. I am Chapal Mehra and I am associated with an organisation called Survivors Against Tuberculosis (SATB)³³. I will speak mostly in Hindi because I think everyone understands it better and I am comfortable with both English and Hindi. I was given the topic to talk about inter-sectoral collaboration and gaps in TB space. But I would like to go back a little bit because SATB was probably the first organisation to work with TB survivors.

I would like to mention that I have worked in HIV programmes and also worked jointly with LGBTQ community for many years with respect to their rights and the movement that took shape around this issue. When I started working in the TB space, the weirdest thing I felt was that in any TB policy making spaces or events organised for addressing the TB issue, TB survivors were never there and these policy making processes rarely referred to TB survivors, at least, I have not witnessed their presence in these processes and conversations. Whenever we raise this issue, the national programme people would ask us why they should call TB survivors, what kind of topics that they can engage with survivors, and they don't know what to do with survivors.

We started to work with TB survivors in Mumbai, Pune and Delhi and we realised that a lot of TB patients wanted to share with us a lot of their problems. Their lived experience with TB is not just a story. Instead, we learnt that those stories provide us very important insights into potential do's and don'ts in the TB programme and related matters. These insights into survivors' perspectives guided and informed all our work. In the last eight years since we started this work, there has been a lot of movement around the participation of TB survivors, and much progress has been made. Yet, the problems of the grassroots have not been fully addressed, like, we heard others speak today about not getting the TB medicine and not getting bedaquiline, problems with access to TB diagnostics, and other issues on the ground.

I have been part of two JMMs (Joint Monitoring Mission of National TB programme)³⁴. Currently, we are working in five states. We heard similar stories while working on this mission. These include problems, such as, stockout of medicines, the stigma that TB patients are subjected to, negligence of care and treatment of TB amongst women and Trans persons, and lack of attention to TB care and treatment amongst persons who are HIV positive. These issues prevail everywhere and largely because we are unable to bring TB survivors to the room and talk to them and integrate their perspectives in the TB programme. It is intriguing to note that the programme often refers to a patient-centric approach

³³<https://survivorsagainsttb.com/En/>

³⁴<https://www.who.int/india/news/detail/10-11-2019-joint-monitoring-mission-of-the-national-tb-programme>

in the TB programme, but no patients or survivors are coming to the table or nobody is inviting them to be at the table. If so, how can we make the TB programme 'patient-centric'? I feel this is the weirdest matter and therefore wanted to briefly talk about this here right at the outset.

I would like to mention another important matter regarding community engagement. This is specifically relevant to those related to the field, that is, grass root workers. While I appreciate the significance of 'community engagement' and its central role in the TB programme, the TB programmes rarely explain and discuss what precisely is 'community engagement' and how could it be done well and in a meaningful manner. For example, when we ask programme officials of their expectations about the role of 'community engagement' or training, they generally respond by saying that it is to bring communities into the fold of the TB programme. However, to date, it is not very clear what exactly needs to be done to ensure that communities are involved and how to work for the community. The fact that even now there is lack of TB diagnostics on the ground, and patients do not have access to TB medicines, demonstrate lack of meaningful community engagement. Government makes huge promises over NPY but hasn't been able to deliver expected outcomes.

About two and a half years ago, we objected to the government making Aadhar card³⁵ mandatory to access benefits under the NPY. There were many that said we are against Aadhar and it may lead to frauds; they argued that this would minimise misuse or any foul play in the disbursements. Even now we can observe many grass root level workers demanding Aadhar card. These instances make obvious the gaps between the needs and aspirations of the community versus the programme.

The other issue I would like to highlight is that we feel good by using the term 'community engagement' but it should actually be 'community accountability' (CA). This is because it is our money, the taxpayers' money which the government collects and is accountable to state to the public, on its expenditure. The government is liable to give an account of what has it done to the community. For instance, if we buy a Coca-Cola, we would observe that the company studies its consumer's needs. Unlike this, the government and our doctors decide for us and dictate our wants. This is indeed a difficult disconnect, rather a wide gap, between the system/programme and the community.

Those who work in the space of patient-centric care, they speak of diagnosis, treatment but, our focus is also on mental health, stigma, nutrition or life after TB

³⁵Aadhaar number is a 12-digit random number issued by the UIDAI ("Authority") to the residents of India after satisfying the verification process laid down by the Authority. [from: <https://uidai.gov.in/what-is-aadhaar.html>]

disease, but the programme has exhibited very less knowledge, or has not paid attention or shared opinion on this issue. According to the government and those doctors associated with the medical establishment, (they) assume high-quality care implies higher standards of services, diagnosis and timely treatment. But for a person affected by TB, these issues alone aren't a matter of concern.

I would also like to mention yet another gap, regarding inviting TB survivors and champions to share their experiences at various forums. We have to be extremely scrupulous that the few survivors/champions, having managed to overcome their fear/hesitancy and share their experiences shouldn't be dismissed as sob/sad stories. Communities shouldn't be dismissed, infantilised or made to feel helpless. Communities shouldn't be dismissed by making them feel sad for themselves or helpless. However, over time, TB survivors now narrate their stories without panic, and these are largely stories of resilience and of fighting the odds. It is important for the programme to appreciate these narratives which highlight the gaps in the TB programme from the perspective of the recipients of the programme. Bad experiences of patients in relation to the TB programme illustrate that the programme has failed and indicates that the programme must focus on their needs. The programme ought to consider these experiential narratives as useful facts and convert these to revisit the TB programme from time to time to help avert the recurrence of the issues faced by patients. I think, the government officials should keep this as their major agenda in rolling out the programme and move towards meeting its goals. There are instances where TB patients are pleased with community engagements in a TB programme. They are happy with the intentions of the government that they have secured a place at the table on such platforms. However, such instances are one off and not enough.

I had asked the TB programme officials, during a training session for the champions, what they expect of these champions after their training. Do they have any plan to integrate them in the programme? For example, we wanted to know if they had planned to train others. And if they had plans to use these inputs to educate other people? On a related note, we also enquired when they would involve survivors and champions in the TB programme; did they plan to offer honoraria for their contribution to the TB programme? TB programme officials and other staff are paid staff, but there is reluctance to offer stipend or honoraria to TB survivors when they are expected to work as champions to make the TB programme work. The programme expects that these champions don't need money because they would be motivated themselves to help others having lived through TB. And I'm not sure how that works!

Some people say that the government did some work for us. To them, I would like to mention three issues that struck our country during the COVID-19 pandemic. TB testing was almost stopped and access to drugs was also poor. We had to call from Delhi as we had initiated a COVID-19 help desk, to get the drugs arranged for

the needy at the ATT centres and the third thing is about the fragile system which was badly hit by the subtle stroke of COVID-19. But there were no such help desks for TB patients during the pandemic and patients faced difficulties stemming from the TB medicine stockouts during the pandemic. In my assessment, the TB programme is so fragile that even small shocks to the system leads to collapse in no time. During the pandemic, the TB programme came to a standstill for about six months; almost everything came to a halt in the TB space. This raises questions regarding government's focus on working closely with/for communities. The fact that government couldn't provide medicines and people who got cured didn't receive NPY benefits even after 6 months, indicates the gaps in TB programme.

In closing, I would like to mention that community engagement is a very important factor but government needs to know what community engagement is and the system should know how to do it and what to expect from community engagement. So, when we are invited to speak at various forums about community engagement, we need to ask ourselves what we can do for this community engagement. We should also ask those government officials what all they have done so far in this space of CE in TB programme. In other words, the government has promised us something over the last five to six years, but there is little effort being made to ensure that these promises are fulfilled. We can talk about community engagement only after that. Thank you so much.

Amita Pitre: Thank you so much, Dr Mehra, for sharing your thoughts. You raised an important issue about accountability of the government. You also offered certain suggestions, for example, regarding the need to offer honorariums to TB patients' champions and TB survivors for their time and efforts in the TB programme and contributions they make to meeting programme goals.

Now, I invite Advocate Veena Johari to speak about the numerous issues with regard to access to TB medicines.

Veena Johari | Legal interventions and advocacy on affordability of TB care

Veena Johari: Thank you everyone. This session was very interesting with all the sharing and I am meeting at least some people after almost two years. So, it is a very important session. I will be speaking in both English and Hindi. Just before I go on with the issues of access, I would like to highlight a few aspects. One is about stigma and discrimination matters which we have been discussing since the start of this seminar. One of the most important things about such discriminatory practices within the health care system is that most of the people don't even have the knowledge of the legal issues involved in it, that is; legally such discrimination is not permissible. They don't know about their rights. They don't know what they can do if they face discrimination. We find discriminatory practices prevalent in

many places, such as in employment where TB patients are being eliminated from jobs; in education where children are told to discontinue classes. In health care we find lots of discrimination, though less than before. We also find abandoned patients in hospital wards as the family had run away, leaving patients. In certain instances, patients don't have any forwarding address; family cannot be traced as the slums where they have been living have been raised, and the family has moved out elsewhere.

There is no legal support for people to raise their issues. We are not telling them to go to court and court could be the last option. However, at least send a letter or notice and at least raise your voice towards bringing about changes in the system. We are accepting such experiences as one's own fate, and possibly assuming that it doesn't happen to everyone. Unless we register a complaint and raise our voices, we can't bring about a change or we can't expect a change to happen in the system. Doctors who do complete counselling for HIV patients and inform them about pre-test and post-test, some doctors don't follow these practices when they are treating TB patients. Instead, they tend to be paternalistic towards TB patients and they don't find it relevant enough to inform their patients about what the treatment is and other information relating to the treatment, such as potential side-effects. They just give medicines to patients. Then, what the hell is informed consent! Seeking informed consent in health care settings is the most important medical procedure and this is what is taught or is expected to be taught in medical schools. As a doctor, one needs to take informed consent before any kind of intervention a doctor makes. It is very important to take informed consent before doing any test or treatment. Doctors need to tell patients about the side effects, risks, alternatives only, after which one can start treatment, if patient agrees.

There are a lot of advantages of interactions with patients as part of seeking informed consent. Firstly, patients will have better adherence to treatment and they will come and inform the doctor if they have any side effects so that doctors can at least medically manage it. This is very important. But if the patient or family who is taking care doesn't even know, then how can they approach for a management defect. That was one very important aspect.

There are many populations who are completely neglected, such as those in prisons where health care provision is a completely different ball game. Khageshwar mentioned that it takes many days for the system to return the sputum sample result to patients. The same situation is seen in prisons, too. The prison health authority/system collects sputum samples, but returning results takes at least about 14 days. No one knows where collected sputum samples are getting stored, what conditions they would be, and whether sputum test results would be genuine or fake ones. The other is the mobile populations who face problems getting TB treatment as they move from one location to another. It is not known as what are the referral and follow-up procedures for such mobile

populations? There should be a continuous audit of these systemic matters and an assessment of how it works with various populations. We always speak about remote populations, but some attention needs to be given to other populations, such as the ones I mentioned as well.

I would like to now briefly talk about the issue of criminalising TB patients. Earlier during the seminar, a colleague spoke about how a TB patient has run away and that one needs to arrest him. This is a very big issue, that is, the criminalisation of already vulnerable TB patients. In this regard I would like to note that the government had put out a notification in 2018 which warranted that all healthcare workers, be it pharmacists or counsellors, are required to notify the government about TB patients when they come across them. Failure to notify, as per this notification, would attract a criminal case against the concerned individual under Sections 269 and 270 of the Indian Penal Code (IPC). These sections can be invoked to ensure that nobody spreads infection of a dangerous disease if one is malignantly or negligently indulging in transmitting a disease dangerous to life. When the government issues such a notification, it doesn't seem to think through the repercussions it would have for patients and their families? There are people on the side, who have been giving drugs without notifying. Pharmacists and chemists have stopped stocking TB tablets as they are afraid of cases being filed on them if they cannot notify. This is one example of the fact that the government has done things without understanding the issue in context, and the implications of its policies to TB patients. The government tends to think that it will work just by putting out such notifications and setting rules. But that is not the way it works on the ground. The government needs to start from the grassroots level and it needs to involve people in the policy-making processes.

The bottom line is that when we don't include people who are affected the most in such processes, we end up with ineffective policies and top-down approaches, that have not really effective and we have witnessed it a lot. In HIV, it has been the bottom-up approach that has helped people and this is how it generally works in any programme.

I will now talk about some of the issues relating to medicines — the stock-outs, the availability, the affordability and also about the MDR medicines where the patent is a big issue, especially of newer medicines and the MDR medicines like bedaquiline and delamanid. Most of these medicines are patented and the pharmaceutical companies will continue to file other patent applications for their variants, such as a fumarate salt of the drug or a crystalline form of the drug to extend the patentability. Anyway, these companies have secured patents for these medicines for 20 years, that is, no other companies can manufacture these drugs for the next 20 years. They still want to extend patents to 25 years by applying fumarate or crystalline form. During these 25 years, they have the expectation that one company will manufacture and deliver medicines to the entire population,

which is ridiculous thing to even think of. We are seeing that even in cases of COVID-19 vaccines, only one or two companies are manufacturing them. Now, however you tell the government to issue a compulsory license for emergency situations by reviving public sector undertakings to manufacture drugs, it doesn't work and hasn't worked during this on-going pandemic.

In India, there is lot of know-how in technology information in the area of generic manufacturers and they are able to manufacture TB drugs, but they won't. It has been 20 years since the Doha Declaration³⁶ was adopted. I will now mention some important points about Doha Declaration, a TRIPS agreement (Trade-Related Aspects of Intellectual Property Rights)³⁷. In 2005, their patent law was revised, especially as changes happened in the area of product patents. The Doha Declaration states that if due to public health issues you need a drug, then the government can invite other companies to manufacture a drug. In India, there is also a drug price control order where we can control the prices of medicines. To what extent the government adopts this policy guidance is another matter. We will keep telling them all the time but they won't listen to us. In this regard, bedaquiline and delamanid have patents valid until 2023 and they can extend it up to year 2026 or 2027.

In all these years, the government has given compulsory license only to one single drug namely, nexavar, meant for the treatment of kidney cancer. Other than that, they haven't done it for any other drug. Government suggests applying for a voluntary license. However, that is not right because by opting for voluntary licensing, the price of drug remains high and unaffordable. Also, the company who holds the patent dictates to these manufacturers with voluntary licensing for a drug as to whom they can sell and at what prices, which is not useful. Therefore, the only meaningful options are issuing of compulsory licenses for emergency medicines so that more manufacturers come forward and hence the stock out of medicines and the non-availability can be avoided. This also helps in lowering of prices as more manufacturers imply competitive pricing in the market. We have witnessed this case of medicines for HIV where in the company which was selling a particular drug for USD 20,000, the price eventually came down to about USD 1000 as a result of the entry of generic medicines manufactures.

We will not be able to bring about meaningful changes in the TB programme until

³⁶The flexibilities identified in the Doha Declaration include "the right to grant compulsory licenses". A compulsory license is issued by a government authority or a court to make certain use of a patented invention without the consent of the patent holder. This mechanism is generally present in most patent laws, is recognized as a permissible option or flexibility under the TRIPS Agreement, and has been used by a number of WTO members in the pharmaceutical field. However, TRIPS rules originally restricted compulsory licenses to serve mainly the domestic market, unless they were issued to deal with anti-competitive behaviour. [from: wto.org/english/tratop_e/trips_e/pharmpatent_e.htm]

³⁷https://www.wto.org/english/tratop_e/dda_e/dohaexplained_e.htm#trips

we adopt a rights-based approach to it. The government will always claim that they are implementing the programmes with a right-based approach. However, they have not addressed grassroots level concerns in any of their programmes. They have many things mentioned on the paper, but in reality, what is happening is what you all have witnessed and what you all have experienced. This demonstrates that we all have to work towards programmes that are designed and implemented drawing upon a rights-based approach to health problem. I will only say that knowledge of one's rights is very important and its implementation is equally important. This requires us to think 'out of the box' to help people to make regimen complaints and at the same ensure that the programme supports them with legal aid when needed. Upon failures and noticing gaps on these fronts, we need to make a noise and to raise our voices with the government to bring about change. That is all I have to say! Thank you.

Amita Pitre: Thank you so much, Veena. I think you did a good job by reminding us that going to court is not the only thing one can do to ensure rights, but there are multiple ways in which we can seek accountability from the government because the court system doesn't function at all well in India. But there is a lot that can be done, and I am sure Anupama, the next and the last speaker today, will discuss some of these issues relating to government's accountability, and how it could be ensured by working with groups and communities.

I invite Anupama to present her views on the matter. I had an opportunity to work with Anupama and REACH on the gender assessment of the TB programme. The results were despairing and also surprising because TB is thought to be mostly a men's disease and women patients are mostly made invisible. The programme has also neglected women because the focus in TB epidemiology is mostly on the pulmonary form of the disease, whereas women are known to suffer from extra-pulmonary forms more than men do. There is a need for a strong gender perspective to be integrated into programme design, implementation guidelines and policies. Further, despite the close connection between TB and HIV, there is hardly any convergence between the TB and HIV programmes. It was also observed that pregnant women and mothers who had just delivered were at high risk of TB but this aspect has not been given attention in India's TB control programme. I invite the speaker to discuss some of these relevant concerns, without which a holistic approach to TB is unachievable.

Anupama Srinivasan | Experience with REACH and engagement of TB survivors

Anupama Srinivasan: Thank you, Amita. I am glad to see many of the past friends present here, who were part of REACH's journey. I would like to share briefly about what REACH has been doing and what we intend to do over the next few years. We started working with TB champions in 2016. Since then, we have

grappling with learning more about the role of TB champions in advocacy, patient support or directly in peer support. Prabha would remember some of our initial/early discussions as part of those conversations. As Chapal and Nandita mentioned, we wanted to empower these TB champions to really be part of the solutions, and not just for the purpose of seeking their inputs, for putting out a problem statement. It was indeed a tremendous learning curve for us between 2016-19. We invested a lot of time in working with the programme to understand why it needs TB champions at multiple levels including the central TB division and at state, district and facility levels.

REACH has been attempting to create identity for TB champions, designing capacity building interventions, and supporting some survivors-led networks, such as TB Elimination from Jharkhand (TEJ) Network and TB Mukta Vahini (TMV) Network. I would like to emphasise here that the role played by REACH has been primarily facilitatory. We are trying our best not to be prescriptive and learning from TB champions and their experiences working on the ground. The most important challenge before us is charting out the way forward for this work with TB champions. We are trying to figure out ways of involving more and more TB champions, meaningfully and respectfully in the National TB control programme. We are trying different models to achieve this goal, which I would like to share briefly given the time constraints.

As we are aware, a lot of scholarship is available on accountability and community monitoring. So, we have developed a tool called Community Accountability Framework (CAF)³⁸. This is a tool which is being tested in some districts, for measuring quality of care of TB services, similar to what had been presented by Dr Anurag. For this purpose, TB champions are trained to collect data from people with TB including their specific experiences relating to TB care and to consolidate data collected at the level of TUs. For example, in Giridih district of Jharkhand, there are nine TUs. In this initiative, TB champions would collect information on the major aspects of TB care, such as access to information, timeliness, respectful communication, stigma, etc from each of these nine TUs and consolidate these data. In another instance, at a TU in Tamil Nadu, this initiative helped to bring forth an issue relating to the non-use of a weight band which is being used in TB programme to determine the dosage of the TB regimen every time medicines are dispensed. Dr Anurag had mentioned earlier the importance of weight bands in TB care. However, during the COVID-19 pandemic, medicines were being dispatched without complying with this protocol as nobody was using a weighing machine. This issue emerged through the CAF survey and was presented to the Medical Office (MO) of the PHC by the concerned TB champion. The champion had

³⁸<https://twitter.com/SpeakTB/status/1373889522295971851>

been persistent in following up with the concerned MO at this PHC until a weighing machine was used for all newly diagnosed cases and those coming for follow-ups to this PHC.

I would like to reiterate that these daily engagements are between the TB programme and the champions, and we from REACH aren't part of these day-to-day affairs. Through this CAF, we are trying to establish a relationship of mutual trust and respect between the programme and the community. In parallel, we are steering a health systems capacity building initiative namely, "achieving excellence in TB care and services". This is becoming essential as the TB champions' expectations are increasing as we are training more and more of them. It is important that these champions are welcomed and their services are valued by the community. This requires a change of mind-set, which, of course, is a slow process and there isn't any magic bullet for this to happen. We can only keep ticking away, and persistently.

Yet another project which is in the pipeline from REACH through which TB champions will be leading support hubs at the TU or DTC facility level. This will be initiated at 400 facilities in 80 districts across the country with the mandate that TB champions will act as peer support to TB patients and provide person-centred care. The theme of person-centred care is a subjective one and can't be decided by any outsider. It has to come from people with TB and those who have survived TB. The earlier speaker, spoke about sustainability of programmes. REACH is also working on this by working towards strengthening survivor-led networks, yet another important aspect of the ongoing TB programme. Funders and organisations involved in projects cannot be forever; strengthening and supporting networks to become sustainable is essential. At the end of the day, the public health system, the programme, the private providers and the communities are going to remain, the lattermost as representatives of the TB affected communities. This is also an attempt and we are not sure as how this will unfold in the coming times and quality of its implementation on the ground. Again, there aren't any easy answers and magic bullets for making it a success.

Lastly, I would like to briefly touch upon the matter relating to honorarium to be provided to survivors who serve as TB champions. Many of the earlier speakers engaged with this topic substantially, and Bijayalaxmi raised this issue more explicitly. I would like to mention that REACH is engaged with about 400 to 500 TB champions who receive INR 5000/- to INR 8000/- per month through funded projects. This has been possible as these projects have a lot more flexibility in utilising funds. But when it comes to government-run programmes, which Bijayalaxmi rightly pointed out, there are delays in disbursement of allocated

³⁹<https://www.nhm.gov.in/index4.php?lang=1&level=0&linkid=36&lid=40>

funds. We have been advocating with the programme officials to bring in sustainability by including specific line items in the Programme Implementation Plan (PIP)³⁹ of National Health Mission (NHM) for reimbursements of costs or paying honoraria to TB survivors and patients. Delays in payment of honoraria are certainly a challenge to be addressed in the coming times if the programme is to become sustainable.

To sum up, I would like to restate that as TB champions are being increasingly accepted it is necessary that their own views regarding their role are taken into account. Some might be comfortable with direct service delivery and care, and some others may be comfortable with engagement with advocacy. We, therefore, need to consider these skills as parts of the whole and try to discover ways in which the survivors can genuinely contribute to TB care and service delivery programmes. They are to be respected and listened to not only for the purpose of building community capacity with inputs from communities, but also to be involved in strengthening programme capacity. Thank you once again to the organiser for having me here.

Amita Pitre: Thank you, Anupama. With this, we now open the session for discussion. I invite Sunita and Anant to join to moderate the discussion. We will take some questions and comments and we are extending the session to another 30 minutes for discussion.

Sunita Sheel: Thank you, Amita. We will have some questions.

Amita Pitre: I can see a comment in the chat on testing of haemoglobin done under the RATIONS study. Questions are invited from the participants. I can see one hand.

Sunita Sheel: Can I ask in the meanwhile, until people are gathering their thoughts? I just want to say that this is across the programmes for various health conditions and it is not only about tuberculosis programmes. In this regard, I would like to make two points: one, a question to Anupama and the others. As you know it cannot become person specific within the system and the persons who are holding offices in the public healthcare system. Instead, it needs to be a system-wide practice making it vibrant and resilient, and for it to come forward and respond to and deliver on what they're supposed to deliver. I have come across very good individual health care providers within the public health care system at secondary and primary level in cases of gender-based violence or abortion care. I noticed that it all depends on the commitment of a particular person, and probably also depends upon the personality or disposition of a particular health care professional. So, I think this is a problem and is concerning.

Two, I would like to know from Bijayalaxmi, who has worked with JSA. I know that JSA has been involved in undertaking community-based monitoring. Are there any sort of experiences of that kind of monitoring in relation to TB programme, as we

have been talking about social accountability, a cross-cutting theme across the health conditions?

Amita Pitre: We will collect some questions and speakers/witnesses can then respond to them. So, I will call out Dr Anurag Bhargava, then Prashant Sharma and Khageshwar for their questions and comments.

Anurag Bhargav: Thanks, Amita. I would like to try locating TB care within the larger setup of primary care in India and will take just one minute to do so. I think that TB care can be viewed in a very positive way and as a programme which can revive primary care in India. In the 1980s, primary health centres (PHCs) in India were not doing anything except treating just some minor ailments, dispensing contraception pills and immunising children. Tuberculosis programme has pushed the healthcare system to take, at least, certain diagnostics further down beyond district level. We are talking about the logistics changes, but still nothing has happened although some of diagnostics have reached to the PHC level. First, the programme enabled bringing microscopes into PHCs, and now there are TB-PCR (polymerase chain reaction) diagnostics available down to the level of CHCs, hopefully. The TB programme can have a bidirectional relationship with primary health care where we push primary care systems to provide care for TB, diabetics, and other diseases. The provision of these services will strengthen the credibility of primary health care. The WHO's conception of primary health care included addressing aspects like nutrition in communities. If we address malnutrition at the community level in India, including adults, it will have massive benefits which will go beyond TB.

At the moment, TB care programme has gathered momentum and we need to transfer and push that momentum to the primary care level so that all the patients benefit. Poor persons are stigmatised and discriminated in the health system. When I was working in a medical college in North India, medical professionals talk in a different tone to people coming to hospitals from rural areas, which was not acceptable to me. I think the state of TB programme within the health care system is indicative of how the system responds to the poor in India, while the state of nutrition of the poor in India is indicative of how the political system responds (or fails to respond) to this massive public health problem faced by the poor.

We can also look at the TB programme in yet another positive way, especially in the face of the COVID-19 pandemic. It is the TB programme which made it possible for India to combat COVID-19 because our health care system has been equipped with PCR machines because of TB. So, everybody in TB network should say that because of TB diagnostics machines, we could easily diagnose COVID-19 in India. The COVID-19 pandemic has really impacted India's health care system, but we should also say that due to the TB network, we could somehow diagnose persons with COVID-19.

For a more inclusive change, we should be accountable for other diseases, not just TB, and we should broaden our agenda and include issues relating to patients with all other diseases as well. We don't need champions and counsellors only for TB, but for every other disease. I really feel that working on the ground, and when we meet people, we come to know that they have solutions in their hands and they have thought through it all.

Lastly, I would like to say that among structural problems, it is unacceptable to have stock-outs of medicines/drugs. In 2010, may be Anupama and Chapal concur with me, a particular set of people was handling the logistics chain in India and it was working smoothly. Logistics is a completely different ball game which requires expertise. The change in logistics resulted in major problems in placing orders and maintaining the logistics chain.

Amita Pitre: Thank you so much. Your inputs have been valuable ones and it is much appreciated. I would now like to call Prashantji for inputs and comments.

Prashant Sharma: I do not know if any of you have had a chance to visit Sikkim to appreciate the situation there. However, I have a question for everyone here. With regard to the idea and strategy of empowering TB champions, how do you see sustaining their work and what might be the mechanisms that will work the best to sustain their work and involvement in the TB programme?

Amita Pitre: Khageshwarji, I now invite you to share your comments and present your questions.

Khageshwar Kumar: Thank you. Yes ma'am, I have a question about a patient who is diagnosed with TB in X-ray and his haemoglobin (Hb) level is less than 5 grams and he was put on TB treatment. But in our programme it is said that TB medicine should not be started if Hb level is low. In such instances, patients run the risk of dying and I know of some such cases. Are there such patients in the programme who are not MDR or sensitive to TB drugs and may also have low Hb levels yet they are put on TB medication?

I feel that the patient should be given some supplements and medications to improve his haemoglobin levels and then put on ATT, which may have saved his life.

Amita Pitre: Thank you, Khageshwarji. So, I will ask Anupama to respond to community level related questions and then we can request Anurag to respond to questions related to medical aspects.

Anupama Srinivasan: Sustainability of programmes is always a million-dollar question. There are two routes to be considered for sustainability beyond the projects. One way is for the NTEP to invest in communities directly. This can be translated as having budget line items in PIPs. For instance, there are mandatory line items in the budgets for private sector engagement and community

engagement as well. Some of the states have already taken initiatives to pilot test utilisation of funds allocated under this line item. But as rightly pointed out by Bijayalaxmi, there is a considerable gap between the policy statement on paper and implementation on the ground. The fact that many champions have not received payments for the work carried out by them on the field is definitely not acceptable and has to be addressed. In the long run, if we are really concerned about sustainability, then we need to integrate these activities/components into the public health system.

The other potential route is to strengthen survivor-led networks and manage support hubs at the facility level, as it exists in the case of the HIV programme. Prabha can speak to 'Touched by TB'⁴⁰ and Chapal to Survivors' against TB networks. And if these networks are strengthened at the service delivery level to manage support hubs, it will be helpful.

REACH intends to establish 400 such support hubs manned by TB champions, initially receiving payments from the organisation; hoping to gradually transition into the Programme, in the long run. Dr Anurag added to this, stating Bihar, Jharkhand, Chhattisgarh, 'Touched by TB' are already registered as independent organisations and can technically receive money themselves. In the long run, rather than placing the onus on individuals, strengthening networks is what we need to really focus on. This is not a quick fix though, but somewhere in the future to aspire for.

There was also a question and just to quickly respond to Dr Sunita. I agree that systems cannot function based on individual preferences and decisions. One day an interested STO and on the other an uninterested one, it definitely cannot function this way and we have seen this happening in many of the programmes. This requires a more systemic approach and there is still a long way to go for us to progress in this direction. Contrarily, individual role-models from the programme side are also important. This will help to look back and fall upon in taking tiny steps towards institutionalising such best practices by these role-models. I hope I have not missed any other question.

Amita Pitre: Anupama, just to add to the questions asked, is there any attempt at strengthening the TB network and getting connected to the broader community monitoring that is happening within JSA, for example, or let us say with the help of JSA? So, that is what Anurag was saying, that it shouldn't become a movement for TB alone but should become a movement for strengthening primary health centres (PHCs) and every other health-related problem.

Anupama Srinivasan: The answer for today is "not yet", due to the fact that these

⁴⁰<https://www.tbonline.info/posts/2017/5/3/touched-tb-coalition-tb-people-india-launched/>

Survivor-led networks are still young. For instance, TEJ network has around 300 TB survivors, all engaged at different levels. Khageshwar may be highly engaged but not all others are to the same level. But, during the COVID-19 pandemic, a lot of these TB champions played an important role in promoting vaccine uptake, in COVID-19 appropriate behaviour, in TB-COVID-19 bi-directional screening. There is lot of potential, but we still have to work towards this, being cognisant of not burdening the networks with these responsibilities very early either, but in the long run these can surely be considered.

Amita Pitre: I request Anurag to respond to the medical question and then I will let Rupa Kumari to make her comments.

Anurag Bhargav: The low levels of haemoglobin amongst TB patients is yet another example which shows how we have been ignoring this obvious problem in our population and have been blindly following the guidelines in the TB programme. Haemoglobin levels must be checked in all patients with TB in the same way that they are screened for diabetes and HIV. However, this is not done in the programme. We have included this in our study – the RATIONS - and we have found that there is a significant correlation with anaemia. But sometimes severe anaemia can occur in patients that Khageshwar is referring to. I don't think TB therapy has to be stopped in such cases, but instead one could initiate iron therapy after 15 days of TB therapy for such patients. For some patients there might be need for transfusion of blood. In our study, we have found out that after undergoing transfusion of blood those patients who were in life-threatening situations got better and they were saved. So, anaemia is an important co-morbidity related to malnutrition which should be checked amongst our TB patients and we should give appropriate treatment in response to correct it.

Amita Pitre: Rupa Kumari please come in for your question or comments.

Rupa Kumari: Ma'am, I have a question. I got a call from a DR-TB patient at Bihar. After completion of her treatment, she had a relapse of MDR-TB. She wanted to know the reasons for her relapse despite taking medications regularly and having appropriate height, weight and BMI.

AmitaPitre: Thank you, Rupa Kumariji. Dr Madhavi or Dr Anurag please come in for answering this question.

Anurag Bhargav: When we speak of individualised treatment, that is, the treatment is determined based on the outcome of diagnostics. But drug resistance patterns are not captured properly or diagnostics are not being used as per the protocol. Use of diagnostics differs from state to state. For example, some carry out CBNAAT while others carry LPA (Line Probe Assay). The sensitivity testing for the first- and second-line TB drugs is not taking place properly. Patients suspected of DR-TB are receiving drug regimens, that is also not up to the mark. This explains the problems Rupa, you mentioned and the difficulties TB patients face

on this front.

Another issue is recurring TB. On this, I note that the treatment of TB carried out in India records the highest percentage of recurrence in the world. About 10% of TB patients develop TB again within two years due to various factors. The first reason is that we haven't developed an individualised treatment strategy. We are providing six months of treatment for one with mild TB as well as one with advanced TB. If we provide treatment for longer duration to advanced TB patients, it may prevent recurrence of TB amongst TB patients. The second reason is under-nutrition which doesn't get corrected in TB patients till the end, which usually results in recurrence of the disease. The disease recurs if a patient is diabetic and is not controlled, or if a patient is alcoholic or smoker. Hence, if the TB guidelines consider the ground realities and adopt a holistic approach, then it will be beneficial. The system of tackling DR-TB isn't perfect yet, even in terms of diagnostics, and hence this problem.

Amita Pitre: Ganesh wants to say something, I can see. Please come in.

Ganesh Acharya: Thank you, Amitaji. In my opinion, person/patient-centred care cannot be standardised. It depends on that individual/person's needs, his habitat, whether Adivasi or tribal, whether he has food to eat, what sort of work he does; all these matters. It is not to be looked from a medical lens only — about diagnosis, disease, treatment; we need to consider individual needs — what problems they have which impacts their health. There is a need to simplify the concept of person/patient-centred care. We do not have any laws on anti-discrimination, preventing a person from suffering discriminatory treatment. I am concentrating on access to treatment for TB mainly because there has been hardly any progress in inventing newer anti-TB drugs, whereas in HIV in the past 40 years, more drugs have been discovered. I feel understanding the problems of people is important for the success of any public health programme.

Amita Pitre: You have pointed it correctly. We say that programmes should be patient-centric, but we don't know how to operationalise this. I can see that Bijayalaxmi and Anurag want to speak. Please come in with your comments and we will wind up since the session time is almost over. Then I will request Sunita to take over for the closing session. Bijayalaxmiji you can take 2 minutes for your comments.

Bijayalaxmi Rautaray: Thanks, Amita. I just want to add something to what Ganesh had said and it is absolutely right. When a patient is not taking medication properly, it is important to think of TB as a social problem and to look at it through that lens, rather than blaming the patient directly. There is no effort made to find out why patients stop taking their medicines. One needs to check whether there exist any problems in the system or with health care providers who have given medicines to these patients. With a humanistic approach, we can

do the work of taking care of TB patients righteously. There are a lot of patients who died because they didn't get their medicines on time. Our attitude towards TB patients should change, and we need to always have a positive approach towards TB patients, which can change the scenario in TB care spaces. Thank you so much.

Amita Pitre: Thank you. Anurag, please come in.

Anurag Bhargav: I can show you our article⁴¹ which discusses the concept of patient-centred care. We talk about patient-centred care but nobody has defined it. Generally speaking, we identify three aspects of TB care. The first aspect is treatment of the TB infection and infection-centred care, in which one is addresses only the TB germs. We are still not able to tackle the infection component of care adequately and effectively because MDR cases are still not cured effectively and there are also problems in testing. So, these are the gaps and constraints in this first aspect of TB care, which is infection-centred.

The second aspect is disease-centred care, where we focus holistically on the effect of the infection on the patient in terms of its extent and also look at coexisting diseases. We need to evaluate patients from a clinical perspective by checking their weight and noting the presence and severity of under nutrition, and if they have any other related diseases like diabetes, HIV or chronic respiratory diseases. There are gaps in this too, which are not fully tackled, as currently, even patients with severe under nutrition and TB in India do not get nutritional support, and many patients fail to get adequate care for coexisting diseases like diabetes. And the third aspect is that of patient-centred care, which is in the apex of this pyramid where we are asking patients about their problems, any stigma they might have been experiencing, and any discrimination they might have been subjected to. However, our current system is very fragmented, and we have not reached anywhere close to what is required in relation to the aforesaid three aspects of TB care. We were thinking that with the introduction of the government's NPY, TB care has become patient-centred. But no, TB care has not become patient-centred. The reasons being we have not yet addressed the co-morbidities of TB patients and not addressed the concerns and care needs of DR-TB patients. So, as a framework, I can share that article and please advocate for filling the gaps in the TB care programme with regards to these three aspects. Now, WHO appeals for person-centred TB care in which we will be guided by their expectations, values, and preferences. That is impossible without plugging these gaps in the existing system of care, and also listening to patients what their

⁴¹Bhargava, A., & Bhargava, M. (2020). Tuberculosis deaths are predictable and preventable: Comprehensive assessment and clinical care is the key. *Journal of clinical tuberculosis and other mycobacterial diseases*, 19, 100155. <https://doi.org/10.1016/j.jctube.2020.100155>

expectations and preferences really are. So, this is a frame work we can circulate it and people can look into it. Thank you.

Amita Pitre: It is time to wrap up the session. So, I am now handing over to Sunita and Anant for closing remarks. Thank you to all the participants for a very rich discussion.

Sunita Sheel: Thanks, Amita. So, big thanks to everyone who participated in this witness seminar. We had a very insightful discussion and I learnt a lot of things. TB is really not my space. I found it very useful to hear those experiences. I would like to thank Anurag and Madhavi who helped us in identify speakers and witnesses from the TB space. We thank each one of you for your engaging participation in the seminar today.

Before we close, I thank my colleagues, especially Parimala, who looked after most of the preparatory work and communication with speakers; and other colleagues, Sharanya, Mahendra, and Vijay. We will contact all of you individually via emails to seeking your approval to put this discussion out. If there are no further questions, or any closing remarks, we can close it. Thank you, once again.

ANNEXURE: 1
THEMATIC SCHEDULE OF WITNESS SEMINAR

A witness seminar

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

Opening remarks on the thematic	Indicative discussion points with focus on role and extent of engagement with/involvement of communities in TB Programme development, implementation and evaluation in India
FMES WHO Project team	<ul style="list-style-type: none">• Welcome and• Introduction to the theme of the witness seminar and the relevance

1435-1625 Hrs |

Theme 1: TB prevention and care in India: Voices from the ground

Moderated by Anant Bhan & Sunita Sheel

Note to the witnesses: Invited witnesses to present brief remark for about 8-10mins 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

Structure: 8-10 mins introductory remarks by witnesses followed by open discussion for about 30 mins seeking comments and additional inputs from the house

Mrs Rupa Kumari	<ul style="list-style-type: none">• 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• Your views on what needs to be changed in National TB programme in India and how can it be done, and how can survivors be part of this.
Ms Nandita Venkatesan	<ul style="list-style-type: none">• 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• Your views of intersectionality and/or any advantages you may have had given your location in terms of schooling/ education, being based in urban centres, and an edge that is offered by being in better economic position• MDR-TB and the support available for these individuals
Ms Mridula Das	<ul style="list-style-type: none">• 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 programme (eg: consuming Anti Tubercular Treatment (ATT) and out of pocket (OOP) expenditure for TB care)• Best practices and gaps in the engagement with the TB programme in her opinion.

<p>Mr Ganesh Acharya</p>	<ul style="list-style-type: none"> • 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 • Experiences as a TB patient and survivors advocate during the on-going pandemic and disruptions it caused to TB care • 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 • Intersection with the TB programme and does it support and involve survivors
<p>Ms Prabha Mahesh</p>	<ul style="list-style-type: none"> • psycho social counselling to TB patients: how important and who is best placed to do this? Role of peer support mechanisms • Networking of TB patients- has this been organic, why has it picked up in the last few years? Does the programme support it?
<p>Moderated discussion on Theme 1 1525 - 1600 Hrs</p>	
<p>Break 1600 – 1610 Hrs</p>	
<p>1610-1800 hrs Theme 2: Programmatic, Legal and Policy Engagement Moderated by Sunita Sheel and Amita Pitre</p>	
<p>1610 – 1640 Hrs</p> <p>Insights from working in different states, especially the ones from the Eastern and North-Eastern regions: Assam, Odisha and Sikkim</p> <p>Structure: 10 mins talks by witnesses</p>	
<p>Mr Prashanth Sharma</p>	<ul style="list-style-type: none"> • Experiences of working in Sikkim with focus on engagement with the state government for TB diagnostics and care options • Locating your TB advocacy efforts in your engagement with marginalized communities for basic health care as TB survivor and advocate for TB patients and survivors • Your take on role of community engagement in the coming times in TB prevention and care programme, and how it can be achieved and integrated in the programme and policies

<p>Ms Bijayalaxmi Rautaray</p>	<ul style="list-style-type: none"> • 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 • Opportunities and threats from your experiences of employing a humanistic approach to safeguard rights of persons with drug resistant TB
<p>Mr Khageshwar Kumar</p>	<ul style="list-style-type: none"> • Experiences and insights from your work as part of the TB Elimination network in Jharkhand • Quality TB care in the public health system • Role of survivors and champions in highlighting and responding to these issues
<p>1640-1710 Hrs</p> <p>Insights from intersectoral and intersectional engagement at programmatic, legal and policy level</p> <p>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</p>	
<p>Dr Chapal Mehra</p>	<ul style="list-style-type: none"> • Insights from multi-stakeholder engagement in recent times with focus on rights-based approach in TB care, and developing gender specific TB guidelines; • 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?
<p>Ms Veena Johari</p>	<ul style="list-style-type: none"> • 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; • 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? • How can we enable survivors and TB champions to be able to better advocate for their rights and needs?

<p>Ms Anupama Srinivasan</p>	<ul style="list-style-type: none"> • 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 • Some of the key learnings with focus on engagement with communities and other key stakeholders towards influencing programmes and policies; and more importantly implementation of these on the ground - has it made any difference on the ground
<p style="text-align: center;">Moderated discussion on Theme 1 and 2 1710 -1755 Hrs</p>	
<p style="text-align: center;">Closing remarks 1755 - 1800 Hrs</p>	

About the organisers

Forum for Medical Ethics Society

The Forum for Medical Ethics Society (FMES) was founded by a group of doctors in 1989. Its primary purpose was to highlight issues in medical ethics and generate discussion around them. FMES was registered as a Trust and a Society in 1995. It is commemorating its 30th year in 2022. Towards achieving reforms in the system, it recognised a long-term commitment that must combine activism with education and sensitisation of health professionals and society. At the same time, the group felt it ought to work for the development of bioethics as a discipline in medical schools and humanities.

Over these three decades, FMES established three robust platform complementing each other. They are *Indian Journal of Medical Ethics* (IJME) (since 1993), National Bioethics Conference (NBC) (since 2005), and Health, Ethics, and Law Institute for Training, Research and Advocacy (HEaL Institute) (since 2018).

Health, Ethics and Law Institute for Training, Research and Advocacy

HEaL Institute is set up to develop FMES' programmatic work in bioethics. It conceives health most comprehensively taking into account social and political determinants of health of people and beyond. It is committed to taking up socially relevant empirical and theoretical research, as well as critical policy and programme analyses to inform advocacy work at various levels and contribute to making a difference to peoples' well-being, especially of the underserved and underprivileged. While health and its determinants are centre-staged, our multidisciplinary and multi-sectoral approach facilitates and enables us to critically engage with law, regulations, constitutional entitlements, and the historical context of matters at hand alongside socio-cultural-political-environmental aspects.

Center for Nutrition Studies, Yenepoya (Deemed to be University), Mangalore

Established in October 2017, the Center for Nutrition Studies (CNS) at Yenepoya (Deemed to be University) (YDU), Mangalore aims to foster nutrition-related activities relevant to India. Our vision is a healthy and developed India, free of malnutrition, where individuals and communities can attain their true potential.

Problems of nutrition are the largest single contributor to the burden of disease both at the global level and at the national level. In India, the problem of under-nutrition is an underlying contributor to the high burden of infectious diseases in children and adults. There is need for an academic institution to engage with nutrition as a core and cross-cutting issue with a focus on research, capacity building and evidence-based inputs for policy. The Center for Nutrition Studies was launched to address this need.

The work of the faculty at the Center has informed policy at a national level, brought nutrition at the centre stage in TB care. The Center is engaging with the Ministry of Health and Family Welfare, National Tuberculosis Elimination Programme (NTEP), UNICEF, National Centre of Excellence and Advanced Research on Diets (NCEARD) in field of Tuberculosis and Nutrition, Maternal Nutrition, Adolescent Nutrition for advocacy, implementation, policy and planning.