



Proceedings Report of

A Witness Seminar on

**Tracing the historical trajectory of
community engagement in TB-related
public health interventions in India**

Held on Thursday, October 21, 2021

Co-organised by

**HEaL Institute, FMES; and
CNS, YDU**

Editors:

**Sunita Sheel Bandewar, Anant Bhan,
Parimala S and Sharanya Sreekumar**

March 2022

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
(HEaL Institute), Forum for Medical Ethics Society (**FMES**);
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Center for Nutrition Studies, Yenepoya (Deemed to be University)

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

Supported by

**The UNICEF/UNDP/World Bank/WHO Special
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Diseases (TDR)**
[Grant Number: P21-00344]

Hosted by
HEaL Institute, FMES

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Abbreviations

AIIMS: All India Institute of Medical Sciences

ASHA: Accredited Social Health Activist

BCG Vaccine: Bacillus Calmette–Guérin Vaccine

BMI: Body Mass Index

CHC: Community Health Centre

COVID-19: Coronavirus Disease of 2019

DBT: Direct Benefit Transfer

DOT: Directly Observed Treatment

DOTS: Directly Observed Treatment, Short course

DTO: District TB Officer

DR-TB: Drug Resistant Tuberculosis

FMES: Forum for Medical Ethics Society

FMR: Foundation for Medical Research

FRCH: Foundation for Research in Community Health

GCTA: Global Coalition of TB activists

GoI: Government of India

HIV: Human Immunodeficiency Virus

HIV-AIDS: Human Immunodeficiency Virus - Acquired Immunodeficiency Syndrome

IASSH: Indian Association of Social Science and Health

ICMR: Indian Council of Medical Research

INH: Isoniazid/Isonicotinic Acid Hydrazide

MDR-TB: Multi drug Resistant- Tuberculosis

MoHFW: Ministry of Health and Family Welfare (Government of India)

MSF: Médecins Sans Frontières/ Doctors without Borders

NGO: Non-Governmental Organisation

NIRT: National Institute for Research in Tuberculosis

NITRD: National Institute of Tuberculosis and Respiratory Diseases

NTEP: National Tuberculosis Elimination Programme
NRHM: National Rural Health Mission
NTI: National Tuberculosis Institute
NTP: National Tuberculosis Programme
NSP: National Strategic Plan
PAS: Para Aminosalicylic acid (Second line anti-TB Drug)
PMDT: Programmatic Management of Drug Resistant Tuberculosis
PLHIV: People Living with Human Immunodeficiency Virus
RATIONS: Reduced Activation of Tuberculosis by Improvement of Nutritional Status
RNTCP: Revised National Tuberculosis Control Programme
SCC: Short Course Chemotherapy
SEARO: South East Asia Regional Office
SHTW: Streptomycin-Isoniazid Twice Weekly
SOCHARA: Society for Community Health Awareness, Research and Action
TB: Tuberculosis
TCC: Technical Coordination Committee
TRC: Tuberculosis Research Centre
VHSNC: Village Health, Sanitation and Nutrition Committee
UNICEF: United Nations Children's Fund
USHA: Urban Social Health Activist
USAID: United Nations Agency for International Development
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, '**Tracing the historical trajectory of community engagement in TB-related public health interventions in India.**', 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-YDU) co-hosted this witness seminar on Thursday, 21st October, 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 long standing 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 domains for extending support is implementation research on infectious

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

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 Low and Middle Income Countries (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



Dr Beena Thomas She has completed her Masters in Social work and PhD from Madras University. She is trained in behavioural aspects of HIV/AIDS as part of the Fogarty postdoctoral AIDS international training Programme. She has been dealing with psychosocial issues around TB and HIV, services include counselling, strategies to improve patient compliance, working with families, rehabilitation of patients and documentation. She has expertise in HIV and stigma, community engagement relevant to TB, counselling, evolving strategies to improve patient compliance, working with families, rehabilitation of patients and documentation.



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



Dr Debabar Banerji A nonagenarian social scientist and public health scholar, he started his career as a physician in Western Tibet and interior Himalayan tribal regions. Born in 1930, he graduated in medicine from Calcutta, worked as a social scientist at the National Tuberculosis Institute, Bangalore (1959-64), and at the National Institute of Health Administration and Education, New Delhi (1964-71). As chair of the Centre of Social Medicine and Community Health, School of Social Sciences, Jawaharlal Nehru University, New Delhi, at its inception, he laid its foundation with strong academic content rooted in the Indian context.

His publication in form of papers in reputed journals, chapters in books and monographs cover a number of facets of the relationship between health technology and formulation of people-oriented health programmes for India. A study of this relationship in nineteen villages from different parts of India for a

period of nine years (1972-81) has been one of his major research contributions. His book, 'Poverty, Class, and Health Culture in India' is an outcome of this study. He is also the author of 'Family Planning in India: A Critique and a Perspective', 'Health and Family Planning Services in India: An Epidemiological, Socio-cultural and Political Analysis and a Perspective', 'The Making of Health Services of a Country, Postulates and a Theory', 'Social Science and Health Service Development in India: Sociology of Formation of an Alternative Paradigm'.

He challenged the status quoist approach of dominant public health. His seminal work in formulation of the Tuberculosis Programme and in analysing the political economy of the health services is well recognised nationally and internationally. He has demonstrated an interdisciplinary integration that provided alternative ways of thinking about the problems faced in public health, and thereby, has singularly contributed to the creation of an unquestionably significant space for social sciences in public health. He continues to publish analyses of prevailing trends in health systems and their political economy even while he points out the directions for the creation of a more pro-people public health.

He has been honoured the Lifetime achievement award in the field of Public Health by the IASSH (Indian Association for Social Sciences and Health).



Dr Kuldeep Singh Sachdeva He has graduated from Maulana Azad College and trained in TB and chest diseases from the VP Chest Institute at the University of Delhi. He served as ADDG in Central TB Division, MoHFW (Ministry of Health and Family Welfare), has experience in drug procurement, logistics management and TB programme. He was the Nodal officer for:

(1) Drug Resistant TB (2) Laboratory (Quality, scale up) (3) Operations Research (4) TB-HIV Collaborative activities (5) TB-Diabetes Collaborative activities (6) Donor Coordination (Global Fund, World Bank, UNITAID, USAID) (7) Paediatric TB (8) Procurement (9) Health System Strengthening. He was the resource person for capacity building in rational use of drugs, procurement, and logistics management. He currently serves as Regional Director, The Union South-East Asia, The International Union Against Tuberculosis and Lung Disease.



Ms Leena Menghaney is a lawyer and the Global IP Advisor for the Access Campaign in Médecins Sans Frontières (Doctors without Borders). She works with other experts and in partnership with patient groups and civil society to increase access to affordable vaccines, medicines, and tests in low- and middle-income countries for diseases like HIV, drug-resistant

TB, Hepatitis, cancer, and COVID-19.



Dr Muniyandi Malaisamy He serves as Scientist 'D' and HOD, Department of Health Economics, ICMR-National Institute for Research in Tuberculosis (NIRT¹), Chennai. He is an expert in Health Economics and has completed his PhD from the International Institute for Population Sciences, Mumbai in 2005. He has been involved in diverse socio-economic, behavioural and epidemiological research and intervention projects in the context of improving population health. He has contributed as a principal investigator (PI) and co-investigator in various research projects. He is also the coordinator for Regional Resource Centre for Health Technology Assessment in India (HTAI²) at ICMR-NIRT, Chennai. He has made significant scientific contributions to documentation and dissemination of research findings. He has 95 research papers published in reputed indexed peer-reviewed journals with high impact factor.



Dr Nerges Mistry She is the Director and Trustee of The Foundation for Medical Research (FMR³), Mumbai and The Foundation for Research in Community Health, Pune. A microbiologist and immunologist by training from the University of Mumbai and The University of Birmingham, UK, Dr Mistry's work encompasses infectious diseases with a recent focus on the molecular epidemiology of multidrug resistance tuberculosis and the mechanisms of acquisition of rapid drug resistance in tuberculosis and its public health implications. FMR was contributor of over 7500 TB strains for Whole Genome Sequencing (WGS) led by the University of Oxford to better diagnostic sensitivity of drug resistant tuberculosis (DR-TB).

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

¹<https://www.nirt.res.in/html/history.htm>

²<https://htain.icmr.org.in/>

³<https://fmrindia.org/>

developed a mask-based aerosol capture method for COVID-19 to understand viral transmission and are currently engaged in:(i) designing cost-effective measures of pooled sampling for community screening; (ii) concurrent single sample testing for TB and COVID-19; (iii) Use of SARS-CoV-2 genomics to explore virus pathogenesis

Dr Mistry has over 105 publications in peer-reviewed journals and has been a principal investigator of over 50 major projects. She serves as an expert on the Global Coalition Against Tuberculosis (GCAT) and is an Advisor to the TB PPM Learning Network and also a member of the National Technical Expert Group on Diagnosis of TB under National Tuberculosis Elimination Programme (NTEP⁴).



Dr Rohit Sarin He is the Advisor and had been the Director of the National Institute of Tuberculosis and Respiratory Diseases (NITRD⁵) and has experience of over three decades. He has been the recipient of the Karel Styblo Public Health Prize in 2017. He is a medical graduate with specialised training in tuberculosis. He is a post-graduate teacher for DNB Students of Respiratory Diseases and is a National Trainer for the Revised National TB Control Programme (RNTCP⁶). He worked as WHO National Consultant for over three years and was instrumental in framing and pilot testing of the RNTCP at the Central TB Division, Ministry of Health. He was deputed as a temporary advisor of WHO from time to time on various aspects of the Tuberculosis Programme and its Control in the South-East Asian Region. He was the SAARC Trainer for MDR-TB and DOTS Plus.



Dr Sunil Kaul A public health doctor graduated from the Armed Forces Medical College (AFMC), Pune and currently the Managing Trustee of the Ant⁷ (The Action North East Trust), an NGO based in rural Bodoland in Assam. He is the founding trustee of this organisation. His areas of interests have been Malaria, Tuberculosis, Maternal and Child Health, Mental Health and more importantly the social determinants of health. He completed his Master's in Public Health (in developing countries) from the London School of Hygiene and Tropical Medicine. He had also served as the State Advisor to the National Commission for Protection of Child Rights and as Advisor

⁴https://www.nhp.gov.in/revised-national-tuberculosis-control-programme_pg

⁵<http://www.nitrd.nic.in/>

⁶<http://www.nrhmhp.gov.in/content/revised-national-tuberculosis-control-programme>

⁷<https://theant.org/en/>

to the Commissioners appointed by the Supreme Court on the Right to Food PIL. Sunil has more than 10 years of experience as an army medical officer and 27 years of experience in the development sector.



Dr Thelma Narayan She is the Secretary of Society for Community Health Awareness, Research and Action (SOCHARA⁸) and is a figure well-known amongst the Public Health fraternity. She has graduated from St John's Medical College of Bangalore and has her post-graduation in Epidemiology. She was awarded a PhD by the London school of Hygiene and Tropical Medicine in 1998 for the Study of policy process and implementation of the NTP (National Tuberculosis Programme) , India. She has served as the Director of SOCHARA and School of Public Health Equity and Action (SOPHEA⁹). She is the member of the Advisory Group on Community Action for Health of the National Health Mission (NHM¹⁰). She has written extensively on Tuberculosis, its bio-social implications and the social paradigm associated to diseases. She has to her credit a large number of reports, publications and papers. She has worked closely with the Government of India in conception of the National Mental Health Programme¹¹.



Dr Vineet K Chadha He is currently the Advisor in Public Health at National Tuberculosis Institute (NTI¹²), Bangalore. He has worked in multiple positions at the NTI and has operational and programmatic expertise with TB control. He was the Consultant for TB for the WHO in Indonesia, Korea and Bhutan. He has provided technical assistance to TB Unit, WHO, South East Asia Regional Office in preparing the Annual TB Report titled "TB Control in the South East Asia Region, 2010". He was involved in comprehensive TB epidemiological assessments in Timor Leste and Bhutan in 2013 and 2014, respectively. He has technical expertise on the functioning of District TB centres and implementation of TB programme for more than three decades.

⁸<http://sochara.org/>

⁹<https://www.sochara.org/sophea>

¹⁰<https://nhm.gov.in/>

¹¹https://www.nhp.gov.in/national-mental-health-programme_pg

¹²<https://www.ntiindia.kar.nic.in/>

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 the 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.

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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 Programme.

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



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), 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), 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 specialized 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 PROGRAMME AND ITS EVOLUTION IN INDIA

Moderator: Dr Anant Bhan

Anant Bhan: We're delighted to have Dr Debabar Banerji here. Professor Debabar Banerji is one of the most eminent and respected social scientists and public health professionals in India. He is an Emeritus Professor at, and was instrumental in setting up the Centre of Social medicine and Community Health in the Jawaharlal Nehru University (JNU). He laid the foundation and was critically involved in the evolution of the tuberculosis (TB) programme in India. He has authored several papers and critiques on the public healthcare system in India and of the WHO, and has several years of hands-on experience of the health programmes and policies in India. He has received numerous awards, including a lifetime achievement award from the Indian Association of Social Sciences and Health (IASSH).

So, Professor Banerji, thank you so much for joining. We have requested you to kindly share your thoughts on how the TB programme evolved in India. In terms of historical facets, can you share your perspectives about how community and public engagement was viewed in those early days, and how those challenges impacted the implementation of that vision? Moreover, what are your thoughts on how things are today and what needs to be done in the future? Therefore, I would like Prof Banerji to kindly start his comments now and we request you to kindly speak to us for the next 20-25 minutes. Now let's hear from you, Professor Banerji.

Debabar Banerji | Evolution of National Tuberculosis Programmes over the past decades

Debabar Banerji: I was very happy to receive this invitation, although I'm quite old, to get this invitation from your organisation. And as I set about to do that work, I could gather an enormous amount of material. So much so, I had to decide to cut down the material by almost 90% and present only 10%. And then I discovered that I will not perhaps have the time to present even the 10% of it.

Coming to the basic question of TB, my memory stretches to some 60 to 70 years in the past from now. When I started getting interested in TB, it was an experience to know the works of PV Benjamin, the then Tuberculosis Advisor to Government of India (GoI). We had BK Sikand, the Director of New Delhi TB Centre, who had done some seminal work on the domiciliary treatment of TB in the city of Delhi. That was in 1955. And finally, we had CG Pandit heading the Indian Council of Medical Research (ICMR) who could contribute so much in contrast to what is

happening to ICMR today. It was a great opportunity for me to go back to these eminent people. There were eminent people in the World Health Organization (WHO), South-East Asia Regional Office (SEARO) in Delhi, such as Chandra Mani who served as Director, WHO-SEARO, between 1948 and 1968, and Halfdan T Mahler¹³, who later held the office of the Director-General WHO, Geneva from the year 1973 to 1988. He was an intensive advocate of Bacillus Calmette-Guérin (BCG) vaccination in India. Jawaharlal Nehru and Rajkumari Amrit Kaur provided the leadership, even though the total budget for the First Five-Year Plan for TB was merely Rs 14 lakhs. Despite knowing that our resources are limited, both of them were very keen that we reach the unreached with reference to TB. It was a great experience for me now to look back on those great days.

Actually, CG Pandit¹⁴ started what is called the National Sample Survey (NSS) of TB in 1955-58 and encountered enormous difficulties in carrying out a national level survey of a big and diverse country like ours. But he continued his efforts, and in spite of the delays and the problems, he could come out with very reasonable data on the epidemiology of TB at that time, which provided the baseline for all the TB-related work subsequently. And it also gave almost chilling discovery that the prevalence of TB was much more extensive than we had earlier imagined — it was not an urban disease. So, it was a great finding. Pandit started another thing and that was the famous Madras Tuberculosis Chemotherapy Centre (TCC)¹⁶, which undertook the very difficult task of comparing home treatment with sanatorium treatment (Madras Trial¹⁷).

India has carried out a number of such outstanding research studies but were unfortunately not properly attended to by the people from the West, who are now trying to teach us what to do with TB in India. Particularly, I'm talking of the Revised National Tuberculosis Control Program (RNTCP). I feel very sad, not because of any Indianness, but because of lack of academic rectitude. When you

¹³Perakath Vergese Benjamin @https://en.wikipedia.org/wiki/Perakath_Vergese_Benjamin

¹⁴Dr Chitaman Govind Pandit was the first full time secretary of Indian Research Fund Association, redesignated as ICMR in 1948.

¹⁵Dawson, J. J., Devadatta, S., Fox, W., Radhakrishna, S., Ramakrishnan, C. V., Somasundaram, P. R., Stott, H., Tripathy, S. P., & Velu, S. (1966). A 5-year study of patients with pulmonary tuberculosis in a concurrent comparison of home and sanatorium treatment for one year with isoniazid plus PAS. *Bulletin of the World Health Organization*, 34(4), 533–551. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2475991/>; Watts, G. (2010). Wallace Fox. *The Lancet*, 375(9720), 1076. doi:10.1016/s0140-6736(10)60467-9.

¹⁶<https://www.nirt.res.in/html/history.htm>

¹⁷Dawson, J. J., Devadatta, S., Fox, W., Radhakrishna, S., Ramakrishnan, C. V., Somasundaram, P. R., Stott, H., Tripathy, S. P., & Velu, S. (1966). A 5-year study of patients with pulmonary tuberculosis in a concurrent comparison of home and sanatorium treatment for one year with isoniazid plus PAS. *Bulletin of the World Health Organization*, 34(4), 533–551. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2475991/>; Watts, G. (2010). Wallace Fox. *The Lancet*, 375(9720), 1076. doi:10.1016/s0140-6736(10)60467-9.

have material available from eminent journals that you simply ignore (is unfortunate). So, I would submit, that this is a basic question of ethics in academic field. I will come back to it perhaps later if I have time.

The TCC Madras Study showed that one can treat TB equally well at home even in slums, with very poor nutrition conditions than in sanatorium, using first-line drugs namely, Isonicotinic Acid Hydrazide (INH) and streptomycin, with conversion of the TB cases being much beyond 90% in both the cases. This had far-reaching effect and a major shift in the treatment practice of TB all over the world. I underline particularly the West that had been preaching us for long that you cannot treat TB without incurring high costs. Then, the cost went down extensively from Rs 20,000 to as little as Rs 1,100. So, it was a major gain for a country like ours. And, thanks also to our leadership, which had visualised doing this sort of work. TCC also did the low-cost small course TB treatment referred to as Short Course Chemotherapy (SCC). They also made major epidemiological, clinical, biochemical and bacteriological contributions. I will not go any further into it. It is well established and well prepared, but is little understood even when we were formulating the RNTCP.

This made two eminent persons in India, P V Benjamin and Halfdan T Mahler²⁰, dare to approach the government to build up a programme to deal with the problem on a national scale. Interestingly, Jawaharlal Nehru agreed to set up what is now called National Tuberculosis Institute (NTI²¹) in Bangalore in 1959. He himself came down to Bangalore to inaugurate this institute. Our courage in setting up not only the TCC, but also the NTI in Bangalore with a mandate to NTI to build up a nationally applicable, socially and epidemiologically acceptable tuberculosis programme for India was fruitful. They brought in epidemiologists, TB control specialists, bacteriologists, health statisticians, public health nurses, X-ray engineers and very interestingly, social scientists, into the NTI. The NTI had equal representation for social scientists in all the main decision-making processes under TCC. This Committee dealt with all the technical issues and in close alignment with the mandate that was given to the NTI by the government.

On a side note, one very interesting feature at NTI and TCC was, we mostly used the word “We” rather than “I”. The reason being it was an interdisciplinary joint thinking that used to take place involving intense debate and discussion, which I rarely find today. Anyway, that was a great thing that shaped NTI’s institutional ethos during those days. We, in the sociological section, were trying to find out as to where do we go from here.

²⁰<https://pubmed.ncbi.nlm.nih.gov/12288991/>

²¹National Tuberculosis Institute (NTI) was established in 1959 at Bengaluru by the Government of India in close collaboration with the World Health Organization (WHO) and United Nations Children’s Fund (UNICEF) at the AVALON building made available by erstwhile Maharaja of Mysore.

Almost unintentionally, we ended up quoting Mao Tse-tung²³ (former Chinese communist leader), who had said, "Go to the people and learn from them". We wanted to go to these people and learn what do they do when they have TB. It so happened at that time we were having a major TB programme in Tumkur district of Karnataka. We undertook an epidemiological survey. We took a sample of cases found in Tumkur and conducted a very carefully designed sociological survey, including the very carefully chosen control system or control population to find out what did these TB patients do when they had the disease.

To our surprise and to the surprise of all the members in the TCC and elsewhere, that half of all TB patients in Tumkur district had gone to a doctor in a health institution in Tumkur. And they were dismissed with a bottle of cough mixture. So, this was the main finding, that there are people who are coming to a healthcare institute, to the doctor and it is the great doctor who throws the patient out with a bottle of useless mixture/syrup. That was a major breakthrough, that is, there is a tremendous unmet need felt for TB services, even in the remotest parts of the Country.

The second question was how do we diagnose individuals with TB in villages? In this context, we found out that these health institutions had a technician with a microscope for malaria work, and we could find that all these TB cases had chronic cough for up to 20 days or more who have been visiting health institutions. So, we thought that we could train these laboratory assistants to do smear examination of all chronic cases who visited the centre to identify the untreated TB patients by microscopy. So, it was a major breakthrough for us and we called it 'giving a social dimension to epidemiology'.

Then came the question as how do we treat these diagnosed patients, and we found that the health centre/health institution or primary health centre have staff which can cater to organising a domiciliary oral treatment free of cost. Remember, that was the main thing inspired by Jawaharlal Nehru that we will give free treatment, unlike sanatoria and other places, which we had. And so, these people then were being treated free of cost, and given one month's treatment, and the treatment was supervised by the field staff, who go to the villages of patients and find out whether they were taking the treatment. Note that, at that time, we were providing free INH and thiacetazone treatment, which we later tried to change to rifampicin.

We also found that the existing district TB clinics can offer referral facilities to those cases that could not be diagnosed by sputum examination. And the district TB officer can also offer training and supervision to the work that is being done at the village level and at the level of the health institutions.

²³https://en.wikipedia.org/wiki/Mao_Zedong

So, these three elements — one, when we talked of social dimensions of epidemiology; two, when we talked of treating, and diagnosing people through smear examination and referrals; and three, which is also very important, is we used the existing health services and discovered them as an integral part of the TB programme — became the main central theme/backbone of the future national tuberculosis programmes. Social dimension and epidemiology of tuberculosis, social orientation of technology, the smear examination, and integration of tuberculosis with the general health services, because most of the TB work was being done by the trained general health service personnel.

At NTI, we also discovered that we had to constantly confirm our presumptions that people come with cough, especially chronic cough, they can be diagnosed, and treatment can be organised and can be set up by the health institution.

Our colleagues in NTI have repeatedly checked this assumption that this shall happen. That gave rise to the formation, what is called the National Tuberculosis Programme (NTP). When we were reasonably satisfied that these things can be done, we devised with the help of what is called operational research and systems analysis, a design for the district level study in Anantpur district of Andhra Pradesh. It was to find out whether actually, NTP can be implemented at the district level, including the district TB centres. The data that we collected very carefully proved that it can be done in rural districts at an extensive scale with the district TB centre acting as a referral point, training centre and a supervisory centre. This confirmation of the operational research study in Anantpur emboldened us to draw the outline of the NTP. Our outline included team training of a number of people who would be running the programme at the periphery, as well as at the district centre and in the headquarters.

We also looked into this, often repeated fear of what is called ‘defaulter rate’. We again asked a question — were people so stupid that they would die and not take the treatment? We discovered that the major problem of individuals defaulting was to do with administrative and organisational flaws in the program. We also anticipated that it would be a very big task to translate the Anantpur experiments across India. Although we know, let me tell you, the Anantpur trial was a test run for the NTP to be scaled up for across India scale. Yet, we were very careful in doing so given the fact that India is a big country. At the time, there were 3000 to 3500 districts, now there are 700.

I will say, very briefly, that NTP was accepted by the GOI for implementation in 1963. Later it was approved by the WHO Expert Committee on Tuberculosis. The Union (International Union Against Tuberculosis and Lung disease)²⁴ followed WHO. Before I close, I would like to mention two points. One, was the curse of the

²⁴<https://theunion.org/>

time bound, target-oriented Family Planning Programme (FPP) that India was running, which destroyed the infrastructure of health services and for which we are still paying the price for; two, that out of nowhere we got the RNTCP. I was surprised that RNTCP, with the backing of the WHO and the World Bank (WB), tried their best to wean India away from NTP to go on for RNTCP, promised that we will control TB — “Control” is an epidemiological word. And finally, now they are talking of even eradicating TB from the world. It is well known, that no country in the world has managed to do so.

With this, I will stop here.

Anant Bhan: Thank you so much, Prof Banerji. An absolute honour to hear from you for all of us who are students of Public Health. To, of course, have you today with us, is very special. Your reminiscences based on your vast experience have been very useful in being able to share these thoughts with everyone.

Thanks so much. So, I think as we have discussed earlier what we will do now is have a few more interventions, including lead interventions by a few more colleagues who are here today, and then, we will continue with an open discussion.

So, in the first section which I am moderating we will have 3 more interventions where we have requested the interventions of around 8-10 minutes each from all of you, just so that these are place holders for the discussion where it would be more of a moderated open discussion as I had mentioned earlier.

Next, I will call on Dr Rohit Sarin and request him to talk about TB therapy specifically in India, the drugs which have been historically rolled out in that programme, and now with Multi drug Resistant TB (MDR-TB), and also with the advent of many other interventions in the public health programme and short-term therapy etc.

As a clinician who has been treating TB patients for many years, what are your perspectives on how the programmatic side and the treatment side of the programme evolved? Have we really reached a stage where we can say we are moving towards or are we at a stage where there is patient-centred care in India? And if not, what do you think are some of the factors that may explain the failure of making TB care patient-centred in India, and how can we get there?

Over to you, Dr Sarin for your thoughts

Rohit Sarin | Clinician's perspective on Tuberculosis therapy in India

Rohit Sarin: Thank you and I would like to echo the thoughts of my other colleagues in the context of what Dr Banerji discussed. I had the pleasure of meeting him during the transition of NTP to RNTCP and he still is the same in terms of his clarity in concept and communication, as he was 25 years ago.

As far as the treatment of tuberculosis is concerned, I think I will just say prior to the chemotherapy, most of the treatment relied upon good food, fresh air, isolating the people in sanatoria and hoping that the individual survives. About 25% of the TB patients did survive; though, the large majority of them did die. The drugs which came up initially were isoniazid (INH) and streptomycin given for a longer duration of 18-24 months. Administering streptomycin injection IM (intramuscular) was considered a herculean task then, which led to trials with streptomycin and INH twice a week (SHTW²⁵) as it was popularly called, at the chemotherapy research centre, currently NIRT. This SHTW regimen was the first look of directly observed treatment short course (DOTS), wherein streptomycin injections and INH doses were given to the TB patients who visited the health facility. This showed very promising results of over and above 5% success rate from the already existing rate.

With newer drugs coming up viz., para aminosalicylic acid (PAS) and thioacetazone, the treatment options slightly changed. The duration was reduced in what is called as SHE by HE regimen²⁶. But at that point of time, it was only INH and thioacetazone with streptomycin given for only 3-4 months, as the treatment of TB. DR-TB was not that commonly known. People/patients who did not respond to treatment were left to their fate, destined to die.

With the development of laboratories and expansion, terms like non-response to drugs, and (drug) resistant TB became familiar. This particular treatment option which was there for a year to a year and a half, of the INH and thioacetazone which was augmented with streptomycin in the initial three months of the treatment, carried on in the programme for many decades. This was administered through the General Health services, with a District TB centre in each district. This served as the nodal point functioning with its core staff, getting reports from the peripheral sputum microscopy laboratories and X-ray centres available at the community health centres (CHCs).

So, the patients came to any of these facilities; peripheral microscopy centres or CHCs, for getting diagnosed and collecting their medications. The medications were given as domiciliary treatment, for it was already proven domiciliary treatment is effective and not that infectious as compared to the hospital-based management, as had been informed by Dr Banerji. The domiciliary treatment consisted of collection of drugs for a month and refilling after return during the next month.

²⁵<https://medicalguidelines.msf.org/viewport/TUB/latest/9-1-standard-first-line-treatment-regimens-20321981.html>

²⁶SHE stands for 'Streptomycin (S), isonizad (H), and ethambutal (E)' regimen; and HE stands for isonizad (H), and ethambutal (E)' regimen. World Health Organizaton. (2003). Treatment of Tuberculosis: Guidelines for National Programmes. WHO/CDS/TB/2003.313., 3rd edn. Available from: <https://www.who.int/docstore/gtb/publications/ttgnp/PDF/2003.313.pdf>

In the late 70s and the early 80s, we had rifampicin, which was a major breakthrough anti-tubercular drug, with the possibility of shortening the treatment duration to less than a year. Any treatment less than a year continues to be called as SCC. So, with the coming up of rifampicin and ethambutol, it was thought that initial two months of rifampicin, isoniazid and ethambutol, followed by seven months of rifampicin and isoniazid, i.e., a total of nine months of treatment will be sufficient to cure TB. Further with the advent of pyrazinamide helped to further shorten the treatment from nine months to six months. Now, again during this period you see, at the NIRT Chennai²⁷, they did the research in 18 districts in different parts of the country, when this treatment was introduced.

And it was then considered what could be the best possible outcome with this particular treatment. However, it still fell short of 60%, in terms of the treatment success rate, but was still double of what SHTW regimen was achieving. With the newer regimens the success rates of treatment were seen to be more and sometimes doubled, with shorter durations. In longer duration, since pyrazinamide was expensive it was agreed upon to administer it for initial two months followed by INH and thioacetazone for six months, that is, 8 months therapy; leading to the genesis of SCC. Within the programme settings, we had eight months of therapy and that again carried on for quite some time. Initially, this rifampicin-based regimen was limited to those individuals who were sputum smear positive and for the others we continued with the one-year regimen on INH and ethambutol (HE) or with INH and thioacetazone.

On subsequent review, we found the TB situation in the country continues to be the same. There were lot of articles from NTI which showed that we had really not made a dent in TB despite all the efforts in establishing centres, network of diagnosis and treatment. A country-wide review on where we had gone wrong was conducted and even before that, the TB Association of India²⁸, conducted a conclave in Surajkund, Haryana, in which we were a part. They tried to address some vital issues on the reasons of non-performance of NTP, low success rates of 25-30% and the reason for increasing defaulters.

They came up with a whole list of findings and then again in 1992, the International community aggregated to review the whole aspect of TB from an outsider's perspective. The weaker areas in the TB programme were identified and addressed by revising the whole program. Though there weren't basic differences and the programme continued to rely on its strength: the domiciliary treatment, general health services and treatment delivery. The logistics support was made more easily available; and so were the drugs. The strategy was pilot tested and then adopted in the whole country. During this whole course, clinicians

²⁷<https://www.nirt.res.in/html/history.htm>

²⁸<http://tbassnindia.org/History.html>

who came across non-responsive patients were requesting laboratories to know what was happening. As it was only solid culture then, rifampicin resistance (RR) was identified. So, here was a challenging situation where the bacteria was actually resistant to the wonder drug, which actually shortened the treatment. We had to digress back to older long duration treatments, particularly for DR-TB. The initial treatment regimens were primarily on clinical individual aspects rather than on the programmatic front. We started treating patients in hospitals with again an 18-month regimen; it used to comprise of kanamycin, cycloserine, ethionamide and PAS. These were the four drugs we were relying on and the injections were given anywhere from 3 to 6 months, and we continued with the rest of the treatment.

The drug resistant TB was a global problem and it was considered to follow a programmatic approach rather than just clinical management. WHO established the Global Green Light Committee²⁹. And our institute, the National Institute of TB and Respiratory Diseases (NITRD), undertook the first pilot in the country, to understand the usefulness of programmatic delivery of drugs. And, then we started on with giving these drugs that were very costly, to the patients in the field under the DOTS programme. So even DR-TB management was being done as DOT and we were relying on the basic drugs which I have just mentioned — kanamycin, cycloserine, ethionamide and PAS — because these drugs had not been used by the patient earlier.

We found that it was a successful implementation; we could achieve success rate even in the programmatic setting. However, it involved a lot of monitoring a lot of supervision and so on. And as you all know that then came the newer drugs, the newer diagnostics, then a situation where the individuals became resistant to most of the drugs we were using for, you see, drug resistant TB, and then came the development of Category³⁰ IV³¹, and Category V by the GoI, and in the private sector, well, the same drugs were being used but in different combinations and for different durations.

And we had of course, difficulty in standardising these treatment regimens. Today, we have a national program, which talks about mono resistance to isoniazid which has to be managed, and we have a treatment regimen for those six to nine

²⁹https://www.who.int/tb/challenges/mdr/greenlightcommittee/glc_faq.pdf

³⁰<https://tbfacts.org/treatment-category/>

³¹Treatment 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.

months of treatment with rifampicin, ethambutol, pyrazinamide and levofloxacin. And, then we have a shorter MDR regimen; earlier the shorter regimen contained an injectable kanamycin, but gradually it is being phased out and replaced by bedaquiline-based treatment options. And then of course, we have the longer 18 to 20 months treatment with bedaquiline-based regimen, along with levofloxacin and newer repurposed drugs like linezolid, clofazimine and cycloserine. So globally also, as the thinking changed within a country, also the priorities changed in terms of the treatment regimen, the duration of treatment, and so on.

And now, we are talking that the present treatment is still not good enough because this treatment in clinical trials is giving us good results, but in the programme setting the treatment is of longer duration. So, the question was how to shorten it? Then, we observed that individuals were getting resistant even to quinolone, which was considered as a very good drug. And that you know, the Extensively drug resistant TB (XDR-TB) definition emerged. So, treatment options were very limited because we could not give the quinolone to these individuals nor could we give any of the other drugs; with the coming up of delamanid³² and now with the coming up of pretomanid, there is a possibility of reducing the treatment from about 18 to 20 months to about six months. And, I opine that future research would reduce the duration of treatment for drug resistant forms of TB.

With respect to treatment delivery, patients were not complying well. Hence, DOTS was considered, and initially, we never used to promote family DOTS, but now drugs can be collected from the health facility and can be given at home by a trained family member. The individual/patient would come to the health facility every week or once in 2 weeks to collect the drug. With technology the modes of treatment delivery are also changing. We have 99 DOTS³³, video-assisted observation and other treatment adherence strategies. With these, the future is right because not only we have something for drug sensitive TB, but also for drug resistant TB as a form of shortened treatment. Thank you so much.

Anant Bhan: Thank you so much, Dr Sarin, very kind of you to share your perspectives, and especially from a clinician perspective because I think that gives us a good snapshot of how things have evolved on the treatment side, some of the challenges, and also some of the positives. I'm really glad that you feel as an experienced clinician that the future is bright. Hopefully that is indeed the case over the next few years, especially because you've had a tough time over the last

³²https://apps.who.int/iris/bitstream/handle/10665/137334/WHO_HTM_TB_2014.23_eng.pdf

³³99DOTS 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>

few years. Even today, I was reading in the newspaper, concerns around drug stock out. So, that is also something that should be addressed.

Dr K S Sachdeva, is of course, a very experienced programme administrator in the TB space. He's been involved in multiple ways in the TB programme in India for the past many, many years, and has good and deep understanding of how things have evolved. Now, Dr Sachdeva, what we want you to reflect on is the TB treatment, and the response that has evolved from sanatoria and hospital-based care to then domiciliary care. We've seen the national programme also evolve from the earlier initiatives in the 1950-1960, to the RNTCP in 1993 to the National Strategic Plan (NSP) for TB Elimination. How do you see based on your own experience of being at the realm, and being involved in many of these programmes, how the monitoring measures/actions are also a part of this evolution that the programme has looked at diagnostics, treatment guidelines, but also the involvement of patients and communities? So, I request you to kindly share your own thoughts and perspectives. Over to you, Dr Sachdeva.

Kuldeep Singh Sachdeva | Formulation of National Strategic Plan for elimination of Tuberculosis

Kuldeep Singh Sachdeva: Thank you, Dr Anant Bhan.

A few of my thoughts will now be shaped by what my earlier speakers have said. I haven't prepared any outline for my talk and this would be more impromptu and recollections of matters relating to the evolution of the TB programme in India. The topic given to me is to talk on NSP, process of development of NSP, development of its diagnostic and treatment guidelines, and future of these programmes.

First, I want to instil a lot of optimism here that a disease about 5000 years old, though Wikipedia says it's 20,000 years old, is which we are thinking of eliminating. At this point in time, it's quite a way in the history of mankind that with these advancements in science and social sciences, the National programme is now able to talk of eliminating the disease. Irrespective of the time frame or targets set for this, the very idea that we are buying in this thought means there is something more upcoming in future, better than earlier years. We never thought of elimination about 10 years earlier.

Second, evolution of the programme over the years has been complex. Previously, with fewer drugs, the programme was relatively simple to implement informed by a few principles. Now, when I try to enlist various components of the programme, there are close to 20 to 30 components of the programme. Each of these components require a different skill set and warrants a multi-disciplinary team who can bring to the table a mix of expertise. For example, the team needs to comprise of experts in TB, experts in diagnostics, public health practitioners, experts in partnership engagement, experts in communication, social sciences

professionals, procurement and supply chain management experts, and so on.

You need a good mix of expertise and professionals to take you to that end game of Tuberculosis in India and this gets reflected in the NSP. The latest version of NSP is available on the website of the NTP. At the same time, in planning a document such as the NSP, trying to fit in all the components, reaching out to people to end a disease that has been in existence for long, like TB, is indeed a complex task. I agree with Dr Rohit Sarin, that this requires more of collective wisdom than individual insights into the TB epidemic. So, when you try to make a plan for a country or specifically a country-wide plan, such as, NSP, one has to try reaching out to many, aiming at informing the plan by collective wisdom and by building a consensus around such a strategic plan. There are, of course, individuals who may not agree to many components of the programme, but the goal is to get the majority to agree upon most of the components of the programme. This is one thing which I wanted to place on the table.

I have been part of developing two NSPs. One was developed about 12/13 years ago in 2007-08. It was a very inclusive process and almost all stakeholders were involved at various points in time in finalising the NSP. The process was also quite iterative. During the development of such a nationwide plan, it usually undergoes 15 to 20 iterations enabling consideration of all comments received from all stakeholders and to be able to finalise the plan without having any comment left out without deliberations and collective decisions on the same. This whole process may take close to a year with a minimum of 20-25 consultations with various groups. The draft plan is then put out for suggestions and comments which are incorporated in the document towards finalising the same. The development of the latest NSP which is applicable for the period 2017 to 2025 is no exception to these processes and the overall approach to it. For example, it followed the same approach of being inclusive, evidence-informed and reliance on collective wisdom. All sciences, social, management and medical sciences have to be taken into consideration when making these plans.

So, I will be looking forward to the questions because what I say here will be more generic.

Then on the spectrums of various committees, like how are treatment guidelines and the diagnostic guidelines developed? The field of diagnostics and treatment has seen very rapid changes in the last decade, from just only smear microscopy and X-ray being the two tools available with the National Programme for two decades earlier to be at a stage which I consider as we are actually spoilt with availability of spectrum of choices. We now have so many options that you have to really go through all the options and see what will work best for the country to implement. So, we have seen rapid changes in diagnostic spectrum, that now we look at diagnosing TB in less than an hour.

We end with a sensitivity close to 100 which was never possible earlier. We also now look at reading radiographs using artificial intelligence-based technologies. As Dr Sarin mentioned earlier, that drug resistant TB which was not in the reckoning when initially NTP was conceived. Then within drug resistance theory from molecular diagnostic to doing drug susceptibility testing for various drugs to genomics, we look at targeting genes and identifying which genes are responsible for which mutations and which are responsible for drug resistance. And furthermore, to know those mutations which are clinically relevant and then, offering treatment which is more patient-focused and making an individualised treatment regimen within the limits of possibility.

So, we are almost there from a scenario where it used to say that microscopy only detected 50% of those who have TB to a stage we have reached, a new scenario now, where in we can look at atoms and genomics within that. Having said that, the programme has not lost sight of the other components which are more social, and patient-centric which is the theme of discussion today. So, a host of new interventions have come up from partnership with civil society. The public sector has taken a back seat allowing patient provider support agencies to interact with community and patient.

Of course, there are also direct interactions at various points in time with civil society and the community in each and every aspect of decision-making. The programme has community engagement involving pro-active learning from other programmes and being part of each and every committee. The programme has worked at length and breadth in addressing all components. The challenge currently is about these many components and someone or the other advocating for specific components of their interest. Look at the component of direct benefit transfer (DBT) or direct cash transfers to patients and some of the health workers and other communities who support the programme. The transfer is happening to a large extent to the tune of 70 to 80% of beneficiaries getting those transfers. In a country as wide and large as India, there are always a few slippages here and there and you will see pressure groups coming from all sides. Also, the challenge for the programme is on which component to focus more so that it gives you the right kind of push for an accelerated reduction in TB incidence to be able to reach the target of elimination by 2025.

The programme is getting ready to serve all those challenges to meet this target, and they are putting their best foot forward on all these aspects. Coupled with this, it is not only about the challenges of newer treatment options becoming available every day but also a lot of advocacy and pressure groups emerging on introducing each and everything which comes as a new scientific discovery in the global world to be adopted under the program. But as already alluded to, the process actually involves collective decision-making. Dr Sarin is part of the few committees, chairing a few other committees under the national programme, and

is also engaged with policymaking processes. He said that all policymaking should emanate from the scientific evidence which is well-documented in scientific literature.

So, the committees involve a range of stakeholders and at present there are about 12 committees under the national TB programme. We found that the committees were also working in silos. And that's when we decided that one or two representatives from each committee would be part of each and every committee to sort of disseminate and transfer knowledge across committees. This, we hoped that each committee is aware of the entire spectrum of activities going on with the national programme and are able to take a decision in its entirety by taking a holistic worldview of the programme.

So, I think I should stop here. The point which I would like to reiterate, is that with so many components in the programme, there are different skill sets required, all of which may not be with the Ministry of Health and Family Welfare (MoHFW). Being cognisant of the same, I have been advocating to engage with other ministries who can play a proactive role in addressing some of the issues which are beyond the purview of MoHFW. For instance, the DBT is facing a huge challenge in opening of a genuine bank account. This whole process of opening an account, transferring money through the public finance management system is not the strength of the MoHFW. We, therefore, need to seek other expertise in this space. Having said that, even then I think the MoHFW has done a wonderful job of doing everything which hasn't been their core strength and delivering almost 80% of expected results in reaching out to those in need and contributing to delivering social justice.

I'll stop here and wait for questions which may be more pointed, more critical, and will try to answer those. Thank you, Dr Bhan

Anant Bhan: Thank you so much, Dr Sachdeva. It is very kind of you to share your own perspectives on the programmatic evolution, as well as what have been some of the inputs which have gone into it, what are some of the challenges; and I'm glad that you are also very much like civil society advocating that health is, of course, larger than just the Ministry of Health, that we need to get all of these other ministries involved because it's a social justice, political, and also a finance issue that we need to have that secure line of funding continuing for TB programmes in India.

We will now transition to Dr Vineet Chadha. He, of course, has been involved in many ways in some of our key TB Institutes. So, we've had NTI, which was set up in 1959, in Bangalore, the NITRD, which was also set up in the 1950s and the Tuberculosis Research Centre (TRC), in Chennai, as well. So, we've had so many institutes which have been in a way designed and situated to focus on TB. How have these national TB Institutes been typically involved in the evolution of the TB

programme in India? What has been their contribution to TB care, TB as a public health issue? And again, how these institutes look at involving communities and patients? Over to you, Dr Chadha, for your thoughts on this.

Vineet K Chadha | Evolution of National Institutes of Tuberculosis

Vineet K Chadha: Thank you, Dr Anant. I have been called upon to talk on the evolution of the work of National TB Institute, and on the engagement and role of communities and patients in TB care. Well, I like to begin by thanking the organisers who gave me the opportunity to be part of this group. It has been absolute delight to listen to all the three previous speakers.

The NTI³⁴ was conceptualised in 1959 to formulate a practicable cost effective and socially acceptable community-based NTP in order to control TB. The concept of 'control of TB' was then defined as considerable reduction in disease burden in terms of incidence and mortality over a reasonable time period. This need was realised after the Nationwide TB disease prevalence survey³⁵ undertaken during 1955-1958³⁶ by ICMR, which revealed that the disease was all pervasive in every nook and corner of the country. Hitherto, TB care services were being provided mainly by a few non-government organisations (NGOs) and missionaries mostly concentrated in cities. It was to the credit of the then authorities that the necessary infrastructure for NTI was set-up on an amazingly fast track basis. Equally commendable was the zeal and dedication of the workforce of NTI that they began the task of formulating the programme strategies in right earnest.

NTI started its learning by conducting its studies on a sizable population in Anantapur district in South India. It soon realised that the immense problem of TB cannot be conquered by establishing clinic-based services alone. Thus, due emphasis was given to providing community-based services and with the involvement of the community. In fact, in the Anantapur experiment, panchayat members and local volunteers actively participated in referrals for diagnosis and what was then called 'case holding'. Meanwhile, community-based studies were also initiated by NTI in Tumkur district³⁷ and rural Bangalore to find out not only the health seeking behaviour of TB patients, but also the natural history of disease in the community including its transmission dynamics. Evidence was quickly generated about the optimum mix of screening and confirmatory diagnostic tools. As you have heard, the domiciliary treatment strategy was rolled out with inputs from the classical study of 'home versus sanatorium treatment' carried out by then newly set up TCC in Madras and also actually the inputs from the seminal

³⁴https://en.wikipedia.org/wiki/National_Tuberculosis_Institute

³⁵<https://ntiindia.kar.nic.in/cddistrictlevel/ielearn/category/Scientific%20Articles/IJTUCH93.pdf>

³⁶https://ntiindia.kar.nic.in/docs/nti_annals/pages/ANNALSThegenesis_25.htm

³⁷<https://www.ijfcm.org/journal-article-file/2148>

work of the New Delhi TB Centre which happened to be amongst the very first TB centres in the country. NTP was then duly pilot tested in the entire district of Tumkur, and thus, the national TB programme was born in 1962. That the evidence-based programme which took a concrete shape in about 2.5 years from the time the idea was conceived, was indeed a commendable achievement! In fact, there is a statement on record made by Dr D R Nagpal that when they started NTI, they thought it would take about 10 years to formulate a viable programme. And so, it was really a remarkable feat.

In fact, this study of sanatorium versus home-based care was the first such study in the world to show us the importance of DOT, which was, of course, not incorporated as part of the NTP strategy in the country at that point of time. And in fact, one of the principal investigators of this study, Dr Wallace Fox³⁸ implemented DOT based on his experience in Chennai, in Hong Kong and other countries and it came to India after 30 years or so. DOT is one of the core components of the WHO recommended DOTS strategy (internationally recommended strategy for TB control) adopted by the country in mid-1990s under the RNTCP.

It was soon recognised that there was a dearth of skilled medical and paramedical professionals to tackle the huge problem in a big country like India. The challenge of creating skilled TB cadre also fell on NTI which it accepted gleefully. It also took over the burden of monitoring and supervision as also providing feedback to State and District authorities all over the country on their NTP performance parameters. NTP was the first national health programme which was not only evidence based but also adopted operational research as one of the essential components with the aim of continuous evolution and improvement. National TB Programme later re-named as RNTCP and now as National TB Elimination Programme (NTEP³⁹) has thus been continually evolving not only in terms of incorporating newer interventions but also improved implementation of the existing ones. National institutes, such as, NIRT⁴⁰ and NITRD have also contributed immensely in this direction.

Later, two rounds of National Risk of TB infection surveys⁴¹ spear headed by NTI not only formed the basis of case finding target but also demonstrated the positive trajectory of the impact of TB.

NIRT, according to me, has the distinction of having undertaken the biggest number of landmark research studies anywhere in the world — be it the

³⁸<https://www.theguardian.com/world/2010/apr/04/wallace-fox-obituary>

³⁹https://www.nhp.gov.in/revised-national-tuberculosis-control-programme_pg

⁴⁰<https://nirt.res.in/>

⁴¹https://ntiindia.kar.nic.in/paper_up.htm

epidemiological and immunological aspects of the disease, the drug delivery systems or drug trials. These efforts ultimately lead to formulation of effective drug regimens and treatment strategies which have been adopted all over the world. It continues to do so by ever evolving newer, shorter, safer and more cost-effective treatment strategies specifically for various forms of drug resistant TB as well as its prophylaxis. It also exhibited some landmark implementation research projects like the 'Model DOTS project' in Tiruvallur district and 'TB free Chennai', and now 'TB free Madurai'. Earlier demonstration projects for community-based DOT were also carried out by these institutes and this formed an essential component of the DOTS strategy.

NITRD, New Delhi, as mentioned by Dr Sarin, has also been an epitome of clinical excellence in treating TB patients including those with severe complications and drug resistance. Its recent efforts in the form of 'weekly ECHO⁴² (Extension for Community Healthcare Outcomes Project) clinics and 'Difficult to treat TB clinics' is facilitating skill transfer to several TB workers, and thus, benefiting lakhs of TB patients across the country. Some of its outreach demonstration projects have also helped to evolve field operations. In the meanwhile, New Delhi TB Centre has continued to support the Delhi State authorities in providing perhaps one of the high-quality TB care amidst all the challenges of the capital city, which sees a lot of migrants from all over the country including a large number of homeless people.

These institutes also helped build the TB research capacity in the country. These institutes along with recently added institutes also serve as National Reference laboratories and are striving hard to ensure availability of quality assured laboratory-based diagnosis including using newer diagnostics, for drug sensitive as well as drug resistance TB.

Recently, NIRT, where I am part of some of its scientific advisory committees, has embarked upon quite a few 'community engagement' demonstration projects. All the institutes also contributed in revising the training content from time to time and in providing high level technical assistance to the Central TB division⁴³ with NITRD leading in this direction. The NIRT, in particular, also contributed immensely demonstrating involvement of private sectors as well as the community in projects like TB-free Chennai. These National level institutes are also shouldering the major responsibility of the currently in-progress 'TB vaccine trial', the result of which will hopefully facilitate a faster march towards eliminating TB.

Even though community-based services and community engagement were the

⁴²<http://www.nitrd.nic.in/WriteReadData/userfiles/file/NITRD%20MDR%20TB%20ECHO%20project%20Oct2017.pdf>

⁴³<https://tbcindia.gov.in/>

primary doctrines on which the TB programme in India has been based from the beginning, I feel that the extent of community involvement hasn't been commensurate with its requirements. The burden of timely detection and effectively treating 2.8 million TB cases every year and drastically reducing case fatality cannot be managed without the active participation of the communities. Thankfully, in the recent past, there have been several examples of successful community engagement projects by a large number of agencies including NGOs, corporate sector, and other entities ably supported by the Central TB Division and State TB Units. The recent initiatives of the central TB division in the form of rationalising the role of cured TB patients as 'TB champions' as also engagement of all stakeholders in the form of district, state and national TB forums with similar community structures at the sub-district and lower levels is commendable.

These along with many other efforts towards community engagement are concrete steps in placing TB control in the hands of the community by being partners in devising, innovative interventions in terms of local needs and customs and also in monitoring and advocacy. We have observed during our evaluation visits and joint meetings that even though we have practical policies made at the central and state level, a lot of dilution happens in implementation in peripheral areas. And, I think the involvement of these community structures will provide a great platform to ensure accountability and help in more effective monitoring of the programme.

Other prominent initiative has been the facilitation of 'Patient Support Groups' at local levels which first came into being in states like Kerala and Telangana and now form an essential component of the TB elimination strategy in India, taking TB care literally out of the exclusive purview of the more formal healthcare provider-based care, thus facilitating a more friendly, patient-centric care. These patient-support groups have already helped scores of TB patients in providing all kinds of support such as nutrition supplementation essential for attaining cure, social support, and stigma alleviation.

It is indeed very pleasing to see that the efforts to engage various community structures and TB survivors are now getting due importance, especially after the clarion call in early 2016 to eliminate TB, by none other than our esteemed Prime minister. I feel that the time has now come to amalgamate all the recent efforts and learnings in this direction into a more organised effort of delivery of TB care to communities with and through communities. It will also ensure that TB care services are not hampered in crisis situations like it happened during the ongoing COVID-19 pandemic. I feel that today's seminar is one such step in this direction. I wish the organisers and all the experts a wonderful day of fruitful deliberations ahead and a very fruitful outcome as well. Thank you so much.

Anant Bhan: Thank you, Dr Chadha, kind of you to share your perspectives. I

know you've been involved for decades in the programme and been a critical part of key institutes and so your reflection is also very relevant to us. So, I think we have at the end of the lead interventions for this session.

This is when we want to open up for discussion. So, the idea for the next approximately 30 minutes is for us to reflect on what was shared, but also for us to hear from everyone who is present today, because all of you are key participants in this discussion in terms of your own reflections on the TB programme and its evolution.

As you would have seen in the programme, the first part, i.e., the morning programme basically focuses on the history and the evolution of the programme. And then, we want to, in the afternoon, transition more also on discussing some of the social aspects. So, I think what I will do now is call on individuals who have raised their hand. I can see Thelma, Anurag and Sunil as well. So, if I can ask Dr Thelma, you to go first. Please switch on your video and share your question and your comments. Thank you.

Thelma Narayan: Thank you, Dr Anant. I really appreciate all the presentations made this morning. I think it proves to us that we had some of the best brains in India working on tuberculosis over the years. One of the thoughts that come to my mind based on the experience of the recent pandemic is that given that effort has been made from the 1950s till date on TB with support from the highest levels of decision-making, how the programme fared during the covid pandemic? I would like to have some data, if possible, to know about it (programme functioning on all parameters). I don't have access to such data. If we have done well in TB, during the pandemic this would have been a sterling test for the resilience of the programme, especially if it was already socially embedded. So, I would just like to have some evidence-based inputs with regard to how the TB programme functions during the covid pandemic. Thank you.

Anant Bhan: Thank you, Dr Thelma, I think what we'll do is have a round of questions, and then maybe open it up. So, Thelma's question perhaps, if Dr Sachdeva and Dr Sarin, if you can respond to from the programmatic side and the clinician side as well.

Meanwhile, If I can ask Sunil for your question or comment. Please go ahead.

Sunil Kaul: Yes, I think it's been great listening to everyone. As Thelma said, so many brains and thinking have gone into this issue at hand. I've been a bit cut off from what's happening in TB at the national level as I moved to the North Eastern region of India 20 years ago. When I was working in Rajasthan, I used to be called regularly by the government for consultations even before the RNTCP was formed. We had started the SCC regimen for six months through an NGO in Rajasthan in 1990. During that time when RNTCP was being formed, I had kind of presented out there at that time in the out-patient department, lists of TB

patients which had Shown about 30% were already resistant to rifampicin and INH.

But what is the state now is something which I would like to know? I suspect the worst because for many years, we had the thrice a week SCC regimen. I know that in Assam, for example, where I stay, 15 days a month used to be off and very often the centres will not open, and patients also could not travel because of *bandhs* during the COVID-19 pandemic. I am therefore interested to know the situation on the ground.

Anant Bhan: Thanks, Sunil. Leena, I saw that you have raised your hand, do you have a question?

Leena Menghaney: I have a comment to make. As a person who had prior lung disease and as a woman in a room full of predominantly male policymakers, I just wanted to emphasise my disagreement with the narrative being used to explain the TB programme. One of the primary points I wanted to stress is the level of denialism towards drug resistant tuberculosis. As a result of a slow response to drug resistant tuberculosis, we lost 10 years that would have been better spent in stopping one of our most deadly infectious diseases. We lost a decade while dealing with this culture of denialism and that has impacted India's response to the drug Resistant TB. I believe that TB programme had a certain level of bureaucracy and conservatism. I have been part of the HIV, Hepatitis C and several other vertical health programmes, as well. The programme wanted representation of TB patients, but the conservatism and obstacles held against TB activists was evident, although they are the ones who act on behalf of TB patients.

We continue to be plagued by supply chain issues. I experienced one of the biggest stock-outs of paediatric TB medicines meant for DOTS in children. While I was working with journalists on the ground in different states, trying to determine the extent of the stock-out situation, I was shocked to hear that the tenders had not been placed in time and we had just run out of drugs. A similar problem now plagues the supply of delamanid, which is a chronic problem that has been going on for quite some time. Are we as community encouraged to report these stock-outs? I would say no. In fact, I would say just the opposite. We are scared to report the stock-outs. Activists such as me and others, who actually do work, like Loon Gangte⁴⁴ who reports stock-outs, are gravely endangered by this feeling that we are unwelcome. We should be in the room and we should be allowed to raise these issues regularly.

It would appear that we are not feeling safe with the TB programme and in the context of stock-outs. In my opinion, we are whistle-blowers who have continually pointed out that the files are piled up on the desks of bureaucrats and ministers. I

⁴⁴Interview with Loon Gangte | bilaterals.org

don't agree with this narrative that has been put out here. I agree, millions of lives have been saved and a lot of progress has been made. Yet, I also believe that the TB programme has a culture of denialism regarding various big issues it faces. I am sorry to say this so bluntly. As a result, it's also difficult for us because we are dealing with very high-level bureaucrats who I'm going to have to communicate within the weeks and months to come.

Anant Bhan: Thanks Leena. So, first of all I think all comments including the critical ones are welcome and that's why we are convened here. Of course, every narrative has a counter narrative and we welcome that, especially from members of civil society activists. This is an open forum and of course, is open to all other participants also to share their perspectives. Thank you for sharing.

Anurag, over to you, if I could also request may be to reflect on some of the comments and questions which have already come through because you are also a clinician and somebody who has been involved in TB programme and working at the community level and now in a tertiary institute as well and leading TB research as well. So, if you want to respond to some of the questions and add on some of your own questions or comments.

Anurag Bhargava: All of the presentations were excellent, especially Dr Debarbar Banerji's. His clarity in presentation was astounding.

I would like to say that we talk a lot about the Madras Study. However, I think there is a serious misinterpretation of the Madras Study and the lessons learnt from the Madras study. I think it should be mandatory for everybody who works in TB to have studied the Madras Study. The study report was of 94 pages. In the conclusion, Wallace Fox and colleagues wrote the study report clearly stating that domiciliary therapy resulted in cure rates in a microbiological sense that approached those of sanatorium-based therapy under the conditions in which the trial was conducted in Madras. They clarified that it should not be assumed that equivalent results would be obtained under other conditions unless certain criteria or conditions are met. That was the disclaimer by the research team who led the Madras Study which everybody probably in the programme seems to have overlooked. Adequate supply of drugs including reserved drugs, facilities for drug resistant testing must be available so that if in case that person is drug resistant, alternative drugs may be provided.

Also, facilities must be available for supervision of the drug for the people at the home level, and for bringing them to the hospital in case they develop complications or adverse effects. In the Madras Trial, the family was also given an assistance fund based on the cost of living at that time so that the family can be supported through this loss of employment and hospitalisation of the patient. It is therefore noteworthy that way back during the 1960s when the Madras Trial was designed and conducted, patient and family support and supervision was its

intrinsic part along with medications. Another important feature of this study was that that the patients lived nearby, it did not recruit patients into the trial who lived beyond a five kilometre radius of the TRC.

Then, any epidemiologist would tell you that one cannot extrapolate the findings of one trial conducted on a selected group of patients intensively supervised and supported into a field situation where one is not meeting the other criteria of the original trial. Even the assurance of uninterrupted drug supply in the NTP remained a persistent challenge. As I've indicated earlier, even the Anantpur⁴⁵ pilot study could not provide the two drugs to the patients which were tested in the Madras trial and were given only isoniazid. Predictably many of them may not have improved since single drug therapy is prone to high rates of failure. Could then the patients be blamed if they were not even supplied the required drugs on a regular basis?

I have to say that we seem to have swung like a pendulum from one side to another in this gap ignoring the nuances. Before the Madras study, every TB patient was thought to require sanatorium-based care. After the Madras study, the notion developed that hospitalisation was not required for everybody. As a result, the TB programme over time took the shape of domiciliary TB therapy for everybody regardless of the circumstances. Today in Jharkhand we find that patients who are too sick, who cannot even stand on their own feet are getting domiciliary therapy. Such an approach is neither suggested nor would have supported by the Madras Trial. I think this is the misplaced reading and understanding of the Madras Study. This has led to the government drastically reducing the number of beds for TB at every district level. The question it raises is: how are we going to achieve reduction in TB mortality when very sick patients are not given the essential services they need.

There has been yet another major misinterpretation of the Madras Study. I tried recalculating the weights of the trial participants — TB patients. Their body mass index (BMI) was around 14. The Madras Study showed that weight gain was more than double in the group that got better food in the sanitorium. That is a very important outcome from the patients' point of view. However, after the Madras Study the requirement of a nutritious diet for patients with TB because of their severe wasting was neglected and for decades. We removed the component of food support from the patient's prescriptions and even in patients with a BMI of 14, they were left to their own devices. I think the Madras Trial study should be reanalysed and should be deliberated upon because although a number of factors were considered, some other important ones were left out, such as what will make TB care acceptable, and what will be effective for patients. We chose to pick

⁴⁵https://www.researchgate.net/figure/Mortality-rates-after-TB-diagnosis-in-Anantapur-India_tbl3_269718786

up on certain findings which were convenient to us, and did not give adequate attention to aspects, such as logistics of drug supply, adequate financing and supervision. I have personally witnessed the sufferings of patients and their families in absence of the essential services they ought to have access and it has been very distressing to me as it is distressing to Leena who shared her concerns on this front, earlier in the seminar today.

I saw in a medical college in 1994 where patients came all the way from other states for TB care were being told that at that point in time rifampicin was not there, ethambutol was there. As a result, patients used to return with this drug every time there was a stock-out of rifampicin. Firstly, how can a therapy-based programme basically have such a (major) logistics problem? Secondly, I was running outreach services for an NGO in rural Gujarat where despite my repeated request, they did not start sputum microscopy. They could have easily done it. Lack of availability of sputum microscopy locally meant that a patient with chronic cough had to wait for three weeks to get diagnosed with TB because the sputum samples were being sent to DTC (District Tuberculosis Centre) and there used to be some delay in returning the results to patients.

Another concerning area is that we have been told repeatedly that intermittent chemotherapy is not feasible in Indian conditions since it requires direct observation. And yet we chose that path in 1995. I think there was pressure on us to accept it. We have not discussed the fact that for the first time in the 1990s we had external funding for the TB program. World Bank came forward to support the programme, but possibly on certain conditions to meet which I do not know what they were. It is possible that support was committed on the condition that India would accept the DOTS strategy and intermittent chemotherapy.

The kind of debate and discussion that Dr Banerji draws up to, I think, we missed out on some of those aspects in the later periods. It's good that some of that broad base of discussion has now become possible. However, I would strike a note of caution here. We have not really thought through the epidemiological targets that we are setting for ourselves in India. This is creating a lot of pressure on the TB programme to deliver at any cost on this goal of meeting the target of 'Eliminate TB by 2025'. The word elimination means that there is less than one new case per million per year. Our current TB incidence is 217 per 100,000 per year and even if we do achieve the 2030 targets by 2025 (which is being confused with TB elimination) we shall have 44 new cases per 100,000 per year, or 440 cases per million every year. Right now, we are very far from this target!

I think, the fact that we are trying to get our act together now, say for example, extending support to DR-TB, it would have been better if we did not have targets which we have not discussed in a broader framework and debated the feasibility of this target in India and around the world. As I've mentioned earlier, the RNTCP for all or some of its reservations brought money into the programme, it brought

uninterrupted drug supply, and improved the reach of diagnostics. However, it also led to choosing a form of therapy which was not certainly patient-centric because a lot of people were not able to go to a facility three times a week to access it.

I think we need to have a nuanced understanding of the problem at hand. The number of persons at risk of TB in India, those with latent TB infection is more than 400 million, and social factors like poverty and under nutrition are the underlying causes of the progression of this infection to active TB. As Dr Sachdeva said, it is not a matter for the Health Ministry alone, or for us as TB specialists alone to solve it. In fact, it is a much bigger issue, requiring us to address the primary determinants of health, especially the poor. It seems to me that we are coming full circle back in terms of our approach to responding to the TB prevalence/epidemic. In that, we realised that only treatment and supervision-based approach would not work. Now, we are trying to get back to aspects of TB control, such as reaching out to patients, the understanding which was there from the very beginning but we switched on and off on this strategy. In this regard, I would like to point out that unfortunately, we have created the notion of or a category of 'defaulting patients' in the TB programme context without really appreciating its sociological or social epidemiological construct that Dr Debabar Banerji talked about and which had made a deep influence on the programme.

My apologies for taking more time to make this intervention but I thought that sharing these with this group is important. I also point out that I am speaking only from the point of view of somebody very concerned about the health of people in India, particularly the poor and that's my submission.

Anant Bhan: Thank you, Anurag. Blessina, if I can request you to go next with your comments and questions.

Blessina Kumar: Thank you very much, Dr Anant Bhan. I just want to respond that it was very encouraging to hear Dr Banerji, say "Go to the people and learn from them". Somewhere along the way, we have lost this, and yet we all talk about people-centred approaches and people-centred care. I don't know how much we understand what it means for the programmes to be people-centred because we have people calling us every day for help as there are no drugs. Then it takes a whole chain of calling up various people we know, such as WHO consultants, and begging and running for making medicines available for those who fall back on us for such support. As we can imagine, for every person that we extend such help, there would be thousands of people out there who go off tuberculosis medications. Such stock-out of TB medicines has happened over and over again.

In 2014, there was a huge issue of drug stock-outs raised by us, for which we were targeted. It was not an easy time for us and we continue to raise such issues concerning persons with TB. Against this backdrop, I think we need to go back to the basics of how the TB programme started. From what I hear, what does it mean

to be people-centred? Where is the counselling support for enhancing or strengthening adherence to TB regimen by the patients? Why are we so quick to jump on to tracking, monitoring, and placing the blame on the patients? TB programme is one programme, where if one has TB symptoms and enters into the TB programme, it is almost sure that the person loses all dignity. For example, one is treated as someone with no brains. As part of the DOT strategy, one is expected to open one's mouth, and drugs are chucked into your mouth and a glass of water given to you. This has to stop. The introduction of digital technology is useful. But unless and until we ensure that a person's rights and dignity are upheld through that, we cannot accept these technologies; we cannot accept 'under the skin tracking' devices. If you may have been at The Union Conference, you would have heard about these developments, such as a little band-aid-like gadget which is placed on the stomach of TB patients to track if the patient has been taking the medication. Such technological interventions are based on mistrust. I think this need to change, empowering and engaging meaningfully with communities needs to come back to the centre if we want to progress and truly end TB if at all, that's possible. Thank you.

Anant Bhan: Thanks a lot, Blessina. Leena, I see that you have your hand raised, if you can, maybe quickly, just intervene and then, I'll just allow for a last round of responses.

Leena Menghaney: So, I just wanted to say that I am going to address some of these issues of denialism in my testimony. I would like to emphasise the role WHO played in the impact it had on community participation. In Médecins Sans Frontières (MSF⁴⁷), we value neutrality a lot. So, we would not have people from that particular country or region working on particular medical projects to keep neutrality. We understand neutrality very well. But WHO India's current makeup and the people who work for the programme, frankly, tell a different story. What we noticed about WHO India is that when we raise those issues, they often do not play a neutral role in working with communities and with the government. I feel that sometimes one gets more direct openness from Dr Sachdeva (Dr Kuldeep Singh Sachdeva) who worked until recently as a member of the NTEP than someone from WHO India which usually goes into defence mode to deny these problems and gaps when dealing with TB in India.

I could give you several different examples of issues where WHO India itself contributes to the culture of denialism. I consider this as a very big problem in India where WHO does not play the role it is supposed to play, of a neutral technical body which is supposed to be bringing the voices of communities together with technical information and guidance and work with governments. So, I think that the role of WHO India in the perspective of TB is something that

⁴⁷<https://www.msf.org/tuberculosis>

largely needs to be discussed not only in this meeting but also at the global level.

The reason why I raise this is because when issues relating to drug resistance at the beginning of the century came up, the WHO immediately saw it as its failure of the DOTS programme that it had advocated for. But drug resistance was inevitable in some ways, as India allowed TB treatment to be privatised, failed to use fixed dose combinations for DOTS, the lack of patient-centred DOTS and the manner in which the WHO denied space for discussing drug resistance in 2004-2005. It contributed to the inability of the RNTCP to respond in a timely manner. It failed in its technical role. I just wanted to highlight that WHO India is fraught with very conservative officials who would like to sweep issues under the carpet. They have not played the neutral and technical role that they were supposed to play in countries like India with reference to the TB programme, and the TB affected communities. I will stop here.

Anant Bhan: Thanks, Leena. Appreciate that, as well, your honest assessment of the role of WHO. So, we will not share anything in the public domain without the explicit consent of those who have shared that. We will share your comments back to you if you feel there are certain things that you would not like to be put in the public record, that's perfectly fine. So, it is much more important for us to have an honest discussion and learn from each other.

Alright, I think we have around 6-7 minutes remaining before I need to hand it over to the next moderator, Sunil. I did want to also check in with Dr Beena, because I see that you had quite a few thoughts that you shared in the comment section. If there's anything that you'd like to speak for a couple of minutes, and then, I will request the lead people who spoke earlier to respond to any of the questions. Over to you, Dr Beena

Beena Thomas: Thank you, Dr Anant Bhan. I think you are doing a wonderful job in moderating. I didn't want to say anything during the earlier session because of the want of time. So, I have been putting all my comments in the chat box. I love this concept of the witness seminar. So, I was just thinking, at the end of today, I wish we can clearly witness and come out with something that's tangible and sustainable. Because it started off with Dr Banerji sharing perspectives way back in the 1950's, we have been talking about the same thing. I wish that we would talk more about success stories and what really has worked and has been sustainable. So, I think that would be a great way to go because we had discussed this so much. We are talking about it over and over again. But I really wish we can also come out with something that we could recommend, which is here to stay. So, I just wanted to say thanks to FMES, the organisers of this witness seminar.

Anant Bhan: Thank you so much. We are hopeful of that as well. And actually, we realised that maybe, this might be part one of the conversation and we need more threads, but at least let's see what we get out at the end of today.

Okay, now I'm going to request maybe in reverse order to the first few interventions to Dr Chadha, Dr Sachdeva, Dr Sarin and then finally Dr Banerji for any quick responses and also specifically to questions; there were two questions I saw, one was about drug resistance and the second one was about the impact of COVID. So, Dr Chadha, over to you.

Vineet Chadha: As far as the drug resistance is concerned, there was a comment that the magnitude is being brushed under the carpet. I really don't agree with it because you see that there are several studies and surveys which have been systematically undertaken and the results are before us to see. After the inception of RNTCP and after 25 years of RNTCP, we see that the drug resistance, that is, MDR among new cases has remained at about 2.5% and prevalent MDR about 11-12%. And of course, the INH mono resistant TB is also around similar rates. This is irrespective of the lacuna and the defaults and the interrupted drug supply and all that and it has been seen wherever DOTS strategy was implemented.

In fact, before the incidence and mortality starts to decline, the proportion of DR-TB starts to decline. Therefore, it was rather expected that the proportion of DR-TB out of all TB cases would decline. In other countries like the US when they started the DOTS programme, even before the incident TB declined, there was a drastic decline in DR-TB over the first few years. Therefore, the point is DR-TB has not declined in India after the implementation of DOTS strategy contrary to observations in some other countries. The other thing is that so much investment and effort has been made in up scaling the services for DR-TB care, and there has been a tremendous increase in infrastructure in this regard. In fact, even before Dr Sachdeva became DDG-TB, I think his major responsibility was to scale up the PMDT (Programmatic management of DR-TB) programme which was then called as DOTS plus and we have witnessed, in recent times, the difference it has made to the TB program.

In terms of diagnostics for DR-TB, we are now moving to even whole genome sequencing, and of course, the treatment, which was earlier localised to a handful of DR-TB centres, now there is a centre in every district to treat DR-TB and the proportion of funds that go to DR-TB actually is far above the proportion of total DR-TB that is there in the community. But I think, as far as this particular issue of tackling DR-TB is concerned, the achievements in terms of case detection remain below the estimated figures of its incidence. For example, we still diagnose maybe just about 50% of DR-TB cases, we still don't treat all the ones which are diagnosed, and maybe cure just about more than 50% of diagnosed cases. Therefore, there is definitely a scope for further increasing the case finding efficiency which we must do. And of course, the primary reason, I think, is that the involvement of the private sector in drug resistant TB care is not enough to avail the services that are there under NTP. That is one sector I think which needs more attention to be paid in the coming times. Thank you so much.

Anant Bhan: Thank you, Dr Chadha. Dr Sachdeva, can you please come in.

Kuldeep Singh Sachdeva: Thank you, Dr Bhan. I would like to answer what Thelma asked. So, all the programmes fared badly during COVID-19, not just TB. In April 2020, the notification was down by 60% as compared to April 2019. When the lockdown was announced on March 25, 2020 and again, during the second wave in March 2021, the notification was down by 60%. But the point here is not about that what happened during COVID-19. But the point here is when after lifting of the first lockdown and releasing restrictions towards the end of June 2020, the average notifications of two lakh was attained by December 2020 as was during pre-covid times. So, that resilience within the system was there. Similarly, again it's picking up towards 150,000-160,000. This second wave was a little later than the first lockdown. So, the impact was more in May or June 2021. It's picking up again and I believe that by December 2021 it will again attain the level as was during December 2019. There is ample evidence showing full resilience within the health system to get back to the previous status. Even with now lesser manpower because still a lot of manpower from the TB programme works for COVID-19.

But the availability of molecular diagnostics has increased because of COVID-19. From about 1500 machines in 2019, we now have around 5000 machines which is helping in stronger resilience and recovery.

The second point about Dr Sunil Kaul's observation on MDR rates of 30%. That may be the case with tertiary care institutions but as Dr Vineeth Chadha said, most of the surveys including the one considered representative of the country and carried out by NTI in 2019 show declining trends in drug resistance at the community level.

And, in fact, the absolute numbers have been declining for drug resistant TB in India compared to our global counter parts. We have lesser rates of drug resistance compared to what the other global counterparts still have — predominantly, Eastern Europe and Africa. So, the decline may not be what we were expecting but the rates are definitely declining. The absolute numbers are down. In terms of detection of DR-TB again in 2019, of the pulmonary MDR-TB, I think we were close to more than 90% detection. The challenge lies in detecting MDR-TB in extra-pulmonary TB cases.

The success rate has also now improved. For example, the success rate is now 65% in the new regimens. Though we wish to expedite this progress to somewhere near 70 and 80%, it is now at 65%. Leena (Ms Leena Menghaney) raised the question of denialism. So, again, my point here in response to concerns raised by Leena and also Blessi (Mrs Blessina Kumar) is that one should go to the appropriate forums to raise these issues. We have a concept of reach in healthcare programmes and one doesn't have the bandwidth to address each and every issue. Some issues are addressed at a higher level and I think we need to knock the right

doors. The question here is not about me denying but asking right questions in a right forum.

Thank you.

Anant Bhan: Thank you, Dr Sachdeva. Over to you, Dr Sarin.

Rohit Sarin: Thank you, Dr Bhan. And I'd also like to thank all those who have given their comments and suggestions for the programme and the critical view of the programme. There are certain things which one expects idealism but in reality, there are implementation gaps.

And the basic question is, are we moving in the right direction? Issue here is not about reaching the finish line faster as commented by a few on our response being slow. Well, our response to drug resistance is not a new thing. Drug resistance has been there ever since the drugs came into existence. There has been a vast difference in our efforts of deal with drug resistance in these 40 years. So, we are going in the right direction that is something which we need to emphasise.

We could have gone faster. Yes, there is a possibility that as Sachdeva says that okay, if certain issues had moved, as we had thought they would move, we would have gone faster. But then, we live in a real-world situation, we just don't play with theory.

Covid, how that has impacted the programme? COVID-19 has impacted all facets of life and that has affected the TB program. It has affected not only the notifications, but it has affected the mortality also. The deaths due to TB and COVID-19 have increased. Secondly, the system has responded which is a positive sign and strength of the system. But COVID-19, has also shown us the weaknesses in the system. And I think that we should all learn that COVID-19 is just one pandemic which has happened in a very long time. But then we may face similar situations in future so we should be prepared.

Someone talked about, thrice weekly regimen when RNTCP started and maybe the World Bank and WHO insisted on that. I would like to place on record because I was part of the team at that point of time which was working on the development of the programme, that there was no insistence on the part of the WHO or the World Bank for a thrice weekly regimen. Factors like technical issues and operational issues were taken into consideration.

We all understand that there is a lag phase. Whenever mycobacterium tuberculosis is subjected to the drug, and that is the basic principle of intermittent chemotherapy, we also know that there were trials with intermittent therapy in

many parts of the world which had shown success. In fact, not only in HIV negative, but even in HIV positive individuals the Haiti study⁴⁸ very clearly showed that intermittent therapy was as effective with over 81% cure rates or you see the chemotherapy trial in Madras the SHTW, which I talked about, showed better results than daily treatment, thereby very clearly indicating that intermittent therapy is useful.

Yes, what is important in intermittent therapy is that it has to have observation, it has to have adherence, because if one does not have that, then obviously the gains are compromised. Then I would also like to add here the status of DR-TB, someone has quoted a high figure of 30%. Well, that is based on individual studies. Institutional based studies, national programmes have very clearly stated, as well as the national drug resistance survey, which was conducted and published, clearly showed that in new cases the primary drug resistance to rifampicin is less than 3%, and in those who were previously treated, it is less than 14%. So, it is not that there has been a tremendous increase in drug resistance. In fact, on the contrary, as Dr Sachdeva (Dr K S Sachdeva) earlier mentioned, with increase in population the rates haven't increased.

Then I would like to address the logistic issue. What the DOT strategy really does? It is a just a strategy of which one of the components was uninterrupted drug supply, the other was a good quality laboratory. No one can say that it is incorrect as even today we are voicing that.

Yes, the question here is, did it happen as it ought to have been? The gap is in the implementation level, it is not in the strategy. For all those who are critiques to the RNTCP or the DOT strategy, I would restate that as a health strategy they are good, but with implementation challenges which needs to be addressed. The backbone of the NTP continues to be the social components, as was during earlier times with TB care delivered through general health system, of the diagnostic centres and the treatment outlets which remains the same.

So, thank you very much to the organisers for giving me this opportunity to be a part of this particular activity and to share my views on the programme as well as on the questions as far as TB care is concerned. Thank you.

Anant Bhan: Thank you, Dr Sarin, that is very kind of you. Professor Banerji, can you provide us your valuable inputs please?

Debabar Banerji: Thank you, Dr Bhan. I'm glad to hear others.

My feeling is that we had anticipated this in NTI which was echoed by no less a

⁴⁴Chaisson, R. E., Clermont, H. C., Holt, E. A., Cantave, M., Johnson, M. P., Atkinson, J., Davis, H., Boulos, R., Quinn, T. C., & Halsey, N. A. (1996). Six-month supervised intermittent tuberculosis therapy in Haitian patients with and without HIV infection. *American journal of respiratory and critical care medicine*, 154(4 Pt 1), 1034–1038. <https://doi.org/10.1164/ajrccm.154.4.8887603>

person than Haldan Mahler, that “Tuberculosis programme must sink or sail with the general health services”.

As I know, the imposition of the time-bound, target-oriented ‘Family Planning programme’ has created the biggest and blackest blot in the healthcare system in the country and this has not been attended to till now. You can see the present government itself is talking of utterly uninformed issues, what is called health insurance. That is a curative thing. “Where is public health?”

So, the difficulty is lying right at the centre and we will continue to suffer from tuberculosis, as long as we don't build up the infrastructure of the health services, which were destroyed by the family planning programme, then came the RNTCP. Now, there is the government, which talks about eradicating TB by 2025. You see it is making a mockery of the people. They are buying time by talking such rubbish.

That's all Doctor.

Anant Bhan: Thank you so much for your reflections again, Professor. So, now we are at 12:25. We were supposed to end this session, I think around 10 minutes or 15 minutes ago. But I think we had such a rich discussion that it was found that we would go slightly over. My apologies, of course, to Sunil who is moderating the next session.

But I would suggest that maybe we give everyone four- or five-minute bio break.

Then, we reconvene in maybe 5 minutes from now. And then I would also request for those who can stay, we will go over for the next session for another 10 to 15 minutes extra for the time that we have lost. But we will try to wrap up by 2:15 or 2:30 at the maximum. So, Sunil, I will now turn it over to you to suggest how we should proceed with the next session. Thank you.

PROCEEDINGS OF WITNESS SEMINAR

SESSION 2 | TB PROGRAMME AND ITS SOCIAL CONTEXT

Moderator: Dr Sunil Kaul

Sunil Kaul: Thank you so much. It's been a real pleasure to see and hear Dr Banerji as well as everybody else. I think let's come back at 12:30 pm and we have time until 2 pm. It might be somewhat challenging and we shall try to cover the ground as much as possible. I would like to request all the speakers to keep their talks to 8 to 9 minutes in the interest of time. This would allow us to have time for richer discussions. I will go by the schedule that has been given to me. We will have Thelma, Beena, Blessina, then Muniyandi, Nerges and Leena, in this order.

I am Sunil Kaul, a medical doctor with a public health background and I have worked on a host of issues. Once TB space used to be a big passion for me, and Anurag (Dr Anurag Bhargava) tried to get me back into TB. I work in the North East (NE) region of India. To mention briefly, I don't believe in DOTS because it doesn't give any leeway; it sort of impinges on the autonomy of patients. Therefore, I wouldn't agree to participate in a government programme. But I still feel that the community needs to be engaged a lot and I think we will hear everybody else's comments here. To start with, I invite Thelma (Dr Thelma Narayan).

Thelma Narayan | Social paradigm of Tuberculosis

Thelma Narayan: Thanks a lot, Sunil and thanks to the organisers of this witness seminar for inviting me. It is quite a fascinating discussion. My brief was been to talk about the social paradigm of TB, social understanding of non-adherence, and TB from a gender perspective, including treatment of women with TB. So that's a long sort of a list to touch upon over the next eight minutes. I will start with my PhD thesis⁴⁹, which was looking at using implementation science, in fact, looking at the TB programme as a case study. And therefore, I went through a lot of the early documents which Dr Banerji has referred to and Anurag (Dr Anurag Bhargava) also referred to. We truly have an extremely rich history of how the TB programme in India evolved and took shape. I would really recommend that everybody go through those documents if time permits. I can also give you the link to the thesis that I wrote which summarises a lot of the history, and especially up to the 1990s. My work took place between 1995 and 1997.

So, my sense is that actually TB is largely seen as a techno-managerial issue using

⁴⁹https://www.sochara.org/uploads/researchuploads/ZUMTfL_cp_286306.pdf

the scientific lens. It is also a social issue, which a lot of documentation across the world has shown us. And it's very much a humanitarian issue, as well as a human rights issue. So, I personally feel that after 75 years of independence, we need to be much more demanding of ourselves in our ability to reach every person who has tuberculosis with effective diagnosis, treatment and care, and support. We are far from that, as we know. And I think what I value from the research work of the early pioneers is their honesty and truthfulness, which is basic research ethics that is called for. Therefore, I don't think anyone of us on this day, in this room actually would not use an honest lens to look at where we are today. It much depends on the conceptual framework that each of us uses.

When we look at the whole issue of tuberculosis and tuberculosis control in India, as Dr Banerji said and the early documents mentioned, TB would sink or sail with general health services. Having said that, which I think was an extremely important statement, I don't think the TB programme actually made adequate efforts to strengthen the general health services. I don't see their (GoI, or the TB programme managers, researchers and advocates) efforts or their advocacy to strengthen the general health services in any of these documentations.

In the mid-1990s, the rural health services were extremely ineffective, very sparse and of very low quality. So, there is no great wonder that TB was not controlled adequately until then. One of the frameworks that I use is that of different levels of causal analysis of TB and its control interventions. If you look at the surface level of TB, then we look at it as an infectious disease based on the germ theory, and our focus of intervention is on case finding diagnosis, treatment provision, and BCG vaccination. If we look at TB from an intermediate level lens, then we look at more distal causes such as under nutrition, crowded housing conditions, low income, and poor purchasing capacity. Then, we would use a development and welfare orientation to our response of intervention. We are still largely at the surface level; we are not yet working on the distal determinants of TB, which are more socio-political.

Thanks to the work of Anurag (Dr Anurag Bhargava) and others. They have been looking at under nutrition, and it has been successful in it as the programme has responded with provision of nutrition support to TB patients. And the DBT strategy of the government is also helpful. These are all very positive steps. If we are looking at the underlying causes of tuberculosis, and there is global history in this regard, all of which has been documented, then social and economic inequality, access to resources as well as opportunities, and poverty, are some of the major factors which explain occurrence or the continuing incidence of TB cases. Without adequate land reforms and social movements, occupational safety, and such factors, we're not really going to be addressing tuberculosis closer to its roots. For instance, as we all know, silicosis and a range of other occupations, including the health profession puts one at greater risk of developing TB.

In fact, I got TB during the course of completing my doctoral thesis. I will tell you more about it later. Having referred to the three levels of causes - surface causes, intermediate causes, and underlying causes of TB, I will briefly mention the fourth level of causes, that is the basic or root causes. There are huge inequalities and contradictions in the global political economy of health. And I think many of us around the table are very aware of this. The TB literature globally talks about this very openly. But do we act on it? The answer is 'not really'! This is because we get caught up in matters relating to diagnosis and treatment. Therefore, newer diagnostic techniques become very attractive. It is important too; I'm not saying they're not important. But we cannot rest only with these, when we know that there are other underlying root causes.

I think it was brought out by Dr Sachdeva (Dr KS Sachdeva) that there should be an inter-ministerial, intersectional action for tuberculosis within the country. But I would say that such an action strategy ought to exist globally, too. Unless there are more international relations and just trade relations, and unless globalisation and its impacts are looked at by health professionals, I don't think we would see TB really ceasing to be a public health problem. TB and its interventions could be an indicator of how we are doing right now, especially with the Covid, setting us back on many fronts. We will really have to lead in our efforts on these issues.

So, again, I would say that we will not use only scientific ends, but scientific-cum-social ends, which was there in the initial period of the National TB Program. In my opinion, having read a lot about tuberculosis, including its basic biology, it's pretty implausible to have TB elimination. I think we should be more restrained in the goals that we set for ourselves, both within India and globally. If you look at the literature, there were calls for TB elimination, even 60 to 70 years ago, which came mainly from the US. And there are certain lobbies that keep pushing for that, but I do think it is implausible.

Now, what did we do? What did I do as a result of this understanding? What attempts did we make along with a lot of others?

The formation of the Jan Swasthya Abiyan (JSA)⁵⁰ in India as a countervailing power was an effort to engage with the government and the public in order to strengthen the public health system. And the National Rural Health Mission(NRHM)⁵¹ with which we had engaged very proactively and developed really very good rapport and working relations, helped to strengthen the health system and to put in place mechanisms for community participation through the village health sanitation and nutrition committees (VHSNCs⁵²) and the Accredited Social

⁵⁰<http://phmindia.org/>

⁵¹<https://nhm.gov.in/index1.php?lang=1&level=1&lid=49&sublinkid=969>

⁵²<https://www.nhm.gov.in/index1.php?lang=1&level=1&sublinkid=149&lid=225>

Health Activist (ASHA⁵³) programme. Now, I don't think the NTP has engaged proactively or wholeheartedly; but they have given guidelines, etc. But they don't really look at experience from the perspective of ASHAs or VHSNC members, leave alone from the perspective of TB patients.

Low health budgets have continued and privatisation of the health sector is also going ahead. And, there's nowhere in the world that a privatised health sector actually takes care of TB effectively. In fact, a lot of the issues with regard to drug resistance may have their origins also in the practices of the private health system. I see that we've not yet looked at the gender aspect adequately. There has been useful work by Sheela Rangan⁵⁴, Jessica Ogden⁵⁵ and others, which is anthropological in nature. However, that's not been factored in adequately into programme functioning. We are still very much into techno-managerialism. The voices of people, including of women and all LGBTQIA+(Lesbian, Gay, Bi-sexual, Trans, Queer, Intersex and Allies) need to be integrated. I'm happy that there is greater consultation, but that consultation needs to be right down the line and reach the interface between frontline workers and communities.

I think the gender dimension is extremely important. Considerable work has been done on issues relating to women and TB. Broadly speaking, this work suggests that women with TB are considered as a burden, that it has a problem in terms of their marriage prospects and they have difficulty in getting married if they have had TB before marriage. If women have suffered from TB after marriage, they get abandoned, and even divorced, as we all know. This has also been adequately documented over time. Now, having good treatment actually can take care of the stigma but there has to be a conscious effort to do that. I think that stigma has not been adequately addressed. The second thing that we haven't addressed is the training of the health personnel. The system would just assume that every health professional, up and down the line is going to be really sensitive to gender issues. Just let us look at the undergraduate, even the medical courses, and in fact every other health sciences course, which are being driven by forces of capitation fees. Medical education and health science courses have become commercialised. So where is a sense of humanity and social solidarity? Where is there a sense of establishing a rapport with a person with TB who is suffering? I can tell you, having had TB myself, that I almost thought I was dying, it was in the middle of my post-graduation, and I couldn't even walk to the centre.

The last point I would like to mention is that for people who have suffered from TB, the issue of disability definitely needs to be kept in mind because there are

⁵³<https://nhm.gov.in/index1.php?lang=1&level=1&sublinkid=150&lid=226>

⁵⁴<https://www-beta.aminer.cn/profile/sheela-rangan/53f43990dabfaeb22f48ef40>

⁵⁵<https://scholar.google.com/citations?user=S7FGqkkAAAAJ&hl=en>

those of us who had it and we certainly know what it is to have a disability. This is such a widespread problem that it needs to be addressed in the Rights of Persons with Disability (PwD) Act⁵⁶. So I think our health system needs to take this into account too.

My response to a question if we are going in the right direction would be no, we are not going in the right direction. We need to definitely look at gender issues; we need to look at issues of social hierarchy, caste, and class. And these issues are not being considered adequately even sitting in the city of Bangalore, where a lot of the research work was done; there are social differences still existing due to which people really suffer.

Sunil Kaul: Thank you so much, Thelma, for sticking with the allocated time and setting up the stage and raising some important questions. Regarding TB, there are issues at surface level, some other issues at the intermediate level and others somewhat foundational. I personally have always held a position and shared it with friend and colleagues that TB is a symptom of hunger and poverty together. You brought it up very well. I also agree that a gender lens is essential to use for the outcome analysis and all other aspects of the TB programme. For example, gender has also played a role in TB diagnosis. So, we need to play a more proactive role to respond to this problem of under diagnosis of TB amongst women.

With this, I would like to now invite Beena (Dr Beena Thomas) to talk about her own experiences working with tribal communities in relation to TB and TB programme.

Beena Thomas | TB in tribal communities and indigenous populations

Beena Thomas: Thank you, Sunil. Thank you, Thelma. That was really an eye opener. I just like to take on from what Thelma talked about. My task mainly has been to focus on the tribal communities. Working with them has been a great passion as a social scientist who worked with NIRT-ICMR. As a result, I have been involved in quite a lot of work with the tribal communities and have been fortunate to be able to visit many interior villages across 17 states of India.

To start with, I would like to say that considering the fact that we have more than 8.6% tribal population, we need to reach the unreached to which Dr Banerji alluded to. And here was a population which was unreached. The programme had a tribal plan, but a million-dollar question was, how it was being implemented on the ground. The first task was to understand the TB burden (India TB Report 2020⁵⁷). I, with our team, had done a meta-analysis then. We found that there

⁵⁶https://legislative.gov.in/sites/default/files/A2016-49_1.pdf

⁵⁷<https://tbcindia.gov.in/WriteReadData/l892s/India%20TB%20Report%202020.pdf>

were just about seven studies on the burden of TB among the tribal communities. This meta-analysis showed a prevalence of 703 TB cases per 100,000 persons. This was based on very few studies and focused mainly on Central India with the major contributor being Madhya Pradesh. This reflected the urgent need to estimate the burden of TB among the tribal population with a nationally representative sample. This dearth of information prompted us to conduct a nationwide prevalence study to understand the burden of TB among the tribal population in six zones of India covering 88 villages across 17 states of India between April 2015 to March 2021.

Our study findings pointed to a prevalence of 432 per 100,000, which was more than the general population. A pooled estimate done earlier there had shown a prevalence of 296 TB cases per 100,000 persons. I would like to acknowledge the contribution of Dr Chadha in the analysis of our huge data set considering his vast experience. Our sample size though was not calculated for a state-wise, or zonal-wise estimation, but given that background, I'd like to say that when we looked at the data, we found a high prevalence in Odisha and the lowest prevalence in Jammu and Kashmir. So, that's something I need to leave you with. So, the question is, you know, what is it that makes this community different?"

In this regard, I would like to mention that one of the things which we fail to understand in the programme is the social constructs of a disease. Questions such as — how do tribes perceive as the cause of TB?, what do they know about TB?, what do they think about TB?, and what prompts them to seek care? —nobody seems to have paid attention to these aspects. For example, if you look at the communication material, it's all aimed at general population. It is not tribal community specific. It's simply not there. The first thing that we need to think about in any TB control programme is the health seeking behaviour patterns of people or concerned communities, such as tribal communities in this case. As Thelma Narayan said, one finds many reasons why people do not seek care, poverty being one of the main reasons. But also, while we talk in terms of access, one of the interesting things which I would like to bring in today's discussion is the gender constructs of even what are the symptoms that prompt care seeking? The programme goes on insisting on 'cough for two weeks' that should warrant testing for TB infection. And Dr Banerji mentioned that in those days this period of person coughing was longer to be considered for TB testing. But when we looked at the tribal community, we found that there were gender disparities⁵⁸ even in the symptoms that people sought care. Like for men and women, it was blood in sputum which was considered as a significant symptom. For men, it is

⁵⁸Thomas, B. E., Thiruvengadam, K., S, R., Rani, S., S, V., Gangadhar Rao, V., Yadav, R., J, B., Paluru, V., Jacob Purthy, A., Hussain, T., Indira Krishna, A. K., Joseph, A., Kumar Bansal, A., Anand, P., Das, P., R John, K., K, R. D., P, S., Moral, R., ... Kaur, H. (2021). Understanding health care-seeking behaviour of the tribal population in India among those with presumptive TB symptoms. *PloS one*, 16(5), e0250971. <https://doi.org/10.1371/journal.pone.0250971>

weight loss and shortness of breath, and for women, just blood and sputum. We found that, cough did not prompt care seeking, while 90% or more reported cough as a symptom. I think this is a very important observation that the programme understands even as cough is considered the most important symptom, we need to understand that.

When we look at who these people are, we talk with reference to community engagement, it's always ASHA, ASHA, ASHA. There are so many tribal volunteers out there — the tribal youth who are looking for jobs. The programme really doesn't look beyond the ASHA concept. One needs to think of tribal volunteers who can be influential — women, men and their young children. When we used to go there and involve them in our projects, they would be waiting and we witnessed their excitement to be involved in the work we were doing in their communities. I think these aspects need to be considered. Again, I think it needs to be target driven if one looks at what are the reasons for the higher prevalence. For example, as we know, Dr Anurag Bhargava has always been talking about low BMI.

We talk about lack of knowledge. And so that's when I thought what this lack of knowledge means? What are the tribal-specific interventions that we have put in place so far? Should we be talking about throughout rate and not the dropout rate as Sunil (Dr Sunil Kaul) mentioned? Should we be thinking and reflecting about the kind of health system we have and what it is offering when we go out there? There are a lot of facts out there which are much more acceptable to the tribal community compared to the people in the system. Where is this whole concept of counselling in the National TB Programme as it has been in the National Human Immunodeficiency Virus–Acquired Immunodeficiency Syndrome (HIV-AIDS) programme? Counselling was given such an importance in the HIV-AIDS prevention and treatment. But it seems that we do not want to invest on the counsellors in the TB programme. If we can do so, I think that would help in many aspects. In this context, the new strategy of DBT for nutritional supplements raises a question about how it is sustainable. Or should we explore a strategy of need-based counselling to better understand as what can they afford? What is it – food grains – that they have more with them or available in their own context? For example, in Koraput in Odisha, people are so good at growing millets in their own fields and I found it just phenomenal. But they sell out almost the entire produce and keep hardly anything for their own purposes. Later, they fall back on public distribution system (PDS⁵⁹), and we all know what the PDS is all about. Therefore, it is the question as what tribal specific interventions do we have? Can we have counselling service integrated in the TB programme for everyone, that is, even for the general population? Regarding the tribal communities, how do we reach this

⁵⁹https://nfsa.gov.in/portal/PDS_page

unreached? Unless we understand the TB burden, we would not know where to target. It is important that we have focused interventions. And most importantly, we need to have community driven approaches, i.e., let the people judge for themselves. We have this whole monitoring evaluation team that goes from the programme spaces, i.e., within the framework of top-down approach. Should it be a bottom-up assessment of what is really happening? In this regard, we might have a tribal plan, and we might have other plans. But what does that tribal community have to offer? Are they involved? So that is what I would like to say that unless there's this constant community-driven monitoring and evaluation, we cannot, strengthen the health system, or we cannot help healthcare seeking behaviour improve from what it already is.

Before I stop, I would just like to also speak to the question that Thelma (Dr Thelma Narayan) is talking about, i.e., stigma attached to the health condition of TB infection and persons with TB infection. One thing that was phenomenal was that there was really not much stigma among the tribals, you know. They just accept people as they are. We have so much to learn from them. We always go to them with preconceived notions of what we have to push down their throat and where they are getting this TB from. Most of them belonging to a constituency are a kind of migratory population going from one place to the other looking for work. Therefore, who really is responsible infecting people these people? The fact remains that they really don't know about it. How only men can get it or it's because of eating something or because they go out, it depends on their occupation, they have their own constructs, which again, I mean the general populations have their own constructs.

But the tribal population, I think, has their own ways of viewing the disease. And as we know it's terrible as healthcare system is organised. Dr Banerji was talking about these health centres. In reality, there are really no health centres near their villages. They (tribal population) would say that these are two kilometres down and that sub-centres in the vicinity are often closed. You don't have many of the staff there. One of the things that I noticed during my work and visits to remote places is that both the staff and even researchers such as principal investigators would never visit these remote places. One needs to be out there in the field to see the gross realities. As a result, the field investigators would do their own thing. I remember, one of the visits when I went, they were actually collecting data from a different place which was not part of the sampled units. They were doing so because that was more accessible and the other place was interior. So, I said that it is not correct and we need to climb up right there. And I started trekking. And then I find, they say "Madam, how do you trek?". I said, "because if you need to go up, you need to go up, you can't just resort to shortcuts."

So, overall, it was terrible to witness sub centres being closed, or they being set up within schools. It has been so terrible out there. Unless people go there and see it

with their own eyes, the system cannot improve and cater to the needs of the tribal population. One of the places I went, it was just anybody who was posing as a doctor. The person in this case was a pharmacist and he didn't know who we were. He asked us to wait. There was a crowd around him. He was busy diagnosing and prescribing. This happens because doctors refuse to come to these areas to practice. Therefore, the situation is pathetic and is a daily ordeal for people in the area who need to seek healthcare.

Sunil Kaul: Thanks, Beena. Thanks so much. While you speak, your passion for tribals comes out. The first thing which all of us recognise is that they have different kind of self-esteem compared to any others and that's one of the reasons why they reject programmes which are built the way we want it. The way the knowledge of the body or the knowledge of the illness is also structured and I don't think we are even asking the right questions to tribals. So, thanks for bringing that up.

I think I'll ask Blessina to come in now.

Blessina Kumar | Patient advocacy and patient-centered treatment

Blessina Kumar: Thanks so much, Sunil (Dr Sunil Kaul). And thanks to the organisers for inviting me, though, I wasn't sure what was being expected out of me. But it resonated with me what both, Dr Thelma Narayan and Dr Beena Thomas have shared. I had TB many years ago, and I recently survived a very bad COVID-19 infection. I feel like I have a new lease of life. So, with renewed enthusiasm, I push for engaging with the people affected by the diseases to be part of the response and to be valuable partners, rather than just recipients of care. We all talk about people-centred rights-based response to TB, but what does it mean? Affected communities need to be partners and proactively engaged; it isn't something that's going to happen automatically. As long as decisions are made for the affected communities, and somebody else decides what is good or bad, or what the challenges are, the real picture is not clear. We are not able to plan and come up and develop strategies that are relevant to the people on the ground, like Beena Thomas said. I worked extensively in Odisha, in Phulbani with the tribes, and it is so true. It is a whole different ball game altogether. We have to invest in understanding the specific context as we know that one size doesn't fit all.

A part of community engagement means understanding the communities and so, you would know this by working in Assam that the communities are different. We can't have just one brush stroke, one strategy that will somehow magically ensure that this community engagement happens. Many times, the programme looks at TB survivors or what they are calling Champions, as just mini data collectors who can go and find people with symptoms. Yes, all that is true. But where is this valuable partnership? Larger NGOs and International organisations who are applying for millions of dollars, I see, tend to use the Champions and TB survivors

to make their applications seem good.

I sit on committees that review applications. I have been really distressed to see how the affected community is being used! But unfortunately, I think we are missing something there. While we are talking about what are the expectations of the affected communities, which was one of the questions, what does the community need? The community just wants to get the best available highest quality care, wherever the care is sought, and that to be delivered with upholding my dignity and my rights in a non-stigmatising manner. The community would like to have a say in what affects them, and people also would like to have a say in what affects them. It's not like one leaves the self-respect behind when you enter through that door to get TB treatment.

Communities would like to have an opportunity to share the lived experiences because that is the richness that will drive and shape the response. their Lived experiences also help to effectively address the challenges faced by each community. The development of concrete strategies to effectively include the voices of the key affected populations in the development of plans, research, and shaping the discourse on TB continues to be very minimal globally. Sometimes, even with good intentions without the meaningful engagement and inclusions of affected communities, enlightened absolutism could occur. There is need for putting efforts towards empowering communities which is possible by working closely with them. We need to fight the social inequities which put certain communities in situations of poverty and marginalisation. These, which we know, are huge contributors to TB infections. We know that tuberculosis, poverty, and marginalisation are visible consequences of these social inequities.

There are isolated examples of community engagement, like the Community Research Advisory Group (CRAG⁶⁰) of Tuberculosis Trials Consortium. But again, that's really far remote. It is global. There is also the Global TB Community Advisory Board. I think this is an extremely interesting model. I am glad to say that in India, there are attempts to replicate this in our own ways. Unfortunately, if you raise your voice, and say that this is ethically wrong, you are immediately removed from review committees; as I mentioned earlier drawing upon my own experiences. So, I think we need to watch out and keep emphasising that respect for the affected communities and taking into consideration their experience seriously is very important for a better outcome of any TB programme.

To really eliminate tuberculosis, patients, survivors, and affected communities have to be included right from the beginning and throughout the whole process starting from designing a programme through its implementation and all activities to address TB. This needs to be done regularly and systematically rather than in

⁶⁰<https://tbtrialsnetwork.org/crag-community-research-advisors-group>

an ad-hoc manner or as an exception to the normative practices of programme designing. The affected communities should no longer be passive recipients of care but they really need to be valuable partners in decision-making and in making choices and accepting practices that affect them as communities impacted by TB. Community engagement should be non-negotiable. It should be a component that is as important as every other aspect of TB programme whether it is about ending TB or addressing TB. This needs to really move beyond just a 'tick in the box' approach to involving affected communities. I think that's what is really important.

Let's talk about stigma. We undertook an exercise of interviewing people from across the globe and presented these insights in three publications⁶¹, which you may have seen. Each of these three publications documents the experiences of women, children, and men. Many of the women said, "It's not TB that kills. It's actually the stigma because it reduces you so much that you don't have the strength or the drive to even seek care." Now, that's an important issue, it stops you from accessing care, it stops you from adhering to your treatment, it stops you from getting better, it stops you from getting back on track. So, when we are talking about putting patients on treatment, completion of treatment, and treatment success, the stigma needs to be looked at and understand it as a huge barrier to TB care and cure.

If we want to really realise the dream of real engagement of communities, we need to invest in building their capacity and in their empowerment to become those valuable partners. This is because an informed community can really add value to the TB response and address the gaps. We really need to move away from placing the blame on patients, which means changing the language, changing the way we speak. No more 'suspects', no more 'defaulters' and all these stigmatising language/ words need to be removed. We need to value people's experiences, whether they are from a city, urban/middle-class people or illiterate, or tribal people. We need to respect them and take their views into planning the strategies and also implementation of those strategies.

India is a country that is great at coming up with strategies. We have great things planned. But that doesn't turn the tide; that doesn't give us the results as implementation is a problem. And how is it going to change if you don't have a community on your side? So, that's it from me, and I will be happy to take questions. And once again, thank you.

⁶¹(a)<https://stoptb.org/assets/documents/communities/CRG/TB%20Gender%20Assessment%20India.pdf>;
(b)<https://tbcindia.gov.in/WriteReadData/1892s/2581521802Strategy%20to%20End%20Stigma%20and%20Discrimination%20Associated%20with%20TB%2018032021%20New.pdf>;(c)<http://www.tbonline.info/media/uploads/documents/women-and-stigma-full-book.pdf>

Sunil Kaul: Thanks, Blessi. I think we will just ask because you said you have to leave by 1:15? Definitely, if there's any clarification to be given; something which nobody could understand, then let's put that question right now? Otherwise, I think we can wait for questions at the end of the session.

Anurag Bhargava: I had one question. Blessina, is there a need for a specific patient charter to India for tuberculosis? What are your thoughts on that? Thanks.

Blessina Kumar: I think there is a need for a Patient Charter. Anurag (Dr Anurag Bhargava), the problem here is that a lot of it is so donor-driven; it is not based on ground realities. The donors sitting outside of India decide what is good for us. And we as organisations, the larger ones, who are part of The Global Fund⁶², part of USAID⁶³ toe that line. I am really waiting for the time when we would set the agenda on how we want the programme to be and which programmes and how they need to be funded. We did it 25-30 years ago, when we were engaged in work related to community health. We actually said 'No' to donors, and told them what was needed, and they were welcomed if they were willing to fund it, otherwise, we couldn't receive funds from them. Accordingly, we aren't at that stage still.

Secondly, I think the community engagement that the programme is looking at right now, really gives us a false sense of doing well. We are not looking at the affected community as valuable partners. We are looking at them to be like service delivery instruments. When we go and see how many patients have coughed, all that is good. But where is the decision-making partnership? Where is the space for people to say this doesn't work for me? Where is the space for people to come and tell "I have been put on delamanid for the past two months and I haven't received it."

There is no mechanism. And you are shot down if you make a noise about it. So, I think we definitely need a separate patient charter. Yes, I agree that there are responsibilities along with the rights, but we need to really push TB to be a right-based response, which isn't happening right now. I asked the NTP manager many years ago, maybe 10-12 years ago when the patient charter came out. "Why don't you promote it?" He looked at me and said, "This goes against medical people, the doctors; so, we will not use it". This was the response. And I don't think we have moved much far in the past 10-15 years.

Sunil Kaul: Thank you, Blessi (Ms Blessina Kumar), for your response. I would like to now invite Dr Muniyandi to share his experiences. Before that I would like to briefly mention that I didn't even know until recently that is until 2018 that 'Health for All' follow up meeting was held in Astana and that the Declaration at this meeting brought forth the role of 'community engagement' in meeting 'Health

⁶²<https://www.theglobalfund.org/en/>

⁶³<https://www.usaid.gov/global-fund>

for All' goals in a big way. I hope that somebody is listening because it's aligned to the SDGs (Sustainable Development Goals) and to the Universal Health Care(UHC).I think by re-emphasising and reiterating the role of community engagement in the health arena, and that since the Indian Government has been party to the Astana Declaration, we need to work towards making sure community engagement takes place.

Dr Muniyandi, please, over to you.

Muniyandi Malaisamy | Socio-economic impact of Tuberculosis

Muniyandi Malaisamy: Good afternoon to all. I thank all the previous speakers and organisers for giving me this opportunity.

I will start mentioning some points on the historical journey of the TB programme⁶⁴. All of us here today are discussing about the importance of TB programme and what needs to be done now. Is this a new disease to discuss controlling the same? As we all know, it is a very old disease and so much has already been done to control TB in this country. When the programme was reviewed in 1997, it was found that it was not a high priority and that there had not been much investment in the TB programme during that period. The question is: Why they reviewed the programme in 1997? The reason was the Human Immunodeficiency Virus (HIV) epidemic and its increasing global prevalence. The HIV infection rose in the developed countries and the chances/probability of HIV positive people developing TB were very high. As a result, TB control has also emerged as a global priority. This priority was driven by the demands of the developed world and was in that sense a priority for India during that period. Several international organisations had urged India to combat TB. They possibly feared the HIV epidemic, which was already becoming a global pandemic and believed that it could worsen if the TB is not controlled. Therefore, the agenda to control TB was not India's priority as such during that period but it was that of the international agencies. Then, the Indian government revised its TB programme and was named as RNTCP. It was implemented with a robust and evidence-based public health programme, with the help of a loan from the World Bank. Now RNTCP has been renamed as NTEP, which aims at eliminating TB, and the NSP for TB Elimination 2017-2025 has been developed by Central TB Division, Directorate General of Health Services, MoHFW, Government of India.

In 1997, the programme was launched with a World Bank loan, which had to be repaid at a later point in time with interest. Our future generations would be burdened with high financial costs and high TB burdens if we did not properly implement the programme to control TB. Subsequently, there was a demand for new interventions because the TB diagnosis basically comprised of screening

⁶⁴http://apps.who.int/iris/bitstream/handle/10665/44408/9789241500159_eng.pdf?sequence=1

using X-ray or smear microscopy which were very old diagnostic tools. The TB treatment regimen again has been there for very long. When they revised it, they had introduced this SCC for tuberculosis. One of the key questions is: why aren't new medical interventions developed? The answer seems to lie in the fact that during those days TB was commonly called as 'poor man's disease'. TB, Malaria, HIV were characterised as poverty-related diseases. As a result, the developed world exhibited no interest in developing new interventions like diagnostic tools or drug regimens.

When DOTS was introduced, it was projected as the most important component of TB control programme. 'DOTS cure for all' the slogan for TB control. It was soon recognised that patients have their own priorities and needs due to which completion of treatment wasn't possible despite providing free treatments. It appeared that if programme centre-stages patients, it would cure them. Later, when the programme has grown, the problems like mono-drug resistance TB and MDR-TB emerged as newer concerns. It then took the shape of XDR-TB and totally drug resistant TB. This, to some extent, was an outcome of not taking into account the social aspects of TB.

The government has taken much effort to control TB. Yet, we have a long way to go because the symptoms aren't taken seriously by many. Nobody would think that cough is going to kill them. This leads to delayed diagnosis; people tend to not intervene immediately since cough is considered a minor illness. After considerable delay in seeking care, the tendency to go to private clinics implies that they land spending a lot of money. Furthermore, there is also treatment non-compliance. People discontinue medication if they feel better after being on the treatment for a month or two. This was earlier captured in the notion of 'default rate', and now is termed as 'loss to follow up'.

In due course of time, with other developments, the TB control programme lost importance. However, now it has regained importance due to political commitments. The Hon'ble Prime Minister having announced control/elimination of TB by 2025, it has become top priority again. The NTEP has announced as one of its goals to reduce the out-of-pocket (OOP) expenditure which the next speaker would be talking about. In NIRT, many studies are conducted on OOP expenditure and economic burden of TB. Research has demonstrated that patients spend considerable amounts directly and indirectly on TB care, forcing them to become poorer. All these discussions aren't new and have been presented in many forums earlier. We are only reiterating and re-emphasising the known facts regarding implementation, monitoring and evaluation of TB control programme in India.

Recently, several new regimens such as new SCC⁶⁵ (for four months duration) with rifapentine and moxifloxacin⁶⁶ have been developed and this is found to be effective by ICMR-NIRT. Additionally, multiple diagnostic tools, such as, GeneXpert, GeneXpert plus, TruNat, and LPA (Line Probe Assay) have been developed recently to diagnose and treat the disease. When the programme was initially implemented, they primarily focused on the therapeutics that failed to control tuberculosis. The importance of socioeconomic aspects of tuberculosis has been emphasised by most previous speakers. Therefore, we would need to develop multiple non-biomedical models to control tuberculosis, if we really want to control tuberculosis.

Once again, I would like to thank Dr Beena Thomas and others including my senior colleague Dr Vineet Chadha. We are all working together just for TB for more than 20-30 years. Madam (Dr Beena Thomas) has been emphasising in every forum a need for counsellors in TB. When HIV emerged, all the TB programmes got integrated with HIV and then, when these programmes are implemented, all HIV patients are screened for tuberculosis. Similarly, all TB patients are screened for HIV before being placed in these programmes which will treat both diseases.

With respect to COVID-19, not much for me to say as it is already spoken off widely by the media and in the advertisements. The dial tone of every mobile has a message regarding the COVID-19 pandemic and precautionary measures citizens ought to take. This reflects the importance given to controlling its spread and creating awareness. This has also led to discussions regarding the use of masks and its role in TB control. Covering of mouth and nose while coughing is now considered as an intervention to control and prevent spread of TB. Earlier it was HIV and today it is COVID-19 to note the extent of importance given to control these infectious diseases. In other words, when a new disease emerges, it is given much importance. But when it comes to TB, an old disease that kills a lot of people, it will not receive as much attention.

Another important issue is the stigma attached to TB and persons affected by TB. This is due to the infectious nature of tuberculosis. This disease is highly stigmatised and even educated communities are reluctant to discuss it. People fear rejection because of this, and it is quite prevalent. We had conducted a study

⁶⁵<https://www.hopkinsmedicine.org/news/articles/a-shorter-course-for-tb-treatment>

⁶⁶Recent evidence on the clinical efficacy of a Moxifloxacin-based shortened regimen was found to be efficacious as the 6-month regimen. The current 6-month regimen for drug sensitive TB consists of Isoniazid, Rifampicin, Pyrazinamide, and Ethambutol for the initial 2-month intensive phase followed by Isoniazid, Rifampicin, and Ethambutol for the subsequent 4-month continuation phase (2HRZE7/4RHE7). Regimen with the 4-month consisting of Moxifloxacin, Isoniazid, Rifampicin, Pyrazinamide, and Ethambutol for the initial 2-months followed by Moxifloxacin, Isoniazid, and Rifampicin for the subsequent 2-months (2RHZEM7/2RHM7). Shortening the duration of TB treatment regimen is considered a priority for research and implementation under the National TB Elimination Programme

among young females⁶⁷ regarding rejection they faced due to TB disease. The study showed that nine percent of diagnosed TB patients believe they are going to die or felt it was better to die of TB rather than survive. The TB control programme has invested extensively in developing and disseminating Information, Education, and Communication (IEC) material. However, we do not know if it is effective for reducing stigma and spreading awareness about free treatment that is available in India.

Thus, India is facing an unprecedented financial burden to control this disease. New issues, new demands are emerging to control MDR-TB. I would like to note again that social determinants characterise TB, and TB care is faced with economic barriers. I end with that statement. Thank you

Sunil Kaul: Thank you so much. Meanwhile, I think I would request you to look at your chat box, because there are some questions for you and you can take them on later. Yeah, I think thanks for bringing up that. The statement that TB is caused by mycobacterium tuberculosis and many of us say that's a political statement because not more than 10% of those infected would ever get TB in the lives and yet we focus on that but not on poverty or hunger part of it. I think let's go to Nerges and let's hear more about her research.

Nerges Mistry | Indigenous research in development of anti-tubercular drugs

Nerges Mistry: Thank you, Sunil (Dr Sunil Kaul) and thanks to the organisers. And I'm very glad to meet up with friends, both from team 1 as well as team two, particularly delighted to catch up with Dr Banerji. His word hasn't lessened and neither of his messages. I am a biomedical and public health researcher, who is welcomed in this group of excellent activists with a large heart and a large head. I will just start by saying that community engagement means many things to many people. Usually, people think of it as just distributing communication material, or distributing pamphlets or talking to the community. But in my understanding, community engagement means the daily delivery of reliable and patient-centred quality services to the community. Patient centric means, (I use the definition from a well-known public health expert), what matters to the patient, and not what is the matter with the patient.

Since I started my research in TB in the 1990s, by and large inconvenient data was not accepted at the policy level. As Leena (Leena Menghaney) said earlier, it particularly holds true for drug resistance enumeration at the community level. But between 2003 and 2007, even though these data were communicated, they were ignored, perhaps not so much at the local and state level, but certainly at the

⁶⁷Jaggarajamma, K., Ramachandran, R., Charles, N., Chandrasekaran, V., Muniyandi, M., & Ganapathy, S. (2008). Psycho-social dysfunction: perceived and enacted stigma among tuberculosis patients registered under revised national tuberculosis control programme. *The Indian journal of tuberculosis*, 55 4, 179-87.

Centre and even at the level of WHO. However, I must say that since 2012, I feel that the NTP leadership has been a little more approachable and willing, at least to hear honest data. Today, they even try to participate in whatever way they can, even in the generation of data. The organiser of this seminar has given a large set of topics to deal with, probably one of the longest in this theme. However, I will try to deal with most of them in brief. So, with the impetus on a desirable but a fairy tale deadline for TB Elimination and even before that, many academic Institutes such as the Indian Institute of Science (IISc⁶⁸), All India Institute of Medical Sciences (AIIMS⁶⁹), Central Drug Research Institute (CDRI⁷⁰) have embarked on basic and translational research into TB. However, while several novel mechanisms like what are the targets for the anti-TB drugs, and drug targets have been identified, there is yet no indigenous new anti-tubercular drug that Indian researchers have contributed to the TB control programme and which have entered clinical practice. However, over the past at least four to five years, Indian researchers have made contributions in the field of whole genome sequencing. These have been used largely to identify novel mutations, in drugs that are in use in the Indian population that could lead to drug resistance. This may have value particularly for new drugs like bedaquiline, delamanid, pretomanid, and linezolid which are incorporated in short duration regimens or even for preventative therapy, such as isoniazid (INH) and rifapentine.

The willingness of the Central TB division to up skill the National referral Labs to this technology is a step perhaps in the right direction. The extent to which it would be possible, especially given the human resource management policies that exist within the government system, remains to be seen whether these laboratories will respond. But there is already a large private sector plan to push into this space. One of the most important things, I would like to mention is that we must remember that global technologies like this come with global commitments. We therefore have to share this data universally because TB does not stop at borders. TB goes in the air, and it recognises and respects no borders. We should aspire and be willing to share the data and/or insights from the whole genome sequencing globally and not be too secretive about what is the outcome of these efforts here in India regarding the whole genome sequencing exercises. India has also recently joined initiatives geared towards using molecular epidemiology to further the cause of responding to the TB epidemic in terms of the strains that are floating around in the Indian population and where they tend to form clusters and where they can form mini epidemics. We have seen evidence that there are small mini epidemics of tuberculosis that are occurring in several parts of the country.

⁶⁸<https://iisc.ac.in/tackling-tuberculosis-with-an-anti-malarial-drug/>

⁶⁹<https://www.aiims.edu/en/about-us/102-microbiology/1007-mycobacteriology.html>

⁷⁰<https://www.cdri.res.in/tuberculosis.aspx>

Coming back to the issue of drugs, I would like to touch upon the singular lack of research on Indian traditional medicinal compounds that were used specially in West Bengal between 1933 and 1947. Candidates like Ashwagandha, Chavanprash, Bhringarajasva, Thai ginger, Kudzu and Piper nigrum are all excellent candidates for exploring use in TB therapy, also not just as directly antibacterial but to use their ability of facilitating better absorption of the TB drugs in people who are undernourished and also for the purposes of prevention of TB drug resistance. These are some things that have never been explored sufficiently either by AYUSH or by any of our laboratories in a serious way. If we wish to try these, one probably requires laboratories that can fully embark upon research to test efficacies of such interventions involving alternative medicines.

Much has been said about TB diagnosis. This field has moved slightly towards a patient-centred approach in trying to diagnose TB and HIV where sputum production is difficult to manage. One of the things perhaps that is not sufficiently tackled is paediatric TB diagnosis. About less than 10 or 12% of children ever receive a microbiological diagnosis of TB. Therefore, technologies in such grey areas often need to be pursued much more vigorously. Reduction of expenditure is of course a definitive wish list. This is because we know that people who live below the poverty line have a greater risk of disease and also are prone for poor outcomes if medication, treatment and diagnosis are not provided free of charge in the programme. Furthermore, indirect costs or ancillary medication and transport can add prohibitive costs to the treatment. This is true even in drug sensitive uncomplicated TB patients. And this needs to be captured in research studies and put out time and again. One single study is not enough.

A number of recent studies have drawn attention to the distances travelled by DR-TB patients and also Drug sensitive (DS-TB) patients from the time they show symptoms until the initiation of their treatment. DR-TB patients are known to travel a range of 86 to 570 kilometres by the time they access proper treatment. And this is not only due to convoluted pathways of TB care but also due to the poor-quality design of a fragmented healthcare system leading to patients and their families wasting time and energy. One of the causes of catastrophe expenditure to which many of the comments have alluded to about has to make persistent expenditure in a household either due to multiple cases of TB in a family or due to multiple comorbidities.

TB is not the only disease that families face. They face many other comorbidities depending on where they are located. However, convenient clean costing studies do not reflect the totality of financial burdens on the family. It is necessary that TB patients are viewed by the system holistically and take into account their problems and challenges that they're facing to understand the extensive burden they bear of catastrophic expenditure. Today, though there are some information technologies that are being projected as that would enable designing

comprehensive placement of laboratories and setting up clinical facilities in the community. It is believed that this would address the problem of fragmented healthcare pathways. However, this should be done in a decentralised manner and that is not being done. We put TB clinics in schools and some of the maternity centres and god knows where else. Then, of course, another emerging strategy for reducing OOP expenditures is seeking the involvement of empowered TB champions and health activists to put a cap on drug pricing. However, I will leave others to talk about that and invoke the benefits of compulsory licensing. So, I'm not going to talk about that.

It is all about the rural versus urban TB divide. Many of the studies are trying to figure out these rural and urban TB features. However, the problem is many of these are single districts studies which are challenging to generalise. The only study that I came across that actually captures such a divide at the all India district level was the one by Laxminarayan and colleagues in 2017⁷¹. There's just one statement in this report that rural cases are supposed to infect an average of four people per year and remain infectious for period of more than two years. However, urban cases infect an average of 12 persons per year although they remain infectious only for a period of less than one year. And this single statement reflects the delayed diagnosis and poor-quality technologies or their dysfunctionality even if they are as sophisticated as the gene expert and so on. The poorly trained paramedical workers are yet another important problem especially since they cannot extend the right type of support for access and adherence to treatment. Many studies involving TB patients, both qualitative and quantitative, rarely pick up patient outcomes. These are very important to capture. Many studies involving patients deal with examining intervention process but not what the process results in.

I would just like to end by saying that there are some areas where more focus is needed. Because I'm a researcher, it's my job, I think to just highlight the type of studies that Anurag (Dr Anurag Bhargava) is doing, which is akin to the message on nutrition in the historical Papworth Village model⁷². I would like to say as Leena (Leena Menghaney) mentioned previously, paying attention to occupational health, especially because many of the times detection as well as treatment is denied to workers engaged in highly compromising industries, like mining or shipbuilding and so on. This leads to early detection of TB infections and

⁷¹Pandey, S., Chadha, V. K., Laxminarayan, R., & Arinaminpathy, N. (2017). Estimating tuberculosis incidence from primary survey data: a mathematical modeling approach. *The international journal of tuberculosis and lung disease: the official journal of the International Union against Tuberculosis and Lung Disease*, 21(4), 366-374. <https://doi.org/10.5588/ijtld.16.0182>

⁷²Bhargava, A., Pai, M., Bhargava, M., Marais, B. J., & Menzies, D. (2012). Can social interventions prevent tuberculosis?: the Papworth experiment (1918-1943) revisited. *American journal of respiratory and critical care medicine*, 186(5), 442-449. <https://doi.org/10.1164/rccm.201201-0023OC>; Varrier-Jones, P. C. (1919). A tuberculosis colony in the making. *British Journal of Tuberculosis*, 13(1), 14-21.

prevention of complications and deaths. In health systems research, as Professor Banerji said, strengthening the public healthcare system and services is equally important. The importance of having community level people competent to respond to the needs of their own local community is paramount as is their sustainability. These are all important avenues for undertaking research in relation to TB.

Sunil Kaul: Thanks so much, Nerges. We all have a common concern about the issue of ever increasing expenditure. We know that the government has been unwilling to spend on health. In this regard, and as Dr Chaddha mentioned to me, in 1990s, we were discussing TB and we all as activists and NGOs or as civil society had a shared understanding of the issue at hand and we stood together to raise issues with the government. However, in the current context, I think we are missing 'being relevant' with the engagement with the government and policy makers. Yet, we need to keep chipping in on these issues. Nerges (Dr Nerges Mistry), thanks once again for bringing up some of these issues again. I would also like to refer to some of the conversation in the chat box which is highlighting that while the rural-urban divide is well-acknowledged, lumping all urban populations together is not correct. The reason being small and metro cities stand to be vastly different. Also, within urban spaces, populations in richer spaces and in slum areas differ in terms of their access to healthcare and TB care. Thanks for highlighting those aspects, too.

With this, I invite Leena to share her thoughts.

Leena Menghaney | Rights-based approach to Tuberculosis care

Leena Menghaney: So, I'm going to quickly divide the time allocated to me of seven to nine minutes into three parts. I'm going to pick up from where Nerges (Dr Nerges Mistry) left where she said, "What do you mean by community participation and involvement. It should translate into patient-centric services." One of the things that really come out from the experiences of people is that it takes several attempts for them to actually get access to universal drug resistant testing. Depending upon where you are in the country, as part of the way the programme operates on the ground, it will not necessarily send you for drug resistant tuberculosis testing. Recently, the stock out of the gene expert kits takes away the one screening tool from a number of patients, where rifampicin resistance would be highlighted. Then, they would subsequently be referred to the first line and second line drug resistance testing. One of the things that really come out very clearly is that we are still a far from offering universal drug resistance testing to all patients who need it upfront.

One of our experiences has been that such as if you look at the case of Shreya Tripathi⁷³, who went to court. She had been treated for almost four years for drug

⁷³<https://thewire.in/health/multi-drug-resistant-tb-bedaquiline-deaths>

resistant tuberculosis without having her entire resistance profile. She was a XDR-TB patient. Then, newer drugs were being incorporated into her regimen without accurate testing. Now, I'm working with a 12-year-old patient in Mumbai, not as MSF but as an activist. It is very clearly coming out that they (NTEP doctors) think that these drugs are expensive and that they need to be rationed and it is discretionary to offer to patients despite the change in the PMDT guidelines 2021⁷⁴. So, now, if you have fluoroquinolone (FQ) resistance, then you need both bedaquiline and delamanid together in your 18-month regimen. You may get bedaquiline because they have greater stocks of bedaquiline. But often delamanid will not be included despite the PMDT guidelines 2021 clearly states that you are entitled to both regimens if you are a pre-XDR-TB patient with FQ resistance.

From the experiences of the young women that I have worked with since 2014, one, it is clear that universal drug resistance testing is not given to people who need it. Two, that access to better and more oral drugs without injectable regimens is not uniform across the country. There is an issue regarding access to new drugs. It is heavily linked to the fact that the government views patented expensive medicines as a privilege and therefore they are to be rationed and provided to patients on a discretionary basis. Apparently, Mumbai residents are much better at negotiating access to newer drugs than someone in remote areas, say for example, in Bihar. We met Bihar patients who couldn't get access to these new medicines and I ended up having to work with patients and rights organisations to challenge it in courts.

The second aspect I wanted to talk about is that when you talk about community participation and involvement, the first tenet of that is trust and safety. Some of us, treatment activists, have been working on different campaigns across different programmes, mainly on guideline changes, but also on stock-outs and shortages of medicines. Our observations were that activists who actually alert the programme of shortages and stock-outs are systematically targeted in the form of being left out of all meetings or being told not to make a scene about it. The safety of activists raising concerns about shortages and stock-outs in the TB programme is highly suspicious. I would say that, from the perspective of activists, they face a lot of pressure to not report these issues to the media, despite the fact that the media is actually the last resort for activists because we definitely first report to the TB programme. Then, when we don't get a response, we go to the media. So, there's this issue about community participation and involvement when we feel as individual activists that we are being targeted by the programme, when we raise these uncomfortable issues. I have seen this in the context of big organisations, who know that the stock-out occurred months ago, but they don't want to face the programme or speak up or issue a statement on the same.

⁷⁴<https://tbcindia.gov.in/showfile.php?lid=3590>

The last thing I wanted to address was the district TB forum which was considered the counterpart to the People Living with Human Immunodeficiency Virus (PLHIV) networks in the district. Now, district TB forums are not independent entities. In most cases, meetings are run according to local TB officials' whims and fancies, and more often no meetings are convened. Moreover, there's no proper engagement of Non-Governmental Organisations (NGOs) and survivors of TB who would like to contribute to that process. I just wanted to highlight all these three issues and I'm going to stop. Thanks.

Sunil Kaul: Thank you, Leena. That was wonderful and thanks also for maintaining the time. I think, TB and HIV are at times discussed together, especially because HIV positive persons are prone to catch TB infections and are susceptible to TB. Yet, I also understand that HIV patients got much more space into decision making including at policy level. In India, I would give some credit to Dr Sujata Rao for this to happen during those times for recognising the importance of having HIV positive persons at the table. I think, that has not really happened in the case of TB programmes and policy making. One of the reasons for the story to unfold in that manner in relation to engagement with HIV positive persons in HIV policy making and programme designing maybe because there was no cure and no medicines available for HIV at that time. When they came, they had to do much more. In case of TB, probably it was presumed by that we had everything. We are now thinking of eliminating TB I think, we are lucky that it has not been said that TB has already been eradicated. Thanks again, Leena.

I will now open the floor for discussion and Anant will be moderating it as I have to leave. Thanks, everyone and it is great to be back to the TB forum. Thank you, FMES, for having me on board.

Yeah, I can't see any hands raised. So, who would like to comment? Anurag. Okay, yeah, I can see that. Please come in.

Anurag Bhargava: I had made a comment that Dr Nerges Mistry was involved in Foundation for Research in Community Health (FRCH) and you have witnessed your organisation's involvement in TB research. Anything you would like to add who witnessed involvement of FRCH in drafting ICSSR (Indian Council of Social Science Research)-ICMR's 'Health for All'⁷⁵ document then. And also, because FRCH was the first one to document private sector practice in TB Care.

Nerges Mistry: Yeah, so I think Dr Mukund Uplekar and Dr Sheela Rangan's work at FRCH on the private sector model as all sort of efforts had started then for exploring public private partnerships in tuberculosis. I was recently talking to Dr Mukund Uplekar about that and he said that the private sector engagement will work better if the public sector is strengthened to be able to deal with it. For many

⁷⁵<https://hetv.org/pdf/frch-alternative.pdf>

years, the public sector considered the private sector as a competitor and also perhaps the progenitor of the drug resistance that the country was witnessing, although that's not entirely true. But never the less, that's the way it was seen. Another public private cooperation that we are seeing is in the form of Public Policy and International Affairs Programme (PPIA) and then Patient Provider Support Agencies (PPSA) which is funded by the Global Fund and the Gates Foundation and so on. This sort of serves as a testimony to the fact that we do require better public sector organisation for the private sector to be able to contribute to controlling symptomatic TB. But I think much more sort of incisive work needs to be done to see the impact really of the private sector in TB care. For example, does it contribute to better outcomes for TB patients? Does it help respond to the delayed health seeking behaviour? And does it respond to the stigma these patients suffer also stemming from disease pathways and treatment pathways. So, I think this sort of evidence from the field is required before we can register a final judgment on private sector engagement with TB care.

The 'Health for All' strategy by ICMR and ICSSR of course stressed on our comprehensive primary health care system and that was particularly true for the rural areas, where we actually have the lowest cadre in the health care system being told what their role was in TB control programme. It wasn't related to vertical programme but that the emphasis was that the healthcare worker needed to be sensitized towards suspecting disease and then have an efficient referral chain by which the patient could be tackled further up along treatment pathways. But I don't think that's quite been also investigated as to what the effectiveness of ASHA worker is today in the NRHM. The role they play in TB control is quite good at certain places and not so good in other places. But the role Urban Social Health Activist (USHA⁷⁶), the urban counterpart of ASHAs, playing the urban TB control programme is somewhat less known. For example, how is she actually dealing with the TB? What does such a training entail for USHA to play such a role? How is she able to convince TB patients and in vulnerable areas help them able to seek care and ensure safety and then guide them through those pathways? Pieces of evidence on these aspects are yet to be generated. Thank you.

Sunil Kaul: Thank you. Anybody else with a comment because there are no more hands raised that I can see. I'll hand over to Madhavi who's agreed to moderate the session till Anant comes back. Ok, I can see Thelma wants to speak. Please go ahead.

Thelma Narayan: Yes, I just wanted to suggest that those of us, who are very involved in tuberculosis, need to pay equal attention to health system issues and health policy process including the implementation. If we can build a critical

⁷⁶<https://tcurbanhealth.org/courses/india-demand-generation/lessons/enabling-urban-accredited-social-health-activists/>

mass, not only in every state but actually in every district, of people who actively engage with the health system, we can make a greater difference. And I'm talking particularly of the public health system, because we look at it from an equity lens which all of us do, then we have to focus on strengthening the public health system even now. The NRHM and NHM made some difference but actually, it's been a long time since their launch, and I think that stagnation in practice has set in. It's going backwards in certain ways.

So, unless there is a group of researchers and activists and practitioners and there's a critical mass at different levels, who will engage with this issue at hand on an ongoing basis, I doubt that there's going to be any huge change. One way forward is to look at the new health and wellness centres. If one reads the strategy document, it is talking consciously about a Comprehensive Primary Health Care⁷⁷ approach which is important. The officers in charge are called Community Health Officers and they are community health nurses, nurse practitioners or AYUSH doctors. So, I think there's an opportunity for us to engage with that particular concept. We haven't focused on the training of the PHC (primary health centre) medical officer or the staff on health system issues and on how to facilitate community processes. We focused on the biomedical components of the disease.

Community engagement requires health staff at all levels to be trained in the skills of working with communities, respecting their knowledge and life experience, building on their strengths as a major resource for health and wellbeing. Not everybody can dialogue with communities. It is a skill that needs to be learnt and practiced. It's not just writing a narrative, but facilitating a dynamic process and it requires honing of skills, say for example, as how to build community trust; how to plan and run a meeting; how to listen respectfully; how to get feedback on their interaction with patients; how to problem solve with the community and facilitate community processes. Only then I think we can accelerate progress. Just a thought. Thanks

Madhavi Bhargava: Thank you, Thelma. Now we have two hands, Anurag and Leena. Then, Leena can go first, please.

Leena Menghaney: I would like to emphasise that when I started to work on DR-TB, I witnessed people dying one by one within PLHIV Network. So, it was Henry, Mike, Asha. The government kept treating and re-treating them with the same TB drugs. So, my outbursts today were absolutely because of that. But one thing that I really noticed, while working with DR-TB patients is that people live with lifelong impact of the DR-TB on their lives in that, one of the areas that finds no mention anywhere is disability. If you look at the manner in which people had hearing loss

⁷⁷<https://nhsrindia.org/nhsrindia-website-new/comprehensive-primary-health-care>

and they need cochlear implants, or support in dealing with tinnitus. There's absolutely no mention of this in the Ministry of Social Justice or any other institution who work on hearing loss, or what you're going to do with this permanent disability or provide some services for these disabilities. So, even though people say that "HIV is lifelong and TB is not", from my experience it is different. Because I've worked with a lot of TB patients, and I have seen a lot of side effects that they live with for quite a bit of time.

The last thing I wanted to mention is that we are at a point in the health movement, where we are seeing the HIV networks become weaker and NRHM being systematically undermined. It is in very few areas where patients can somehow get involved or people who have been affected by the disease can get involved. So, if one could build platforms in all districts where people with different diseases could interact and actually negotiate with officials who are almost the same, is a very useful idea.

I know that Community Network For Empowerment (CoNE)⁷⁸, Manipur, which started with working on HIV now works with Narcotic Drugs and Psychotropic Substances (NDPS) and drug use, works on viral hepatitis is willing to work in the TB Space. I notice that some of the community HIV networks are evolving right now. And I think it's helpful to reflect on how organisations and movements need to change. So, this is just my thought on this issue.

Madhavi Bhargava: Thanks, Leena. So, I think there are some initiatives in post TB to the sequel now coming from The Union lately. Anurag, if you want to come in now?

Anurag Bhargava: I just wanted to draw the attention because it's a witness seminar. For over past six years I've just been working in South India. For a long time, our only available research data from India was from NTI or NIRT. And I have repeatedly found that our experiences, for example, of working in Chhattisgarh, are nowhere close to what was being reported by NTI or NIRT. There has been a lack of more centres doing research in TB in India apart from the National Institutes. It has now started branched out to some extent, to centres in north India. But for large the only data from India was from Tiruvallur⁷⁹ and that was a model kind of a TB treatment unit centre located in a better functioning primary health system in Tamil Nadu. To me, this remained a kind of a feature of the TB programme in India, i.e., concentration of research in the government institutes located in South India and lacking representativeness. As a result, some of the

⁷⁸<https://www.worldhepatitisalliance.org/member/community-network-for-empowerment-cone/>

⁷⁹Dolla, C. K., Dhanaraj, B., Chandrasekaran, P., Selvaraj, S., Menon, P. A., Thiruvengadam, K., Krishnan, R., Mondal, R., Malaisamy, M., Marinaik, S. B., Murali, L., & Tripathy, S. P. (2021). Prevalence of bacteriologically confirmed pulmonary tuberculosis and associated risk factors: A community survey in Thiruvallur District, south India. *PLoS one*, 16(10), e0247245. <https://doi.org/10.1371/journal.pone.0247245>

aspects such as the issue of TB in tribal communities never got the attention that was required. The reason being that the research was being only done in a particular area. Therefore, I would think that this witness seminar should at least mention that.

Secondly, when one is talking about community participation, setting up the National Institutes and the national programme has been one of the good things. But health being a concurrent subject for state and central government and health administrators, there should have been efforts towards capacity building at the state level, making them equipped for their own decisions. For example, it is logical that diagnosis and treatment protocols for TB are adapted to the local context which is possible only if states are entrusted to do so. However, in reality, they are not involved in deciding on these matters in the TB programme. Contrarily, states rely on the National programme to formulate guidelines to the last comma and full stop! The National programme itself also is now following global guidelines. As a result, this entire aspect of making the programme sensitive to local context and adapt it accordingly is lost. State have not been innovating their own strategies, in fact, they don't have space to do so in the manner in which these programmes are designed and expected to be implemented. However, we have some pleasant examples around, such as Kerala which is just starting community-based support groups or DTO (District Tuberculosis Office) supporting MDR-TB treatment patients with very generous food support. DTOs did not have to seek and secure clearance from anyone. Instead, (they) saw a problem and they worked out a solution and implemented the same. We need to note that over the years there is lack of sufficient capacity building at the state and further down at the local level to respond to the local challenges. As we all know, India is a country with continental dimensions which has implications for epidemiology of TB. For example, TB in the North Eastern region will have a different kind of epidemiology than the rest of the country. Therefore, that is something we need to capture which we have not been able to do well — a shortcoming in itself.

Madhavi Bhargava: Okay. I think we have some more hands raised. Then, you can have, Dr Beena, Dr Muniyandi, Dr Nerges and Dr Anant. So, Beena, would you please like to come in.

Beena Thomas: Thanks, Madhavi. What I wanted to say even as we were talking about is how we bring in changes in the health system. So much research is going on whether it's at National Institutes or NGOs or International organisations, and now, they are the ones who are going right into the field, like your RATIONS study, or what the studies that we have done. Considering this, one of my suggestions is that it's not necessary to wait till the end of such research projects to come out with something that researchers witness in the field. Think this is something that we should strongly recommend. I just want to go with my experience. We all

witness so much. Right? It is possible that it is not part of one's research. But why do you sit over these ground realities as researchers? We close our eyes to these realities on the pretext that these observations in the field don't speak to the objective or aim of my research, and I need to just stick to mine.

Just to give you an example, it was difficult to reach Nicobar Island during the days when I was there. I found the hospital there was a beautiful structure. If I remember it correctly, it was called St James hospital, which is a tertiary level hospital. That hospital had a state-of-the-art facility. But when I looked at the multi-drug resistant ward (MDR ward), it was in a pathetic situation. The toilets were not functional; it was crowded with little ventilation. It was like a sight for sore eyes as compared to this plush hospital. So, I just made it a point to flag it to the superintendent when we went to see him even if it was not part of our research agenda. I took the team along with me to meet the superintendent. I first praised him for the hospital and then I told him about the status of the MDR ward. I said, why is it that the situation is so bad, that it has implications for TB transmission and how does one aim at TB elimination in the Nicobar with such situation on the ground of healthcare facilities and access. He responded by saying that it was never brought to him before. Imagine, such a response coming from a superintendent!

One would take it as the superintendent's role to see that these things happen. But that said, I just wanted to say and by the end of our research, I was so humbled that I was told when we came back, that all changes were made to completely renovate the said facility. And they had done the necessary work for the MDR ward on the Nicobar Islands. I simply wish to make a point here that it is important that we raise issues related to the healthcare system as whole going beyond just the research problem/goals/objectives. Thank you!

Madhavi Bhargava: Thank you Beena. Muniyandi, can you please come in.

Muniyandi Malaisamy: Yes, again, there are some questions in the chat box. One of them is about the OOP expenditure reduction. There are now NTEP targets. While there is time to meet the target of reducing prevalence and incidence of TB, and later eliminating it by 2025 or 2030, the reduction in OOP expenses is expected to occur immediately and such a target is expected to be met by 2020 and 2021. But is there a way to assess it? So far, nothing! Only a few operational researches have been available on this. As for the prevalence, the only data we now have are the national prevalence surveys, which will serve as baseline data. These data are to be used to assess or determine if there is a decrease in prevalence and incidence of TB or not. A recent WHO report⁸⁰ says there is a decrease in TB⁸¹ prevalence. Now again, STOP TB estimates that there is an increase in TB prevalence due to COVID-19 pandemic.

⁸⁰<https://www.who.int/publications/i/item/9789240013131>

⁸¹<https://stoptb-strategicinitiative.org/>

Another question is about TB patients returning to work once they are cured. The TB programme helps patients in vocational rehabilitation. Despite that, there is so much that goes into it, such as the TB patient, when they come for the treatment, they are delayed and they become very sick, and it makes it difficult for them to turn back to normal. It was recently reported that more TB deaths are occurring after cure, but the TB programme focuses only on the bacteriological cause and after treatment completion, patients still suffer sequelae which can lead to early death. Therefore, moving forward, the programme needs to focus on preventive interventions that improve a person's quality of life, early diagnosis and many other things that I do not know how to accomplish. Thank you.

Madhavi Bhargava: Thank you, Muniyandi. Nerges, can you please come in?

Nerges Mistry: Yes, I just like to make two comments. I think one was in relation to what Dr Sachdeva (Dr Kuldeep Sachdeva) said that the rate of DR-TB has slowed down. Yes, but I don't think that should be a cause of complacency. I don't know what biological evidence that such a conclusion is drawn upon. But wherever there are drugs, and particularly when new drugs are being introduced into the program, you may see a dip in the rates for a little while. But eventually drug resistance is bound to develop. It is a natural law. Therefore, I think this over-reliance on drugs, and not enough on preventive measures is something that needs to be flagged. I don't know how much we are spending on drug development and testing out new drug regimens which are all very important. However, we cannot afford to rely only on drugs because drugs will get rid of the bug and will also get resistant to the drug resulting in it becoming more virulent. And so that's one comment.

And I would also like to mention this whole thing of TB centrality. Many of us also who are working in TB for a long time including myself are to be blamed too for this. This TB centrality has been blown to bits by the COVID-19. We have no idea about the extent of collateral damage the pandemic has caused because we don't have data on it. We have hypotheses, we have ideas, we have opinions but we don't know what has happened to TB during the pandemic and how the virus has interacted with TB infections. We do not know how many people are going to die! And I think as time passes, we will get this data. But what it means is it should blow us out of the parking lot for verticality of health programs, and look again very seriously at comprehensive healthcare so that this type of collateral damage does not occur in future pandemics which are bound to be back. That's all. Thank you

Madhavi Bhargava: Thanks so much, Dr Nerges, for saying this. It's very important that you're also talking about not only just pharmaco therapeutics and its innovations, but also, you're talking about prevention, and it says a lot and makes a really important point. Anant, can you please come in now?

Anant Bhan: I think we've had some very insightful discussions. Everyone has

made an important point which is that it's important to engage with the communities and with patients in TB spaces. We may need to think about how do we integrate metrics? Is it possible to actually evaluate whether such community engagement is happening in the TB programme? Is it enough to have token representation of TB survivors on expert committees or perhaps at fancy conferences which often is the case in TB spaces which can also be difficult to access unless one has been specifically invited? How do we go beyond that tokenism to actually involving patients and survivors meaningfully, and what do we require for that to happen? Therefore, if all the witnesses could also discuss these aspects as we conclude, it might point to broad changes that need to be made in the future for TB specifically. Thank you.

Madhavi Bhargava: Thanks. Anant. Then, there was one more question from FMES of whether we can consider the involvement of village health and sanitation committees as platforms for community engagement. Following that, Leena can comment. So, I guess, Thelma, would you like to answer that? How about engaging the VHSNC's for community engagements?

Thelma Narayan: Well, VHSNCs were set up between 2007-2009 based on a pilot project in nine states. It's been a long journey. The Panchayat Raj Act⁸² itself was modified in order to set up VHSNCs which are like the health committee that many of us from the NGO sector are familiar with. We all have worked with health workers and health committees, village health committees, ward health committees. The communalisation component of the NRHM included the simple idea of scaling this up. As of today, there are about five lakh VHSNCs across the country. These form a mechanism for community engagement across the country. Their functionality varies and this is where more work and support are needed.

While there are training modules, they are mainly around accountability and related matters. The effort that is needed is to actually train and handhold the members of the VHSNCs, which is quite a huge task. And there's nobody who is there to do it. So, unless there are NGOs, community-based organisations (CBOs), and other networks and institutions who can step up and join the process, it will be a challenge. Now, NGOs are dying or getting corporatised, because the funding is really being cut. So, the support systems for VHSNCs will need to emerge from civil society keeping in mind that VHSNCs are formed every five years with gram panchayat and municipal body elections. Now, this continuous change is a good thing, because maybe health literacy in the country will increase by this recurring formation.

In Karnataka, VHSNCs played a role during COVID-19. I don't know if you have experienced this in your area, but they formed village COVID task groups which

⁸²<https://www.india.gov.in/my-government/constitution-india/amendments/constitution-india-seventy-third-amendment-act-1992>

included VHSNC members. COVID has provided an opportunity to bring health into the forefront and an opportunity that health facilities have to be used not just for meeting treatment needs but also for progressing towards wellness of all. This should not only be focused on diseases like TB but to address many other related contextual issues.

The whole purpose of a community-led approach is that community members identify what are their pressing issues? We have experimented with this here in SOCHARA. There are issues, such as no electricity and poor water supply in the public toilets. We responded to these issues/requests, and then, get to introduce the topic of communicable diseases and tuberculosis in this case, along with other issues. We can't be un-focused; we have to be health oriented, and then, bring other issues related to health.

Of course, I have a vested interest in this community health approach which is broader. It may not be able to be measured strictly, because one is not looking at a single initiative alone. For instance, we notice that there are a lot of teenage pregnancies in one of the areas that we are working in. As a response to this situation, we are thinking of providing inputs/training in life skills, and create opportunities for education for adolescents in that area. Since we have worked on this in the past, we have introduced these processes. This suggests that one has to be a little nimble, and be able to respond to different issues. I think, this requires involving people from multiple disciplines, and I personally feel that social workers are actually very good at community engagement.

And lastly, a number of universities are introducing Bachelor's in Public Health courses. Therefore, I think, the human resource situation will change in the coming times. We can be proactive in being faculty in such institutions and helping in the curriculum development and in facilitating community immersion for community-based experience, then the VHSNCs can be strengthened. But on their own, I don't think, they can do it without necessary inputs. Thanks.

Madhavi Bhargava: Thanks, Thelma. Leena, can you please come in.

Leena Menghaney: I just wanted to go back to Anant's (Dr Anant Bhan) point that there are these meetings which are very focused on TB decision-makers and then you have a survivor come and speak. First, from my experience in the HIV field, it is the real observation that I have made that the experience of survivors is not taken into consideration in the formulation of the policy. Second, there is this kind of presumption that they will work for free or for a very nominal price. This is from my view that if you really want people who are affected by a particular illness to participate in advocacy, activism, and service delivery which are three different areas, we need a mechanism like PLHIV networks which are funded independently of the government that provides a variety of projects to deliver services.

Therefore, if you want empowerment in the field of TB, you should be able to identify patients, diagnose them, screen them, counsel them, address issues related to livelihood or gender, complete their applications and deliver services, just as HIV networks did before. My experience is that TB networks do need to be formed at the state and district levels but they have to be properly funded and independent from Government. In fact, the rules of the global fund for HIV and TB should be the same. There you have massive funders, giving millions of dollars to World Vision, HIV and everyone else. The problem is that they don't use this model for TB, even though it really works well for HIV, and I find that very problematic actually.

Anurag Bhargava: I just had one more comment before closing. We are talking about TB and the social context. However, I believe that unless there is a broader coalition built around access to care to be able to address issues involved in it; care for chronic diseases which include TB and HIV; and lastly, strategies on how to prevent diseases in order to improve quality of life. We therefore need something which is sensitive to a broader context of TB concerns rather than just specifics regarding TB. As a clinician, I see people struggling with so many other chronic ailments, diabetes, kidney disease and there are overlapping issues across these health conditions. Thus, a broader coalition is needed that will address issues comprehensively. Any coalition that is only confined to TB will be unstable and less useful. Thank you.

Madhavi Bhargava: Anant, could you step in now. I think we need to have closing remarks and matrix as you suggested. Thanks everyone.

Anant Bhan: Thank you to all of the witnesses who spoke at the second and closing session. I think we've gone well over four hours of discussion. I guess there's so much to talk about on the theme. However, we shall now try to wind up. We are very thankful for all of your contributions to today's witness seminar. We are extremely thankful also to Anurag and Madhavi for all of their recommendations in terms of who to reach out to for bringing you all together for this seminar. Thanks also to each one of you for spending such a large amount of time with us and sharing your perspectives and reflecting on your own engagement with TB spaces over decades. Given the constraints of e-meetings, we could not have others for today's conversation. We might be organising part two of this conversation by inviting TB patients and survivors as we are interested to document survivors' perspectives. We shall keep you posted on these developments.

As I said in the beginning, the plan is for us to take what we have discussed documented in the form of a proceedings report. We will reach out to you individually for your permission as we are interested in archiving the recording of these proceedings provide you consent for making it public. The idea is that future students of public health can hear from all of you and of course, Dr Banerji,

listening from their vantage point on how visioning was a big help, what were the initial thoughts and how things took shape regarding the TB programme and how it evolved over time.

Once again, sincere note of thanks from all of us as FMES team and all our collaborators of this project. Thank you for spending time with us. Hopefully, this discussion has been insightful for all of you and we look forward to the follow up. Again, please take care, stay safe; looking forward to talking to you again. Bye for now.

ANNEXURE 1
THEMATIC SCHEDULE OF WITNESS SEMINAR

A witness seminar on

Tracing the historical trajectory of community engagement in TB-related public health interventions in India.

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]

Held (virtually) on Thursday, October 21, 2021 | 10 am – 2 pm

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

**Theme 1: program and its evolution in India
10:15 am to 12:00 noon**

Moderated by Anant Bhan

Note to the witnesses: Invited witnesses to present brief remark for about 10-12 mins each. This will be followed by open discussion drawing upon the thematic points highlighted by the speakers. The themes enlisted are indicative only and to provide a framework for opening the conversation. Speakers are welcome to choose related themes

<p>Dr Debabar Banerji (10:15 am – 10: 40 am)</p>	<ul style="list-style-type: none"> • A critical reflection on the evolution of the National Tuberculosis Program (NTP) over the past few decades: Conceptualization and overall vision, involvement of communities and integration of patients’ perspectives, if any, during planning and implementation of the NTP historically
<p>Dr Rohit Sarin (10:40 am – 10: 50 am)</p>	<ul style="list-style-type: none"> • Evolution of TB therapy in India from conventional chemotherapy to short-course chemotherapy, therapy for MDR-TB. A clinician’s perspective on patient-centered care in India.
<p>Dr KS Sachdeva (10:50 am – 11:00 am)</p>	<ul style="list-style-type: none"> • The process of formulation of the National Strategic Plan for TB elimination in India, the revised diagnostic and treatment guidelines. The Joint Monitoring Mission. Perspectives on more broad-based development of policies and programs, and involvement of patients and communities
<p>Dr VK Chadda (11:00 am – 11:10 am)</p>	<ul style="list-style-type: none"> • Founding and evolution of the work of National Institutes in the National TB program. Responsibilities and challenges. Engagement and role of patients and communities.

Moderated discussion on Theme 1 | 11:10 am – 12:00 noon

Break | 12:00 noon – 12:10 pm

**Theme 2: TB program and its social context
12:10 pm - 2:00 pm**

Moderated by Dr Sunil Kaul

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