

Ramaiah Webinar on Health Care Policies for Neglected Diseases in India

Introduction

Neglected diseases contribute significantly to the global burden of diseases, and India is no exception. The need for comprehensive approaches to tackle neglected diseases has been articulated across the London Declaration on Neglected Tropical Diseases 2012, the World Health Assembly Resolution, 2013 and WHO Roadmap on Neglected Tropical Diseases, 2020 ^[1]. With over half of the 17 WHO listed neglected diseases found at endemic levels, India has approximately 457.4 million people who are infected ^[2], and that a significant proportion of those afflicted are younger children.

Neglected diseases are a diverse set of infectious, non-infectious, and coinfections diseases that affects the poor and most marginalized communities in low-middle income countries. Disability Adjusted Life Years (DALYs) due to neglected diseases contribute around 56 % towards Years Lost due to Disability (YLD) and around 44 % towards Years of Life Lost (YLL). As a result, neglected diseases have largely remained neglected in the global health agenda. India shares the disease burden for some of the neglected diseases which causes millions of DALYs, prevalence, and mortality rates. However, these diseases largely remain under resourced, under diagnosed and under treated. The agenda to achieve health, environmental, economic, social ^[3], and societal wellbeing has to be conceptualized while addressing neglected diseases. To overcome this, the objectives need to be set from the point of identification to levels of prevention, cure, palliation, rehabilitation, education, eradication, elimination, and control. Achieving these objectives requires different constitutional, legislative, economic, regulatory, fiscal/financial, informational, contractual, legal, social, and Research and Development (R&D) policy mechanisms for actions towards outcomes of physical, mental, economic, environmental, social, and societal wellbeing. The need for sustainable and inclusive health care must be built to reframe the approaches to tackle neglected diseases. A combination of these strategies using the many policy instruments requires inputs of different entities. The role of entities such as academia, public, private, and NGO institutions, personnel consisting doctors, paramedics, nurse, and staff, along with community, family, and individual is pertinent.

The Ontology for Healthcare Policies on Neglected Diseases encapsulates the above logic and organizes it in dimensions and elements as illustrated in Figure 1. Based on the ontology, the Ramaiah webinar on Health Care Policies for Neglected Diseases in India intends to frame, highlight, and debate the key issues of the topic.

Ontology for Healthcare Policies on Neglected Diseases in India

The ontology is a structured natural-language visualization of potential pathways for formulating health care policies on neglected diseases in India. Two illustrative pathways are:

- Economic mechanisms for cure of infectious helminth diseases by public institution for societal wellbeing.
- R&D mechanisms for identification of co-infectious diseases by academia for physical wellbeing.

<u>Policy</u>	<u>Objective</u>	<u>Disease</u>	<u>Entity</u>	<u>Outcome</u>
Constitutional	Identification	Infectious	Academia	Health
Legislative	Prevention	Helminth	Institution	
Economic	Cure	Protozal	Public	
Regulatory	Palliation	Bacterial	Pri	
Fiscal /Financial	Rehabilitation	Fungal		
Informational	Education	Viral		
Contractual	Eradication	Ectop		
Legal	Elimination			
Social	Control			
R & D				

Figure 1: Ontological Framework for Health Care Policies on Neglected Diseases in India

The webinar will be a free-flowing, structured brainstorming among academics, policy makers, and practitioners. The ontology will aid in discussing and addressing the need for, the priorities in, and the pathways for an effective management and eradication of neglected diseases leading to health, economic, environmental, social, and societal well-being. The discussion will help formulate a roadmap for research, policy, and practice for formulating policies on Neglected Diseases in India.

Issues

The discussion will focus on the following issues:

1. What should be the objective towards addressing the health care policies on neglected diseases?
2. What policy mechanisms will help achieve different outcomes?
3. What are the entities to be involved in the process?
4. Which are some of the crucial objective-disease combinations to be addressed by policies?

Way Forward

The health care policies on neglected diseases in India must range beyond the current objectives of control and elimination ^[4]. Strong multi-stakeholder partnerships will be the critical to fully understand the burden of the diseases, to increase R&D activities, integrate different approaches to address the disease burden, and build policy interventions. Ultimately, all actions taken towards health care policies of neglected diseases by the stakeholders must result in overall wellbeing of the country and its citizens.

Date: 16 October 2020

Time: 3:00 pm to 5:00 pm (IST)

Facilitator: Dr Arkalgud Ramaprasad, Director, Ramaiah Public Policy Center; Professor Emeritus, University of Illinois at Chicago, USA

Moderator: Dr Nibedita Rath, Scientific Director, Open Source Pharma Foundation

Coordinators: Mr. Ajay Chandra, Research Fellow, Ramaiah Public Policy Center

Ms. Sree Ganga S D, Research Associate, Ramaiah Public Policy Center

Dr Susanna G Mitra, Senior Research Fellow, Ramaiah Public Policy Center

Mr. Nibras K Thodika, Research Associate, Ramaiah Public Policy Center

References:

1. Action on Neglected Tropical Diseases in India.pdf. (2013). Global Health Progress.
2. Hotez, P. J., & Damania, A. (2018). India's neglected tropical diseases. *PLoS neglected tropical diseases*, 12(3), e0006038. <https://doi.org/10.1371/journal.pntd.0006038>
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4. Thomas, Z., Saha, G. K., Gopakumar, K. M., & Ganguly, N. K. (2019). Can India lead the way in neglected diseases innovation? *BMJ (Online)*, 364. Scopus. <https://doi.org/10.1136/bmj.k5396>

List of Panellists

Sl.No	Name	Affiliation
1.	Dr Bheemrao Ugarkar	Private consultant
2.	Dr Chetan Singai	Deputy Director, Ramaiah Public Policy Center, Bengaluru
3.	Dr Chidambara Murthy	Principal Scientist, Central Research Lab, Ramaiah Medical College and Hospitals, Bengaluru
4.	Prof Sudhir Krishna	Professor, National Centre for Biological Sciences, Bengaluru
5.	Dr Mohua Chakraborty	Centre for Policy Research, Indian Institute of Science, Bengaluru
6.	Dr Namitha Kumar	Head Advocacy, Open Platform for Rare Diseases (OPFORD)
7.	Dr R K Shandil	Founding Director, Foundation for Neglected Disease Research (FNDR)
8.	Dr Shambhavi Naik	Research Fellow, The Takshashila Institution, Bengaluru
9.	Dr Tanya Seshadri	Tribal Health Resource Centre, Vivekananda Girijana Kalyana Kendra BR hills, Chamarajanagar