



A Policy for Disease Control

This editorial is based on the article ['A Rare Opportunity'](#) which appeared in "Indian Express" on 11th April, 2019. The article talks about current bottlenecks in rare disease policy and ways to address it.

Human societies have seen a significant decrease in mortality from diseases over the past century. However, as a society, we must still struggle with not only the disease we thought under control but also with the disease that have emerged over last 30 years or are emerging every other day. Such endeavour calls for a sound public health disease control programs. This problem gets further traction due to ever increasing cases like that of **Candida Auris, Nipah Virus, Or The Rare Disease** prevalent in India.

To address this, many programmes are run by the Government of India under the umbrella of **National Health Mission**. However, in dealing with infectious and rare disease, National health Mission has its limitations.

In India, policies have focused largely on medical services. Public health services, and even implementation of basic public health regulations, have been neglected. **There is strong capacity for dealing with outbreaks when they occur, but not to prevent them from occurring.** Impressive capacity also exists for conducting intensive campaigns, but not for sustaining these gains on a continuing basis afterwards.

What should be the guiding principle for dealing with infectious diseases?

A sound public-health infectious disease control program require

- **Science-based policies**, programs, and infrastructure to be in place to prevent infectious disease morbidity and mortality;
- **Rapid identification** and controlling of outbreaks;
- Support for **disease elimination**;
- Prevention and response for re-emerging and emerging infectious disease threats;

Evolving risk factors associated with external drivers such as globalization, displacement of people and climate change reinforce the need for robust and sound public health infectious disease programs.

The existing framework for disease control in India

Historical structure of public healthcare in India:

- **Since the time of independence, the focus in India has been on medical care rather than on public health.** This was partly due to spread of democratic institutions, because electorates typically prefer public funds to be used to provide private goods (such as medical care), rather than public goods (such as sanitary measures to protect the health of the population as a whole).
- **Further, elite capture (of spending, as opposed to grassroots or primary level spending) also played a important role in precarious condition of public health in India.** Public funds for health and education have been funnelled towards tertiary rather than primary levels.

Substantial proportions of the health budgets have been spent on expanding subsidised medical training, public sector employment for medical graduates, and high-end tertiary medical services – all of which largely benefits the middle classes and detracts from the provision of public health services.

- **Further, an inconsistency between constitutional provisions starved public health systems of funds.** Public health services were designated as the responsibility of the state governments, except for issues such as port quarantine and provisions relating to the spread of diseases between states. Moreover, budgetary provisions left little fiscal room for states to operate programmes for which there is little support from the central government, such as ensuring environmental sanitation and other core functions.

Current situation of public health in India

Overview	<ul style="list-style-type: none"> ▪ Of the total current expenditure on health classified by healthcare functions, preventive care accounts for 6.7%. The money spent on curing people on the other hand is 51% of the expenditure with the remaining money being spent on pharmaceuticals. ▪ With 18% of world population, India accounts for 34% of the global tuberculosis burden and 26 % of the premature mortality due to diarrhea, lower respiratory and other common infectious diseases. ▪ Non-communicable disease (NCD) accounts for 55% morbidity and premature mortality. In this context Kerala and Goa have lowest mortality, and Assam, Uttar Pradesh and Chhattisgarh have the highest rates.
Sub-optimal public health system	<ul style="list-style-type: none"> ▪ The Indian public health system makes it challenging to tackle NCDs, which, in the first place, is all about prevention and early detection. It causes us to resort to high-cost secondary and tertiary health care in many cases. ▪ This system also diminishes our preparedness for new and emerging threats such as bioterrorism and compromises our ability to harness the demographic dividend.
Steps taken	<ul style="list-style-type: none"> ▪ The launch of Mission Indradhanush and Intensified Mission Indradhanush as well as the National AYUSH Mission. ▪ Efforts have been intensified for eliminating Neglected Tropical Diseases (<i>NTDs- a diverse group of communicable diseases that prevail in tropical and subtropical conditions</i>). ▪ The launch of National Strategic Plan 2017 that aims to control Tuberculosis.
Constraints	
Prevention	<ul style="list-style-type: none"> ▪ Prevention has been historically, inadequately acknowledged in India. <ul style="list-style-type: none"> ◦ NCD, for example, requires community level interaction but the condition of lifestyle points towards missing interaction (in India). ▪ Most of the human resource in health management is trained towards curative practices. <ul style="list-style-type: none"> ◦ Causes and linkages between risk factors and diseases as well discipline is ignored. Hospitals are run by clinicians with little expertise in health management. ▪ Accountability for ensuring vital public health actions is spread thin as manifested in the fact that preventable risk factors is the cause for a major proportion of diseases in India.
Institutional	<ul style="list-style-type: none"> ▪ There is no single authority responsible for public health that is legally empowered to enforce compliance from other public authorities and citizens, even though several factors may require inter-sectoral action to achieve a measurable impact on population health.

The disjunction between governance and public health management

The rise of infectious diseases is often described in terms of biological processes, but they cannot be reduced to just this dimension. A range of factors play a role, in particular increasing urbanisation and human mobility. Because all parts of cities are now hyper-connected, emerging infectious and tropical diseases such as dengue affect both privileged and more deprived areas, be they in the centre or peripheral or rural zones.

The social and spatial ubiquity of the disease demands a re-evaluation of the geographical and governance models that is being used to govern public health.

The problem lies in inequality in disease management, particularly in large cities and the zones between them. Cities get better infrastructure than its adjoining peripheral areas, for example, Delhi has 35 big hospitals, which is more than NCR minus Delhi combined.

Territories and infectious diseases are thus caught in a sort of **“local globalisation”** that requires a re-evaluation, to question the concepts of borders, mobility and the spread of specific urban models (*like scientific/social models to help explain where different types of people tend to live in an urban area*).

The policy for rare diseases in India

What is rare disease?

A rare disease is a health condition of low prevalence that affects a small number of people compared with other prevalent diseases in the general population. It is estimated that globally around 6000 to 8000 rare diseases exist with new rare diseases being reported in the medical literature regularly. **However, 80% of all rare disease patients are affected by approximately 350 rare diseases.**

Why it is a challenge?

Globally as well as in India, rare diseases pose a significant challenge to public health systems in terms of – difficulty in collecting epidemiological data (*epidemiology is the branch of medical science dealing with the transmission and control of disease*), which in turn impedes arriving at burden of diseases and cost estimations, difficulty in research and development, making correct and timely diagnosis, complex tertiary level management involving long term care and rehabilitation, and unavailability and prohibitive cost of treatment.

Rare Diseases as a public health issue

The field of rare diseases is complex and heterogeneous and suffers from a deficit of medical and scientific knowledge. The landscape of rare diseases is constantly evolving as there are new rare diseases and conditions being identified and reported regularly. This poses formidable challenges in development of a comprehensive policy on rare diseases.

India’s policy towards rare disease

More than 70 million people across India are suffering from rare diseases. India used to have the National Policy For Treatment Of Rare Diseases (NPTRD), with a corpus fund of 100 Crore, but it was withdrawn in December, 2018. Instead the government announced a one time financial assistance for rare diseases.

Why it is done?

The burden of disease is an ever increasing phenomena in India. **Many parts in India still lack in basic health infrastructure. This creates a resource conflict between public health management and rare disease control policy.** The government therefore have to balance the competing priorities of public health in very resource constrained settings.

What is the way out for rare disease policy?

Various committee/commission has recommended policy changes for rare diseases. These recommendations go beyond treatment funding and take a more holistic approach towards rare diseases, encompassing suggestions towards - prevention, awareness creation, training, research and development in treatment and diagnosis, development and manufacturing of drugs for rare diseases at affordable prices, provision of insurance coverage etc.

Is private sector a way out for rare disease?

Private sector is largely driven by the profit motive. Prevention, cure and development of medication for rare diseases take a significant amount of time and resources and that is why the government had to take the initiative in developing cures for rare diseases.

Way Forward (public health and rare disease)

Mobilize public health action at multiple levels	<ul style="list-style-type: none">▪ Public health spending should be increased in accordance with National Health Policy 2017.▪ Health choices and behaviour should be encouraged through policy measures like:<ul style="list-style-type: none">◦ Instruction of Yoga at schools through certified Instructors.◦ Increase Taxes on Tobacco, Alcohol; and sugar-sweetened beverages.◦ Co-location of AYUSH services in PHCs, CHCs and district hospital.▪ Strengthen the Village Health Sanitation and Nutrition Day platform to cover all sections of society instead of focusing only on children.▪ Steps should be taken towards catalysing behavioural change towards a greater recognition of preventive health care.▪ Make nutrition, water and sanitation part of the core functions of Panchayati Raj institutions and municipalities.
Institute a public health and management cadre in states	<ul style="list-style-type: none">▪ Incentivize state governments to invest in creating a dedicated cadre for public health at the state, district and block levels.▪ Characteristics of the cadre:<ul style="list-style-type: none">◦ Train officials in public health related disciplines like demography, and social and behavioural sciences.◦ Hospital management training should be provided.◦ Healthcare professionals should be provided opportunities to rise in the health cadre based services.◦ For taking leadership level position, master level qualification should be made mandatory in addition to specific training.
Institutional mechanisms	<ul style="list-style-type: none">▪ Develop a model public health and management cadre by drawing upon best practices and engage with states to adapt, refine and institutionalize the model.▪ Formulate guidelines to create the cadre, primarily by re-aligning the requisite skill sets of existing functionaries with service conditions.
Create a focal point for public health at the central level with state counterparts	<ul style="list-style-type: none">▪ Create a designated and autonomous focal agency with the required capacities and linkages to perform the functions of disease surveillance, information gathering on the health impact of non-health department. An appropriately empowered and capacitated National Centre for Disease Control may be considered to play this role with support from relevant organizations.▪ Create a counterpart Public Health Agency in each state, where they do not already exist.
Miscellaneous	<ul style="list-style-type: none">▪ Redefine the role of the technical directorate (Directorate General of Health Services) and create a Directorate of Public Health.

Conclusion

To control these diseases in a more sustainable manner, the health of inhabitants has to become a key

factor of urban development. This involves reforming the management of diseases, and hence of urban centres - developing more equitable urban infrastructure - most of all, **developing inclusive cities**. In short, investments are required. However, if the task is important, new approaches and new programmes - for example, smart cities or sustainable towns - may be a means of better containing these epidemics.

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