

Patient Engagement and SDGs: A Perspective from India Experience

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ABSTRACT

India has taken the major transformation reforms and initiatives addressing barriers to universal health care, ensuring healthy lives and well-being for all citizens at all ages (Sustainable Development Goal ‘SDG’-3), post-2015. With the growing investment and development in healthcare in India, the most important barriers requiring constant attention are (i) persistence of stigma, discrimination and societal obstacles associated with the health condition (ii) access to the right information and (iii) timely standard of care. Thus, emphasis on patient-driven policies and programs besides systemic interventions, and healthcare ecosystem partnership is a looked-for social impact. India has adopted patient engagement as one of the tested and validated strategies to achieve the triple aim for value-based health care (better health and better patient care at lower costs), a path towards SDG 3. However, India needs to strengthen the healthcare ecosystem for effective implementation of the patient engagement strategy aiming survival and quality of life. Above and beyond, culture and system of transparency and collaboration need to be improved for ‘buy-in’ of citizens.

Keywords: Patient, SDG, Healthcare, India

Abbreviations: AIDS: Acquired Immuno-Deficiency Syndrome; BMGF: Bill Melinda Gates Foundation; HIV: Human Immuno-Deficiency Virus; INR: Indian Rupees; SDG: Sustainable Development Goals; TB: Tuberculosis; USD: United States Dollars

INTRODUCTION

In the last century, in spite of public health achievements worldwide, the number of deaths caused by preventable diseases continues to rise. Moreover, many low- and middle-income countries, including India are going through an epidemiological transition towards chronic non-communicable diseases [1-3]. This indicates a need to strengthen current policy and programmatic interventions in the local context involving multiple stakeholder cross sectors, together with the citizen. In 2015, the global health community has set people-centered United Nations Sustainable Development Goals (SDGs, #17) for the year 2030 – of which, goal 3 is to ensure healthy lives and promote well-being for all at all ages – and recognized the value of citizen participation in decision-making [4]. Post that India has taken major transformation reforms and initiatives focused on providing essential healthcare services to the entire population, with a special emphasis on the poor and vulnerable sections of the population. The UN agencies provide support to the government in the development of the national plan, strategies and implementation of achieving SDGs [5]. Guided by the facts, one of the key strategic approaches of India is to foster the participation of all key stakeholders (e.g. patients, providers, payors and policy

makers) that have a commitment to the principle of universal access to health care.

In 2015, for the first time, India issued a guideline on the involvement of non-for-profit organization at community level interventions under the National Health Mission, Communicable Diseases, Non-communicable Diseases and other emerging issues [6]. Fifteen years after the last policy, a new India Health Policy was introduced in 2017, which is patient-centric, quality driven, and advocates positive and proactive engagement with private sectors and civil society organizations [7]. With the intent to translate policy into practice, government departments are endorsing various initiatives and innovative demonstration projects and their scale-up to ensure healthy lives and promote well-being for

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all citizens at all ages (SDG 3.0). For example, The National Health Mission allocated INR 267 billion (USD 4 billion) in 2017-18 for improving infrastructure facilities at the district and sub-district levels, ensuring basic health care access to all - making it one of the largest centrally sponsored schemes of the Government of India [8]. Additionally, India launched the National Health Protection Scheme in 2018, a flagship initiative that attempts a comprehensive need-based health care service delivery to the doorsteps of citizens and protecting them from financial risk due to catastrophic health episodes [9]. The design and implementation of the initiative are through strategic partnerships and collaborations with multiple stakeholders, including civil society so as to reach more than 500 million Indians who could not afford medical treatment for illnesses like cancer and heart disease. Likewise, the National AIDS Control Organization has signed a memorandum of understanding with the government department of the north-eastern region to enhance involvement of Self Help Groups (volunteer community groups) in reaching out to high-risk groups and youth. This partnership has three-point agenda (a) early access to prevention and testing services (b) reduce stigma and discrimination against people infected and affected by HIV, and (c) enhance access of social protection by people living with HIV [10].

Guided by the facts, several philanthropic organizations in India, have integrated multi-pronged approach in health care intervention using evidence-based and experience-based interventions. For instance, Tata Trusts [11] formed National Cancer Grid, a network of cancer hospitals and research institutions, patient advocacy groups and charitable institutions across India to ensure greater awareness and accessibility to cancer screening, diagnosis, and treatment. In addition, for the first time in 2018, the cancer patient advisory group was constituted in India, providing an engagement platform for patients, care providers, and policymakers. On the other hand, a 'Peer-to-peer referrals' strategy has been tested and found valuable for increasing testing and detection of infectious diseases (e.g. TB), where peers may have advantages over healthcare workers in both identifying new patients and providing them trustworthy information [12].

With the growing investment and development in healthcare in India, the most important barriers requiring constant attention are (i) persistence of stigma, discrimination and societal obstacles associated with the disease or health condition (ii) access to the right information, and (iii) timely standard of care. The numerous evidence [13,14] have concluded that patient participation and engagement in healthcare may significantly address the above-mentioned barriers with two ethics integrated explicitly in the system. These ethics are (a) responsiveness towards the patient's vulnerability and (b) shared decision-making that are vital beyond other interventions associated with efficiency and effectiveness of the health care. In the given context, the

value of patient engagement with well-defined pathways is the most likely steps to overcome the aforementioned barriers ensuring positive health outcomes. Thus, emphasis on patient-driven policies and programs besides systemic interventions and healthcare ecosystem partnership is a looked-for social impact in India. Therefore, there is a need to understand more about, "what" as well as "how" of patient engagement along with confounding factors that facilitate the process.

It is well evidenced that patient engagement is important in all fields of treatment, particularly chronic diseases like cancer, diabetes, hemophilia; and its significance can be defined in two ways [15]. First, transform self-stigmatized passive patient to active patient, addressing their challenges from diagnosis to care pathway for improved health outcomes. Second, empower patients to discover, drive and lead in the patient-centric policy and program meaningfully. However, patients or patient organizations require support and resources in transforming their capabilities to effectively participate in the policy-shaping as patient advocates. The most essential prerequisite to truly translate patient engagement strategy into action is 'education on patient's rights' including what are the diagnostic, and treatment options, what should be expected from government and providers, privacy and confidentiality of data, and how to protect their rights.

CONCLUSION

India has adopted patient engagement as one of the tested, and validated strategies to achieve the triple aim [16] for value-based health care (better health and better patient care at lower costs), a path towards SDG 3.0. However, India needs to strengthen the healthcare ecosystem for effective implementation of the patient engagement strategy aiming survival and quality of life. Above and beyond, culture and system of transparency and collaboration need to be improved for 'buy-in' of citizens.

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