



Framing Women's Health Issues in 21st Century India - A Policy Report

The George Institute for Global Health India, May 2016.



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Foreword

Does the Indian healthcare system treat the women of the country in a fair and just manner? And what can we do to make sure that it can first recognize the needs, and then develop effective and sustainable programs to remove barriers towards achievement of optimal health for Indian women?

We know that overall life expectancy has increased in India over time, women in fact have a higher life expectancy than men, and there have been substantial improvements in the management of conditions that were responsible for the largest number of deaths and disability amongst Indian women 25 years ago. The maternal mortality rate – an important healthcare indicator – has fallen from 57 per 1000 live births in 1990 to 28 per 1000 live births in 2015.¹ The Indian healthcare system has made tremendous strides, and the large Indian hospitals are considered at par with the best in the world.

This good news, however, masks a number of festering and emerging challenges – one of which is how to provide optimal healthcare to 50% of its population – the women. A depressing fact in the Indian healthcare system is the remarkable lack of any data that can provide any level of gender specific analysis of disease burden. In fact, the 2013 Global Burden of Disease (GBD) report singled out India to point to the overall lack of data.

Despite suggestions that non-communicable diseases (NCDs) are rising among women and replacing the traditional causes of morbidity and mortality, the healthcare delivery system and research focus for women remains stuck in the field of sexual and reproductive health (SRH). Data from elsewhere in the world show that women with diabetes and hypertension are more likely than men to develop some complications, but this is not widely recognized.

Several groups have made calls to address the growing NCD epidemic amongst women (and men), and for taking a life-course agenda that integrates care for SRH issues and NCDs in women. This is also reflected in the new United Nations (UN) Sustainable Development Goals (SDGs) that aim to promote healthy lives and well-being for all, as well as gender equality.

Towards this end, The George Institute for Global Health, India organized a women's health policy dialogue in Delhi on March 15. Participants included an array of stakeholders working in the area of women's health – from academics and doctors to civil society members, media and corporates. Prominent among them were the Australian High Commissioner to India, scientists from the Indian Council of Medical Research, Ministry of Health and Family Welfare, members from non-governmental organizations, public health experts, researchers, and journalists. The discussions covered the current scenario of women's health in India, the changing causes of their morbidity and mortality, and the need for a more responsive health system.

This report contains a summary of discussions on how to appropriately understand the health needs of Indian women in 2016, and what we need to do to create a healthcare system that is free from gender bias



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38% FEMALE FATALITIES
DUE TO NCDs in 1990
FEMALE FATALITIES
DUE TO NCDs in 2013 **60%**

Summary of Key Recommendations

- Governments, inter-governmental agencies and non-government organizations need to broaden their focus on women's health to include NCDs. They need to recognize and adopt a life-course approach while advocating the women's health agenda. Else, the ongoing health investments will lead to diminishing returns and will not benefit a majority of women.
- The Central and State Ministries and Departments of Health should promote and support the 2015 Global Strategy for Women's, Children's and Adolescents' Health. This entails advocating for, collecting and reporting gendered-analyses of health data at all levels. Sex-disaggregated data collection will lead to better planning and implementation of women-centric health interventions.
- Professional and academic organizations, especially the Indian Council of Medical Research, obstetrics and gynecology societies, academic institutions and universities, should recognize, promote and address a broader, integrated women's health agenda.
- All new research should be designed in such a way as to facilitate inclusion of gendered analyses. It should include women in appropriate numbers, whether it is in the study of biology or environmental factors, examination of variations in access to care and its reasons, or implementation research aimed at providing the best care to women.



"...non-communicable diseases, such as cardiovascular disease, stroke, kidney disease, respiratory diseases and trauma are the leading causes of death for women worldwide..."

Introduction

Generally, women's health receives attention only during pregnancy and the immediate post-partum period. A women's health agenda was first articulated at the Fourth World Conference on Women held in Beijing in 1995. In the resulting Beijing Declaration and Platform for Action, a roadmap for gender equality and women's empowerment was outlined, with a major focus on reproductive and sexual health (SRH) issues, which were the main killers of women then. As a result of this focus, major gains have been made in this area, with the maternal mortality in India coming down from 5.7% in 1990 to 2.8 % in 2015.¹

At the same time, the issues affecting women's health have undergone a drastic change, and currently NCDs, such as cardiovascular disease, stroke, kidney disease, respiratory diseases and trauma are the leading causes of death for women worldwide – in high as well as low-income countries.² Despite a longer life expectancy, women have a higher burden of disability due to NCDs, like back and neck pain, depressive disorders and respiratory diseases.

Social constructs and biases also leave girls and women more disadvantaged, as evidenced by high rates of sexual violence. The advancement of gender equality and equity, empowerment and elimination of discrimination, are critical to women's health and well-being. This can only be achieved by including the gender dimension in planning health programs and research.

There is a need to provide stronger evidence to demonstrate the benefits of pursuing such a broader life-course agenda for women's health. Otherwise, the ongoing health investments will lead to diminishing returns and will not benefit a majority of women. Given the links between NCDs, maternal conditions and infectious diseases in women, it is essential that women's health advocates and NCD experts unite in their commitment to promote women's right to health throughout the integrated life- course as a central component of efforts to strengthen health systems and to protect women's health.



Women with diabetes have over 40 per cent greater risk of heart attack than men with diabetes, a George Institute study has shown.

Current status

The Indian Council of Medical Research has been at the forefront of the research agenda on women's health in India. As SRH has caused the greatest disease burden to women, almost all programs have addressed reproductive health issues. Recent data from the Global Burden of Disease (GBD) shows that the contribution of communicable, maternal, neonatal and reproductive diseases to deaths amongst Indian women had declined from 53% in 1990 to less than 30% in 2013, whereas the contribution of NCDs to all deaths in women had risen from 38 % to 60 %.³

Currently there are no disease specific data on gender-differences beyond incidence, prevalence, morbidity, and mortality. Despite the emerging knowledge about new risk factors, there is a total absence of evidence around preventive care for women, including – but not limited to – issues around smoking, consumption of tobacco products, alcohol, and substance abuse. Most NCDs are caused by high-risk behaviors. If women are educated about them, and they are made part of behavior change communication programs in public health, the change might be impactful.

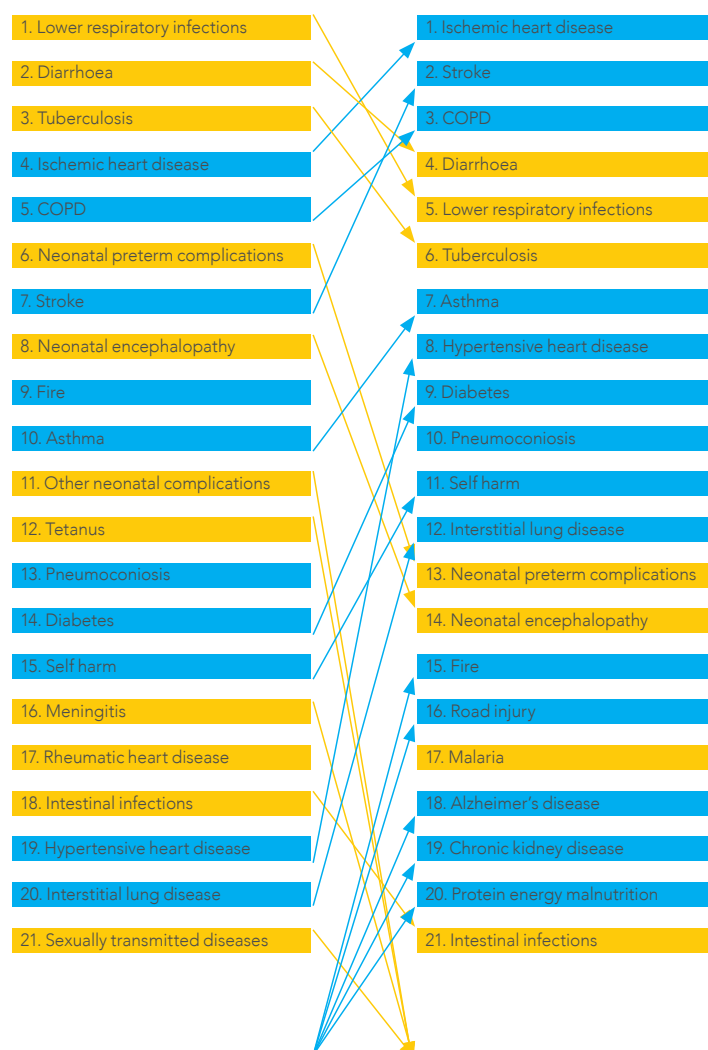
Mental disorders are associated with considerable stigma in India, which leads to massive under-recognition and hence under-treatment. There are virtually no sex-specific data on mental health in India. According to the National Crime Record Bureau (NCRB), housewives constitute the largest demographic group amongst suicide deaths. For the last 25 years, it has stood consistently around 20%.⁴

Beyond these disease statistics, gender disparities exist in healthcare delivery and women's access to treatment as well. Insurance utilization data shows that the claims-to-coverage ratio of health insurance is very low for women.⁵ This can be improved by empowering women; microfinance literature shows that when women are empowered, they file more claims but as mere spouses,

they are 10% as likely to file claims even when they are affected by morbidities in the same way.⁶

NCDs not only affect the health of women and girls, but also the health and life chances of their children. Being born to poorly nourished mothers increases the chances of infants suffering under-nutrition, late physical and cognitive development, and NCDs in adulthood.⁷

Change in mortality patterns among women in India – GBD leading causes of death in 1990 and 2013



Women suffer more, are treated less and have poorer health outcomes.

Challenges

- Despite the well-documented health transition leading to a situation where deaths and disabilities in women due to NCDs, such as cardiovascular and respiratory diseases, cancers, injuries and mental disorders, including suicide, are on the rise, little attention is being paid to addressing these issues.
- Funding agencies, donor organizations and academic bodies are yet to embrace the life-course agenda to women's health, leading to neglect of health of women beyond childbearing years.
- Women provide the bulk of healthcare worldwide, both in the formal healthcare setting as well as in the informal sector and in the home. Yet women's own needs for healthcare are poorly addressed, especially among rural and poor communities.
- Gender inequality, in both biological, environmental and social terms, makes women more vulnerable to certain risks, leading to poorer outcomes. These issues need special attention through independent programs that will be distinct from men's health.
- Extrapolation of health data taken from men leads to under-recognition of the manifestations, severity and consequences of disease, differential access to information and health services.
- Women's household roles impact their health -- such as exposure to smoke and women's limited engagement in physical work. These challenges do not have their solutions rooted in medical health but a holistic approach to public health and inter- departmental partnerships.



44% THE INCREASED RISK OF DIABETIC WOMEN HAVING A HEART ATTACK OVER DIABETIC MEN

27% THE INCREASED RISK OF DIABETIC WOMEN HAVING A STROKE OVER DIABETIC MEN

The Goals of Reform

The main goals of reform in women's healthcare reflect the principles behind universal human rights and the UN SDGs. These include:

- Getting a better understanding of issues around the barriers to delivering quality healthcare to women.
- Sensitizing academic organizations, policymakers, funding bodies, and NGOs to developing an independent women's health research and implementation agenda.
- Optimizing healthcare to women through high quality care.
- Optimizing the experience of women in encounters with the healthcare system through development of a life-course approach.
- Ensuring equity and achieving value for money.
- Providing incentives for behavior change to promote achievement of these goals.

The Indian healthcare system requires discussions, advocacy and research to underscore women's health as one of the focus areas in research and implementation. Such a process can be informed by similar work done elsewhere. For example, sex-disaggregated analyses of data have shown that women with diabetes have a 44% higher risk of heart attack than men with diabetes.⁸ Similarly, women with diabetes have a 27% increased risk of stroke compared to men with diabetes. Given the fact that South Asians are at increased risk of CVD, especially at a younger age, such sex-disaggregated studies are much needed in India. All sections of the society, including men, need to be involved in promoting the women's health agenda.

An example of the type of evidence required to show the benefits of integrating a focus on SRH and NCDs to improve health outcomes for women in South Asia.

In August 2015, an award was made by the Global Alliance for Chronic Diseases, with funding from the Indian Council of Medical Research and the National Health and Medical Research Council of Australia, to support a lifestyle intervention program for the prevention of type 2 diabetes mellitus amongst South Asian women with gestational diabetes mellitus.

Primary research aim: To determine whether a resource- and culturally appropriate lifestyle intervention program in South Asian countries (Bangladesh, India and Sri Lanka), provided to women with gestational diabetes mellitus (GDM) after delivery, will reduce the incidence of type 2 diabetes mellitus (T2DM), in a manner that is affordable, acceptable and scalable.

Research methodology: A new lifestyle intervention program is being developed that will be delivered by auxiliary nurse midwives or their equivalent in each participating hospital, representing a strategy of within-system task-shifting. The intervention will be evaluated in a randomized controlled trial (1414 women from 24 centres) to determine whether it will reduce the incidence of T2DM at a median of 20 months follow-up. This project focuses on generating new knowledge around implementation of a preventive strategy embedded within existing health systems, using mixed-methods evaluation to inform on cost-effectiveness, acceptability and scalability.

Women with type 1 diabetes have a 37 per cent greater risk of dying of any cause compared to men.

Key Recommendations

- **Governments, inter-governmental agencies, non-government organizations, donor organizations and corporate bodies need to broaden their focus on women's health to include NCDs.**

Seven of the top 10 causes of death in women in India are NCDs, led by heart attacks, stroke and respiratory diseases. Despite these data, widespread perception persists that heart disease and stroke are mainly diseases of men, and that if a woman develops CVD, it will not be as serious as in a man.

Moreover, even women do not see it as an important threat to their health. Data also show that women and men who have high blood pressure or who smoke have an equal risk of getting heart attack and stroke, whereas women with diabetes have a higher risk of IHD and stroke compared to men.⁸

Women with type 1 diabetes have a 37% greater risk dying of any cause compared to men with type 1 diabetes. In contrast, women are less likely to receive drug therapy for the management of these risk factors, and are less likely to be referred for diagnostic and therapeutic procedures.⁸

Spurred by these data, a number of organizations and documents have highlighted the need to develop a holistic, life-course agenda for women's health that does not abandon them once the childbearing age is passed. These include the Every Woman Every Child movement (2010), WHO's recognition of women's health beyond reproduction as a new agenda (2013), the Lancet Commission on Women and Health (2015), the Global Strategy for Women's, Children's and Adolescents' Health (2015), and the Global Leader's Meeting on Gender Equality and Women's Empowerment by the UN (2015), leading to commitments by the UN member states.

Major disparities are evident in the provision of care, all to the disadvantage of women in India. It is time that all stakeholders recognize and adopt a life-course approach while advocating the women's health agenda, if genuine progress in women's health is to be realized and the 2030 SDG targets are to be

realized. Else, the ongoing health investments will lead to diminishing returns and will not benefit a majority of women.

The life-course approach extends beyond women's reproductive aspects to encompass women's health at every stage and in every aspect of their lives. It highlights gender as a key determinant of women's health and well-being, and focuses on the fact that women's health needs differ according to their life stages. There is a need to target women in the lower socio-economic strata. As the approach relies on data disaggregated by sex and other important variables such as age and environmental settings, the sex-disaggregated databases at all levels need to be strengthened. Such an approach has the potential to lead to reductions in deaths and disabilities due to NCDs as well as SRH issues.

This agenda cannot be achieved without significant investment, which must come from all stakeholders – both government as well as private sector. Large donor organizations have played an important role in shaping healthcare reforms and agendas in India, and it is imperative that they pivot towards taking a life-course approach to women's health. Similarly, large corporates in India continue to provide admirable support to several aspects of women's empowerment and well-being, including healthcare related issues. It is time that they allocate funds from their CSR budget to support an integrated women's health agenda. This must start by supporting gendered analyses of existing health data – without such analyses reform packages cannot be developed and implemented.

- **The Central and State Ministries and Departments of Health should promote and support the 2015 Global Strategy.**

The governments have set up an excellent framework for provision of care for SRH related conditions, which consists of at least 3 levels of workers. This model has already shown that involvement of non-physician healthcare workers is effective

Diabetes-related excess risk of stroke in women is due to undetected and therefore untreated higher cardiovascular risk profiles in pre-diabetic conditions.

Key Recommendations Continued

in democratizing care delivery and improving outcomes. The same framework can be mobilized to develop a life-course approach to women's care. Such a recommendation is consistent with the National Program for Prevention and Control of Cancer, Diabetes, CVD and Stroke.

The program must make provisions for collecting and reporting gendered-analyses of health data at all levels. Sex-disaggregated data collection will lead to better planning and implementation of women-centric health interventions.

Government and health department officials must ensure that any proposed interventions have been analyzed separately for women and men before making decisions. This would be crucial to attainment of the SDGs.

As these programs are implemented, plans should be put in place for promotion of disaggregated analyses and inequality monitoring as recommended in the WHO Roadmap for Action 2104-19.⁸

- *Professional and academic organizations, especially the Indian Council of Medical Research, obstetrics and gynecology societies, academic institutions, and universities and journals, should recognize, promote and address a broader, integrated women's health agenda.*

The implementation of any change can be realized only when there is systematic engagement with, and monitoring of, all healthcare providers, including both government and private sector. Such a task requires involvement of independent professional and research organizations.

All professional organizations interested in aspects of women's health should develop, irrespective of the primary area of specialization, an integrated women's health agenda.

Societies need to carry out comprehensive and independent evaluation of all new and existing programs, so as to determine how investment in gendered research can provide new knowledge and lead to improved outcomes.

Academic institutes and universities should develop programs for gendered analyses, on the lines of the Advice Paper of the League of European Research Universities (LERU), that provides case studies showing how a gendered approach to science has contributed to increased excellence in science and the production of new knowledge.⁹ These organizations should engage with governments and funding agencies to highlight the importance of gendered analyses, and allocation of funds for this purpose.

- *All new research should be designed to facilitate inclusion of gendered analyses. Such a step will be crucial to formulating gender-specific strategies when needed.*

Effective and collaborative research, data collection, monitoring, evaluation and knowledge transfer to advance the evidence base on women's health is necessary for framing better policies. Social research and clinical studies should make it a point to include as many representative women as men.

All government and private organizations, NGOs, foundations, etc. engaged in the provision of healthcare should promote, produce and report gendered analyses of healthcare statistics. This recommendation particularly applies to agencies that hold large insurance datasets, both in the government and in non-government sector. Resources should be allocated to:

- Continuous monitoring of gendered analyses of healthcare statistics.
- Examine pathways and quality of care for women at all levels of the health system.
- For gender-neutral conditions, determine whether these pathways differ for men and women.
- Identify evidence-based strategies that could be implemented to ensure women receive the best available care.

Mental health needs to be made an integral part of the women's health agenda in India.

Key Recommendations Continued

Funding bodies, such as the ICMR, the Department of Health Research and the donor bodies should recognize the need to promote such research and bring out specific calls for proposal. In particular, funds should be allocated within the ICMR to develop a program of research in this area.

In order to develop evidence that is directly applicable to women, research projects should include women in appropriate numbers - whether in the study of biology or environmental factors, examination of variations in access to care and its reasons, or implementation research aimed at providing the best care to women.

- *Empower and educate women to take charge of their own – and their families' health.*

There needs to be impetus on educating women to bring fundamental behavioral change and awareness of innovative approaches to improve healthcare of themselves and their families. Women should be sensitized by the primary-level health systems about the importance of having a healthy lifestyle and inculcating it in their family.

Women in uninsured households should be taught the virtues of using microfinance and insurance to access healthcare. They should be taught about the importance of filing claims and participating in decision making around healthcare delivery in the family.

Socio-behavioral researchers should develop interventions to raise overall attention to women's health among communities, emphasizing the life-course agenda and including NCDs, mental and respiratory disorders and de-addictions. Such interventions should be culturally sensitive.

Mental health needs to be made an integral part of the women's health agenda in India, and conversations should focus on removing the element of stigma around it. This requires behavioral change communication in the health system to primary-level health workers and through them to the communities.

A woman empowered with knowledge about the disease and risk factor burden, can be transformative to the health of entire families. Such empowerment is required early - the existing Adolescent Reproductive and Sexual Health (ARSH) clinics can serve as the ideal vehicle for such initiatives.

- *Moving from conversations to action needs careful planning, extensive discussion and consultation, and a staged approach.*

Increasing broader public awareness that there is scope for improving our healthcare system through modifying funding approaches is an immediate priority. The concept of patients as partners in care must also be acknowledged in this context. Political buy-in and commitment to reform is also essential. A broad constituency is needed to reach agreement and drive change that outlasts the political cycle. Community and non-health agencies should be given a voice in health pathways and in the bundling of services.

An important opportunity exists to learn from other schemes within and outside the health sector and from overseas. For example, the NDIS (National Disability Insurance Scheme) is a useful case study for patient-driven service delivery policy reform.

Evaluation and staged implementation of programs are needed to generate the evidence base to ensure effective roll-out of reforms. Consideration should be given to forming a reform 'statutory body' with a permanent secretariat to continue the reform process and monitor progress.

The Way Forward

The development of an independent women's health program that takes a life-course approach to improving their access to healthcare is needed to enable management of all issues that affect women's health. This should include improved management of sexual and reproductive health issues, integrated with the management of chronic diseases, including cardiovascular diseases, cancers and mental health. It should also encourage prevention and remove barriers to healthcare utilization. Such an agenda could be developed by the following approach:

- Increased focus on the collection and use of data disaggregated by sex and age, as well as other indicators relevant to women's health and survival.
- Improved partnerships and synergy between government and non-government (international and local) bodies working on women's health.
- Staged implementation of individual programs of reform, building on existing programs such as the primary care SRH program, accompanied from the outset by rigorous evaluation and routine collection of appropriate data.
- In the longer term, rolling out of such reforms across the entire geography.
- Expansion of existing IT capacities for data collection and analysis.

- Significant investment in change management processes by government as well as private providers – in particular, the infrastructure costs that might be incurred in implementation of these programs.
- Corporate organizations to recognize the importance of an integrated women's health agenda as an important Corporate Social Responsibility, especially in light of the SDG No 3, and allocate funds to support gendered analyses of health data and improved understanding of care pathways for women.
- Improved investment in primary care to ensure that development of NCDs in women can be prevented.

In fabricating these reforms there needs to be broad and ongoing consultation and consideration of all perspectives – public and private sectors, insurance companies, and the patient-consumer.

This recent round table meeting represents the first step in this process and is particularly relevant, given its timing alongside the announcement of the SGDs, and as a natural follow up to steps recommended by major global organizations.



Thank you

The George Institute, India is grateful for the participation of the following representatives in the roundtable discussion that is the basis of this report:

Abha Mehndiretta - World Bank/Nice International

Dinesh Sharma - Senior Journalist

Harinder Sidhu - High Commissioner of Australia to India,
Australian High Commission

Karthikeyan G - Department of Cardiology, All India Institute of
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Robyn Norton - Principal Director, The George Institute for
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R.S Sharma - Head, Reproductive Biology and Maternal Health,
Indian Council of Medical Research

Sanjiv Kumar - National Health Systems Resource Centre

Shamika Ravi - Brookings India

Smita Mahale - National Institute for Research in Reproductive
Health, Mumbai

Suneeta Mittal - Fortis Memorial Research Institute

Naveen Bagalkot - Shrishti School of Design, Bengaluru

Namita Chandhok - Indian Council of Medical Research

Mohuya Chaudhuri - Independent Journalist

Sapna Desai - Researcher

Aarti Dhar - Independent Journalist

Neeru Gupta - Indian Council of Medical Research

Shahid Jamil - Welcome Trust - DBT India Alliance

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Shimona Kanwar - Times of India, Chandigarh

Sushma Kapoor - Senior Advisor, Global Health Strategies

Rahul Kaul - Biovoice

Simi Khan - Mamta

Amit Khanna - The George Institute for Global Health, India

Aparna Khanna - Lady Irwin College, University of Delhi

Renu Kohli - Pepsico

Venkata Krishnan - Indian Institute of Technology, Mandi

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Pallab Maulik - The George Institute for Global Health, India

Sumita Mehta - Independent Journalist and Consultant

Neelima Mishra - National Institute for Malarial Research, ICMR

Prashant Mishra - British Medical Journal

Syed Nazakat - Health Analytics India

Pooran Pandey - UN Global Compact Network India

Renu Rawat - PHD Chamber of Commerce and Industry

Alpana Saha - The George Institute for Global Health, India

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Chesta Sharma - PwC, India

Radhika Shrivastav - Healthy India Alliance

Shalini Singh - Indian Council of Medical Research

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Tanya Spisbah - Australian High Commission

Leena Sushant - Breakthrough

Oommen T.K - George Institute for Global Health, India

Karan Thakur - Apollo Hospital

Ramana Thakur - Indian Institute of Technology, Mandi

Yasmin Zaveri - Embassy of Sweden

The George Institute for Global Health

About The George Institute for Global Health

The George Institute for Global Health (TGI) was established in India in 2007 to generate high-quality evidence and improve the health of millions of Indians by reducing premature deaths and disability from non-communicable diseases, such as cardiovascular disease, diabetes, kidney disease, stroke, mental health, and injuries.

TGI India's research uses innovative approaches to create system-wide change for people at the bottom of the pyramid, to develop affordable and scalable solutions, and to empower people to improve their own health.

TGI also conducts research and advocacy around areas traditionally neglected by the healthcare and policy community - the health of women and girls, adolescents and promoting healthy eating.

One of the top ranked medical research institutes in the world for impact, The George Institute, India partners with over sixty national and international institutions such as the Public Health Foundation of India, the Postgraduate Institute of Medical Education and Research, University of Hyderabad, and has affiliations with the Universities of Sydney, Oxford and Peking.

With researchers in Delhi, Hyderabad and around India, TGI India is a terrific example of collaborations between Australia, UK and India working together to improve people's health.

Local innovation and medical research expertise paired with a global reach embodies The George Institute, India.

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