



Indian Medical Parliamentarians' Forum Newsletter

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(Interim) Budget Session Issue

January-February 2024

The Interim Budget Session 2024, a significant event in the parliamentary calendar, commenced on Wednesday, January 31st, 2024, and concluded on Saturday, February 10th, 2024, after nine sittings over eleven days. This session was marked by the President's address to both Houses of Parliament on January 31st, 2024, inaugurating the legislative year. Notably, this session serves as the final parliamentary sitting for the 17th Lok Sabha as the nation gears up for the upcoming General Elections 2024.

On February 1st, 2024, Union Finance Minister Smt. Nirmala Sitharaman presented the Interim Union Budget for 2024-25. With an ambitious vision for a Viksit Bharat by 2047, the budget significantly emphasizes Nari Shakti, proposing key initiatives for women's health and empowerment. Among these is a vaccination program aimed at preventing cervical cancer, targeting girls aged 9 to 14. This initiative is a crucial step towards reducing the prevalence of this preventable disease and underscores the government's commitment to women's health.

Additionally, the budget highlights the consolidation of various maternal and childcare schemes to streamline and enhance their effectiveness. Further supporting the Digital India initiative, the Union Finance Minister announced the expedited nationwide rollout of the newly designed U-WIN platform. This platform will play a pivotal role in managing immunization efforts, bolstering Mission Indradhanush, and ensuring comprehensive coverage across the country.

This issue of the IMPF Newsletter delves into critical health topics, including rare diseases, cervical cancer, and immunization for healthy ageing. It reflects the government's focus on enhancing healthcare accessibility and quality. We extend our heartfelt gratitude to all the contributors whose insightful articles make this edition informative and relevant.

As we elect a new government, let us remain committed to the shared goal of a healthier, more prosperous India.

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India's Bold Move to Eradicate Cervical Cancer: Nationwide HPV Vaccination Program

India is set to roll out a nationwide HPV vaccination program, aiming to reduce cervical cancer rates significantly. With a population of 511.4 million women aged 15 years and older at risk, the urgency is apparent. Each year, 123,907 women in India are diagnosed with cervical cancer, and 77,348 succumb to the disease. Ranking as the second most frequent cancer among Indian women, cervical cancer is predominantly caused by human papillomavirus (HPV) infection, responsible for 95% of cases. Alarming, 83.2% of invasive cervical cancers in India are attributed to HPV types 16 and 18.

Cervical cancer ranks as the fourth most common cancer among women worldwide, with 90% of the more than 348,000 deaths in 2022 happening in low- and middle-income countries. Recognizing this, India plans a national drive to vaccinate girls aged nine to fourteen against HPV. Union Finance Minister, Smt. Nirmala Sitharaman announced this initiative in the Interim Budget 2024-25, emphasizing the government's commitment to Nari Shakti and aiming for a Viksit Bharat by 2047. Although the exact date for the campaign rollout is yet to be announced, the intent is clear: to prevent cervical cancer through widespread vaccination.

While HPV vaccination was introduced in India in 2008, it has not yet been included in the universal immunization program. However, states like Punjab and Sikkim have successfully implemented the vaccine, achieving a 97% vaccination rate among targeted girls. The national rollout is anticipated to follow this success, contributing to the global efforts to eliminate cervical cancer. In March, global health organizations, including the World Health Organization (WHO) and Gavi, pledged nearly \$600 million in new funding to eliminate cervical cancer. These efforts, if realized, could mark the first time the world eliminates a cancer through vaccination.

Despite declining rates of cervical cancer in India, the journey to elimination remains long. The country records one new case every four months and one death every seven minutes. Currently, there are approximately 340,000 cases of cervical cancer in India, making it the third most common cancer overall and the second most common among women. In 2022, over 127,000 new cases and about 80,000 deaths were reported.

Cervical cancer accounts for one-tenth of all cancers in Indian women. The highest incidence rates are observed in the north-eastern states, with Papum Pare in Arunachal Pradesh and Aizawl in



Mizoram reporting 27.7 and 27 cases per 100,000 women, respectively. Conversely, Dibrugarh district in Assam has the lowest rates, with about five cases per 100,000 women.

Approximately two-thirds of Indian women diagnosed with cervical cancer die from the disease, indicating late-stage presentation and inadequate preventive services. Screening in India involves visual inspection of the cervix after applying diluted acetic acid, primarily through the public health system. However, estimates of women screened for HPV vary widely. A 2019 study found that less than one-third of urban women reported being screened, while the National Family Health Survey (NFHS-5) data indicates only 1.97% of women have been screened.

In 2008, India licensed two HPV vaccines: Gardasil (quadrivalent) and Cervarix (bivalent), both of which provide approximately 90% protection against cervical cancer. In September 2022, India launched Cervavac, a home-grown HPV vaccine. However, HPV vaccines in India are currently available only through private practitioners, with low uptake due to high costs, misinformation about safety and effectiveness, and cultural perceptions.

Despite these challenges, health experts are optimistic about the impact of a national HPV vaccination program. A comprehensive program supported by reliable, evidence-based communication campaigns and accessible both in and out of schools could be transformative. A locally manufactured HPV vaccine would also significantly shift the global supply dynamics.

HPV vaccination is seen as the best defense against HPV-related cancers. India's strong track record in childhood immunization and the recent COVID-19 vaccination campaign bodes well for including the HPV vaccine in the national immunization schedule, which will undoubtedly boost the fight against cervical cancer.

- Dr. Sanjay Jaiswal
Member of Parliament (Lok Sabha)

Navigating the Complex Landscape of Rare Diseases: Unveiling the Challenges and Pursuing Solutions

In healthcare, rare diseases occupy a distinct space marked by complexity and often a lack of attention. Despite their low prevalence, these diseases collectively affect millions worldwide, presenting unique challenges for patients and the medical community. India alone is home to 70 million patients suffering from various rare anomalies and disorders. The resilience of these patients navigating a world of uncertainty and limited resources underscores the urgent need for comprehensive support.

The Ministry of Health and Family Welfare (MoHFW) took a significant stride with the National Policy on Rare Diseases (NPRD) in 2021. This community-led vision encourages active participation from all stakeholders, reflecting the government's commitment to addressing rare diseases. By fostering a collective approach, the policy acknowledges the diverse needs of people living with rare diseases (PLWRD) and establishes a foundation for comprehensive support and advocacy.

The NPRD 2021 categorises rare diseases into three groups based on severity and treatment costs, with Category 3 being the most severe and financially demanding. The government introduced a crowdfunding mechanism to tackle the high treatment costs of Category 3 diseases, coordinating efforts between hospitals, Centres of Excellence (CoEs), and potential donors. While this is a significant step, the challenge lies in garnering support from Corporate Social Responsibility (CSR) and Public Sector Undertaking (PSU) organisations. The success of NPRD hinges on the involvement of these entities, highlighting their crucial role in addressing the needs of rare disease patients.

Although the government-enabled crowdfunding platform is crucial, a comprehensive strategy is needed. Focusing solely on treatment funding may neglect other vital components, such as preventive measures and alternative interventions. Broadening the scope to include initiatives for early detection and holistic healthcare is essential. This strategy not only addresses the immediate needs of patients but also creates a sustainable healthcare system for managing rare diseases.

Prenatal and natal genetic testing are crucial tools in the comprehensive strategy for rare disease management. These tests provide invaluable



insights into a foetus's or new-born's genetic composition, empowering parents with critical knowledge about their child's health and enabling early intervention. This proactive approach can make a significant difference in the lives of these children.

Inclusivity in clinical research is also vital. Prioritising the enrolment of Indian patients in global orphan drug trials provides access to innovative treatments and contributes to a worldwide initiative to enhance our understanding of rare genetic disorders. However, the underrepresentation of Indian patients in these trials raises questions about the inclusivity of clinical research in India. Fostering a more equitable approach to clinical trials is essential. Participation in international orphan drug trials among individuals of Indian origin is pivotal for advancing research and developing tailored interventions for rare diseases in the Indian population.

A multidimensional approach is essential as we navigate the complex landscape of rare diseases. The NPRD 2021 and associated initiatives signal a turning point in addressing the complexities of rare diseases. From crowdfunding and enhanced genetic testing to early diagnostics and comprehensive support systems, addressing rare diseases requires a concerted effort from the medical community, policymakers, industry, and society. A comprehensive approach will ensure that no one with a rare disease is left behind in pursuing a healthier, more equitable future.

Dr. Nalini Kaushik

DevUp Global Consulting Pvt Ltd
Founder- BleedEqual

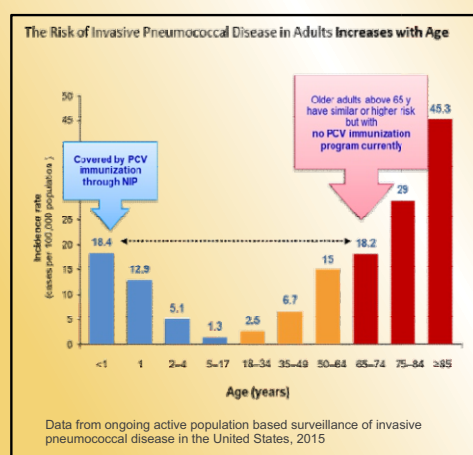
Immunization for Healthy Ageing

India's Universal Immunization Programme (UIP) is a global health and development success story. As one of the largest public health initiatives, it annually targets approximately 2.67 crore newborns and 2.9 crore pregnant women. Besides reducing the risk of diseases, this immunization programme has saved millions of lives and prevented countless episodes of illness. Beyond individual health benefits, vaccination decreases healthcare utilization and preserves economic productivity.

Given the rising population of older adults and the UN's designation of this decade as one for healthy ageing, now is the opportune time to focus on vaccinating those aged 60 and above, particularly those with co-morbidities and immunosuppressed conditions. This initiative is crucial for several reasons.

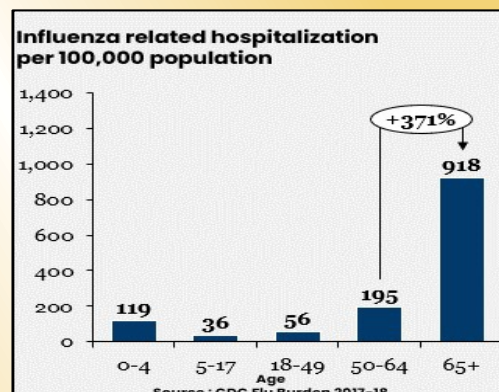
First, from a demographic perspective, the older adult population is approximately 20% larger than the population of children aged 0-4 years. By 2036, it is expected to be nearly three times that of the 0-4 age group.

Second, this demographic bears a high burden of co-morbid conditions, significantly increasing their overall risk profile. According to the LASI study, it is estimated that every second person over the age of 60 has at least one co-morbid condition. These conditions predispose them to infectious diseases like pneumonia and influenza. For example, the risk of severe outcomes from vaccine-preventable diseases like invasive pneumococcal disease or influenza-related hospitalization is higher in this age group compared to children under five. (See graphs).



Third, older adults exhibit the highest health mortality and morbidity indicators, contributing to a significant healthcare burden on society. The hospitalization rate for this group is 60 cases per 1,000 population per year, more than double the overall population rate of 29 cases per 1,000

population per year, as reported by the NSSO 75th round data.



India faces a high burden of vaccine-preventable diseases, and the growing elderly population with weakened immune responses due to chronic illnesses underscores the need to prioritize immunization as a measure to optimize existing health systems and reduce adverse outcomes.

Many vaccines have already been approved for use in India, with guidelines established by technical advisory groups and associations of medical professionals. Some states, such as Meghalaya, recommend specific vaccines in their health policies. Additionally, government schemes like the National Action Plan for the Welfare of Senior Citizens aspire to provide vaccination services for older people. Pilot projects have also been initiated in various parts of the country, such as vaccinating selected groups of those aged 75+ at AIIMS with influenza and pneumococcal vaccines and vaccinating over 4,000 elderly individuals in Tamil Nadu's old age homes with the pneumococcal vaccine.

Given vaccinations' cost-effectiveness and public good nature, various stakeholders must take a leading role in this initiative. Key actions include incorporating vaccines into public and private health insurance schemes for the elderly, incentivizing vaccine inclusion by rationalizing GST, launching dedicated awareness and communication campaigns, and considering the inclusion of vaccines in all other health and social welfare programs designed for the senior population.

Promoting immunization among older people will not only protect a vulnerable segment of the population but also enhance the overall health and productivity of the nation. As India continues to advance its healthcare system, ensuring the health and well-being of its ageing population through comprehensive immunization efforts is a critical step forward.

Dr Anil Bonde, MP

Member of Parliament (Rajya Sabha)

Addressing the Burden of Endometriosis: An Urgent Call for Policy Reform in India

In recent decades, the overall life expectancy of women in India has significantly increased, thanks to advancements in managing conditions that were once the leading causes of death and disability among women. However, despite this progress, women's potential lifespan is often curtailed by insufficient healthcare and restrictive social norms. To ensure that the Indian healthcare system can effectively address the specific needs of women, we must acknowledge both the strides made and the challenges that persist.

A critical challenge lies in providing holistic healthcare that addresses the rising incidence of non-communicable diseases (NCDs) among women, which are beginning to replace traditional causes of morbidity and mortality. Despite this shift, healthcare delivery and research for women remain predominantly centered on sexual and reproductive health (SRH). Initiatives such as the National Programme for Prevention and Control of NCDs (NP-NCD) and the Reproductive, Maternal, Newborn, Child, and Adolescent Health (RMNCH+A) strategy fail to address widely prevalent NCDs such as endometriosis and polycystic ovary syndrome (PCOS).

Endometriosis, a chronic condition affecting 10% of women of reproductive age and up to 50% of infertile women, has an estimated global prevalence of around 190 million cases. Characterized by the presence of endometrium-like tissue outside the uterus, endometriosis leads to severe pain, infertility, and other physical and mental health issues. Despite its prevalence, the condition remains largely underdiagnosed and inadequately managed, with many patients experiencing substantial psychological distress, including anxiety, depression, and a diminished quality of life. Postoperative management is often plagued with complications and prolonged recovery periods, further exacerbating the mental and physical toll on patients.

Despite the severe implications of endometriosis, the absence of targeted policies and dedicated resources hampers effective management and support for affected women. Recognizing the urgent need for action, PAIR Academy launched the "Women with Wings" initiative, a comprehensive program to bridge the gaps in endometriosis care in India. This initiative adopts a systematic, multi-step approach to raise awareness, foster dialogue, and advocate for policy change.

The first step involved conducting surveys and Focus Group Discussions (FGDs) titled "EndoTalks," which engaged over 100 patients in sharing their lived experiences. These discussions highlighted the numerous hurdles endometriosis patients face, providing a foundation for targeted interventions. The insights gathered were consolidated into various awareness tools, including a guidebook, a coffee table book featuring patient stories, and a patient journey map. These resources were disseminated among stakeholders to promote understanding and empathy within the medical community.

"Women with Wings" also organized social media campaigns, expert sessions, and webinars. During Endometriosis Awareness Month in March, activities like the "EndoRuns" brought together survivors, healthcare providers, and advocates to raise national awareness in 10 cities. These events successfully engaged thousands of participants, amplified by media coverage, reaching over a



million followers. The initiative also established the Endometriosis Patient Support Group, providing a platform for individuals to share experiences and access support. Over 2,000 members benefit from referrals, post-surgery rehabilitation, and disease management assistance via the group. The program has also nurtured patient advocates, known as "Endo Warriors," to further the cause through personal storytelling and advocacy.

Although progress has been made in building the capacity and resources of women who have endometriosis, there is a critical need for policy reforms to advance treatment options, expedite

diagnosis, and reduce the financial burden on patients. Currently, many women are compelled to pursue expensive fertility treatments, which are often not covered by health insurance due to the procedures not being recognized as necessary interventions for endometriosis. Additionally, the shortage of endometriosis specialists in the country hampers timely diagnosis and treatment. Policymakers must recognize the profound impact of this condition and take decisive action to support millions of women suffering in silence.

– Mugdha Barik & Dr. Ratna Devi
Patient Academy for Innovation and Research (PAIR)

Empowering Bharat: Revolutionizing Assistive Technology

Punarjeeva Technology Solutions is at the forefront of India's assistive technology and rehabilitation landscape. Committed to empowering individuals with disabilities, the older, and those who have dementia, Punarjeeva blends innovation with compassion to create a range of patented technologies. These innovations not only aid in rehabilitation but also uplift the human spirit. In line with the Indian ethos of inclusive growth and 'Aatmanirbhar Bharat,' Punarjeeva's mission is to foster independence and enhance the quality of life for its users, demonstrating technology's immense potential in building a more inclusive and empathetic society.

Innovative Products and Technologies to address various needs:

1. **Samatved:** This advanced system rehabilitates lower limbs, using cutting-edge sensor technology to improve mobility and strength. It offers a new lease on life for individuals facing mobility challenges.
2. **Hasht:** Designed for upper limb rehabilitation, Hasht combines sophisticated sensors with interactive software to enhance motor skills and talent, empowering users to perform daily activities more efficiently.
3. **Nibodh:** This cognitive therapy platform uses engaging activities powered by artificial intelligence to aid cognitive development. It is particularly beneficial for individuals with intellectual disabilities and dementia, helping them retain and improve their mental functions.
4. **Tatvika:** A virtual reality-based therapy system, Tatvika offers a holistic approach to

rehabilitation and learning. It incorporates full-body exercises and simulations, making therapy sessions effective and enjoyable.

Impact and Empowerment

The transformative impact of Punarjeeva's technologies is best understood through the lives they have touched:

1. **Enhancing Independence:** Punarjeeva's products have significantly improved daily living activities, enabling users to regain independence and dignity. For instance, individuals using
2. **Samatved** report remarkable improvements in mobility, reducing their dependence on caregivers.



3. **Boosting Confidence and Morale:** Punarjeeva's technologies have a profound psychological impact beyond physical rehabilitation. Users often report enhanced self-esteem and a renewed sense of purpose. Hasth has been instrumental in helping individuals re-engage in hobbies and work, reinstating their roles in their communities.
4. **Community and Family Integration:** Nibodh and Tatvika help users reconnect with their families and communities by facilitating better cognitive and physical functioning. This reintegration is crucial for mental health and societal inclusion.
5. **Testimonials and Success Stories:** Heartening stories from users across India exemplify the life-changing effects of Punarjeeva's technologies. These narratives are not just testimonials to the products but also the resilience and spirit of the users.

Punarjeeva aligns its mission with India's national goals by supporting 'Aatmanirbhar Bharat' by developing indigenous healthcare technologies. The company fosters an inclusive society, ensuring individuals with disabilities are not left behind, reflecting the ethos of 'SabkaSaath, SabkaVikas, SabkaVishwas.' Punarjeeva's successful collabo-

rations with government institutions, like Buds Schools and Special Education Needs Schools in Kerala, demonstrate its alignment with healthcare initiatives. Celebrating 'AzadiKaAmritMahotsav,' Punarjeeva embodies the spirit of freedom and empowerment through innovative and resilient solutions.

Punarjeeva envisions nationwide accessibility of its technologies, fostering an inclusive society with government support. The company seeks collaboration for nationwide expansion, aligning with 'Digital India' and 'Make in India' initiatives. It proposes integrating its solutions into existing healthcare and social welfare schemes to reinforce the government's commitment to inclusivity. Punarjeeva urges investment in its innovative R&D to revolutionize assistive technology. With government backing, Punarjeeva aims to contribute significantly to initiatives like the 'Accessible India Campaign' (Sugamya Bharat Abhiyan), promoting a barrier-free environment for all citizens.

Punarjeeva Technology Solutions is dedicated to aligning its goals with the government's vision of an empowered, inclusive, and technologically advanced nation. Together, they can create a resilient and compassionate society. For more information, visit Punarjeeva Technology Solutions.

Robin Tommy

Punarjeeva Technology Solutions, Kerala

Ageing in India: Inclusive Care through a Systems Thinking Approach

Over the past two decades, India has made significant strides in improving its healthcare system, resulting in increased life expectancy and reduced fertility rates. However, this progress has also led to a demographic shift, with a rapidly growing elderly population. By 2050, it is anticipated that one in five Indians will be elderly. The doubling rate of older people in India aligns with Asia's average and is slightly below the global average. By 2036, the elderly population in India is projected to increase from 10.1% in 2021 to 15%.

India's ageing population exhibits a north-south dichotomy. Southern states and northern states such as Himachal Pradesh and Punjab are expected to exceed the national average for the elderly population by 2036. In contrast, states like Bihar and Uttar Pradesh will remain below this average. Elderly individuals face numerous health challenges, including chronic diseases primarily attributed to non-communicable diseases (NCDs)

and communicable diseases like TB and lower respiratory infections. Rural living exacerbates healthcare accessibility issues. The increasing elderly population intensifies dependency ratios, particularly impacting older women. Additionally, economic vulnerability is heightened by high out-of-pocket healthcare expenditures, which account for over 70% of older people's health costs.

The National Policy for the Healthcare of the Elderly (NPHCE)

Launched in 2011, the NPHCE aims to provide elder care through a three-tier public health system. However, significant gaps remain in addressing the comprehensive needs of older people, including mental health and disabilities. The NPHCE programme, functioning in silos, lacks integration with social welfare programmes. There is an urgent need to revisit the existing service delivery framework. A comprehensive situational analysis is required to map the services the elderly need and

identify the services currently offered within the system to determine the additional services required. Integrating daycare, residential aged care, and home care into the existing service delivery framework could reduce out-of-pocket expenditures for older people.

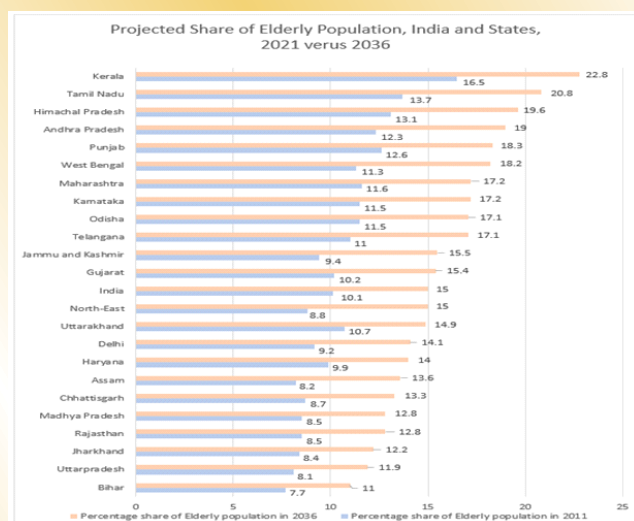


Figure 1. Comparative analysis of state-wise share of elderly population in 2011 and 2036.

Policy Areas for Action

Older people in India face significant challenges related to healthcare and socio-demographic factors. Adopting a systems thinking approach, the following policy recommendations are proposed for an improved care framework:

a) Governance

The existing governance structure for older people is fragmented and managed by separate ministries, leading to potential inefficiencies. Reevaluating this structure is essential for comprehensive care and fostering intra-sectoral and intersectoral convergence.

b) Service Delivery

Elderly needs encompass health, social support, and daily assistance. While some government programmes address these aspects, critical services such as Alzheimer's and dementia care are primarily handled by the private/non-profit sectors, resulting in limited rural access and high out-of-pocket expenses. Policies should regulate and encourage public-private partnerships and expand care models to rural areas. Integrating

multiple pension schemes at the national level should also be explored.

c) Human Resources

The private sector primarily caters to urban and rural elderly people, focusing on curative care. To enhance the capacity of public health teams for quality home-based care, the composition of public health teams needs to be reevaluated. Reintegrating male multipurpose workers (MMWs), particularly in areas with high elderly populations, and exploring the inclusion of physiotherapists in primary healthcare teams could be beneficial.

d Training Courses on Home Care and Rehabilitation

Specific training programmes should be mainstreamed to address the rising need for home-based and rehabilitation care. Limited institutions offer these courses and need broader availability to utilise India's demographic dividend effectively.

e) Community-Based Interventions – "One-Stop Platform"

Establishing a "One-Stop Platform" at the community level is crucial for comprehensive elderly care in rural areas. Models such as the "Chandrapur Model" (Health and Social Support) and "Grama Hiriya Kendra" (Aanganwadi for older people) offer valuable insights. These platforms facilitate health check-ups, identify social needs, and ensure enrolment in welfare schemes. Integrating these into the National Programme for the Healthcare of the Elderly can enhance effectiveness and significantly improve the care framework for older people in India.

In conclusion, India's ageing population requires an inclusive care framework that addresses the diverse needs of older people. By adopting a systems thinking approach and implementing these policy recommendations, India can ensure better healthcare and social support for its elderly population, fostering a more inclusive and caring society.

– Dr Ankur Nair

Specialist, Health Planning, Health Systems Transformation Platform, formerly with elder care portfolio, Tata Trusts

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