All against THE BIG C

Partnerships are proving to be potent in coping with the cancer care challenge

FEVER PITCH
A community initiative takes on encephalitis in Uttar Pradesh

INTERVIEW
Horizons speaks to developmental psychologist Anita Raj

VOICE FOR VICTIMS
Victims of violence find justice and rehabilitation in Maharashtra
Hey have money for food or for medicine, not both,” a doctor is quoted as saying in our cover story in this edition of Horizons. The doctor was explaining the deathly dilemma facing patients without the means to access cancer care and treatment. Helping such sufferers is among the main objectives of the extensive and varied cancer care programme of the Tata Trusts.

Affordable, inclusive and high-quality cancer care are central to the model, which pulls together the preventive, the promotive and the curative to enable treatment for everybody. We feature three components from the model in the cover story: the building of two new cancer care facilities in Varanasi; the expansion of, and what this means for, the path-breaking Tata Medical Center in Kolkata; and a comprehensive community-based project in Assam. Collaboration is the most crucial ingredient in ensuring the success and sustainability of these initiatives.

Collaborations, especially with government agencies and institutions, are a dominant theme in most of the Tata Trusts’ programmes. The special report in this issue — on a community health undertaking to tackle ‘acute encephalitis syndrome’ in Uttar Pradesh — and our spread of feature stories highlight the fact.

The effort to enhance education outcomes in eight states; the rice fortification project in Gadchiroli in Maharashtra; assisting the Mumbai Police in setting up an archives; and the initiative, also in Maharashtra, to deliver justice to victims of violence — all of these are examples of partnerships that have borne social fruit.

Also on the magazine’s menu this time are two contrasting interviews. Magsaysay Award winner Bezwada Wilson speaks about manual scavenging and the degradation those forced to practise it have to live with, while Anita Raj, a stalwart at the University of California, San Diego, sheds light on developmental psychology, public health and sexual abuse.

A different framework of social development informs the piece by design strategist Deepa Prahalad, who argues for making design and innovation work for the benefit of all stakeholders. Similar in spirit, if not subject, is the opinion piece by the Tata Trusts’ Sugandhi Baliga, who raises a shout for India to begin a national discourse on happy and healthy ageing. And in Showcase, we look at how Antaran, a Trusts initiative, is helping Assam’s women-centric handloom sector.

Cheers, and all the best for the new year.

Christabelle Naranka

We hope you will help us make Horizons better with your valuable feedback. Please do write to us at horizons@tatatrusts.org.
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Antaran, a joint initiative involving the Tata Trusts and the University of the Arts London (UAL), will collaborate to help rejuvenate the handloom sector in the eastern and northeastern regions of India. As part of the effort, students from UAL will visit handloom clusters, engage directly with artisans and participate in on-field projects.

Commenting on the venture, Sharda Gautam, head of crafts at the Trusts, said, “This partnership is going to create an opportunity for the crafts sector and the artisans involved.” UAL’s director of international relations, Juliette Sargeant, added: “[It] will offer UAL students the chance to work alongside, learn from and collaborate with local weaving communities.”

Antaran, which runs projects in Odisha, Assam and Nagaland, is aimed at giving a boost to the ailing small-scale handloom industry by nurturing artisans and encouraging them to spread their wings into designing and entrepreneurship.

Startups get a shot in the arm

Google Developers Launchpad (GDL) and Social Alpha have initiated a partnership to support social impact startups in India’s growing entrepreneurship ecosystem.

The partnership — tagged as ‘Social Alpha Powered by Google Developers Launchpad’ — will help startups gain access to resources, including expert mentors, tools and methodologies. The intent is to build businesses that can ride on technology to create social impact.

Social Alpha, which is backed by the Tata Trusts, will be the first enterprise from India to collaborate with the GDL programme, and will join a growing network of independent accelerators across Latin America, Africa, Europe and Asia.

Said Manoj Kumar, the chief executive of Social Alpha: “… our portfolio companies need access to world-class technologies, especially in the areas of data science and machine learning. Our partnership with the Google Developers Launchpad programme will address this gap.”

The tie-up will focus on supporting startups that have started incorporating artificial intelligence and machine learning technologies in their work.

Prabhat and Kuriyan win big

Prabhat and Priya Kuriyan were awarded the Big Little Book Award 2019 for the best children’s author (Hindi) and best children’s illustrator respectively at the Tata Literature Live! festival held in November.

The jury for the awards, instituted by Parag, a Tata Trusts initiative, consisted of renowned poets, authors, writers, graphic designers and painters. The Big Little Book Award has since its inception in 2016 selected one Indian language for the prize every year. The award recognises literary work produced for children.
Jaga Mission wins honour

The Jaga Mission (also called the Odisha Liveable Habitat Mission), an initiative supported by the Odisha government and the Tata Trusts, won honours recently at the India Geospatial Excellence Awards.

The Jaga Mission aims to transform slums into liveable habitats, with civic infrastructure and services that are at par with developed areas. The aim is to improve the quality of civic infrastructure and services, while providing better access to livelihood opportunities.

The pilot implementation of the Mission happened in nine urban local bodies. The intent has been to promote sustainable habitat development through equitable supply of land, shelter and services.

Farming a better tomorrow

The Collectives for Integrated Livelihood Initiatives (CInI), a Tata Trusts initiative, has partnered CropIn, an agricultural technology firm, in a project that seeks to improve the livelihoods of tribal households across central India.

The partnership is part of CInI’s Lakhpati Kisan – Smart Villages programme, which is working to raise more than 100,000 households out of poverty by employing better agricultural practices. Started in 2018, the project banks on the SmartFarm solution developed by CropIn — an early adopter of artificial intelligence and data in this field — to enhance the livelihoods of some 4,300 farmers in Jharkhand’s Gorabanda and Dhalbhumgarh regions.

SmartFarm depends on real-time satellite-based plot monitoring to intervene at every stage of the crop lifecycle and it also employs other technology tools.

Women are the focus in entrepreneurship push

The Tata Trusts have come together with Cisco to implement ‘Program Saksham’, which is gearing up to build a band of 3,500 rural women entrepreneurs in 16 districts of Uttar Pradesh and Bihar.

The objective of the project is to increase access to opportunity through the teaching of basic entrepreneurial skills to these women and by helping them become self-sufficient through the setting up of small enterprises.

“There is still a huge gap that needs to be bridged in order to boost women entrepreneurship in the country and that’s the reason for our collaboration with Cisco,” said Raman Kalyanakrishnan, head of strategy at the Trusts.
Partnerships pave the way

Cancer is the target and coming together to form a common front against it is the need. By Philip Chacko

Preventive and promotive over curative — that’s the case being made for the nature of cancer care India needs to nurture. It’s a way of thinking that has begun fuelling results on the ground, through collaborations driven by governments at the state and the centre, the creation of networks, systems and infrastructure, and the use of technology.

Partnerships are the key. As the cancer statistics for India get grim and grimmer, it becomes ever more obvious that the responsibility for cancer care and treatment in the country cannot be the government’s alone. Just as obvious is the necessity to embrace a more inclusive and people-oriented way.

A grassroots cancer care project in Assam is attempting just that, reaching a wider populace with screening and awareness programmes while also providing care and treatment to patients. The newly established twin cancer centres in Varanasi cover a different, more specific requirement, as does the Tata Medical Center in Kolkata.

The Tata Trusts are the common element in all three of these ventures. Contributing to the cause of cancer care in India has been a constant for the Trusts since 1932, when Dorab Tata, then head of the Tata group, donated ₹2.5 million for research in leukaemia (the disease had taken the life of his wife, Meherbai, two years earlier).

The Trusts have enriched that legacy in the years since, notably by establishing the Tata Memorial Hospital in Mumbai in 1941 (handed over to the Indian government in 1957) and the Tata Medical Center in Kolkata in 2011. Less prominent are a host of cancer care projects the Trusts have been involved with across the country.

Helping deliver affordable, accessible and high-quality cancer care, particularly to underserved communities and the poor, is the objective for the Trusts. As the efforts showcased in this section indicate, much has been accomplished. And there’s much, much more left to be done.
Cancer is the second biggest killer in India after heart disease

More than 50% of new cancer cases in the country involve women

Breast cancer is the most common cancer in India (14% of cases)

Head and neck (10.4%) and cervical (8.4%) are the next most common

Sources: The Lancet; WHO (figures are for 2018 unless otherwise mentioned)
Oasis of care

Two new cancer centres in Varanasi are providing patients with high-quality and affordable care and treatment in a region crying out for both
Stuck in a limbo between hope and helplessness, Pradeep Gupta was close to giving up when he came to the Homi Bhabha Cancer Hospital (HBCH) in Varanasi to find care and a cure for his disease-stricken aunt. “We have got a lot of support from the doctors and the staff here, but the future fills me with dread,” says Mr Gupta, a Varanasi native who appears resigned to whatever that future may bring.

The positives are scarce for Mr Gupta and less so for 45-year-old Leelavati Devi, diagnosed with advanced breast cancer and currently undergoing a chemotherapy course that costs ₹25,000 for every cycle. The treatment charges have driven Mr Gupta, who draws a meagre salary from his job at a local electronics shop, and his joint family to the brink. The silver lining for them is the quality of care Ms Leelavati receives and the money raised by HBCH to meet her expenses.

One new, one rebuilt
That’s par for the cancer care course HBCH has set for itself since opening its doors in May 2018. Located in Varanasi’s Lahartara area, the hospital is a refurbished and reinvented avatar of what once was the Indian Railways Cancer Institute and Research Centre. And the 180-bed HBCH now has a sibling, the Mahamana Pandit Madan Mohan Malaviya Cancer Centre (MMMCC), a sparkling new hospital that has come up in the campus of Banaras Hindu University (BHU).

They may be separated by 7km but MMMCC and HBCH function as a single entity, operating under the wings of, and to standards set by, the renowned Tata Memorial Hospital (TMH) in Mumbai. MMMCC, with 350 beds and space for services to be added on, is the bigger of the two. It started functioning in July 2019 and is nearly fully operational. Together, the combine will go a long way in bringing top-notch
and affordable cancer care to a region crying out for it.

What’s remarkable about MMMCC-HBCH is the attempt to replicate the exceptional TMH template of cancer care and treatment, where no patient, no matter his or her paying capacity, is turned away. This is no easy task in a geography that carries a heavy poverty load, where the inability to bear medical costs often condemns patients to life-and-death choices. Just as remarkable is the pace at which facilities for the two hospitals were completed. The HBCH project took six months to finish and MMMCC came up in 10 months flat.

Forward as one
None of this would have been possible without the power of collaboration. MMMCC-HBCH has been created thanks to a partnership involving the Atomic Energy Commission — TMH’s parent institution — and the Tata Trusts, which funded and undertook the construction work. Also in the mix was the Prime Minister’s Office, ensuring timely clearances and speed of execution in a land not known for either. Indian Railways and BHU pitched in with the required land parcels and more.

The two-hospital initiative has had to cope with a cat’s cradle of complexities to become reality. Going by how the people at the centre of it all have benefitted — patients trying to beat back cancer — the effort and the hard work have been worth it.
“We have treated more than 15,000 patients since we opened,” says Satyajit Pradhan, the director of MMMCC-HBCH. “We have dispensed medicines costing in excess of ₹190 million during this period and they have been made available at 62% less than the printed price. We have a patient welfare fund that has disbursed ₹50 million to 1,500 patients. And these people have received world-class treatment.”

Help of this kind is a lifesaver for patients without the means to access cancer treatment, an expensive proposition more often than not. “Many of our patients come from some of the poorest regions in India, from Uttar Pradesh, of course, but also from Bihar, Jharkhand, Madhya Pradesh and Chhattisgarh,” adds Dr Pradhan. “As somebody once said, they have money for food or for medicine, not both.”

The good doctor’s words reflect the TMH culture of cancer care. It’s a way of thinking that the 700-plus staffers at MMMCC-HBCH — more than 50 of them doctors — have imbibed from the mother organisation. A fair number of them have experience of working at the TMH centres in Parel in Mumbai and in Kharghar in Navi Mumbai, and their commitment to the cancer care cause runs deep.

Care comes first
“Improving the quality of care provided to patients is our main objective,” says Priyathama Yadav, a nurse with HBCH for two years. “It makes me happy and proud to care for our patients. It’s great to see a smile on their faces. I struggle sometimes, though, especially when explaining things to people with end-stage cancer.”

Ms Yadav calls the hospital her second home — “In fact, I spend more time here than at my own house,” she says — and that’s the spirit inculcated by the TMH connection. Her colleague Rajni Baghel, who worked with TMH in Mumbai for 15 years before moving to Varanasi, talks up the teamwork factor. “In the TMH culture, no one person is responsible for patient care; the full team is necessary,” she explains. “We truly are like a family.”

Having all hands on deck and labouring in unison is crucial for MMMCC-HBCH, which kicked off slowly and without fanfare but is now busting at its seams with patients. More than 1,000 cancer cases are registered every month at the two hospitals and the number will rise when MMMCC gets to all systems go.

The challenges posed by the patient rush are steep. “The toughest problem is finding the right personnel,” says Rakesh Mittal, the deputy director of MMMCC-HBCH. “India lacks skilled professionals; our education
system seems able to produce only clerks. Doctors, nurses, technicians — they are all in short supply. Then there’s the issue of arranging financial support for poor patients. Our social workers are forever trying to bring local philanthropists and charities on board, but it’s very difficult. Varanasi is not like Mumbai in that regard."

Dr Mittal remains optimistic, however, that tomorrow will dawn brighter. “The backing of the Trusts and TMH’s hand-holding have made everything possible here,” he adds. “The advantage we have is that the TMH system we are following is very easy to implement. It is clean and transparent.”

There are two categories of patients, general and private, in the TMH scheme of treatment and the charges they pay vary: 30% of patients pay nothing; 30% pay 5% of what is spent on them; 20% pay 20% over the cost of treatment, and 20% pay 60-70% over cost. That makes for, as TMH director Rajendra Badwe puts it, a socialistic model in cancer care and its costing.

In comparison with TMH, its inspiration and guiding light, MMMCC-HBCH has plenty of distance to cover. But it has got off on the right track and is taking strides to match its amenities to the acute cancer care need of a huge ‘catchment area’. The equipment and the people are in place, teething troubles have been overcome and a system for efficient and cost-effective treatment is firmly in the slot.

**Division of services**

Down the line, a division of services between MMMCC and HBCH is being planned. When that happens, HBCH will concentrate on three specific forms of cancer — paediatric, blood, and bone and soft tissue — while MMMCC will handle solid tumours. Meanwhile, a facility for bone marrow transplants is being readied and work is underway on a cancer registry for Varanasi district to better understand the threat of the disease in the immediate surroundings of the two hospitals.

The expectation is that MMMCC-HBCH will, in time, offer all that TMH does at its centre in Mumbai, but this could do with some tempering. “TMH-Mumbai is a 78-year-old institution; we are less than two years old,” says Swagnik Chakrabarty, a doctor who has served at both places. “Even so, in patient care, services and equipment, we deliver almost everything that TMH does. What we really need are good and dedicated people to come and work here.”

Dr Pradhan considers MMMCC-HBCH to be a blessing for the people of Uttar Pradesh and beyond. “This looks like a corporate hospital but our charges are like that of a government hospital, or even less,” he says. “Cancer patients from here don’t have to run anymore to Delhi, Kolkata or TMH in Mumbai for treatment — because TMH has moved to Varanasi.”
Neelima Dalvi has no qualms about stretching her arms every which way in search of support, resources, alms, call it what you will. The cause — securing financial assistance for the care and treatment of poor cancer patients — makes the effort worth it, and Ms Dalvi, a medical social worker, understands the difference this can make.

“We try to ensure that no patient goes untreated due to lack of money,” says Ms Dalvi, who moved to the Homi Bhabha Cancer Hospital in Varanasi 10 months back after a 30-year career with the Tata Memorial Hospital (TMH) in Mumbai. There’s more to it than monetary matters, though.

“Medical social work is a science,” explains Ms Dalvi. “We set definite parameters and processes so that the emotions of patients and their caregivers can be harnessed in a way that allows us to step in with help. This help has to be structured and transparent, and it has to follow certain standard operating procedures.”

Counselling and mediation between patients and doctors are components of what Ms Dalvi and her colleagues offer. But finances are the most compelling need in a region where poverty is endemic. “We have to strive very hard to get funds and accommodation for our patients and their caregivers,” adds Ms Dalvi.

Ms Dalvi’s job is made tougher still by the social stigma, fuelled by illiteracy and prejudice, that cancer patients have to live with in this part of the country. “Finding accommodation for patients and families who come from faraway places is a big challenge,” says Nizamuddin Khan, an assistant medical social worker with the Varanasi initiative. “Many lodging places refuse to accept them. They think cancer is contagious.”

The need to raise resources is never-ending and that is what Ms Dalvi and her team have focused attention on. “We have started going to the people of Varanasi, tapping philanthropists and charities,” she says. “We are making headway.”

Counselling of patients and their caregivers is almost as critical as getting finances in place. “We find parents and other caregivers who want to abandon treatment,” says Ms Dalvi. “We try everything under the sun to convince them to continue with the medicines, to not give up.”

Vikas Nishad, a fisherman from Nakhas Sadar in Uttar Pradesh’s Jaunpur district, is certainly not giving up. He’s looking after his 16-year old niece, Saumya, who is suffering from acute leukaemia, and there’s no end to the gratitude he feels for the help he has received.

“I have found hope here,” says Mr Nishad. “Our doctor says Saumya has a 50% chance of getting well. I’m praying she pulls through.”
Rajendra Badwe has an uncommon knack for rendering the complicated in simple terms. He has skills of a greater order as well: the director of the Tata Memorial Centre (TMC) in Mumbai is counted among India’s outstanding cancer surgeons and he is an administrator of rare acumen.

Dr Badwe speaks here about what makes TMC an extraordinary institution, the way ahead in coping with the country’s mounting cancer burden, and how, at a personal level, he manages the stress that is a cancer surgeon’s constant companion.

What is it about TMC that makes it special, particularly in the Indian context?
There are three parts to the TMC vision of cancer care in India: uniform treatment across the country; an affordable care model; and the providing of care through a network that is sentient to local needs. To create a network, make it functional and then to develop its brand equity is a 20-year effort. But we had to build this immediately and that’s why we now have the National Cancer Grid, which connects about 180 centres across India and covers 75% of patients. The target here is uniform care. Uniform care means uniform guidelines. Our consensus guidelines have predefined what needs to be delivered and how it can be delivered. The stress is on evidence: is it good enough, unequivocal, robust and implementable? And the evidence shows this is implementable. The National Institute of Health, United States, conducted a survey in low- and middle-income African countries on their practices in cancer care. The most common guidelines being followed, it was found, were from TMC.

Were these guidelines designed for poor countries?
No, they were designed so as to be implementable even in countries such as the United States, but the
focus was on evidence and on cost-effectiveness. I could give you equal-outcome options; some cost $100,000, some ₹100. We know from evidence they are identical; the outcomes are no different.

We have done some tweaking to address an essential question: what do I do with these guidelines if I don’t have the infrastructure for everything? So the guidelines defined the minimum infrastructure required to treat a cancer patient. There’s another aspect and this is gaining importance globally.

If I am treating 10 patients a year, my outcome is different than if I am treating 100 patients a year, and different again if I am treating 150. Somewhere it plateaus off and you arrive at a critical number where you get the best results.

We have pooled resources to treat patients properly. There are limitations, essentially with human resources. Finding this is not easy because human resources to treat cancer patients are not available off the shelf — they have to be created. We need a convergence of human resources and infrastructure. What to deliver is known, who to deliver to is being expanded, and how to deliver is managed by infrastructure and personnel.

**What is the TMC model?**
It’s a sustainable model that delivers high-quality service. It is a model that has stood the test of time, with a unique culture of care that we inherited from the Tatas. We would like to implant this culture at the places we are spreading to, in Uttar Pradesh, Punjab, Assam and Odisha.

The TMC model emphasises treating the entire spectrum of society, and that is vital. Government hospitals for the poor and high-end private hospitals for the rich make for a polarised healthcare delivery system. It’s not sustainable. You need a system that will treat everybody under one roof.

There are two advantages in this approach. One, you get to see the disease in its full range. Understanding the whole picture is what TMC has done since its inception. We have 30% of patients who don’t pay us anything, another 30% who pay 5% of what we spend on them, a further 20% who pay 20% over the cost of treatment, and the final 20% paying 60-70% over cost. Such cross-subsidising enables us to treat everybody.

We look after 85,000 new cancer patients a year and we have 550,000 follow-up cases. We have a recurring budget of ₹3 billion a year and a further ₹1 billion for education and ₹1 billion for research. With our payment model, we generate ₹2.6 billion. That means the government shells out just ₹400 million a year for the entire load of patient
treatment at TMC. There is no other model like this.

Uniform care and focused clinical services can fuel a 10% improvement in outcomes in a year. Compare that with the 2-3% improvement that new drugs have delivered globally in the last decade and what can be achieved is clear.

As for the culture, our doctors, nurses, technicians and others are stakeholders in the hospital. This is a group of individuals who have their heart in the right place.

How successful have you been in taking the TMC culture to other places?

I think we have been pretty successful. The people we have in Varanasi, for example, had three years of training at TMC in Mumbai. A few don’t fit into this culture and they go way. That’s better than to have square pegs in round holes.

You mentioned Africa learning from the TMC model. What, and from whom, has TMC itself adopted over the course of its evolution?

We are the most cost-effective of cancer care centres. We have had teams from the Yale and Wharton business schools visiting us in Mumbai to understand how we do this. The MD Anderson Cancer Center registers 25,000 new patients annually and has about 1,300 full-time medical staff. We register 85,000 new patients a year and we have some 600 staffers. That’s less than half their staff strength, dealing with a patient load that’s thrice as much.

A TMC doctor cannot treat all and sundry; he or she has to concentrate on one facet. I treat breast cancer and nothing else. I cannot solicit patients from outside; the hospital decides who I should treat. I do research and it’s in the public domain — which means everybody can benefit from it — and that is incentivised.

Why does India not have more institutions like TMC across the country?

That will happen. The model we are following is being sought by the [Union Department of Health and Family Welfare], which wants to implement it at various places. The model is socialistic in nature. Fees collected from paying patients are pooled and then distributed to our doctors based on their research output and grade. The more research I do and the greater impact this has, the higher my pay grade. This grade decides how much of the shareable income generated comes to me.

And that gets some extra money in the doctor’s hands? It doubles their salary.

What is your view on the distributed care model for cancer care and treatment that the Tata Trusts have been pushing ahead with?

That model is no different from the model we have suggested for the whole country: a spoke for every 15 million people and a hub for every 50-60 million. The idea is to bring service delivery in cancer closer to the patient’s home. It’s exactly the same as that which we are looking to create.

Does cancer research get prominence in India?

No, it does not, not at the moment. There is a fair amount of support being given for laboratory research, but clinical research, which finally puts the molecule under the microscope, is not supported so well. There is a
reason. The instrument that supports laboratory research is typically calibrated for a three-year period. Clinical research, on the other hand, takes up to 10 years. We have no mechanism to support such long-term endeavours in greater numbers.

What about you personally? Do you get time for research? Well, we need to create the time — get into that minute and stretch it a bit. Delegation of work is what gives me time.

There must be a lot of administration work as well? Yes, for sure. It’s a killer because it’s not my core competence. I was not trained in it; I have learned it on the job. But I find administration is about people management. It is about common sense.

It is said that cancer surgeons are the most psychologically distressed people in the doctor community. As far as I am concerned, quite the contrary. In whichever walk of life you may be, there can be no stress if your heart is in it. The stress may come because of that little difference between sentiency and sensitivity. You are receiving and interpreting everything with a great amount of affection, but you are not affected by it.

These are life-and-death situations that you deal with. Of every 100 patients being treated at TMC, 50 of them, in general, live 10 years or more after treatment has commenced. Comparisons with other diseases are not valid. If I treat 100 ageing patients with diabetes, about 70% will die within 20 years and the deaths begin from year 10 onwards. In cancer, the deaths will occur within the first three-four years. That’s because cause and effect are very close to each other in cancers. When cause and effect are far separated, the perception of something being lost is not as substantial.

I remember telling this lady she had breast cancer. She started crying and I tried convincing her that it was curable, to no effect. I then asked her to wait outside my consulting room. She went out and I must have had two more consultations before she walked back in. She was smiling and I asked what had happened? “I saw this poster on the wall that said one out of 30 women in India will get breast cancer,” she said. “I just felt that since I have got it, 29 others will not.” What had changed? Nothing; it was a matter of looking at it differently.

Is it true that you tossed a coin to decide whether to pursue medicine or engineering? Yes, it’s true. I had stood first in mathematics in Bombay University but I also wanted to get into medicine. I was fortunate in that I went for medicine, although I was better in mathematics.

So you could have become an engineer? Yes, and I'm sure the universe would have conspired to make me as successful.

How has the collaboration with the Tata Trusts gone? I think there is a feeling that the Trusts are a sanctuary that will always be there for us. But I must also say that the Department of Atomic Energy [under which TMC functions] has been extremely generous with the hospital.
**Bigger and healthier**

The Tata Medical Center in Kolkata has expanded to better fulfil its mandate — providing inclusive and top-notch cancer care

It looks like a shiny corporate establishment, has a cadre of first-rate professionals dedicated to delivering high-quality care, and its services come swaddled in empathy and an acute understanding of the realities of India. The Tata Medical Center (TMC) in Kolkata is one of its kind, an institution where the care of cancer patients happens in a manner and in an environment far removed from the typical.

Set up in May 2011, TMC is clocking ever more miles in the quest to find its very own sweet spot in cancer care. What this means, essentially, is securing the resources to treat a greater number of patients who cannot bear on their own the bankrupting burden imposed by a disease that remains an ogre, relentless in character and dreadful to battle.

**Viable and sustainable**

To accomplish that while remaining viable today and sustainable in the days to come is the hard challenge TMC faces. The degree of difficulty is made steeper by the unyielding march of cancer in the region — east and northeastern India — that the Center serves.

The riptides have had an effect on the model of cancer care TMC swears by, but that has not dragged it into deep waters. TMC took in more than 18,500 new patients in 2018 and it currently handles in excess of 1,200 outpatients a day. The majority of these patients have had their treatment subsidised to some extent, and the Center has still managed to stay in safe, if not shiny, financial health (it expects to have a surplus of more than ₹100 million at the end of 2019-20).

Created by the Tata Trusts, with contributions coming in from Tata companies as well, TMC is in
STANDING TALLER

TMC was created by the Tata Trusts in 2011. A second phase of construction, completed in early 2019, has enhanced its capacity and capabilities.

18,500+ New patients (2018)

1,200+ Outpatients per day

34,100+ Day-care patients (2018)

437 Number of beds

5.4 billion Cost of phase I

2.6 billion Cost of phase II

The Tata Medical Center in Kolkata has added beds and capabilities.
superior shape now to fulfil its mandate. A phase II renewal, completed in January 2019, has raised the Centre’s capacity to 437 beds, enabling it cope better with an unending rush of patients. The consequent need for further finances to continue helping the underprivileged among them is always an accompanying factor.

“The cost of treatment for most cancers is pretty high and unaffordable for the average Indian family,” explains VR Ramanan, the deputy director of the Center. “Most of our costs, including bed tariffs and medicines, are highly subsidised and we offer a lot of funds, which we receive from donors, to poor patients. But in spite of that our patients struggle for financial support.”

A second issue, adds Dr Ramanan, is getting the “right-minded doctors, nurses and other technical staff” for the cause. “The job can be demanding and we can never match the salaries offered by corporate, or even government, hospitals,” he adds. “Our attrition rates are a big bother.”

There is also the obligation for TMC to maintain its status and its standards as an academic and a research centre of the highest order. “This requires plenty of resource inputs and, given our present condition, it has brought us to stretching point,” says Dr Ramanan. There are inherent advantages that TMC can draw on, though, not least with the people in its ranks.

**Doctor-centric as well**

“We have a patient-centric approach, for sure, and a doctor-centric approach as well,” says Manas Roy, a surgeon who has been with TMC from before it became functional. “In contrast to corporate hospitals, the doctors here don’t have financial targets to meet. We don’t do any private practice and there is a trustworthy team to cushion the impact of work.”

Tough decisions are routine for Dr Roy and he has the personal experience to guide him. “Oncology is not like a buffet; we have to pick and choose and it’s complicated with the terminally ill. My dad had severe brain cancer and I chose to stop chemotherapy due to the side effects. I believe the experience made me a better doctor. I can relate to those in similar situations.”

Moses Arunsingh, a radiation oncologist with TMC for 18 months, sees the patient-doctor equation at the hospital through the lens of a training stint he had at the Leeds Cancer Centre in the United Kingdom. “We had about 15 patients a day there, 20 maximum; here I am responsible for 70-80 patients every day,” he says. “Also [since the British government’s health service covered it], I did not have to worry about affordability or expenses while prescribing treatment. In India, affordability is the key. Everybody is spending out of their own pocket.”

Nursing superintendent Piyali
Bose points to the psychological strain of caring for cancer sufferers. This springs from the state that patients and their caregivers slip into. “People detected with cancer are severely stressed and so are their family members, and deaths are frequent,” she says. “Preventing the burnout of nurses is crucial, because being a nurse in a cancer hospital can be exhausting. Night shifts — the silent hours, as they call it — are particularly daunting.”

A few months back, Ms Bose had an even more daunting problem to deal with. This happened when TMC lost 175 nurses over three days after the whole lot left to take up state government jobs offering higher pay scales. “We extended the work timings of those who remained, we stayed back, we moved on,” says Ms Bose, who heads a team of 484 nurses, 83 of them men.

The exodus of nurses is likely to continue as West Bengal inducts more of them into its government hospitals setup, but TMC is determined to not get caught out the next time. “We extended the work timings of those who remained, we stayed back, we moved on,” says Ms Bose, who heads a team of 484 nurses, 83 of them men.

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Improvisation aside, the impulse to improve is not lost on TMC. “We certainly can get better, our doctors included,” says Dr Mahajan. “We need to train our doctors, nurses and other staff even more in customer care. Every cancer patient comes with a lot of anxiety; we have to handle them correctly. This also depends on the stress that our staffers undergo while at work. If we are overcrowded and handling too many patients, it doesn’t leave much time for good communication.”

**Bonding with patients**

“We try to do our best but we are also human,” says Manideepa Ghosh, a nursing supervisor with TMC since 2013. “Patient care at a cancer centre is never easy, but what strikes me most about this place is the bonding between patients and staff; you don’t see that at many hospitals. As for the pressure here, it has become part of my life.”

The future for TMC looks promising, and just as challenging as what has passed. The expansion programme has brought a bunch of benefits beyond the desperately wanted enhanced capacity. The Center can now take in student doctors for speciality training programmes; equipment and technical know-how have been upgraded; and there’s a floor exclusively for children. A custom-built laundry, a modern kitchen and extra resources for sterilising operations and robotics surgery have been provided.

The facilities TMC already had in place have profited, too, from phase II. Premashraya, the cut-price residential facility for cancer patients and their families, has an improved paediatric wing and the Center has made dedicated space, at a site adjoining its 13-acre campus, for the Tata Translational Research Centre, where the objective is to improve research quality and output by bridging and blending clinical and laboratory research.

The end goal for TMC continues to be cast in stone: inclusive, exemplary and cost-effective cancer care, particularly for poor patients. And this can be an archetype for India. “I wish more hospitals are modelled along these lines; it would be a boon for the country,” says Dr Roy. “My frustration, as a doctor and as an Indian, is that there aren’t more such institutions.”

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The daycare nursing station at the hospital
Mammen Chandy never tires of reiterating the reason why the Tata Medical Center (TMC) in Kolkata exists. “We have to keep our costs low and find the resources to treat more people who are poor,” says the institution’s director. “That is our mandate.”

There is no shortage of wrinkles to be ironed out for TMC to stay true to its commitment. It helps that an expansion project, completed in early 2019, is better enabling the Center in living up to its promise, but the struggle to remain a sustainable operation as well is ceaseless and immediate.

The soft-spoken Dr Chandy, who has headed TMC since its inception in 2011, talks to Horizons about how the hospital has grown, the multiple challenges it has overcome and, on a personal note, the everyday sorrows and joys of being a cancer specialist.

How has TMC evolved in the nearly nine years since it was established?
When we opened in May 2011, we had only 100 admitting beds and that went up to 140 by 2015. By then we were running at peak capacity — we had to refuse patients — and we had broken even. We needed to expand. We needed to increase bed capacity in order to start speciality training programmes, a necessity because you won’t get junior doctors to come and work here unless you are offering them an education or specialised training. That was our expansion imperative. Also, we had reached a certain standard in terms of equipment and technical know-how, but we needed more.

Phase II was completed in January 2019 at a cost of about ₹2.6 billion, and it has slowly been operationalised. We have enhanced our capacity to 437 beds. We now have a dedicated floor for children, so that everything that a child patient needs is in one physical area. We have the latest equipment and technology, a custom-built laundry, a proper kitchen and extra capacity for our central sterilising operation. Additionally, we are doing a lot of molecular biology.

What is the big advantage you have gained with phase II?
We needed phase II to survive and to thrive, and we somehow managed to find the money for the project from different sources. Our enhanced capacity allows us to be comfortable when it comes to inpatients, but with outpatients we
are already filled and our labs are also running to capacity. As for the overall infrastructure, what we have now is stunningly beautiful. The architecture is by CannonDesign, an American firm, and it is superb. When I come to work, I say to myself, “What a privilege it is to work in this institution and in these surroundings.” You are actually able to do what you are supposed to do.

Despite all the expenditure and the consequent increase in running costs, we are on solid ground financially. We should, by the end of the financial year in March 2020, have a surplus of about ₹100-110 million. This is not sufficient. We are not earning enough to replace high-end equipment and we cannot increase our rates. TMC is surviving on a Robin Hood model: the rich are paying twice what their treatment costs, the poor pay from cost to nil. We are trying to cross-subsidise.

We are earning but cancer treatment is a bottomless pit. The costs are so high that it’s difficult to be viable. We don’t, for example, charge the ‘maximum retail price’ [or MRP] on drugs. That means ₹150 million a year in charity to patients. We can earn if we want to earn, but that is not the purpose of this hospital. TMC is not a corporate establishment. We have to keep our costs low and find the resources to treat more people who are poor. That is our mandate.

We are not saying that we cannot be viable. We are viable, but we will continue to need assistance for capital expenditure. Which is why we approached Tata Consultancy Services for our IT requirement. And we now have a state-of-the-art system as a result. Our radiology division is, I think, one of the best in India. That costs money and somebody has to pay for it. My hope is that we build up our corpus to the extent that we don’t have to turn any patient away, especially not children.

With TMC, the Tatas have created a unique institution. This is a tertiary cancer centre and we have to be the gold standard. We have a protocol wherein the 10% who can afford the best treatment in the United States can have that treatment here. Then there is the 20% in the middle who we charge, followed by the 70% that cannot afford to pay anything. Some of my colleagues say everybody should be on par, but that is not possible.

Are expensive treatments worth the money?
Sure, if you can be cured, but that is not the problem. I was doing my [hospital] rounds this morning and...
there is this father and his [cancer-stricken] son is reaching the end of the road. The father has no money, so I have to choose a pathway. I won’t say, “No more treatment.” I will choose a pathway where you are not selling your house or liquidating your bank accounts. We often have to make decisions based upon financial resources. We don’t want a ₹10-million treatment that will extend a patient’s life by three months.

Science and technology are going at a pace which is unbelievable and there are all these new treatments coming along. As for affording such care, it’s an emotional situation. When you have an only child who has relapsed leukaemia and needs a treatment that costs ₹2.5 million, you are ready to sell your house, your property and everything else to have that treatment.

I honestly don’t think there will ever be a time — and there will not be such a time even in the United States — where every child who has cancer and needs an expensive treatment will get it, or have the state pay for it.

We are struggling with the issue. I cannot put a poor patient on the floor. TMC is entirely air conditioned and there is a cost attached to that. You may say air conditioning is a luxury but it is not a luxury when you consider the fact that it reduces post-operation risks.

Where to from here for TMC?
Further expansion cannot happen here. We have to strengthen the systems we have established such that they can continue, and we have to be economically viable. But I am not so much worried about the viability of the institution as I am about being able to help more and more patients who need the sort of care that TMC can give.

When the whole of phase II is operational, we can have a surplus of about ₹300 million. We have secured financial assistance for patients from the central and state governments and the Dorabji Tata Trust donates ₹4.5 million a month, which we utilise to subsidise treatment. We are using every available resource to reduce costs for our patients. We have a lot of activities to support them and we have social workers for assessment and support. What we don’t have, as of now, is a good donor campaign; we have to strengthen that.

Do patients from this part of India, rather than come to TMC, still go down South or to Mumbai for cancer treatment?
The quality of cancer care in eastern India was so poor that people had lost faith in the system; they would much rather go to Vellore or Mumbai. That is changing. A patient who has gone to Mumbai and then comes here doesn’t go back to Mumbai.

What about cancer treatment in general in India? How has the country been faring?
India has done very well in the production of generic medicines at a much lower cost — it is an example for the world — and we do this without compromising on quality. Drugs that are sold in the United States for $400 a dose are available in India at a twentieth of the cost. Our pharmaceutical industry has done us proud.

In treatment, diagnostics and patient care, you can have whatever you would have anywhere in the world. We are, however, nowhere near global standards in research, in new discoveries, new drugs and new molecules.
It is often said that more and better research improves outcomes. To me research means constantly asking the question: how am I treating my patient? What is the gold standard in the world? If my patient can afford it, can I give him or her that treatment? And are my outcomes as good as anywhere else in the world? We are constantly looking at our outcomes and comparing them with international standards. That’s clinical research and I am happy to say that TMC is doing that.

In just 10 years we have reached a high level of quality and integrity of practice. We are fortunate to have doctors who don’t do private practice. We struggle with nurses but we are trying our best there. We have outstanding technologists and our labs are as good as anything you can get.

Do you get a chance to practice and to do research?

I don’t do research because that is too demanding. I do a lot of clinical work and my expertise is in blood cancer and bone marrow transplants. I still enjoy that; it keeps me going. I love having students asking me questions.

How have you made peace with the stress and sadness of being a cancer specialist?

As an individual you have to grapple with the reality of suffering. I used to do a series for students on the meaning of suffering and I took them through different religions — Judaism, Hinduism, Buddhism, the new and old Testaments — while trying to offer explanations. With time you learn to insulate yourself a little bit from it all, but patients and their problems do affect you.

Just last week we lost a patient and I still haven’t got over it because I feel I’m missing something. I don’t spend sleepless nights over a patient for whom nothing more could have been done. But when something goes wrong and you can’t understand why it went wrong, then it affects you personally. Most of us who have been doing this for many years learn not to let it get to us completely. I think your faith also helps.

We make life-and-death decisions every day. Recently, one of my patients came back here with a critical relapse, four years after I had treated him. Since I had developed a rapport with the family, I could talk to them and explain the situation. There was a nice sense of closure.

I got a Christmas card once from someone whose child had died after receiving good care here. You would be surprised at the number of patients who we treated years ago, who are now grown up and married and have children of their own, and they still keep in touch. When you treat a patient as an individual, you get involved in hundreds of things.
Splitting effect

The ‘distributed care’ project in Assam has the potential to provide a blueprint for patient-centric cancer care and treatment across the country.

What’s the optimum way to help India battle the cancer beast that is upon it? An unfolding effort in Assam — part standard procedure, part improvisation, part experiment — is providing insights and answers.

Preventive and promotive, rather than curative, are the watchwords in the initiative. It concentrates on screening surveys and awareness programmes at the community level, while developing a three-tiered ‘distributed care’ model aimed at enabling patients to get cancer treatment closer to home.

Currently in its first phase, the programme operates under the Assam Cancer Care Foundation (ACCF), set up in December 2017 as a collaborative venture between the Assam Government and the Tata Trusts. Extensive community outreach projects have been seeded in five districts of the state through camps in villages and 10 centres.

Assam is the first and most substantial component of the initiative, which is at various stages of replication in five other
states of India: Maharashtra, Andhra Pradesh, Jharkhand, Odisha and Karnataka. Besides the respective state governments, a host of NGOs and other partners are involved in the collective endeavour.

Assam is an appropriate setting for the programme. It bears an annual load of more than 30,000 cancer cases, 70% of them at an advanced stage. Early detection is the key to changing this grim statistic, which explains the stress on screening — not just for cancer but other conditions as well — and awareness building.

**Detect to protect**

“We want to make people and communities aware of the early symptoms of cancer, and we want to inform them about how to reduce the risk of getting the disease,” says Sanjiv Chopra, a senior consultant with the Trusts. “We want to ‘downstage’ the cancer, catch it at stages 1 and 2, when it is curable. That can happen only through a massive campaign of prevention and promotion.”

Dr Chopra bemoans the elevated status in cancer care of the curative, at the expense of all else. “We have to alter our strategies,” he says. “We have to reach out to the public in the areas where they live and make them knowledgeable enough to catch cancer at an early stage and report it.” The focus in Assam is on precisely that and the logic of it is sturdy.

“India has to cope with more than 1.1 million new cancer cases every year and a huge number of these patients go untreated,” adds

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** Ahead in Assam**

Implemented in partnership with the Assam government, the distributed care programme is a comprehensive and community-centred effort to contain cancer. It has three components:

- Screening surveys
- Awareness building
- Care and treatment

**The distributed care model**

- **Level 1**
  - Full-fledged cancer centres (300+ beds)

- **Level 2**
  - Facilities close to or attached to medical colleges (120+ beds)

- **Level 3**
  - Facilities close to district hospitals (40+ beds)

- The model has been unrolled in 5 districts of the state — Dibrugarh, Barpeta, Jorhat, Nagaon and Kamrup Rural — through community camps, kiosks attached to medical colleges and 10 centres

- The Assam model is being replicated on a smaller scale in Jharkhand, Odisha, Maharashtra, Andhra Pradesh and Karnataka
A screening camp, organised by the Assam Cancer Care Foundation, in progress at a centre in Dibrugarh

Dr Chopra. “Cancer incidence keeps increasing and we keep chasing after treatment. It’s a vicious cycle and we will always fall short.” Patient-centric cancer care, the principal objective of the Assam initiative, demanded a different approach.

The community camps and the 10 centres in the programme help cover most of Assam, the idea being that no person need travel more than three hours to reach the nearest screening station or treatment facility. For the screening itself, the central government’s National Noncommunicable Disease Monitoring Survey — supported with resources by the Trusts — has also come in handy.

Cancer is but one of a variety of diseases the Survey looks to reveal, and this is a help for the programme. “Unless you do an outreach programme, nobody will come to you,” says Dr Chopra. “People get intimidated; they don’t want to step into a hospital for a cancer checkup. This is a big barrier to overcome.”

Going local

Local Assamese health workers have been hired and trained to ensure better community participation. The results have been along expected lines. “People from the community becoming responsible for the health of that particular community — it has been tried successfully in countries like the Philippines, Ethiopia and Thailand,” says Dr Chopra. “These workers find it easier to figure out who is unwell and why.”

ACCF is adding to the screening segment of the initiative by setting up kiosks at five medical colleges. There’s a six-member team to run each kiosk, which has been visualised as a friendly place where, other than screening, people can access information and have queries dealt with.

Technology inputs feeding the programme include a ‘digital nerve centre’, crafted by Tata Consultancy Services, that provides networking and data analysis to better dispense clinical care. There’s also a ‘command centre’ to combine the different elements and procedures in the system. That takes in remote instrumentation, tele-radiology, tele-pathology, tele-genetics, counselling and tele-consulting.

Backing from the Assam government has smoothened the programme’s progress, improving acceptance by the community and ensuring that the infrastructure to treat cancer sufferers is available. The distributed care concept could not have been made functional without such support.
Distributed care is about separating the detection, diagnosis and treatment stages of cancer. Care and treatment are ‘disaggregated’ through the setting up of a network of facilities at three levels. At level 1 are specialised cancer hospitals. Level 2 comprises units attached to government medical colleges with adequate expertise and equipment, and level 3 has primary health centres and district hospitals. “Most important is level 4, our outreach programme,” insists Dr Chopra.

**More in the pipeline**

It is estimated that more than 90% of cases can be handled at levels 2 and 3. Patients can get a diagnosis and a treatment plan without having to travel long distances, leaving only complex cases for level 1. A straightforward outcome here is reduced cost for the patients and their families, not to mention an improved likelihood of receiving and continuing with the necessary treatment.

As the programme matures, its features are being enhanced. Palliative care is a fledgling as of now but the hope is that it will, in time, become an integral piece of the whole. Helping patients find money for cancer treatment is another priority for ACCF, which works on this critical aspect by tapping government schemes and donors.

Finding quality professionals, particularly doctors, to join the programme is an exacting task. The problem is likely to ease with the setting up of the Histopathology Centre in Mumbai. Run by the Alamelu Charitable Foundation, an associate organisation created by the Trusts, the Centre will presently be offering fellowship programmes to student doctors, who could then be absorbed into the operations in Assam and elsewhere.

“Our partnership with the Assam government is for 30 years; that shows our commitment to the long-term,” says Dr Chopra. “A foray so deep into public health, in magnitude or scope, has not been done. We have learned a lot and we are learning every day. We are in uncharted waters, though; nowhere in the world has something like this been tried out. If we can pull it off in Assam, it can be pulled off anywhere in India.”
Fever pitch

The deadly ‘acute encephalitis syndrome’ is the target for Project Prayaas, a wide-ranging community health initiative in Uttar Pradesh.
In July this year, 11-year-old Garima from Pipra Muglan village in Uttar Pradesh’s Gorakhpur district developed fever, had a seizure and then fainted. What saved Garima’s life was the alertness of Malati Devi, a member of the Indian government’s ‘accredited social health activist’ (ASHA) workforce.

Ms Devi realised that Garima was showing symptoms of acute encephalitis syndrome (AES), a dreaded disease that affects the brain and can lead to unconsciousness, coma and worse. “Garima may have died if she hadn’t reached the hospital on time,” says Ms Devi. Garima could easily have been yet another statistic in the grim toll AES has taken in Gorakhpur, where the disease has run riot in recent years.

National uproar
As many as 2,942 of the 4,759 AES cases reported in 2017 in Uttar Pradesh were from Gorakhpur. Children are at the greatest risk. In August 2017 alone, 62 died of encephalitis at the Baba Raghav Das Medical College, the nodal medical facility for AES treatment in the region. The tragic news led to a national uproar.

Tackling the deadly AES menace became a priority and among the initiatives adopted for the task was a partnership between the Uttar Pradesh government and the Tata Trusts to help in the state’s susceptible subdistricts. It was not an easy challenge to confront.

A complex condition, AES is actually a cluster of diseases with encephalitis symptoms, and it mostly affects children and young adults. The three most common causes of AES are Japanese encephalitis, a mosquito-borne viral infection; scrub typhus, a bacterial infection that spreads through mites associated with rodents; and water-borne enterovirus encephalitis. Some dengue and malaria cases can also spiral into acute encephalitis.

The medical solutions for AES are preventive rather than curative, and that was the starting point of the partnership programme. It was decided to take a multi-sector approach to the crisis and the effort began with Project Prayaas, a unique intervention that aims to strengthen primary healthcare services and change the manner in which the community seeks and accesses healthcare.

Slated to run for three years, Prayaas was launched in July 2018 in two subdivisions: Pipraich in Gorakhpur and Uska Bazaar in Siddharth Nagar. The intent has been to develop model subdistricts for health promotion and tackling encephalitis. These can then be replicated across the state. Prayaas also works to create awareness about the importance of identifying any illness — not just AES — in its early stage and taking treatment as soon as possible. As with Garima, this can often mean the difference between life and death.

“Prayaas is a people-based project and it is designed to bring in long-term change,” says MP Cariappa, a retired colonel who is a technical advisor with the Trusts. “What we are trying to achieve here is have people take responsibility for their health. We want to look at healthcare as prevention and promotion.”

Encephalitis is the focus for Prayaas, which has three principal components: mobilising the community, improving the delivery of primary healthcare services, and addressing hygiene and sanitation. At the community level, it is ASHAs such as Ms Devi who play critical roles. They are the ones on the ground, and at the grassroots, ensuring the sustained impact of any health intervention.

ASHAs in the picture
ASHAs, who can help identify an illness in its initial stage and refer the patient to a healthcare centre for treatment, are the fulcrum of the project’s fever-tracking system. They help the Prayaas team track children who need to be vaccinated and make certain they are. These workers also promote the government’s Dastak campaign, which spreads awareness about communicable diseases, hygiene and sanitation by reaching out to the community through door-to-door visits and educative sessions in schools.

Training and mentoring by the Tata Trusts’ team has enabled the building of capacity in the ASHA network. “Earlier, we weren’t sure when or how to refer a patient with fever; then we were taught the ‘traffic-light protocol’,” says Rajkumari Mourya, an ASHA with the programme. The protocol offers a simple guide to understanding the nature of the fever. Green stands for mild (not worrying but requiring treatment),
A nurse completes registration formalities in Gorakhpur’s Kaithwalia village

Prayaas has notched up impressive numbers since it was launched in July 2018

- **350,000** villagers reached
- **3,752** households provided with insecticide-treated mosquito nets
- **28,142** patients treated through mobile medical units
- **250** ASHA workers trained
- **23,865** children being tracked for health-related services

A nurse completes registration formalities in Gorakhpur’s Kaithwalia village
it may seem obvious but it bears repetition — timely access to proper healthcare services saves lives, and this is especially true when it comes to acute encephalitis syndrome (AES).

“Research has shown that there is a delay of about seven days between the onset of fever and admission to hospital,” says Sandeep Chavan, a programme officer with the Tata Trusts. “If this delay can be managed through better primary healthcare services and prompt referral of cases, it could lead to early identification of encephalitis, which in turn means fewer fatalities.”

That’s where mobile medical units (MMUs) drive in. Project Prayaas uses these units to strengthen primary healthcare services in its areas of operation. Each MMU has a team of five — doctor, nurse, lab technician, pharmacist and driver — and is equipped with laboratory facilities that can carry out up to 50 tests.

The doctor at each MMU sees around 2,000 patients every month — children below the age of five and adults with fever get priority — and also conducts home visits where required. What the doctor and the unit deliver can be critical in the remote places where these patients live. “In earlier days, if my child fell sick I would have to go to a hospital in Pipraich or Gorakhpur, which are far away and crowded,” says Shamsher Ali, a resident of Lakhesara village. “With the MMU now coming here, we can get treatment quickly and can also have blood tests done.”

The MMUs also play an important role in the mass health communication campaigns that are run under Prayaas. Videos on various health-based themes are screened in villages and trained personnel conduct awareness sessions on health-related topics.

Given the usefulness of the MMUs, the Prayaas team plans to introduce more of these units when it expands operations. Finding resources for the units and for additional personnel is a constant challenge but the team is confident of coping with that.

Going mobile to travel further

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annually and this comprises a health camp and a felicitation function to appreciate their work. In addition, the Trusts provides financial incentives to the ASHAs (over and above the amount they receive from the government).

The continuous mentoring has brought about perceptible change. “Working with the team has made a lot of difference because I feel more confident,” says Ms Mourya. “Whenever I get stuck, the team is always there to help me out.”

To reduce the incidence of AES, Prayaas took up ways to control the vectors that lead to the disease (rodents, mosquitoes and unclean water). The project team works closely with village councils to build low-cost soak pits that improve water drainage, spray larvicides to reduce mosquito breeding, and clear vegetation to keep rodents away. Prayaas also conducts community campaigns on health issues, safe drinking water, food safety and nutrition, and maternal and child health.

The campaign to encourage villagers to use mosquito nets treated with insecticides, conducted in July 2019, is an example. Says Ram Baran Paswan, who heads the Madhopur village council in Gorakhpur: “I got the net in my house treated and saw that it kept mosquitoes away. After that, I used government funds to buy the insecticide and convinced others to get their nets treated.”

350,000 and counting

Behaviour change and community participation can be difficult to pull off, but the Prayaas team has handled the challenge with aplomb. In the one-and-half years since implementation, the project has reached some 350,000 people.

The plus points accruing to the initiative have been acknowledged by the district administration. “The kind of community participation we have been seeing is because of the Tata Trusts’ efforts,” says AK Pandey, the district malaria officer in Gorakhpur. “Their MMUs provide the first line of screening for diseases, and we are witnessing a gradual reduction of AES cases.”

“With Project Prayaas we are working towards cleaner villages,” explains Dr Cariappa. “If you promote health, every disease, including AES, automatically gets covered. The Swachh Bharat Mission is about behaviour change for a cleaner India. Our effort is, in a sense, about bringing this mission to villages. The collateral benefit is a drastic reduction in the rates of disease.”

By Priyanka Hasangadi
“I was born in a scavenger’s family,” says Bezwada Wilson, a survivor and warrior who has dedicated his life to the fight against manual scavenging in India. The term is euphemistic in the extreme. Manual scavengers are the unfortunates who have to carry and dispose of human excreta — or ‘night soil’, in cuter language — from latrines and sewers.

This age-old practice has been banned in India for more than 25 years but continues to be widely practiced by, almost to the last person, people hailing from the lowest rung of India’s caste system. It is a brutal and degrading business. Literally as well as figuratively, manual scavenging is sickening.

That has not killed it off. There are tens of thousands of manual
Despite India’s decades of progress and social development, the practice of manual scavenging — where human beings belonging to a certain community are employed to clear the excreta of others — is still prevalent. Manual scavenging is illegal, which means that by law no one can employ scavengers. But there has been no conviction over the last 25 years. The Indian Parliament enacted the Rehabilitation of Manual Scavengers Act in 2013, but it has proved insufficient to stop the vile practice. SKA believes about 160,000 people are involved in such work though government data pegs the number at just 54,000.

The truth is that those entrusted with the implementation of the Act are not horrified about humans cleaning toilets. Years of caste biases and prejudices have conditioned them to think that those involved in scavenging — very often Dalits — are meant for such work and that it is justified. They fail to see it as violently abusive and unlawful.

**On manual scavenging and its continuing prevalence**

Despite India’s decades of progress and social development, the practice of manual scavenging — where human beings belonging to a certain community are employed to clear the excreta of others — is still prevalent. Manual scavenging is illegal, which means that by law no one can employ scavengers. But there has been no conviction over the last 25 years. The Indian Parliament enacted the Rehabilitation of Manual Scavengers Act in 2013, but it has proved insufficient to stop the vile practice. SKA believes about 160,000 people are involved in such work though government data pegs the number at just 54,000.

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**On violation of human rights of manual scavengers**

The issue of manual scavenging has two parts to it. The first is the ecological and health hazards. The second is the labour angle. The people involved in the activity are often paid very low wages and, hence, the demand for higher salaries and permanent employment.

For us at SKA, this is not a wage issue. We view it as a humanitarian problem and a human rights issue. While some people say that the situation can be mitigated by providing workers with safety gear, our stand has been consistent: no human should be made to clean human excreta, no matter what. This is about the dignity and self-respect of individuals.
A group of municipal conservancy workers in Panna in Madhya Pradesh set out at the crack of dawn to clean the town’s filthy drains.

A stinking tragedy

According to a government survey (170 districts in 18 states), there were 54,130 manual scavengers across India as of July 2019.

From 1993 to July 2019, there were 814 recorded deaths of manual scavengers while cleaning sewers or septic tanks (data from 20 states and union territories).

Tamil Nadu topped the manual scavenging death-list with 206 deaths; Gujarat was second with 156 such deaths, followed by Uttar Pradesh (78) and Karnataka (73).

According to the Socio-Economic Caste Census (2011), 180,657 Indian households are engaged in manual scavenging for a livelihood.

The 2011 Census of India found 794,000 cases of manual scavenging across India.

Over 98% of those involved in manual scavenging belong to the Dalit community.

40-45 years is the average lifespan of manual scavengers.

Sources: The Hindu; Safai Karmachari Andolan

The black-and-white images running with this interview have been shot by noted photojournalist Sudharak Olwe and are part of an acclaimed series on conservancy workers in India.
Mamta Valmik, a 55-year-old municipal employee, sweeps the ground at the bus stand in Amanganj in Madhya Pradesh. Mamta got the job following the death of her husband, Kirpal, 27 years ago. Kirpal was killed while cleaning a septic tank with five other municipal workers, who were badly injured but survived. Mamta’s son, Surendra, also works with the municipality as a sweeper.
On his early years

I was born in a scavenger’s family in Kolar in Karnataka. My father and brother were employed with Bharat Gold Mines [BGML] as scavengers. Up to class IV, I studied in a school that was exclusively meant for children whose parents were involved in scavenging. It was called the ‘Thoti school’, thoti being the Kannada word for lower caste.

For class V, I moved to Kuppam in Chittoor district of Andhra Pradesh. I was an average student but my teachers thought I was intelligent and could do better. My mother played a big role in me completing my education. She was of the firm opinion that I must study and change the destiny of my family. I ended up graduating in political science from the Dr BR Ambedkar Open University, Hyderabad.

On the formation of SKA

It was during my years in Kuppam that I encountered the darker side of life. Until then I had been living a cocooned existence, insulated from the harsh realities of the work that my community and my family were involved in. The truth was very disturbing and caused me mental agony.
I wanted to change the situation but I was clueless about the way forward. I started travelling to different places in Karnataka to make people aware about their situation and convince them to change. During college, I started noticing that many children from my community dropped out of school to take up scavenging. I realised that if our children could be encouraged to complete school and take up some sort of vocational training, we could break the vicious cycle.

In 1984, I shot off a letter to [then prime minister] Rajiv Gandhi detailing the manual scavenging that was still being followed at BGML and seeking his intervention. I wrote several such letters but never received any response as I had failed to mention my address. Finally, I got a letter from the BGML technical director.

He informed me that manual scavenging had been continuing at the mines for over 114 years and that the mine management had taken several steps to do away with dry latrines and spent a lot of money. I found the truth to be something else. Manual scavenging was still prevalent and the money spent by the company to convert the dry latrines had been siphoned off. I approached the media and a furore broke out. BGML was forced to convert all its dry toilets, prevent manual scavenging and rehabilitate the 107 people it had employed to clear toilets.

Over the years, a need was felt to create an organisation to eliminate manual scavenging. In 1994, I, along with Dalit activist SR Sankaran and Paul Diwakar, a retired bureaucrat, founded SKA. Our goal is to end the practice of manual scavenging and help those engaged in it find dignified work. We are now active in 22 states and have about 5,000 volunteers and 270 full-timers working to root out this vile practice.

**On partnering the Tata Trusts for change**


During the hearing, the apex court had to be informed about the number of manual scavengers in India. We had no such data and little means to carry out a survey to collect this data. That’s when we approached the Tata Trusts for support. It was thanks to them that, in 2005, we could collect data from 370-380 districts spread across 18 states. The survey gave us good data and helped bolster SKA’s image and credibility.

**On remaining hopeful**

When we started SKA, we believed that manual scavenging could be rooted out by 2010. That has not happened. The practice continues in several states, Uttar Pradesh, Madhya Pradesh, Bihar, Gujarat, Uttarakhand, Jharkhand, Rajasthan and Maharashtra among them. But we continue our work and we are hopeful that it will come to an end in a year or two.
Members of the Dom community from Thillaigaon village in Hathni in Bihar. Almost all Dom men work as manual scavengers or sanitation workers. The community, which lives on the outskirts of the village, faces humiliation on a daily basis. In April 2018, many Dom houses were burnt in a fire. The cause of the blaze remains unknown. Some say it was accidental; many think otherwise. As the Dalit writer and poet, Om Prakash Valmiki, said, “Only those who face discrimination can know its sting.”

Geeta Kisan, a 48-year-old conservancy worker, goes about her job in Bhagwatpura in Meerut in Uttar Pradesh. “I have been clicked several times by journalists and social organisations, but nothing has really worked in our favour,” she says.
Leg up for learning

Rural schools have been the focus of a multidimensional approach to enhance education outcomes for students in eight states

The meaning of madrasa is ‘a school for Islamic instruction’, but Mustafapur High Madrasa (MHM) is a lot more than that. This modest institution in Mustafapur village in the rural reaches of West Bengal’s Hooghly district stands apart for the manner in which it has blended traditional religious learning with modern pedagogy that embraces the study of maths, science, language and, not least, the digital world.

MHM is one of the 63 madrasas, spread across six districts of West Bengal, that are part of the Integrated Approach to Technology in Education (ITE) programme of the Tata Trusts. Implemented in eight states of India since inception, this multidimensional initiative aims to enhance teaching and learning outcomes for middle- and high-school students in rural areas.

ITE’s intent is to help bridge the digital divide in schools where the technology
chasm is the widest. The schoolchildren in the programme, the majority of them first-time computer users, learn through a variety of projects to improve analytical thinking and retention skills. For teachers, there is professional development and capacity building. Teachers design learning activities and students use technology to further their learning.

MHM’s 317 students — more than 200 of them girls — are the ones most enthused about their exposure to the digital world. "Our children have responded very well," says Mohammed Mallick, the articulate headmaster of the madrasa. “They are eager to learn more about new technologies and we are looking forward to an acceleration of the IT programmes taught in our school.”

Collaborating for good
The Trusts have worked in collaboration with the state governments, the Tata Institute of Social Sciences (TISS) and a clutch of nonprofits to implement the initiative. Coordinators and workshops, technology tools and a recast pedagogical framework are important components in an effort that is not dependent on content or language. And neither does it need always-on internet connectivity.

Piloted in West Bengal’s Murshidabad district in 2012, ITE has grown in the years since to become an effective solution in pulling up those previously lumbered in learning by lack of infrastructure and proper systems. The programme has ‘master trainers’ to tutor teachers and, for students, activity-based projects that are embedded in their syllabus.

Lesson plans incorporate the real-life experiences of the children, who get to use technology tools to collect data, analyse information, organise knowledge and present findings while audiovisual formats help to better understand the world around them. Students also get to interact with

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Adding it up

The Integrated Approach to Technology in Education (ITE) programme works to enhance teaching and learning outcomes for middle- and high-school students in rural areas.

The programme has benefitted more than

30,000 children
850 schools

It has been implemented in
8 Indian states

West Bengal  Uttar Pradesh  Odisha  Maharashtra
Jharkhand  Assam  Uttarakhand  Gujarat
Nalbari, a small town in Assam that was a hotbed of anti-government militancy through much of the 1990s, is a blooming example of what can be achieved if peace and a proper education are given a chance.

Nalbari is one of the six districts in Assam where the Integrated Approach to Technology in Education (ITE) programme of the Tata Trusts has taken root. The programme covers 50 rural schools in these districts, and to ever-deepening effect.

“Technology is replacing textbooks,” says Bubul Sarmah, the principal of Adarsha Vidyalaya, an English-medium school in Chenga in Nalbari. “Children working on a project on floods, for instance, are provided cameras and encouraged to go out to affected areas, take photographs and to make presentations and videos.”

The ITE initiative in Assam goes beyond school boundaries. Students and teachers organise community-based projects in nearby villages, interacting with farmers, the elderly and groups of mothers. “The idea is to increase awareness about technology and strengthen the relationship between the school and the local community,” says Prithibhusan Deka, president of Gramya Vikash Mancha (GVM), the NGO that partners the Trusts in the initiative.

Teachers and students make presentations to the community on social issues such as child marriage, child labour and substance abuse. It’s a far cry from how it used to be — “There were problems everywhere,” adds Deka — but the restoration of law and order in the region has put social development back under the light. ITE has added to the brightness.
their peers in other schools, develop individual as well as collaborative abilities, and improve their communication skills.

The Trusts’ implementing partner for the programme at MHM, where it has been running since January 2016, is the Vikramshila Education Resource Society, an NGO that has been active in teacher training and curriculum design. Madrasas, in particular, are in acute need of the kind of expertise and enhancements that ITE can deliver and MHM is one among those that have benefitted in West Bengal.

It started with a four-month certificate course for madrasa teachers, conducted with the support of the state government by TISS. Thereafter, ITE was launched in four private madrasas in Hooghly district. IT courses were conducted for students from classes V to VIII. Alongside, 28 madrasa teachers from six districts in West Bengal completed the certificate course. They became master trainers and passed on what they had learned to 351 ‘outreach teachers’.

**Network of the enlightened**

The progress made through the project is evident. “There has been a rise in student engagement, dropout rates have fallen, students are moving away from rote learning and they are able to connect better with others,” says Babita Dutta Majumder, a senior manager with Vikramshila. Parents, too, have come on board as good results begin to yield.

The transformation wrought by ITE is clearly visible at the Nadia Model Madrasa (NMM) in Nadia, about 120km from Kolkata. This is an English-medium madrasa — it also has Arabic in the syllabus — with 700 students and 10 teachers. “ITE has helped improve the performance level of our students, and it has helped bring about changes among teachers as well, says Maman Halsana, who heads NMM.

The shift away from antiquated modes of teaching has been facilitated by the use of computers. There are 40 of them at NMM and they have been put to quality use. “Without computers there can be no sustainable education,” says Abid Hussain, Director of Madrasah Education (DME), West Bengal.

DME has under its umbrella 650 institutions with some 600,000 students. According to Mr Hussain, more and more of these schools want to be part of the ITE initiative. “We are creating an atmosphere where technology can be deployed for students,” he adds. “What they learn in class can be applied in their projects.”

The change brought about through ITE is noticeable in the attitude of girl students, now more convinced than ever that they need to go to college and further. With the girls-to-boys ratio in West Bengal’s madrasas at 65:35, that is encouraging news. In the past, many of these girls would drop out of school and early marriage was common.

“In earlier days education was not a priority for girls in West Bengal, but today they want to study more and are willing to postpone their marriage plans,” says Mr Hussain, who adds that religious leaders and parents have accepted the transformation that is occurring in the state’s madrasas. The proof of the pudding lies in the changed outlook of the students themselves. Many want to appear for competitive exams and some have gone abroad for higher studies.

“ITE has generated a sense of eagerness among the children to explore and to create; it has, equally, encouraged and enabled teachers to evolve their pedagogy,” says Panchalee Tamulee, a programme officer with the Tata Trusts. “Teachers and students are co-learners in a school ecosystem that is geared to creating knowledge for everybody involved.”

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*By Nithin Rao*
Free WiFi at 4,791 rural railways stations across the country — that’s the goal of a partnership programme on the fastest of tracks

The two young men have plugged into the free WiFi service being provided by Indian Railways at its stations and they are among thousands of Indians availing the facility. That figure will likely jump to millions when the objective of an ongoing partnership between the Railways and the Tata Trusts is realised — providing WiFi access for free at 4,791 railway stations across the country. More than 3,000 of these stations already have the service in place and the vast majority of them are in rural regions. The overriding intent behind the Railways-Tata Trusts collaboration was to ensure greater adoption of the internet and enable India’s vast hinterland of rural communities to benefit.

The initiative began in late 2018 with a pilot project where internet connectivity was set up at eight stations between Bengaluru and Mysuru. The big and proper free WiFi plan started being implemented in July 2019 and progress has been exceptionally fast since.

Speed was of the essence and the spread of places to be reached was the stiffest challenge. It has all to do with size and the reason is simple: Indian Railways is a behemoth. With a track length in excess of 120,000km, some 8,000 railway stations and about 1.3 million employees, this is an entity — an institution even — that carries more than 23 million passengers and 3 million tonnes of freight every single day.

Enabling internet connectivity has been a long-time goal for the Railways but there were a host of hurdles in the way. Over the years, 1,600-plus railway stations, most of them in urban centres, had been WiFi-enabled. That was the easier part. The tough nut to crack was going rural, which meant offering the service in outback locations.

The remote challenge

“We had to get the equipment transported, assembled and commissioned at the remotest of sites,” says Sreeram GC, a technology advisor at the Trusts. “This was something that even RailTel [the telecom infrastructure provider owned by the Railways] had not been able to accomplish for years.” The Trusts pulled in external expertise to manage the technical aspects and RailTel itself has been a key partner.

Equipment selection is a crucial factor in ensuring the facility’s viability and the Trusts have chosen the advanced GPON (Gigabit Passive Optical Network) and
switching (carrier ethernet) technologies. “This was a critical factor because the equipment is out in the open,” explains Mr Sreeram. “We found that this combination meets all the requirements: managing dust, the weather and vibrations from passing trains.”

The job of installing and commissioning the equipment was assigned to Bengaluru-based Tejas Networks, which has experience of setting up WiFi spots in rural India, having completed a project connecting some 5,000 villages to the internet grid. Tejas put its teams in the field and they fanned out across the railway-station network to set up the infrastructure. The task of project management and auditing was given to Tata Communications Transformation Services.

A collaborative endeavour all the way, the project has come up solid and at speed. “Within three months we had installed the equipment at more than 3,500 stations and commissioned it at more than 3,000 stations,” says Mr Sreeram.

Under their ‘digital transformation’ portfolio, the Trusts have employed technology in a number of interventions. Among the standouts: 60,000 rural women being trained to use digital devices for the benefit of their communities; data analytics becoming a part of daily governance in several districts; and migrant children getting the benefit of digital education cards.

With the free-WiFi project, the home straight has come into view but the pace has slowed. “The last 500 stations are the most challenging,” adds Mr Sreeram. “They are the most remote, many with no power or fibre connectivity, or with bandwidth issues. We are trying out different solutions in these places.”

Once complete, the project will be a tremendous asset to the nation. The system can supplement BharatNet, the public sector broadband network that aims to eventually connect more than 250,000 village councils. “The government can use the Railways’ WiFi infrastructure to connect local schools, hospitals and community centres to the net,” says Mr Sreeram.

The biggest beneficiaries, of course, will be rural residents, primarily passengers and others who visit railway stations. For them, free WiFi translates into getting on the digital track at no cost. And there’s no danger of getting waitlisted.

By Gayatri Kamath
It’s late morning and Anasuya Netam is preparing lunch at her home in Lendhari village in Maharashtra’s Gadchiroli district. As she cleans and sorts the rice grains, she comes across one that looks a little different. Instead of throwing it away, she smiles and touches her baby bump. The grain is a fortified rice kernel (FRK), good for her and her yet-to-be-born baby’s health.

FRKs are an innovative way to deliver essential nutrients to pregnant women, children and anybody else needing it, particularly vulnerable communities. Made from rice flour, each FRK is enriched with iron, folic acid and vitamins B1 and B12. When mixed with conventional rice and cooked normally, fortified rice can help tackle several deficiencies while improving overall health.

Gadchiroli is the setting for the rice-fortification pilot project introduced by the Tata Trusts in 2018 in partnership with the Maharashtra government. The choice of district is appropriate. Located in a tribal belt and beset by a long-running...
Maoist insurgency, Gadchiroli is one of Maharashtra’s most backward districts. The health indices of the region portray a story of poor nutrition, with government data showing more than half of the district’s pregnant women, young mothers and under-five children as being anaemic.

The two subdistricts in the pilot intervention — Bhamragad and Kurkheda — were picked because a baseline survey conducted prior to the project’s launch put them at the extremely unfavourable end of the health spectrum.

**Deficient all around**

The Trusts had teamed up with Indian Institute of Health Management Research, Jaipur, for the survey, which covered 900 households in 30 villages. The key findings: high all-round incidence of anaemia and iron deficiency; more than 60% of adolescent girls showed signs of nutrient deficiency; more than 35% of lactating mothers and 50% of pregnant women were anaemic.

Populated by the Mandia and Gondi tribes, literacy levels are extremely low in the region. Early marriages are commonplace and young mothers are mostly unaware of nutritional requirements. To make matters worse, the villagers’ diet is devoid of cereals and low on plant as well as animal protein. That makes iron deficiency the norm.

The rice-fortification initiative attempts to correct the diet anomaly by adding micronutrients to the villagers’ staple food — rice. It’s a subject the Trusts have gathered expertise in, and experience of, over the years, primarily through their partnership with the Food Safety and Standards Authority of India. The Food Fortification Resource Centre, set up and run jointly by the two organisations, enables the fortification with micronutrients of staples such as milk, salt,

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**Milling about with clear and present intent**

Hyder Panjwani of Jena Agro Processing is an old hand in the rice-milling business. But he and his brother Salim were initially puzzled by the requirements of the Tata Trusts when the rice-fortification programme was being finalised.

Integrating local rice millers into the project was one of the big challenges that the Trusts faced. The millers were apprehensive about investing in an activity which did not promise profits. Consequently, only two of the eight rice millers associated with the PDS programme in the region agreed to participate.

Jena Agro, based in the town of Armori, became part of the programme after the Panjwani brothers, their doubts cleared, came on board. The Trusts team worked closely with Jena Agro to devise a new blending system. Assembling and fabricating local components, they came up with a blending system that cost just a tenth of the one initially envisaged. The improvisations in the design were so efficient that the blending accuracy was about 96% — much higher than the desired 91%.

Jena Agro’s success has spurred Gadchiroli’s rice milling businesses to offer their services for the next stage of the initiative, when the programme is scaled up to cover the entire district. As for the Panjwani brothers, they have become complete converts. “The Tata Trusts’ faith and zeal motivated us to participate in this programme,” says Hyder Panjwani.
wheat and rice at an all-India scale.

Gadchiroli, however, was a different ballgame. This was the first time that the Trusts were attempting an intervention strategy through the public distribution system (PDS). To do it well, the Trusts and the Maharashtra government began by getting the local rice millers on their side.

Rice millers are an important cog in India’s food ecosystem. They process raw paddy into the rice that goes into the PDS supply chain. This rice is then despatched to fair-price (or ration) shops, which sell them to the community at subsidised rates. For the pilot programme, the rice millers were to be provided with the FRKs, which had to be mixed in a precise ratio of 1:100 (1 grain of FRK for 100 grains of conventional rice). This meant the millers needed new equipment in the form of a blending system that was affordable and reliable (see Milling about with clear intent on page 51).

Acceptance problem

With the blending systems in place and working successfully, the government despatched the first batch of fortified rice to Bhamragad and Kurkheda in January 2019. Shortly thereafter, the Trusts team came up against an entirely unexpected obstacle — the intended beneficiaries. These were rural people, mostly from impoverished backgrounds, and they did not know much about the scheme or its positives. When they sorted the rice while cleaning it, they came across the FRKs. Since the kernels looked and tasted a trifle different when raw, there were murmurs of adulteration. The Trusts’ team soon found itself in the middle of a rumour storm — that ration rice was being contaminated with ‘plastic rice’.

“There were some viral videos about the ‘plastic rice’ — manufactured in China, no less — floating on social media,” says
Sonal D’Souza, a programme officer with the Trusts, “and that created some misconceptions among a few people.” The team had to work overtime to kill the kernel canard.

Community workshops were organised at various places, including village councils and local government offices. Local administration officials and prominent members of the local community were roped in to explain the principles and advantages of fortifying rice. Additionally, village self-help groups and childcare centres conducted cooking sessions with rice-based recipes.

Blind tasting sessions were held to demonstrate that there was no difference in the taste of FRK-blended rice once it was cooked. Alongside came banners and leaflets extolling the virtues of micronutrient-fortified rice. The communication campaign bore fruit and locals soon became convinced about the many health benefits of consuming fortified rice.

State support counts
The state government’s support for the pilot project has been a crucial factor in the success of this unusual public-private partnership. “The efforts of the local administration and the fair-price shop owners have convinced us sure that the fortified rice provided to us will improve our overall health,” says Chinnu Mahaka, a villager from Hemalkasa in Bhamragad.

The district officials acknowledge the Trusts’ role in driving the project. The Trusts have worked on multiple aspects to bring the programme up to speed: partnering district authorities to understand the PDS supply chain, identifying the specifications of the blending system, assessing the capacity of
the local rice millers, pitching the idea to them and, finally, implementing the on-ground blending process with a miller who was open to trying out the new and improved process.

“The technical expertise that the Trusts brought to the table was invaluable,” says Shekhar Singh, the district collector of Gadchiroli. “As administrators, we are well-versed with logistics and supply parameters, but for the technical aspects, especially on-ground implementation of the blending systems at rice mills, we needed expert hands.”

The experiment at Gadchiroli has paved the way for a new strategy to counter the nutrition-related health afflictions of rural Maharashtra. The central government’s Department of Food and Civil Supplies is now scaling up the Trusts’ initiative to cover the remaining 10 subdistricts of Gadchiroli.

News of the Gadchiroli initiative has reached the ears of the NITI Aayog, the policy think tank of the Indian government, which earlier this year showcased the project as the ‘best case success in health and nutrition innovation’. The central government is now thinking about piloting a similar initiative in one district each across 15 states.

What the Gadchiroli programme shows, most of all, is the potency of a win-win relationship that involves various entities. What it also reveals is that community health improvement initiatives at the village level cannot but be collaborative. ■

By Jairam Pai
Past forward

The Mumbai Police has set about preserving records that reveal a treasure trove of cases and criminals stretching back more than a century.

It’s not something that you normally see law enforcement people caught up with. In an extended and brightly lit room, 20 police personnel are working to preserve the heritage of the Mumbai Police. They are not shuffling paper; instead, they are piecing together archival material, some of it a century old. Rather than investigating criminal cases, they are uncovering the history of law and order in the ‘maximum city’.

Documents, posters, pamphlets and other records — the Mumbai Police Archives (MPA) project has gathered together these and more as it works to highlight a legacy that would have been consigned to dust and mould had it not been for Dattatray Padsalgikar, Mumbai’s former police commissioner who, inspired by the police museums he visited in New York and London, thought of creating a similar experience in Mumbai and approached the Tata Trusts for support. That was the beginning.

Today the police archives occupy most of the ground floor of the Foreign Resident Registration Office in Dhobi Talao in Mumbai. For longer than anybody can

The records, some of them in tatters, required delicate handling and care.
remember, it used to be the place where material related to old cases, criminals and procedures were sent for storage. It was both repository and dumping space, with rooms full of tattered files, many dating back to the British Raj.

This hidden collection of criminality housed casework on some of India’s most sensational crimes and criminals, among them Ranga (Kuljeet Singh) and Billa (Jasbir Singh), hanged for the kidnapping and murder of two children of a naval officer, and Raman Raghav, the serial killer who terrorised Mumbai’s street dwellers.

When the Tata Trusts team took a look at the wealth of material in the archives, they proposed a project that involved preserving it with the aim that narratives for the Police Museum could be pulled out from here. “We needed the stories from the archives but we had no idea how to go about putting things together,” says a senior inspector who heads the archiving and conservation project. “The Trusts saw the value of what we had and agreed to train us.”

**History's paper trail**

The historical worth of what the archives contains is high. “Any social or political history of Mumbai with law and order references would be incomplete without the documents we have here,” explains a senior member of the Mumbai Police Foundation (MPF). “For example, [VD] Savarkar was detained and questioned in this building. We have the chair in which he sat. Nathuram Godse’s confession is here. If you look at all the papers, the evolution of India’s politics — from freedom fighters to national parties — is recorded here.”

The exact value of what the archives holds is still to be determined but there is no doubting its significance. “We have not started studying the material in detail but we know that there is a lot of historically important information,” says a member of the MPF.

The Trusts came on board in May 2018 to fund the project and provide guidance on archiving and paper conservation techniques. Since the Trusts could not fund the Mumbai Police directly, a separate entity called the MPF was created with the police commissioner as head. The commissioner called for volunteers and about 40 police personnel came forward.

These volunteers are regular police people who have opted to put down their guns and batons and work instead on a different facet of the organisation. “We knew about arrests, station diaries and court cases, but not archiving,” says one of the team members. “This project was a
challenge and all of the volunteers are learning something new.”

The task in front of the team was huge. The project started with 77 police digests — the earliest dating back to 1937 — each containing hundreds of pages of weekly reports from the office of the police commissioner. In addition, there were papers stuffed inside 800 wooden boxes and nearly 400 tin boxes, and even more tied up in files and cloth bundles, some from as far back as 1910.

Most of the labels on the files and boxes had faded and some of the oldest papers were in tatters. The project demanded expert help to salvage the material and put things in order. The archiving task was sourced out to Eka Archiving Services.

Eka director Deepthi Sasidharan calls the MPF archive an important resource on Mumbai through the 20th century. “However, any archive is only as good as the ability to find what one is looking for. The Eka team has sorted, catalogued and organised this archive, working alongside members of the police force who have learnt the basic procedures of archiving,” she says. Eka trained four volunteers in archiving methods: reading each document, identifying and recording key words, and creating an indexed database that is uploaded on a computer for easy retrieval.

The second part of the project was conservation and the Tata Trusts reached out to Himalayan Society for Heritage and Art Conservation (HIMSHACO), headed by well-known conservator Anupam Sah.

HIMSHACO trained a second group of volunteers in paper conservation, a long and painstaking process that involves numbering individual documents, airbrushing the dust and then deacidifying each sheet of paper to prevent further degradation. Once the sheet of paper is dry, it is lined on both sides with translucent sheets of very fine Japanese tissue paper, with attention being paid to repairing...
damaged spots and strengthening crumbling borders. “This technique will help these documents last several hundred years, if stored in ideal conditions,” says Paroma Sadhana, programme officer with the Tata Trusts who is coordinating the archiving and conservation effort.

A volunteer can process an average of eight sheets of documents a day — pages that are seriously damaged can take much longer — and the team covers about 150 a day. Once all the sheets of a digest are dry, they are stitched and bound in the original order, encased with a hard cardboard and bound with rexine and leather, with the title of the digest embossed on its cover.

Conservation and more

It was the sheer volume as well as the sensitive nature of the archives that led the Trusts team to decide that it would be better if police volunteers were trained to handle the work rather than engaging external experts. The archiving training took just six months, and the conservation training has been underway for more than a year and is yet to be completed.

“Conservation and archiving of all the papers is a huge task and it will take years to complete,” adds Ms Sadhana. Since not all the papers need to be handled with the same amount of care, MPF has deputed six police officers to go through the documents to assess what needs preserving.

Also, now that the archives have been organised, police personnel can more easily analyse the importance of the contents and, in time, allow the narratives preserved within to emerge for public viewing.

Although work is in full swing, the project has faced some challenges. Regular transfers and sudden calls to duty are par for the policing course, thereby disrupting the carefully planned schedule and process.

The original team of 40 has come down to 30. Additionally, Mumbai has had three commissioners of police in the last few years; briefing the new commissioner and tweaking the administrative chain of command invariably leads to delays.

However, each successive police commissioner has not only commended the project, but also supported it as well as the work of the volunteers. Setting up a management structure has been one of the biggest challenges of this project, one that has relied heavily on the commitment of the police volunteers under training, and they have more than delivered.

The grant from the Tata Trusts to the MPF came to an end on October 31, 2019. The deliverables included an archiving and conservation procedures manual that will help the MPF team maintain quality and train future volunteers. Key sections of these manuals will be translated into Marathi for ease of understanding.

In spite of the relatively modest paper conservation lab that has been set-up, the police volunteers are well equipped to continue the task ahead of them. What began as an initiative to set up a museum has expanded to become a full-blown archival effort. This should prove invaluable in preserving the countless stories of the men and women in uniform who have helped uphold the law in a difficult-to-police metropolis.

By Gayatri Kamath
Victims of crime deserve to have access to justice, assistance, restitution and compensation, but the policies and practices of our system are not good enough to reach these to them.” There’s a hint of despair in Pravin Khandpasole’s tone as he explains the ground realities facing those who have suffered violence in their lives.

But Mr Khandpasole, not one for dwelling too long on downsides, prefers to concentrate on solutions. That’s the objective with which he and his wife, Jyoti, established Disha, an Amravati-based voluntary organisation that supports victims affected by violent crimes.

Set up in 2008 and operating in Maharashtra, Disha is involved with victims and their families, the community and the official apparatus to create a more responsive criminal justice ecosystem.

‘Equality in access to justice’ is the objective for Disha, which has been backed by the Tata Trusts since 2014. A cornerstone for the organisation is its ‘victim assistance programme’ (VPA), which helps victims of violent crimes – including homicide, domestic violence and sexual assault – with legal guidance, counselling and rehabilitation, and through advocacy.

Support or help desks at police stations for those approaching the authorities, legal interventions, emergency aid, assistance in availing government schemes, training and educational sessions with the police and the judiciary – Disha and its social workers go
Showing the way back

Prithi (name changed) is one of Disha’s beneficiaries in Amravati district. Sitting in a dark room in her home, she narrates the tragedy that struck her life in 2018. “My eight-year-old son was going to school when he was kidnapped and brutally killed.” The child was from an earlier marriage and Prithi’s second husband, a heavy drinker, was hostile towards the boy. “When the police caught him, he admitted that he had killed my child,” says the distraught mother.

The police were understanding but the killer was soon out on bail. “He called me and threatened me,” says Prithi, “but thanks to Disha I have become bold and am not worried now.” Social workers from the organisation often call at Prithi’s home and help her manage her life and look after her six-year-old daughter. Disha has also provided legal help and encouraged her to take up odd jobs. “They coordinate with government officials to make things easy for me,” she adds.

Apart from homicide cases, Disha also supports victims of rape and sexual assault, where, in a majority of the cases, the perpetrator is a relative or a neighbour. One girl was barely four when she was sexually abused outside her house by a minor boy in the neighbourhood. After the attack, Disha volunteers helped the victim heal physically and psychologically, and also encouraged her to commence her education.

In another instance when an 11-year-old was sexually assaulted by her neighbour, the support and guidance provided by Disha volunteers helped the victim’s mother fight the community which was compelling her to not file a police complaint. The child is now a sprightly teenager, an expert at tailoring. She shyly shows off the dresses she has stitched, saying she wants to become a dressmaker when she grows up.

Another victim, a young boy, had been assaulted by a neighbour when he was seven. He has now grown into a lanky teenager, very protective about his younger brother and close to his mother. These are the people that Disha helps — through rehabilitation, counselling, legal backing, educational support and by providing livelihood opportunities. True to its name — which translates as ‘direction’ — Disha shows victims of violence and crimes the way back into the light.

Call for compensation

From its inception, Disha has been advocating with the Maharashtra government to formulate laws or amend existing ones to ensure compensation for victims of crimes. It has filed public interest litigations in the Bombay High Court seeking government compensation for dependents of victims.

In the context, Maharashtra Victim Compensation Scheme (MVCS), enacted in 2014, has been a boon. The scheme ensures payments of compensation up to ₹200,000 for loss of life, permanent disability, acid attacks, etc. “The amount is low but the legislation is a welcome step,” says Ms Khandpasole.

Women and children take up much of Disha’s attention. Its team works closely with women whose husbands have been killed by relatives or neighbours. “The wives often bear the brunt,” says Ms Khandpasole. “Apart from the loss of a
loved one, they also face alienation, especially if the perpetrator is a person of influence in the neighbourhood.”

Disha also manages help desks at more than 30 police stations in rural Amravati. Mr Kishore Tawde, the assistant police inspector at the Asegaon-Purna police station, believes Disha’s volunteers have been doing remarkable work by resolving domestic disputes, helping needy victims and by reducing the load on the police. “Such social service is very useful, especially in sensitive cases involving women and children,” he says.

The support groups that Disha runs encourage victims and family members to move on with their lives. Children need extra care. “Their education is often disrupted, so we try to bring them back into the stream and we help young adults with skills development to improve their employability,” says Ms Khandpasole.

Collaboration and close cooperation with the district administration and the police department are vital planks for Disha. It has developed training modules for the police and conducted training programmes at the Maharashtra Police Academy in Nashik and other police training centres. Disha also holds training sessions with the judiciary, medical officers
and public prosecutors to sensitise these key stakeholders.

In spite of all the effort, Mr Khandpasole is concerned that the progress being made is slow. “If you check the status of MVCS, it sometimes seems that things are as pathetic as they were in the past,” he says. Lack of push and commitment have undermined a scheme that came into force after Disha had filed a public interest litigation to ensure compensation to needy and poor victims across the state.

Crime aplenty but...
Official figures reveal that in most districts in Maharashtra with significant crime rates, there were few recommendations for compensation by courts and the scheme was hardly ever availed. In Mumbai, for example, there were 154 murder cases in 2016, but none of the dependents were recommended for MVCS. In Pune, out of 259 murders, only four applications were received for compensation — and they have yet to receive any payments.

“The scheme won’t work if victims and their relatives do not get guidance on processes or necessary documents,” says Mr Khandpasole, who believes that change will come only by working within the system and pushing for appropriate responses from judiciary and government officials. The Khandpasoles are keen that India should, like many developed countries, adopt the ‘victim impact statement,’ which allows victims to talk about their hardships and also takes into account their need for rehabilitation while passing an order or judgement.

Victims of crimes need to be heard, and then some. By shining a beam on their rights and their requirements, Disha has provided a voice to the powerless and the legal wherewithal for them to fight back.

By Nithin Rao
Thread-setters

It’s a women’s world in Assam’s handloom sector. Unlike other handloom centres such as Tamil Nadu and Uttar Pradesh, where men handle the weaving and women are restricted to pre-loom activities, in Assam women dominate the entire process, from spinning and dyeing to weaving and, ultimately, selling the finished product. Antaran, a Tata Trusts initiative, enables these women weavers to improve their skills and learn how to be entrepreneurs.

Renuka Kalita, from Nahira in Kamrup district, winds spun yarn on a bobbin in a pre-loom process.
Dipika Kakati and Mamani Kalita (Chapathuri village, Kamrup) prepare the warp, the base for weaving. Warping in Assam is still done using traditional methods.
Bijaya Das (foreground) and her sister, Thageshwari (Guimara village, Kamrup) provide finishing touches to the warp. Once the warp is completed, the process of denting and drafting the yarns follow, providing thickness and patterns to the fabric.
Lila Kalita (Chapathuri village, Kamrup) attaches the warp to the loom as she prepares for denting and drafting. This involves fitting the warp on the loom and layering the fibre according to the design.
Firoja Begum (Simina village, Kamrup) hangs the woven fabric out to dry after washing it to remove stains.

Pallavi Medok from Dhemaji weaves traditional Assamese designs.

Firoja Begum (Simina village, Kamrup) hangs the woven fabric out to dry after washing it to remove stains.
‘Sexual abuse is a social and health issue as well’

Anita Raj has a lot on her professional plate. A developmental psychologist and global public health researcher, she is the founding director of the Center on Gender Equity and Health at the University of California, San Diego (UC San Diego), and a professor in the institution’s departments of medicine and education studies. Dr Raj is also a ‘Tata Chancellor Professor of Society and Health’.

The quantity of Dr Raj’s responsibilities, while vast, is of less import than the quality of the research she has been involved with over the course of a strikingly brilliant academic career. UC San Diego has been both safe harbour and anchor for Dr Raj, who was born and lived in Mississippi, USA, before moving to Georgia to pursue her education, inclusive of a master’s and a doctorate.

Dr Raj, who has been an advisor to UNICEF and the World Health Organisation and has addressed the United Nations General Assembly on child marriage, speaks here to Christabelle Noronha about her work and her research. Excerpts from the interview:

It takes a thick paragraph to include all the work you are involved with, your research and your responsibilities. What’s the intersection?

If you want it in one sentence, I’m a professor whose research and academic courses focus on applying advanced social science and data science methodologies to understanding and eliminating gender inequities in global health and development. This work is not limited to the greater vulnerability of women and girls in the face of sexual violence and the ongoing ‘son preference’ in India. It also takes in the heightened exposure of men and boys in relation to issues such as occupational risk and alcohol use.

One of the best parts of my job is that my research is linked to my educational responsibilities at UC San Diego. I teach graduate courses on behavioural theory and its application to public health education models and to survey development. These are things we do on the ground in our field research as well.
How is developmental psychology responding to the complexities of the modern world? How has it changed down the years?

Developmental psychology, historically, emphasised individual cognitions and behaviours across the lifespan. Our approach now brings a more social and intersectional lens to this work, considering the role of social groups and social systems as well as the intersecting social inequities that unfold in the context of caste, income and, of course, gender.

For instance, ‘son preference’ is seen in India in quite unique ways, and tackling the problem requires cultural and contextual considerations. Similarly, female genital mutilation, a traditional practice that compromises the mental and physical health of girls, is seen in specific cultural contexts. You cannot rely on a cookie-cutter approach to deal with these concerns. Rather, you need cultural humility and participatory
engagement, allowing affected communities to be the guide in the search for practical and policy solutions.

When it comes to gender equity and health, how do the prisms through which we view the subject change from country to country, culture to culture? What stays the same everywhere?

Across societies, we see similarities in values and beliefs with respect to what men can do relative to women and, correspondingly, gender differences in opportunities and resources offered. Women, for example, are less likely than men to be employed, obtain equal pay for equal work, or move about freely in public spaces without being sexually harassed. In contrast, men are more likely than women to be employed in high-risk occupations and to have social or time restrictions placed on engagement with their children.

There are differences, nonetheless. India contends with son preference in ways and at levels seen in few other places in the world. Deep-seated cultural beliefs and restrictive gender norms ensure that this concern persists. We are finding in our research a shocking lack of change in excess female infant mortality.

India has had a plethora of government health interventions for socially vulnerable sections of its populace. To what extent has the purpose of these interventions been served? How can we, in your view, do better?

The structured and committed public health efforts in India can serve as a model to the world. The shifts we have seen in infant and child vaccinations and the reduction in social inequities, including gender inequities, is laudable. However, more clinical commitment from health systems and better value and support of community outreach efforts could strengthen this work.

There is much research documenting the value of ASHAs [accredited social health activists] in improving maternal and child health outcomes, but these are incentivised rather than salaried positions, undermining their value in clinical care and for the community. Additionally, while health systems have worked to improve outreach to our most socially vulnerable families, this has not included families in which son preference may compromise the survival of girl infants.

How critical is the mother-and-child equation in public health and the delivery of it? What’s holding India back here?

Improvements in institutional delivery, antenatal care, childhood vaccinations, etc. are well documented and this demonstrates the strength and capacity of the Indian health system. Concerns include ensuring a strong and valued workforce and, in particular, our largely female frontline providers, among them nurses and ASHAs. Devaluation, mistreatment and overburdening of these cadres of providers compromise quality of care in

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**No country for women**

- India has topped a list of 10 countries rated to be among the world’s most dangerous for women (survey by Thomson Reuters Foundation, 2018)

- Nearly 360,000 cases of crime against women were registered across India in 2017 (National Crime Records Bureau)
delivery and also result in high turnover and vacancies in these positions, affecting access to care.

**How do we get more committed doctors and other medical staff, professionals who can fulfil their responsibilities?**

I think the key is to provide stable salaries and a supportive work environment. In that sense, I do not think this is an obstacle just in India. We have many countries with high rates of unemployment and, simultaneously, a nursing shortage. India has a highly qualified physician workforce, but the number of these physicians, especially female physicians, in rural areas is low. Again, this is not unique to India.

We have some upcoming studies regarding the value of financial compensation, respect and support for nurses and ASHAs, as well as access to female physicians in rural India. I think India is in a unique position to create a model of higher quality care through better treatment of its healthcare workforce, especially its vastly female frontline providers. The evidence is clearly there to show the value of this approach. What’s needed is political will.

**MeToo provided an avenue for those who had suffered sexual harassment to have their say. How has the movement evolved, globally and in the developing world, since it burst into public consciousness?**

One of the most important elements of progress I have seen come out of the MeToo movement and, preceding it, the Nirbhaya case in India is greater recognition that the ‘shame’ is on the abuser, not the abused. Women sharing their names and experiences, publically and demanding accountability, is a societal shift. My generation of women should thank my daughter’s generation for demanding this change in society. More, certainly, can and should be done, but this developing shift against shaming and blaming victims is progressing.

An important first step is to recognise that sexual harassment and assault — all forms of violence against women, in fact — are not just criminal justice issues but social and health issues as well. There is not always sufficient evidence or agreement in an incident of violence, but that does not mean the person making the accusation does not feel traumatised.

What perhaps warrants even greater attention is that these abuses are occurring on a daily basis, and with impunity. People are largely in agreement on what constitutes abuse, but they do not feel it is their place to say something when they see or suspect it. I think that is why the ‘Bell Bajao campaign’ was so influential. Apps from Safetipin for women in India have been used to mark locations and experiences of public sexual harassment. These are wonderful examples of collaborations to affect change. They speak to the value of social change efforts that go beyond criminal justice reforms.

“One of the most important elements of progress I have seen come out of the MeToo movement ... is greater recognition that the ‘shame’ is on the abuser, not the abused.”
Sexual abuse in India is on a scale that has led to it being considered the most dangerous country in the world for women. How can Indian society rein in the horror?

I think the report of India being the most dangerous country in the world for women is questionable. But our research has found that the reporting of such crimes remains rare, and conviction rates have not improved at all. India and, frankly, all nations and societies have to recognize to a much greater extent that these abuses are unacceptable, whether they occur in marriage and in families or on the street, and that those engaging in them should be held accountable.

You are a ‘Tata Chancellor Professor of Society and Health’ at UC San Diego. How did this come about and what does it entail?

My chancellor at UC San Diego, Pradeep Khosla, brought Mr Ratan Tata to our campus and I was invited to meet him to share information about my work in India. I am not sure how I got so lucky to have been selected for this opportunity, but I think it may be because I feel a genuine connection and love for India, where I have worked for more than 15 years. Though I was born in the United States, I define myself as Indian. This is my heritage and my country and I’m proud to be Indian.

How did you get interested in public health and why did you decide to make it your chosen field of study and scholarship?

My parents absolutely wanted me to be a physician; it just was not my interest or passion. But they instilled in me a sense of social responsibility and the recognition that good health makes for strong societies. Public health is about ensuring good health and high-quality healthcare for all, and I liked the combination of social contribution and methodologic rigour in research that this field offers. It is also multidisciplinary, so I get to work with physicians, nurses, economists, political scientists, engineers and policy experts. I am constantly learning new things and getting to work on building solutions using multilevel and sustainable approaches.

Of all the themes you have researched or been otherwise involved with, what interests you the most and why?

That is so hard. I love all the things I get to do. That is the best part of my job. I am always learning and we have so much diversity in the subjects that we tackle. I come from a background of sexual and reproductive health and maternal and child health, but we are looking at issues such as climate change and health now. It is amazingly interesting.

It is particularly stimulating that I work more with Indian academic institutions. We have a partnership with the International Institute for Population Sciences [in Mumbai], where we get to have our students and postdoctoral fellows and junior scientists train together. This has been both fun and fulfilling.

“The structured and committed public health efforts in India can serve as a model to the world.”
UC San Diego appears to have been both lode star and home base for you. What is it about the institution that appeals to you? UC San Diego is an extremely creative and collaborative environment, with brilliant and really nice professors and students. If you can think it, then you can find the partners to create it with you. At the same time, if someone else thinks it, they bring you in to be a part of creating it. Team science is really fostered, so it is common to see groups comprising physicians, psychologists, engineers, economists, demographers, political scientists, education experts and public health researchers working together to tackle problems.

Given the many ‘work’ hats you have on, how do you make time for ‘life’? What about pursuits outside of work?
My family is central to my life. I am married to an amazing person [Jay Silverman] and he is a professor at UC San Diego who just happens to work in my field and is also a professor with the same institution. We have a daughter in college and a son in high school. We are close to my parents and siblings and their families as well as my husband’s parents and siblings and their families. That keeps me grounded.

Given that my husband and friends are part of UC San Diego, a lot of creative work ideas get generated during walks on the beach and dinners out. But it never feels like work; it just feels like fun.
There is no understating the importance of design and innovation, which are central to the idea and the ideals of working for the benefit of all stakeholders.

The call for business to play a larger role in society is being heard around the world. In addition to corporate social responsibility initiatives and philanthropic efforts, companies are trying to incorporate social impact into their operations. The chief executives of 181 American companies recently signed a pledge with Business Roundtable, the nonprofit based in Washington DC, to run their companies “for the benefit of all stakeholders — customers, employees, suppliers, communities and shareholders.” Delivering on this promise, however, depends on more than just good intentions. It demands innovation and design.

The challenges companies are grappling with today — sustainability, skilling, health and security among them — require widespread collaboration and experimentation. Design, a process of synthesising different ideas and preferences and motivating behavioural change, is crucial in this context. Successful design also inspires people far outside their industries. Apple’s offerings, for example, motivated many companies to sharpen usability. The ‘one laptop per child’ idea had its difficulties but it revealed a commitment to reaching the world’s poor and forced their peers to consider inclusion. The success of the product was limited, but the importance and urgency around the vision has grown as inequality has increased worldwide.

Companies and nonprofits embracing design can potentially impact more people than ever before. More than a billion people have moved out of extreme poverty since 1990, there is a global payments infrastructure in place, and cellphones are everywhere. ‘Big data’ exists for rich and poor alike today and the narrative of business as a force for good has gained traction. Design can deliver profit and impact in the following ways:

**Design transforms market size**

There is perhaps no better testament to the power of design than the rapid adoption of cellphones. The first generation of these phones were comically large and bulky, and the market for them could not have been expanded to current levels even with lower prices. A better understanding of the consumer, rapid experimentation, new business models, improved infrastructure and the overload of features in today’s cellphones illustrates the power of innovation to transform a ‘want’ into a ‘need’. Policymakers can create an enabling environment and incentives, but business leaders and social innovators must imagine and manifest consumer aspirations.

**Design increases social impact**

Ideas, even the very best ones, do not have an effect in a vacuum. Even where profit is not the central objective, innovation (in offerings as well as narratives) is required to drive behavioural change. The concept of Indian independence, for instance, existed for at least 50 years before Mahatma Gandhi. But it was not until the
creation and widespread adoption of the spinning wheel and the narrative of self-sufficiency that the objective was realised. Many of the success stories of innovation in history and in technology reinforce this message – great design must increase inclusion.

**Design helps people cope with change**

The study of innovation tends to focus on identifying trends. However, several of these changes are felt and experienced before they can be precisely measured. For example, most people understand that many families today have two working parents, that fathers are choosing to take a more active role in parenting, and that there are same-sex couples raising children. Designers must serve as ‘translators’ — helping people cope with change, not merely describing it. This can start with simple and meaningful steps, like putting a diaper-changing station in the men’s restroom.

The excitement about design can at times seem at odds with reality, as we have also become aware of its potential to harm. Algorithms control many aspects of our daily lives, our behaviour and preferences can be more easily tracked, and business models can be engineered to favour some parties at the expense of others. I believe all of these issues underscore the importance of understanding design well enough to raise the issues in time and make the necessary corrections.

My father, the late CK Prahalad [management expert and Padma Bhushan awardee], always emphasised that innovation is not just about ideas; it is also about ideals. The big success stories of business and social innovation in the past decade share a common thread — the willingness of the organisation to struggle with questions of fairness and equity. Apple had brilliant design but it could only deliver that special experience because it found a way to tap and compensate the efforts of hundreds of thousands of programmers outside its walls.

Muhammad Yunus, the Nobel Peace Prize winner, did not change banking because he discovered a new mathematical theorem. He began with deep empathy. An abiding concern for fairness will make the difference between the companies and countries that create opportunities and the ones that create and attract opportunists. Today, consumers are adding their voices and choosing to engage with businesses that align with their values. Your design will show them your values.

*A portion of this piece was adapted by Ms Prahalad from an earlier submission: Thinkers 50 – Innovation@Work*
Young at 60, active at 80

Retiring the worn-out concept of workplace retirement is an appropriate way for India to begin a national discourse on happy and healthy ageing

In this age of alternative thinking, there is one vital battle that we all must fight — against the idea of retirement. As a society, Indians — typically urban, male, middle class and in the service sector — believe in the holy grail of retired life starting at 60. There is an overwhelming desire to set aside the office briefcase, let the railway pass expire, bid goodbye to colleagues and settle down to a life of ease. And deadening boredom.

That attitude has to go. It’s a stereotype and we need a social movement to change it, much like the movement against patriarchy. Why? There are several reasons, and they are tied up with economic and personal health.

Let’s crunch some numbers. It’s true that India is a young nation, with about 372 million children below the age of 14 and only 100 million above 60. But as the decades pass swiftly, that ratio is going to reverse. Several demographic studies for India have projected that the number of senior citizens in the country will cross 300 million by 2050. That’s close to the population of the United States.

Better healthcare and food security have led to increased longevity. India had only 0.4% of citizens over the age of 80 in 1950. This number has now jumped to 0.9% (in a much larger population base) and will reach 2.6% of an estimated 1.7 billion people over the next three decades. That means about 45 million 80-plus geriatrics to be cared for. Additionally, over 70% of all seniors will be in rural areas, putting that much more pressure on the government and its social services.

India cannot afford to have such a large and unproductive citizen base. China’s ageing population and economic slowdown should be a warning bell for us, a signal to urgently start changing our civic and social infrastructure to deal with the needs of the elderly. Germany, the United States, the United Kingdom, Japan and Australia are among several nations that are working to raise their pension age towards 70. It is well past time India walks the same path.

Old but not out

As individuals, too, we cannot afford to retire as early as 60. To sit idle and not be actively engaged is an invitation to illness. The number of noncommunicable diseases linked to sedentary lifestyles are increasing by the day. On the other hand, we see around us a number of shining examples of active senior citizens who continue to enjoy a full life.

Indeed, seniors can be significant contributors to the economy rather than a liability to be accounted for in the national budget. Also, there are untapped business opportunities in unitising the talent pool and abilities of senior citizens.

It is time to start a national discourse on what makes for happy and healthy ageing. We need to build a social fabric...
where 60 is not an expiry date for productivity. Attitudes need to be altered; no more thinking of rest, retirement or relaxation. Instead, we need to find passions, pursuits or a purpose. Elders can and should think about volunteering, community engagements, re-skilling, second job opportunities, etc. Through such continuous engagement, we can keep mind and body alert.

Another point that needs debate is the role of the government in dealing with the elderly. World over, governments are creating programmes and institutions for seniors. But in South Asian cultures, and India in particular, the traditional belief is that the family is responsible for its aged. That needs to change as well.

**Start with healthcare**
The government has to recognise that our growing demographic of silvers needs attention. Healthcare is a good place to start. India has introduced the National Programme for Health Care for the Elderly (NPHCE) but the allocation for it in the 2017-18 union budget was just ₹105 crore, later revised downward to ₹80 crore. That is woefully inadequate for a national scheme.

The other issue is that budgetary funds for elderly care are distributed across myriad schemes promoted by more than a dozen union ministries. Although the government has introduced a number of benefits for seniors, their impact is lost because there is no mission to address the issue holistically. We need a single ministry and a strategic plan, based on data, to drive new ideas and innovative programmes enabled by technology.

A significant part of the Tata Trusts’ elder care programme involves advocacy and engagement with the Ministry of Social Justice and Empowerment and the Ministry of Health and Family Welfare. The Trusts’ programme is aptly named Elder Spring. The interventions here are based on making ageing healthier and less stressful. Towards that end, we have started three verticals: strengthening healthcare systems; enabling systems for happy ageing; and a toll-free response system (14567 in Hyderabad) for seniors.

In the rural sector – specifically in Chandrapur in Maharashtra, Medak in Telangana and Yadgir in Karnataka – we are helping the state put into operation a comprehensive health initiative by facilitating NPHCE. Under this programme, primary health centres focus on geriatric clinics for one day in the week. About 30,000 people have received health cards and services through the project.

In Bhubaneswar, Odisha, we have started an activity centre where seniors engage in yoga, music, dance, art and more. The centre has received a tremendous response and we are in conversation with the government to expand the initiative. The vision is that every ward in the city should have one such physical space where seniors can participate and remain active. In this model, we encourage user fees to involve the community in the centre’s running. We also encourage corporate entities to participate in setting up such centres in partnership with the government.

The Trusts are tweaking this urban model for rural regions. The concept of a rural recreation space for elders is alien to India because the rural elderly have no retirement; typically, they continue working until they are too frail or ill. We are working with village councils to start activity centres that will be run by government-appointed workers or volunteers (we now have 42 such centres in Maharashtra, Karnataka and Telangana). The elderly come for two-three hours a day
and participate in different group activities. The vision is that every village should have one such space, funded by the local council.

The third intervention is a toll-free helpline in Hyderabad that we call a connect centre. Volunteers listen, converse and engage with seniors and help them manage issues such as loneliness, pensions and legal cases. About 14,000 calls have been received in just seven months. We have served 3,500 people and assisted in rehabilitating more than 100 homeless cases.

We offer information mapped to Hyderabad city (such as contact details for old-age homes), emotional or counselling support (for seniors who face harassment), backing in cases where homeless seniors are rescued from the street, and legal advice in property and abuse cases. This platform will aggregate all the information related to various service providers in the elderly care sector. The intention is to grow towards a national platform that can serve the seniors of this country, a public-private partnership with central and state governments on board and support from companies.

All of the Tata Trusts’ interventions in elder care are meant to help build a senior-friendly environment and find innovative solutions to care delivery and engagements. The belief is that an active mind and body can keep health issues at bay and reduce the burden of care for families and society.

The need of the hour in India is for stakeholders to collaborate and work together to support our young demographic in participating in the development and growth of the economy, even as it ages over the next three decades. We need to encourage the new philosophy of ‘re-living’ instead of ‘retirement’ at 60. That is the essence of the Tata Trusts’ Elder Spring programme.