A MONOGRAPH

Investing In Cancer Prevention

A Decade and Counting

Narotam Sekhsaria Foundation

“

Today we fight.
Tomorrow we fight.
The day after, we fight.

JIM BEAVER

”

ACKNOWLEDGEMENTS
This report presents the work of Narotam Sekhsaria Foundation in cancer care and prevention over the last decade. We would like to thank every author who has contributed to the monograph and guided us in our endeavours, as well as all the people who have worked tirelessly behind the scenes to make our work possible.

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Contents

“By the time you finish reading this sentence, two people will be diagnosed with cancer.”

1.0 Introduction

1.1 PREFACE

Cancer Treatment In India: The Way Ahead

PADMINI SOMANI
DIRECTOR
NAROTAM SEKHSARIA FOUNDATION

It would be obvious even to a casual onlooker that cancer care in India is fraught with problems. The majority of Indians are unaware of cancer symptoms and they fail to catch it early; less than 30% of the cancer cases in India are detected in stages I/II.[1] Many Indians lack the knowledge that cancer can be linked to environmental or lifestyle factors.

The state also fails them with its inability to ensure adequate and evenly distributed facilities. Many districts do not have the pathology and cytology services that can diagnose cancer, resulting in many patients being left undiagnosed and, therefore, untreated. Moreover, cancer treatment facilities are located in metropolitan regions and the cost of availing them is exorbitant.

India lacks a uniform cancer prevention strategy despite the disease's high prevalence. There are no uniform or dedicated information, education, and communication (IEC) modules, resulting in governmental and civil society organisations carrying out cancer awareness programmes in an ad hoc manner.

As there is no universal cancer screening programme, a majority of the patients in India are diagnosed at an advanced stage, leading to higher mortality rates and higher expenditure. Consider paediatric cancer which enjoys a high rate of successful treatment worldwide, but not in India due to the lack of access to quality care and support systems. Our end-stage cancer patients suffer because there isn't adequate awareness or availability of oral morphine, which can relieve cancer-related pain.

Most cancer programmes in India are funded by the central government, while smaller initiatives are supported by the private sector. The National Cancer Control Programme (NCCP) was

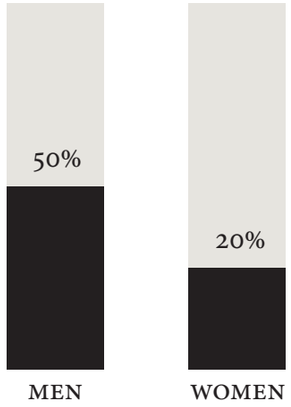
1 E&Y Call for Action: Expanding cancer care in India, July 2015.

established in 1975–76, which, in turn, promoted the setting up of regional cancer centres and oncology wings in medical colleges, and supported the purchase of tele-therapy machines. A district cancer control programme, too, was initiated but could not be sustained. However, the sad truth is that all these investments are simply too inadequate to meet the growing demands for cancer treatment in India.

With this background, the Narotam Sekhsaria Foundation is committed to contribute to cancer care with a life cycle approach.

Prevention

At least 30% of India's cancer burden is potentially preventable by tobacco control. The most useful prevention strategy is reduction in consumption of all forms of tobacco. Currently, about 50% of cancers in men and 20% of cancers in women are related to tobacco use. Tobacco addiction is the primary cause of head, neck, and lung cancers in India. Unless checked, in the next decade tobacco will cause more than one crore deaths. These cancers can be prevented to a large extent through a comprehensive tobacco control programme, which should include awareness, education, legislation, community participation, and tobacco cessation services. A healthy lifestyle helps prevent many noncommunicable diseases such as cardiovascular disorders and diabetes. Therefore practices such as getting adequate physical activity and avoiding alcohol should be a part of overall health promotion programmes. Cancers related to infectious agents such as the human papilloma virus and the hepatitis B virus can be prevented through vaccination strategies. Hence, the foundation would like to deepen its interventions in the area of cancer prevention by supporting tobacco control initiatives.



Cancers related to tobacco use.

Early detection

Early detection and immediate treatment is the only way for cancer treatment to be effective. Spreading awareness about cancer and its early signs is the most important requirements. For example, creating vigilance about lumps, sores that do not heal promptly, abnormal bleeding, persistent indigestion, and hoarseness.

Evidence shows that instead of universal cancer screening, it should be carried out only when its efficacy has been confirmed. Large-scale screening programmes should be introduced only when there are adequate human resources available to perform the tests; facilities for diagnosis, treatment and follow-up of individuals; and the prevalence of the disease justifies the effort and the cost incurred for the universal screening. Considering the latest population-based data, screening can be advocated for cancers of the cervix and the breast. It is important that such programmes concentrate on those at greatest risk of invasive cancer: this would mean women aged 35–60 years for cervical cancer and women aged 40 years or more for breast cancer (mammography programmes can focus on those aged 50–69 years).

The foundation is keen on focusing on two important aspects of early detection:

1 Early diagnosis of cancers that are curable if detected early: Cancers of the cervix, breast and mouth can be treated successfully if early detection is promoted using public education and training of primary healthcare workers.

2 Population-based screening: Identification of people with asymptomatic disease by conducting simple tests.

Treatment

The foundation believes that good quality cancer treatment facilities should be available to everyone, irrespective of their paying capacity. The standard way to go about this would be to formulate guidelines for integrating treatment resources with early diagnosis and screening programmes, and to provide therapeutic treatment in cancer hospitals. All aspects of curative treatment such as surgery, radiation, chemotherapy, hormone therapy facilities should be available to, the most crucial being the availability of trained human resources and new technology. The foundation will intensify its focus on capacity building so that trained professionals are available to all cancer hospitals.

Palliative Care

We believe that all cancer patients should have a pain-free life, irrespective of the possibilities of cure. Palliative therapy and care, including symptom control and pain relief, are important in developing countries because a large number of patients cannot avail of curative therapy. The foundation's commitment to palliative care focuses on the following programmes:

- Creating a conducive environment through policy-level changes.
- Making systemic changes that will enable the availability of oral morphine at all levels of healthcare facilities.
- Integrating palliative care in cancer management.

"We believe that everyone should have access to high-quality cancer treatment, regardless of their socioeconomic situation."

Well-wishers

The foundation's work has evolved over the years with guidance from experts in the field who are also our well-wishers.

I am immensely grateful to Dr Sultan Pradhan for his scientific and programmatic direction in shaping the head and cancer support programme at the foundation. His relentless support and advice has helped us in developing the programme, taking it to scale and creating an evidence-based model.

I would like to thank Dr Vish Viswanath for his support in introducing scientific rigour and a strong research component in the tobacco cessation programme implemented by the foundation. We are confident that under the leadership of Dr Vish, the foundation's partnership with the Harvard School of Public Health, India centre, will create several meaningful avenues for the interaction between academia and civil society organisations.

Dr Anil D'Cruz deserves a special mention for partnering with the foundation in furthering the goal of capacity building in the head and neck cancer space.

Dr Bachi Hathiram and Dr Vicky Khattar, have contributed in demonstrating a successful public-private partnership model in head and neck cancer treatment in Mumbai.

After working for a decade on prevention and curative aspects of cancer care, when the foundation decided to integrate the arm of palliative care, Dr MR Rajagopal provided us with the opportunity to partner with and learn from the initiatives of Pallium India.

Our partners on the ground, MASUM, Gram Shikshan Foundation, St Jude India, Salaam Mumbai Foundation, and Sanjeevani have given us the opportunity to support some innovative and path breaking work.

1.2

The NSF Journey

2003

Instituted fellowships for head and neck cancer surgery at Prince Aly Khan Hospital (PAKH) and Tata Memorial Hospital (TMH).

2008 – 2010

Initiated cancer research at PAKH.

2009 – 2010

Organised head and neck oncosurgery conference at King Edward Hospital (KEM).

Funded the NGO MASUM for early screening of cervical cancer as well as for capacity building at the grassroots level.

2010 – 2011

Provided institutional grants to TMH, Sion and Nair Hospitals for capacity building and equipment.

2010

Set up a 16-bed oncology ward at PAKH.

Launched Tobacco Awards for organisations working in the field of tobacco control. The organisations are rewarded with monetary grants.

2012

Organised orientation and training of PAKH physicians and administrators for tobacco cessation at Mayo Clinic's Nicotine Dependence Treatment Center, USA.

2013

Initiated LifeFirst programme for tuberculosis patients, through the Revised National Tuberculosis Control Programme (RNTCP) in the Vasai-Virar region.

Funded a community level, advocacy-based tobacco control programme across 33 Maharashtra districts.

Supported early screening for cervical, breast and oral cancers as well as strengthened referrals for speciality care through Gram Shikshan Charity Foundation.

2014 – 2017

Collaborating with the Salaam Bombay Foundation on 'Global Bridges Grant by Pfizer' to build capacity of tobacco treatment specialists in India.

2015

As part of the Global Bridges Grant, launched a series of training programmes to build capacity in tobacco cessation in partnership with the Dana-Farber Cancer Institute, Affiliate of Harvard Medical School, Boston, USA.

1.3

Cancer Burden In India: Extent, Causes and Challenges

LENI CHAUDHURI
VICE-PRESIDENT
NAROTAM SEKHSARIA FOUNDATION

Extent

Cancer has become the biggest threat to humankind not only in India but globally. It's the second most common disease after cardiovascular disorders to cause maximum deaths in the world (Jemal et al., 2007). In India, with around 700,000 people dying from cancer every year, it is one of the leading causes of death. As per the Indian Census data cancer is the seventh leading cause (accounting for 5.4%) of the total medically certified deaths across India. A million new cancer cases are diagnosed in a year in India. Data from the National Cancer Registry Programme shows that cancers of the oral cavity, lungs, oesophagus, and stomach are most common among Indian men. Cancers of the cervix, breast and oral cavity are the leading cancer sites among Indian women.

Lung Cancer The National Cancer Registry Programme of the Indian Council of Medical Research (ICMR, 1988–89) collected data from six different parts of the country, including both rural and urban areas. It showed that Delhi has the highest number of cancer cases among the five metropolitan cities studied. The total number of cancer patients reported in Delhi was 13,920, with 6,815 males and 7,105 females. Delhi was followed by Mumbai with 8,505 cancer cases (4,170 male and 4,335 female). The third in the order was Bangalore with 5,250 cancer cases (2,262 male and 2,998 female) and Chennai came fourth with 4,824 cancer cases (2,296 male and 2,528 female).

Breast Cancer The most widely prevalent malignancy type diagnosed among women in India is breast cancer (Yeole et al., 2003). According to a survey conducted by ICMR from 1982 to 2005 in Delhi, Mumbai, Bangalore, and Chennai, the incidences of breast cancer have doubled. There has been a steep increase in the incidences of breast cancer in India with around 100,000 new patients being diagnosed every year (Yip et al., 2006; Michael et al., 2003). The cancer registries have recorded a 12% rise in cancer prevalence between 1985 and 2001, which amounts to a 57% increase in cancer. (Yip et al., 2006; Hadjiiski et al., 2006).

Stomach Cancer Among all forms of cancer the fifth most prevalent in India is that of the stomach (Parkin et al., 1999). In India, stomach cancer is most prevalent in the northeastern states. According to the National Cancer Registry stomach accounts for cancer in males in Chennai from 1990 to 1996 with Age Adjusted Rate [(AAR) = 13.6/105], followed by Bangalore (9.5/105), Mumbai (6.4/105), Delhi (3.9/105), Bhopal (3.4/105) and Barshi (1.2/105). In Mizoram, AAR of stomach cancer has been found to be high in both males (39.1/105) and females (14.4/105) as compared to other parts of India.

Gallbladder Cancer With an incidence rate of 4.5 to 10.1 per 100,000 population, gallbladder cancer is the most common form of malignancy in the northern part of India (ICMR, 1996. Singh et al., 2004). It was first diagnosed during laparotomy and laparoscopy procedures, which were expected to confirm the presence of benign gallbladder diseases (Misra et al., 1997). The cases of gallbladder cancer are the highest in the Ganges delta (Kaushik et al., 1997). 70%–90% of patients with gallbladder cancers have gallstones associated with gallbladder carcinoma and 0.4% of all patients with gallstones have gallbladder cancer (David et al., 1997).

Cervical Cancer During last few decades, cancer of the cervix has emerged as the most widely prevalent form of malignancy among women (Parkin et al., 1992). Though population based studies on the prevalence of cervical cancer are not available in India, a few micro studies show that the number of cervical cancer cases has been decreasing. According to a study conducted in Bangalore in 1982, every year 32.4 cases per 100,000 population were reported which dipped to 27.2, 18.2, and 17.0 in 1991, 2001, and 2005, respectively. Some years later a study conducted in Delhi showed that 25.9 new cases of cervical cancer per 100,000 women were reported. Similarly, Mumbai recorded 17.9 new cervical cancer cases per 100,000 population in 1982 followed by 12.7 in 2005. Chennai showed similar results where in the past two decades cervical cancer prevalence had a 50% decline, with 41% in 1982 decreasing to 33.4% in 1991 and 22.0% in 2005.

Delhi had the highest number of cancer cases in the 5 metros.

Oral Cancer According to ICMR data the incidence of oral submucous fibrosis has been increasing, contributing to the occurrence of oral cancer (Gupta et al., 1998). At present, oral cancer is the fourth most prevalent in males after lung, stomach and liver cancers; oral cancer is the fifth most common cancer among females after cervix, breast, stomach and lung cancers (Park, 1997). According to Regional Cancer Centre (RCC), Kerala, oral cancer comprised 14% of all cancers, out of which 17% cases were in males and 10.5% in females (Padmakumary, 2000). The Agra, Allahabad, Mainpuri, Varanasi and Moradabad belt of Uttar Pradesh also reported high incidences of oral cancer. (Wahi et al., 1965).

With

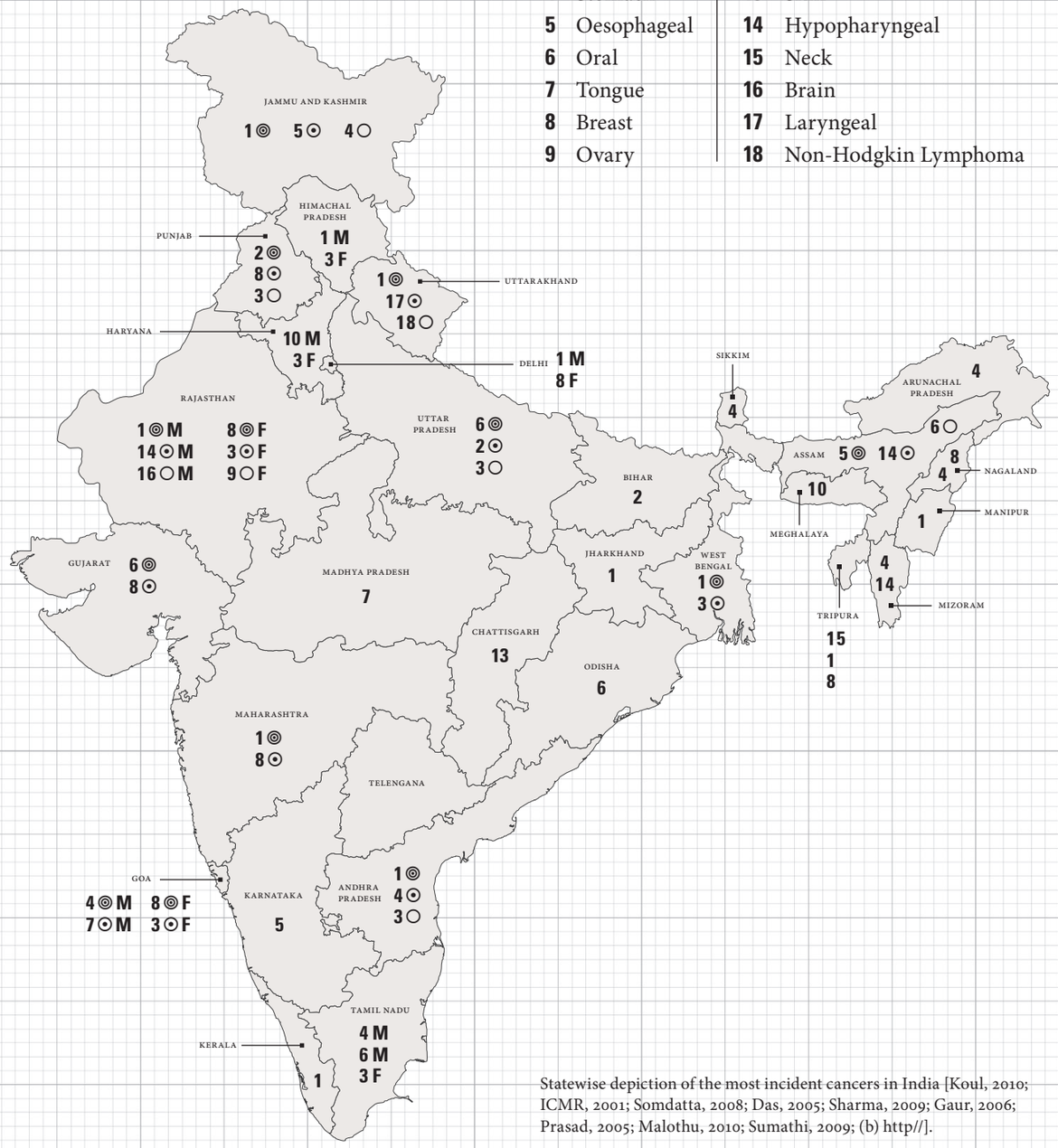
700,000

Indians dying from cancer every year, it is a leading cause of death.

Cancer incidences in India: A state-wise depiction

M Males	◎ Highest incidence
F Females	⊙ Second-highest incidence
	○ Third-highest incidence

1	Lung	**10**	Oropharyngeal
2	Gallbladder	**11**	Prostrate
3	Cervical	**12**	Nasopharyngeal
4	Stomach	**13**	Skin
5	Oesophageal	**14**	Hypopharyngeal
6	Oral	**15**	Neck
7	Tongue	**16**	Brain
8	Breast	**17**	Laryngeal
9	Ovary	**18**	Non-Hodgkin Lymphoma



Statewise depiction of the most incident cancers in India [Koul, 2010; ICMR, 2001; Somdatta, 2008; Das, 2005; Sharma, 2009; Gaur, 2006; Prasad, 2005; Malothu, 2010; Sumathi, 2009; (b) http//].

Cancer Prevalence Across Indian states:

According to the National Cancer Registry data, lung cancer is the most common cancer across states in India. The most affected states are Jammu and Kashmir, Himachal Pradesh, Delhi, Uttarakhand, Rajasthan, Maharashtra, Jharkhand, West Bengal, Andhra Pradesh, Kerala, Tripura and Manipur. The second most prevalent form of cancer is that of the cervix. States of Himachal Pradesh, Haryana, Rajasthan, Goa, and Tamil Nadu have very high incidence of cervical cancer, followed by West Bengal, Punjab, Andhra Pradesh, and Uttar Pradesh. Breast cancer is most widely prevalent in Himachal Pradesh, Delhi, Rajasthan, Nagaland, and Goa, and the second most common form of cancer in Punjab, Maharashtra, and Gujarat. Stomach cancer is the third most prevalent in India, with the highest incidence in Sikkim, Arunachal Pradesh, Tamil Nadu, Mizoram and Goa. Stomach cancer is the second most common cancer in Andhra Pradesh and Nagaland, and the third most common type of malignancy in Jammu and Kashmir. Head and neck cancer is widely prevalent in the east and northeastern parts of India. States of Jammu and Kashmir, Assam, and Karnataka also have very high prevalence of esophageal cancer. Oral cancer occupies the third position among all cancers in Goa and Assam. Though not very common, gallbladder cancer has been diagnosed in certain parts of Punjab, Uttar Pradesh and Bihar. Madhya Pradesh has highest incidence of tongue cancer followed by Goa. Haryana and Meghalaya have high records of Oropharyngeal cancer. Cancers of the skin, laryngeal and non-Hodgkin's lymphoma are not very common in India and few cases have been diagnosed in Chhattisgarh and Uttarakhand. Few cases of ovarian cancer, brain cancer and prostate cancer have been reported at some places in Rajasthan.

Causes

Chemical, biological and other environmental factors are responsible for the proliferation of carcinogens. When carcinogens intermingle with the DNA of normal cells, a series of complex multi-step processes occur which are then responsible for uncontrolled cell proliferation or tumours (Carmaeia, 1993). Both internal factors like hereditary mutations, hormones, and immune conditions and environmental factors such as tobacco, diet, radiation, and other infectious agents can cause cancer. A large number of cancers are caused due to lifestyles and food habits (Helbock et al., 1998). Data shows that when compared with the Western world, Asians have 25 times and 10 times lower proportion of prostate and breast cancers respectively, which may be due to the nature of their lifestyles.

The most common forms of cancer in India are those of lung, cervix, breast, stomach, and head and neck.

Tobacco consumption is the biggest cause of cancer in India. Smoking, chewing, and snuffing tobacco contribute to 65% of the cancer occurrences in men and 85% of the cancer occurrences in women. Tobacco consumption can cause cancers of the oral cavity, pharynx, esophagus, larynx, lungs and urinary bladder. Tobacco smoking in the form of bidi (a thin, South Asian cigarette type structure—tobacco flakes wrapped in a tendu leaf, tied with a string at one end) (Behera et al., 2004) and cigarette (Notani et al., 1974) cause 87% of lung cancers among males and 85% among females. After tobacco, alcohol consumption is the next major reason for cancer, particularly colorectal for cancer (Baan et al., 2007).

Cancer Prevention and Control

There are four key approaches to cancer control—prevention, early detection, diagnosis, and treatment and palliative care.

Prevention In the fight against cancer, prevention is the most crucial approach. Prevention is an effective, inexpensive long-term method of cancer control. Public health education focusing on the detrimental effects of tobacco, alcohol, and obesity, creating awareness about the benefits of physical activity, promoting healthy dietary practices, reducing occupational and environmental exposures, immunization against hepatitis B virus and safe sexual practices are key factors in preventing cancer (Dinshaw et al.).

Screening and Early Diagnosis The cancers of the oral cavity, uterine cervix and female breast can be detected early through periodic screening. Pap smear and mammography are the accepted standards for early detection of cervix and breast cancers in developed countries. The prevalence of cervical cancer has reduced significantly in India and abroad through regular screening. Though there are no international standardised practices for early detection of oral cancers, oral examination with adequate light is a reasonably good screening method for early detection of pre-cancerous lesions of the oral cavity.

Challenges

Systemic Barriers The National Cancer Control Programme along with the establishment of the 21 Regional Cancer Care Centres had a huge impact on cancer treatment in India. But while the programme positively affected the field of radiation oncology, it did not create any successful prevention and screening programmes. As a result there is no organised screening programme for any of the common cancers in

the country and most cancer centres provide only opportunistic screening services. The allocation of resources is skewed towards treatment rather than prevention and there is a poor recognition of low technology approaches. Other major barriers include:

- Lack of essential drugs and minimum standards of healthcare in low-income countries (including India) and amongst disadvantaged populations.
- Lack of appropriate human resources.
- Lack of effective linkages with control programmes of other diseases (other noncommunicable diseases, HIV/AIDS, reproductive health, etc.)
- Lack of effective intersectional approaches necessary for primary prevention.
- Insufficient involvement of the community and nongovernmental organisations.

Key macro solutions for cancer control:

- Formulating comprehensive cancer control strategies.
- Reducing the cost of treatment.
- Developing public health programmes that address the allied causes of cancer (tobacco, nutrition, and infections).

Limitations of Screenings Although there is enough evidence to show that mammography can lead to considerable reduction of mortality from breast cancer, particularly among women above 50 years, high costs of screening facilities and imaging technology hinder the adoption of the method as a routine public health measure. Since the facilities are largely available in the private sector, it is used by women who can afford it, rather than those who need it. This skews the availability and accessibility of the facility. The incidence of cervical cancer has been arrested globally due to the widely used cytology based examinations. In India there are major limitations in conducting the cytology based examinations due to the absence of trained manpower, infrastructure, logistics, quality assurance, frequency of screening, and costs involved.

Treatment From a public health gain perspective the most efficient way to address the problem of cancer is to have an expansive prevention programme, and effective and primary healthcare. A good referral mechanism and tertiary care facilities complete the cycle. In India, most of the tertiary care facilities are provided by the private health sector. However, considering the most people from the lowest wealth quintile need access to good tertiary care facilities, there is a need for greater public investment in health. Programmes such as the National Rural Health Mission, Rashtriya Swasthya Bima Yojna and others have definitely improved people's access to healthcare. The Regional Cancer Care Centres at Ahmedabad, Chennai, Guwahati, Mumbai, and Thiruvananthapuram, and their outreach programmes, have been an important step in this direction. However, the challenges due to non-availability of specialists, high drug prices, and skewed distribution of radiation therapy still make cancer care inaccessible to a vast majority of the Indian population.

Smoking, chewing, and snuffing tobacco contribute to

65% and 85%

cancer incidences in men and women respectively. Tobacco consumption is the biggest contributor of cancer in India.

Palliative Care

Although the World Health Organisation has defined the foundation for palliative care to be integrated in any healthcare system, patients in India suffer due to lack of trained human resources, adequate number of hospices or home-based palliative care services, leafing to a severe shortage of pain relief facilities.

Economic Burden of Cancer

Indians are at high risk of acquiring cancers due to steep rates of smoking, tobacco use, occupational risks, and unhygienic living conditions. Since there is a huge gap between the proportion of cancer patients and the availability of treatment facilities, there is a heavy burden on the economy of the country. Though the data on the effect of cancer on Indian economy is not available. However, some indirect assessments can be made on the basis of direct expenses such as buying medicine, hospitalisation, pathological tests, physician fees, travel, lodging. Indirect costs of cancer include loss of income during treatment, premature death and effect on the income of other family members. Together they are a huge economic burden (Popkin et al., 2001). In 2007, Abegunde et al. calculated the effect of cancer deaths on Indian economy. According to the study, there has been a steady increase in the number of cancer patients as well in the extent of the country's economic burden. By the end of 2009, there were 9,62,832 cancer patients in India and cancer's economic burden was USD 274.10 million. Similarly, the number of cancer patients in 2010 was 9,79,786 with a total economic loss of USD 270.06 million. This shows a direct relationship between the number of cancer patients and economic loss.

Conclusion

There is enough knowledge available globally to explore the burden of the disease on the population and the economy, and allocate adequate resources for maximum impact. Since a large proportion of cancers is preventable, it is important to develop a network of preventive programmes which are evidence-based and ensure equitable access to, and provision of, quality care. The programmes should include a treatment delivery system which is sensitive to cultural differences, individual attitudes, and other determinants of access to healthcare. At a macro level, important steps include formulating comprehensive cancer control strategies, reducing the cost of cancer treatment so that people can afford it irrespective of their financial condition, and developing public health programmes which address the allied causes of cancer such as tobacco addiction, unhealthy eating habits and infections.

1.4

Economic Transformation and its Healthcare Ramifications In India

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India is on the cusp of profound social transformation that cuts across education, politics, culture and health. The significant advances India has made in its economy are only matched by the far-reaching impact of these changes on health. While the economic transformation has received considerable attention, the growing demand for health services and the need for catering to the health requirements of more than a billion people needs more concerted, determined, and thoughtful planning and execution.

There are two unique features of social changes in India that have significant implications for public health. One is the epidemiological transition where the burden due to chronic disease such as cardiovascular disease and cancer is growing along with the continuing burden from infectious diseases. Two is the demographic transition where declining fertility rates are matched by a large cohort of young people whose public health needs will determine the course of demand for health services for the next few decades.

Take chronic disease, for example, which imposes a significant burden, resulting in 6 out of 10 deaths. It is not just the sheer number that is disturbing but

"Unlike in advanced industrial economies, cancer deaths in India are rising among those 70 years and younger, indicating a growing burden."

the fact that most of these deaths occur in the most productive years of life, 30–70 years. This gives an idea of the burden imposed by chronic disease in India. Cancer, too, is a significant burden. About a million new cases of cancer are recorded every year, accounting for 600,000–700,000 deaths in 2012 (Mallath et al., 2014). More interesting, unlike in advanced industrial economies, cancer deaths in India are rising among those 70 years and younger, indicating a growing burden. Most common cancer among women is breast cancer, followed by cervical cancer, and, among men, it is lung and oral cancers. Oral cancer incidence is increasing and shifting to younger ages (Gupta, 1999; Gupta et al. 2014). The estimated economic burden of noncommunicable diseases (NCDs) will be close to USD 6.2 trillion for the period of 2012–30.

Another feature of note about the state of health in India is that while India has made significant strides in improving public health, the benefits have not accrued equally across population groups and geographies. For example, those from lower socioeconomic position face a disproportionate burden compared to the higher socioeconomic position groups (Gupta et al., 2014; Reddy, 2011; Reddy et al., 2005).Similarly, while the overall fertility rates have declined steadily, the rates are much higher in rural areas compared to urban areas. Similarly, fertility rates are disproportionately higher in certain states.

Addressing these growing problems is, as they say, not rocket science. For example, we know that close to 50% of the cancers are preventable if we address risky behaviours associated with tobacco use and energy balance (nutrition and physical activity), eliminate infections, and provide access to screening and preventive services such as pap smear and HPV vaccination. Effective interventions to promote healthy lifestyles and preventive behaviours exist, although we need to learn how to implement them at a large scale.

So, what can be done? What is called for is a multilevel and multi-sectoral approach that marshals resources from public, private and nonprofit sectors to intervene at individual, community, organizational and policy levels. The comprehensive approach to cancer prevention covered in this monograph is an outstanding demonstration of such a multilevel and multi-sectoral approach. The actions and activities driven by the Narotam Sekhsaria Foundation—which brings together public and private sectors and intervenes across different levels from people in remote tribal districts to major urban hospitals—demonstrate how interventions adapted and customized to Indian conditions can be effectively used to make a dent in the cancer burden. In addition, the work here also showcases how interventions need not always lead to differential outcomes for different social classes. In fact, work by the Salaam Bombay Foundation is an excellent example of effective intervention in tobacco prevention at a younger age among children in materially deprived circumstances. What is less appreciated is that the impact of intervening in preventive services goes well beyond the focus of the intervention—say tobacco prevention—to developing the life skills to tackle other issues at the individual level, and the creation of a platform to address other social burdens at the societal level. Such a "halo" effect is not always noticed or appreciated, but is worth noting.

This monograph provides an outstanding roadmap of what can be done to stem the cancer burden with leadership from a nongovernmental organization that brings together varied actors to work on prevention, and create an impact at scale.

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2.0

Building Professional and Infrastructural Capacities

2.1 FOREWORD

The Role of Public-Private Partnerships In Tackling Head and Neck Cancers

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Cancer is a leading health problem in India with a prevalence of 2 million to 2.5 million, with approximately a million new cases added each year. A third of these cases are head and neck malignancies, making them the most common cancer among Indian men. Tragically, around 70% of those afflicted are diagnosed with advanced disease.

Until recently, head and neck cancer specialty was literally a no-man's land, handled only by general surgeons and Ear, Nose, and Throat (ENT) specialists. Even among cancer hospitals, only a few had dedicated head and neck teams. This was an anomalous situation since the incidence of head and neck cancers in India (and elsewhere in South Asia) is high due to widespread tobacco chewing, making it a peculiarly regional disease. Compare this with North America, where head and neck cancers are uncommon, and tobacco smoking takes a toll in the form of lung cancer.

Until the mid-1970s the Tata Memorial Hospital (TMH) in Mumbai was perhaps the only institute that provided acceptable standards in head and neck surgery, with three units dedicated to this subspecialty. Even here, there was no Indian database and surgeons followed Western treatises for guidance on treatment. In due course, successive TMH teams developed new surgical techniques suited to the Indian context, collected and analysed data, and organised training programmes for young surgeons in every part of the country. These initiatives were soon replicated in the All India Institute of Medical Sciences in Delhi, the Gujarat Cancer Research Institute in Ahmedabad, the Kidwai Memorial Institute of Oncology in Bengaluru, among others. The spotlight was on head and neck oncology and many wanted to practice it, but training opportunities were woefully few.

It was against this backdrop that the Narotam Sekhsaria Foundation came forward as one of the

first philanthropic organisations to establish training fellowships at TMH and PAKH to increase the limited number of institution-sponsored fellowships that were then available. These fellowships allowed doctors in general/ENT/maxillo-facial surgery to take up head and neck surgery. Over the years, scores of trained and committed head and neck surgeons completed these fellowships and have taken up leadership positions in various parts of India. However, since trained surgeons choose to join private institutions, the needs of the poor remained unattended. The Narotam Sekhsaria Foundation stepped in once again with another initiative called public-private partnerships (PPP).

The World Health Organisation advocates PPP as an important component of health sector reforms, particularly in developing countries. And while the Indian government policies seem to echo this recommendation, there are very few successful models.

In 2005, the Narotam Sekhsaria Foundation mooted the idea of a PPP to merge the skills and entrepreneurial spirit of the private sector with the reach and welfare orientation of the public sector. This resulted in partnerships between the ENT departments of Nair and Sion Hospitals, both medical colleges of the Municipal Corporation of Greater Mumbai (BMC), with the department of surgical oncology at PAKH, a private institution. To its immense credit, the BMC quickly endorsed the proposal and agreements between PAKH and the two BMC hospitals were signed in early 2008.

The objectives of this PPP seem modest, but go a long way in bridging the demand-supply gap. The programme familiarises ENT specialists with the clinical presentation and management principles of head and neck cancers. The PPPs also seek to ignite, in a few, an interest in head and neck oncology. Most important, such PPPs help hone the skills of head and neck surgeons to ensure better patient outcomes.

At present, robust partnerships operate at both locations. Patients are examined and treated surgically at municipal hospitals. And, in case of special requirements, they are transferred to PAKH and operated free of cost.

Week after week, over the years, trained head and neck surgeons from PAKH went to these two medical college hospitals to operate, supervise and guide. Today, ENT faculties at both these hospitals regularly perform complicated head and neck surgeries. It took time to get where we are, but that's in the nature of such advanced training. Meanwhile, hundreds of patients have benefited from being treated with the highest standard of care. The beneficiary institutions have become centres of excellence in head and neck care. Associated facilities like speech and swallowing rehab, counselling, and palliative care are needed for ENT departments to emerge as truly regional referral centres. As always, much remains to be done.

Today, the Narotam Sekhsaria Foundation continues its support, as it has over the years, by providing finance, high-end equipment, encouragement and inspiration. Both the fellowship programmes and the PPPs bear living testimony to the high commitment, vision and leadership of the men and women behind the Narotam Sekhsaria Foundation.

"Until recently, head and neck cancer specialty was literally a no-man's land, handled only by general surgeons and ENT specialists. Even among cancer hospitals, only a few had dedicated head and neck teams."

NSF Hospital Partnerships

LINKING PUBLIC AND PRIVATE HEALTHCARE SECTORS

Lokmanya Tilak Municipal Medical College and General Hospital
Mumbai

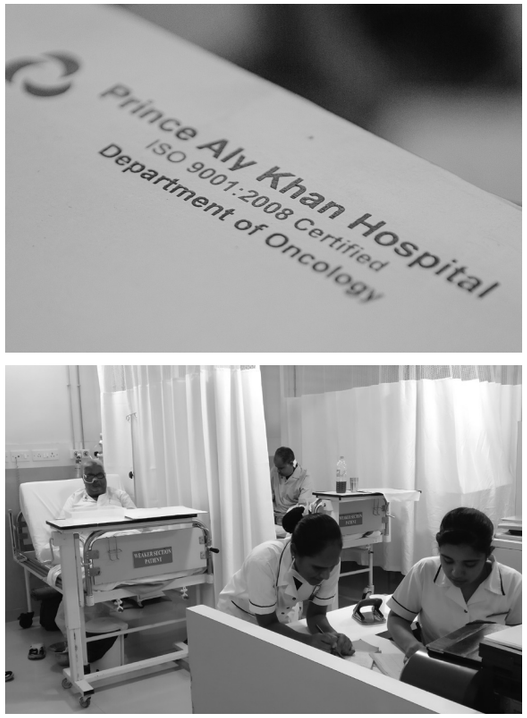
Commonly known as "Sion Hospital," Lokmanya Tilak Hospital is managed by the Municipal Corporation of Greater Mumbai. The hospital has about 1,500 beds and is best known for its trauma-care facility. Its doctors attend up to 6,000 outpatients daily, and treat over 80,000 patients admitted here annually.

The Narotam Sekhsaria Foundation aided a key infrastructure upgrade of the hospital's ENT and Head and Neck Surgery department. It helped the hospital obtain the much needed Valleylab Electrosurgical Cautery Equipment.

TN Medical College and B.Y L Nair Charitable Hospital
Mumbai

Located in central Mumbai, Nair Hospital is a 1300-bed multispecialty tertiary care centre. With 250 senior staff members and 400 resident doctors (mainly postgraduate medical students), this public hospital cares for over 1 million outpatients annually. The total number of hospital admissions exceeds 37,000 every year.

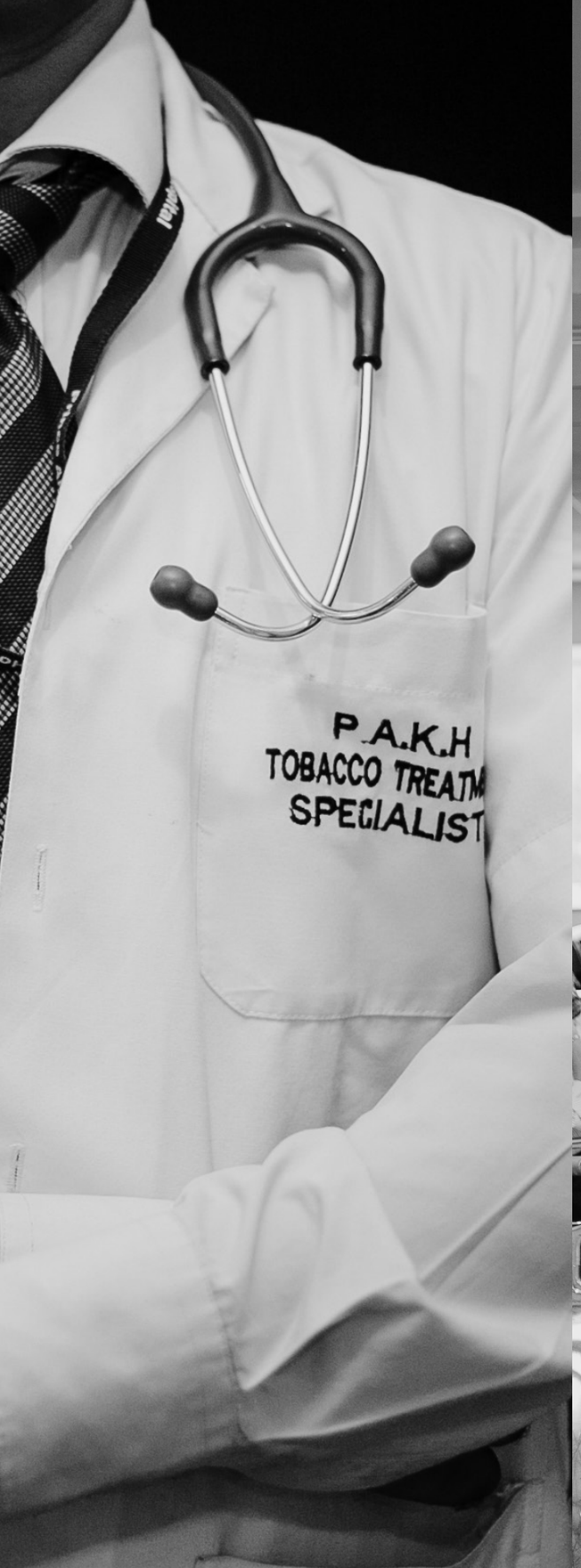
The Narotam Sekhsaria Foundation assisted with an infrastructural upgrade of the ENT and Head and Neck Surgery department. With the foundation's support, the department now has Valleylab Electrosurgical Cautery Equipment.



Prince Aly Khan Hospital
Mumbai

Equipped with a three-room operating theatre complex, an intensive care unit, an intensive cardiac care unit, a neonatal ICU and a renal dialysis unit, the 167-bed charity-run hospital offers state-of-the-art infrastructure. Almost a third of the 125,000 patients who visit the outpatient department every year don't pay any hospital fees.

The Narotam Sekhsaria Foundation has partnered with Prince Aly Khan Hospital to construct a specially designed, 14-bed oncology ward, along with equipment support and staff capacity building in laryngotracheal surgery.



Public-Private Partnership Vision

Combine the knowledge and skills of the private sector with the reach and welfare orientation of the public sector to address the demand-supply gap.

Setting Up a PPP For Head and Neck Cancer Surgery

DR SULTAN PRADHAN
CHIEF OF ONCOLOGY SERVICES
PRINCE ALY KHAN HOSPITAL, MUMBAI
AND
DR KAMAL CHEEMA
FORMER CEO
PRINCE ALY KHAN HOSPITAL, MUMBAI

Prelude

In its official policy statements, the World Health Organisation (WHO) advocates the setting up of public-private partnerships (PPP) as an important component of health sector reforms, especially in developing countries.

Although PPP has been a buzzword in India for years, there are only a few success stories. A case in point is the partnership between PAKH, a private institute, and two institutes run by the Municipal Corporation of Greater Mumbai (BMC), Lokmanya Tilak Municipal General Hospital and BYL Nair Hospital. This partnership successfully serves the needs of patients suffering from head and neck cancers, a major health problem in the Indian subcontinent.

The Problem

Cancers of the oral cavity—larynx, pharynx and sinuses—as well of the neck are conventionally grouped under head and neck cancers. They comprise over 25% of all cancers in India (in contrast, head and neck cancers make up for only 4% of all cancers in the United States). The high prevalence, attributed largely to rampant tobacco chewing in South Asia, makes head and neck cancers a peculiarly Indian or Subcontinental disease.

Head and neck cancers comprise over 25% of all cancers in India; in contrast, they make up for only 4% of all cancers in the United States.

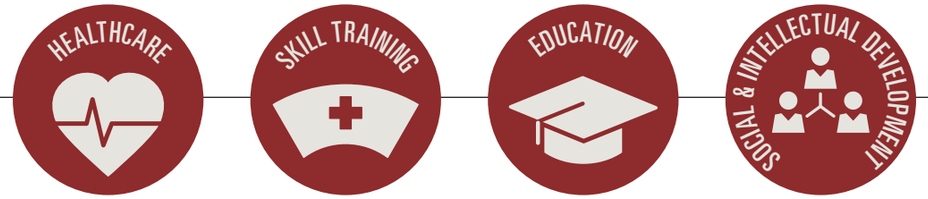
Even though surgery is the primary form of treatment for a large majority of these cancers, head and neck surgery was the most neglected subspecialty of surgery until recently. There were too few surgeons training in head and neck surgery to help manage the 250,000 to 300,000 new cases occurring among Indians annually. It is estimated that only 10% to 15% of the patients suffering from head and neck cancers reach treatment centres that offer a reasonably acceptable standard of care.

Established Regional Cancer Centres in the public sector try their best to cope with the caseload, but it is often beyond their capacity. For this reason it is not unusual to find patients registered with early cancer become inoperable during the long wait for surgery.

Every year

30,000

new cases of head and neck cancers are diagnosed in India but only 10% to 15% of the patients receive standard care.



The Solutions

Several cancer centres do an excellent job of offering residencies and fellowships for training in head and neck cancer surgery. Professional societies and foundations focused on head and neck oncology, too, conduct laudable work in organising conferences and workshops for the future generations of specialists. Even then, however, the gap between demand and supply remains wide.

For effective and quality treatment to become available to all, healthcare facilities closer to the grassroots (read: public hospitals) need to develop capacity. As the first step, a larger number of major hospitals in the public sector need to set up facilities to provide services for routine head and neck cancer surgery.

Head and neck checkups should become a part of the ENT departments of every medical college hospital in the public sector. Not only will this provide the underprivileged timely intervention, but also shorten the long waiting lists at cancer centres. Moreover, ENT postgraduate students will get adequate exposure and training to be able to handle such cases in their practice later on.

It is important to note that there is nothing lacking in terms of infrastructure in these ENT departments to perform routine head and neck surgery. The only shortcoming is the lack of training in the subspecialty. This training is best provided at the physicians' workplace so that the department's functioning doesn't suffer.

The Way Ahead

A step in this direction was taken when Mr Narotam Sekhsaria, chairman of the Narotam Sekhsaria Foundation, and Dr Sultan Pradhan, chief of oncology services at PAKH, put their heads together and came up with this vision:

"Combine the knowledge and skills of the private sector with the reach and welfare orientation of the public sector to address the demand-supply gap."

The result was a proposal of partnership between PAKH and the ENT departments at Sion Hospital and Nair Hospital, both respected organisations with niche specialties. Both Sion Hospital and Nair Hospital are also major teaching hospitals within the jurisdiction of the BMC, attached to medical colleges offering undergraduate and postgraduate courses.

However, the hospitals had little expertise in oncology. With the enthusiastic support of the heads of their ENT departments—and the willingness, direction, and support of Dr Sanjay Oak, director of medical education at these hospitals—a proposal was framed. The BMC quickly endorsed the proposal and agreements between PAKH and the two hospitals were signed in early 2008.

In order to ensure long-term sustainability of the model, the training was carried out at the municipal hospitals.

The objectives of the partnership are:

- To hone the skills of the ENT faculty interested in head and neck surgical oncology, enabling them to lead the subspecialty within the ENT department.

- To provide exposure to ENT postgraduate students and to familiarise them with clinical presentation and management principles of head and neck cancers, the outcome of which hinges on early diagnosis and treatment.

- To inspire ENT postgraduate students to pursue head and neck oncology as a career.

Current Status of the PPP

Robust partnerships operate at both the locations with the able leadership of the ENT heads, Dr Bachi Hathiram (Nair Hospital) and Dr Renuka Bradoo (Sion Hospital). Under the guidance of Dr Sultan Pradhan, PAKH surgeons operate regularly at these municipal hospitals to provide hands-on training to the ENT faculty. The local faculty is now performing a number of surgeries confidently. Over 800 patients have been examined and nearly 350 operated upon at the two municipal hospitals. If special days are assigned for head and neck surgery and OPD visits, the waiting time for patients will shorten while boosting general awareness of this important subspecialty.

The philanthropy of the Narotam Sekhsaria Foundation, which supports the human resource costs and has donated high-end equipment to the programme, has been central to the success of this PPP.

2.4 PUBLIC-PRIVATE PARTNERSHIPS (PPP)

Establishing State-of-the-art Head and Neck Cancer Services Along With Head and Neck Surgery at Nair Hospital

DR BACHI HATHIRAM
HEAD OF ENT DEPARTMENT
BYL NAIR CHARITABLE HOSPITAL,
MUMBAI

Our healthcare delivery system is constantly evolving, and justifiably so. The fact that our country is gradually becoming a hub for medical tourism indicates, to a large extent, the credibility of healthcare provided; of course, to a great degree that means the care provided by the private sector in the major metropolitan cities. But a large majority of the consultants working in private sector hospitals are products of public medical college hospitals. So it would be reasonable to assume that the knowledge imparted during the formative years would eventually impact the credibility of the entire nation's healthcare delivery system.

In 1997, the World Health Organisation (WHO) defined "Health Sector Reforms" as "a sustained process of fundamental change in policy and institutional arrangements of the health sector usually guided by the government." The organisation mentioned public-private partnerships (PPP) or "joint ventures" as reforms.

In this backdrop, let us consider the fact that over one-third of all cancers in India occur in the head and neck region. In the Western world, head and neck cancers account for less than 10% of all cancers. The high incidence of head and neck cancers in India is further complicated by the fact that there are few trained head and neck oncosurgeons, and the majority of them are located in metropolitan cities. Due to this paucity of expert surgical care, many patients are referred for primary radiation therapy, irrespective of the stage of the disease and possibility of a successful outcome. A dozen regional cancer centres spread throughout the country manage the bulk of the cancer patient load in our country. Many of these centres—government-funded—are overburdened with patients, with long waiting lists and no specialised head and neck cancer divisions. Hence, those who can afford it prefer treatment at private hospitals that handle a significant chunk of the country's cancer care.

The concept of health insurance in India, though growing in awareness, is not widely prevalent and affordability is a major problem.

Given their strengths and weaknesses, in order to operate in the best interests of the healthcare system, the public and the private healthcare sectors cannot operate in isolation. There is also a growing belief that the public and private healthcare sectors can potentially gain from one another. It is keeping these thoughts in mind that we embarked upon the pioneering task of establishing a PPP at the ENT department at the BYL Nair Charitable Hospital in Mumbai with the help of Dr Sultan Pradhan—one of the leading oncosurgeons in India—and his team from PAKH, Mumbai.

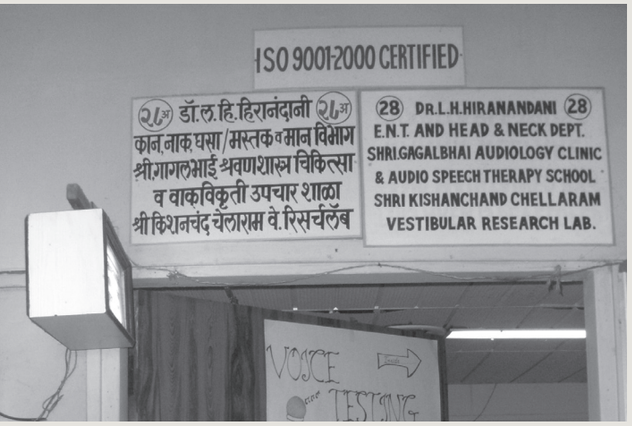
Why was this alliance needed in the first place? The ENT Department at Nair Hospital was already an established and prestigious academic tertiary care referral centre, offering services in ENT as well as head and neck surgery in the public sector for the last 40 years. However, there was no streamlined process for the patients. Moreover, PAKH was a renowned centre of oncosurgery, particularly head and neck cancer surgery, under the leadership of Dr Pradhan. It had always been Dr Pradhan's dream to have an outreach programme so as to increase the number of centres providing dedicated and quality care to patients of head and neck cancers, which are some of the leading causes of death in our country. Also, with his team of trained surgeons, Dr Pradhan had the manpower and ability to facilitate such an outreach venture.

The conception of this alliance was the brainchild of two stalwarts—Dr Sanjay Oak, the director of medical education and major hospitals at the Municipal Corporation of Greater Mumbai (BMC), and Dr Pradhan. After preliminary meetings, where the medical and administrative heads of both the institutions agreed to the joint venture in principle, began the Herculean task of obtaining the necessary permissions from the authorities concerned. As is always the case for anything beneficial to poor patients, the BMC was receptive to the concept, especially because it posed no financial burden on the corporation or the patient, and a few weeks and several documents later, the joint venture was sanctioned.

> "We have to keep in mind that the trainee of today is the consultant of the future. We must train him or her in the field of head and neck oncosurgery for the benefits to reach every afflicted individual."

On February 1, 2008, an agreement was signed between PAKH and the BMC-run Nair Hospital towards the establishment of the PPP for the purpose of developing head and neck oncology services as a specialty in the ENT department, and head and neck surgery at Nair Hospital. As per the agreement, all such surgeries were to be performed at Nair Hospital by a team comprising surgeons from both the hospitals. The patients would not pay extra for the expertise provided by PAKH surgeons. In addition, patients requiring LASER surgery for head and neck cancer would be treated free of cost at PAKH since Nair Hospital did not possess such a machine.

The management of head and neck cancers differs from cancer of other body parts, in that it affects



"There is a growing belief that the public and private sectors in healthcare can gain from one another. Keeping this in mind we embarked upon the task of establishing a PPP at the ENT Department of Nair Hospital in Mumbai."

numerous vital functions such as respiration, speech, swallowing, etc., besides having grotesque cosmetic defects/deformities that are difficult to conceal/correct. Such patients often require radiation and chemotherapy alone, or in combination with surgery. Their rehabilitation lasts from a few months to years, even after definitive curative treatment.

The department of ENT and head and neck surgery at Nair Hospital already had a lot going on in its favour. Nair Hospital is the only hospital under the BMC to have a radiation oncology centre. It is geographically located adjacent to the Nair Hospital Dental College, which is the only BMC-run dental college, and has a full-fledged prosthodontics department that provides prosthetic reconstruction for postsurgical patients if required. Nair Hospital is also the only BMC hospital to have an audiology and speech training school, which is important for post-operative rehabilitation of speech and for swallowing. The hospital also boasts of an efficient department of plastic surgery that carries out reconstructive surgery. Most important, the department carries the legacy of Professor LH Hiranandani, one of the world's best-known cancer surgeons of his time who established as well as promoted the department. Being an ISO 9001 certified department, it constantly strives for improvement and perfection in patient care.

Today, we can prove with statistical data and audits that the PPP has achieved resounding success. The programme is going strong and numerous philanthropists have regularly encouraged it with generous donations and grants, prominent among them being the Narotam Sekhsaria Foundation.

In the process of realising the dream of Dr Pradhan and Dr Oak, we have managed to bring under one roof state-of-the-art head and neck cancer care to the masses at a nominal cost, solely because of this PPP. This is truly the need of the hour given the rising number of head and neck cancers in our country. The fact that poorer sections of society with limited access to good healthcare are getting more afflicted with head and neck cancers as compared to the well-off sections, this need becomes all the more urgent. We hope this is the beginning of a movement wherein the lacunae in healthcare throughout the country can be filled and eventually lead to improved healthcare for the common man through such partnerships.

We do have to keep in mind that "the trainee of today is the consultant of the future," and strive to train him or her in the field of head and neck oncosurgery if we want the expertise to benefit every afflicted individual.

Developing Head and Neck Surgery at Lokmanya Tilak Municipal General Hospital

DR RENUKA BRADOO
HEAD OF ENT DEPARTMENT
LOKMANYA TILAK MUNICIPAL GENERAL HOSPITAL (SION HOSPITAL), MUMBAI

Mumbai has two parallel healthcare systems. One comprises the elite, tertiary care private hospitals that cater mainly to the well-heeled, higher echelons of society. The other, which is the workhorse, takes care of a much larger percentage of the population, and includes municipal hospitals.

The Municipal Corporation of Greater Mumbai (BMC) has three such major hospitals in the city. The fact that they are extremely overcrowded is common knowledge, but what very few know is that these are teaching hospitals with attached medical colleges, where future generations of doctors are trained and nurtured.

Public and private healthcare services have distinct identities and follow different paths. But every once in a while, these paths meet for a common purpose—and the result is special. One such private-public enterprise has been undertaken by Prince Aly Khan Hospital (PAKH) along with two municipal hospitals, namely Lokmanya Tilak Municipal General Hospital (commonly known as Sion Hospital) and the BYL Nair Hospital.

Not only are the ENT surgery departments at Sion and Nair Hospitals well-equipped, they are leaders in the field of medical teaching. However, the heads of department in both these hospitals—Dr Bachi Hathiram at Nair Hospital and yours truly at Sion Hospital—felt that a specialised service dedicated to managing patients with head and neck malignancies was a necessity.

The incidence of head and neck cancers in India is among the highest in the world. A major proportion of head and neck cancer patients in Mumbai receive treatment at Tata Memorial Hospital, run by the central government. The lack of separate oncosurgery programmes at general hospitals means they are able to treat fewer patients. Also, postgraduate students training to be surgeons in these hospitals have limited exposure to the management of head and neck cancer cases.

"Public and private healthcare services have distinct identities and follow different paths. But every once in a while, these paths meet for a common purpose—of excellent patient care—and the result is special."

Dr Sultan Pradhan, who, for more than two decades headed the head and neck oncosurgery department at Tata Memorial Hospital, is the current head of these services at PAKH. He offered to help set up specialised oncosurgery programmes at both Sion and Nair Hospitals. Over the past three years, more than 800 patients have benefitted from this programme. A separate oncosurgery OPD helps in early diagnosis of these patients. By allocating specific days in the operation theatre schedule for these patients, it has been possible to significantly reduce the waiting period for surgery.

2.6

Training Human Resources: Fellowship Programmes

Narotam Sekhsaria Foundation Head and Neck Fellowship Programme at Prince Aly Khan Hospital (PAKH) and Tata Memorial Hospital (TMH).

The fellowship programme was first instituted in 2003 under the guidance of Dr Sultan Pradhan at PAKH. Doctors with a specialisation in medical and surgical oncology were selected for this fellowship under PAKH's head and neck oncology programme led and developed by Dr Pradhan. Until 2013, 52 fellowships were awarded to young surgeons at PAKH.

In 2005, the programme was also introduced at TMH under the guidance of Dr Anil D'Cruz. 41 fellowships were awarded to surgeons at TMH until 2013. The fellowship amount is ₹50,000 for senior fellows, and ₹42,000 for junior fellows.

Support from the foundation has been directed primarily towards infrastructure development, equipment, and fellowships. The foundation has focused mainly on head and neck cancers.

NSF awarded 52 fellowships at PAKH and 41 fellowships at TMH to young surgeons.

Since 2008, the focus was on building capacity at Tata Memorial Centre for Research, providing infrastructural support and strengthening the professional capacity by sponsoring fellowships. From 2002 to 2016, ₹1.32 crore was invested by the foundation on these important developments.

Similarly, at PAKH the focus has been on building better infrastructural facilities and preparing professionals to cater to the urgent need for cancer care. From 2008 to 2013, ₹3.2 crore was invested for these purposes.

"

DR B KARTHIKEYAN

MS (ENT), NSF SURGICAL ONCOLOGY FELLOWSHIP—HEAD AND NECK ONCOSURGEON, SALEM, TAMIL NADU

I am immensely grateful to Dr Sultan Pradhan and NSF for transforming me into a confident and ethical head and neck oncosurgeon. The NSF Fellowship in Head and Neck Oncosurgery at PAKH, under the guidance of Dr Pradhan, is one of the few of its kind in India that equips one to practice the science confidently.

I appreciate and value everything I have learned from Dr Pradhan. The fellowship will forever remain a major contributory force in my future success and achievements. At present, I am a fellow in Italy, learning skull-based surgery under Professor Mario Sanna.

"

DR MARZI MEHTA

MBBS, MS (GENERAL SURGERY), NSF SURGICAL ONCOLOGY FELLOWSHIP, DNB (SURGICAL ONCOLOGY), TMH THORACIC ONCOLOGY FELLOWSHIP, MINIMALLY INVASIVE FELLOWSHIP, AUSTRALIA —CONSULTANT SURGICAL ONCOLOGIST (THORACIC), SIR HN RELIANCE FOUNDATION HOSPITAL, MUMBAI

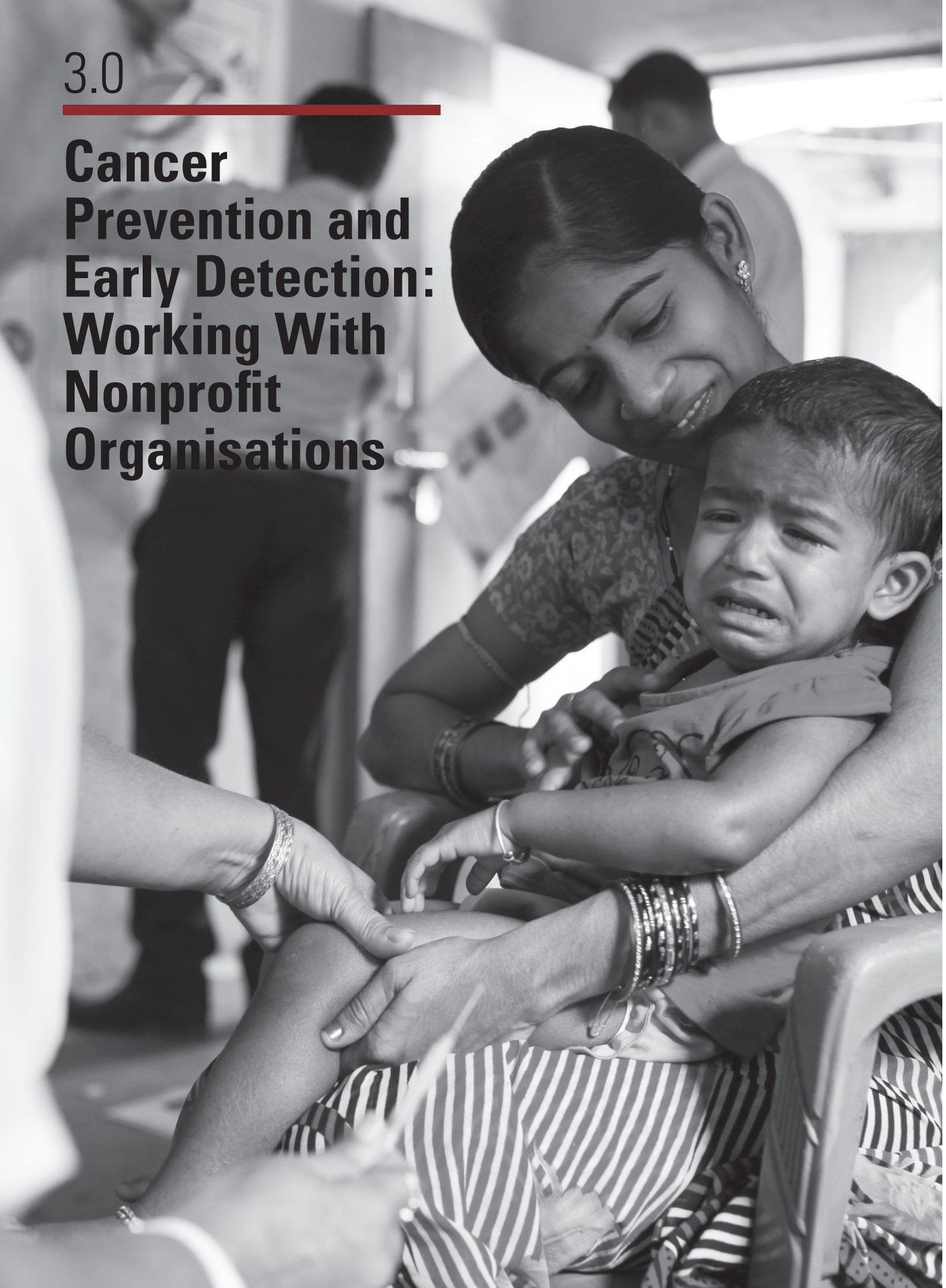
I had the great opportunity to work as an NSF fellow in the field of surgical oncology for two years. This fellowship formed the basis of my introduction to the world of surgical oncology. The training offered under this fellowship was on a par with the best in the world.

The best thing about the programme was the hands-on experience along with guidance from two most eminent surgeons, namely Dr Sultan Pradhan and Dr Rajan Kannan. I will always remember the enormous number of patients as well as the efficiency with which they were handled.

The fellowship, although in general surgical oncology, touched every subspecialty of oncology, providing for an overall development. It thus laid the foundation stone for my future training—in DNB (surgical oncology) at the same institution, in thoracic oncology at Tata Memorial Hospital, and in minimally invasive thoracic oncology training in Australia.

The NSF Fellowship taught me to respect the patients and provided 360-degree training that gave me the confidence to compete with the best in the world. I would encourage young surgeons interested in surgical oncology to undergo this fellowship.

“The NSF Fellowship taught me to respect the patients and provided 360-degree training that gave me the confidence to compete with the best in the world.”



3.0

Cancer Prevention and Early Detection: Working With Nonprofit Organisations

3.1

Adolescent Tobacco Use: A Need For Concern

DR NEHA PARIKH
SENIOR MANAGER
NAROTAM SEKHSARIA FOUNDATION

Globally, noncommunicable diseases have long been a cause for worry. At the sixty-ninth World Health Assembly, countries took stock of the measures to reduce the extent of noncommunicable diseases, including heart and lung disorders, cancer, and diabetes. The Director-General of the World Health Organization (WHO), Dr Margaret Chan, in her address said, "No country can hope to bring down the burden of noncommunicable diseases in the absence of strong legislation for tobacco control in line with the WHO Framework Convention on Tobacco Control."

Countries across the globe are waking up to the menace of tobacco and its long-term effects on the health of an individual. Adolescents are the most vulnerable population, highly susceptible to initiate tobacco use. It is now well established that most of the adult users of tobacco start tobacco use in childhood or adolescence.[1] The global youth tobacco survey shows that a disturbingly high number of school children between the ages of 13 and 15 are currently using or have tried tobacco.[2] Areca nut is the fourth most commonly used psychoactive substance in the world after nicotine, alcohol and caffeine.[3] The use of areca nut, commonly called *supari* in India, is considered harmless in India and is a socially acceptable habit in the country. Chewing of both areca nut and tobacco start early in life, usually as teenagers, leading to chronic compounded health problems in adulthood.

The use of areca nut and tobacco is the most important risk factor in the development of oral

1 Chadda, R., & Sengupta, S. (2003). Tobacco use by Indian adolescents. Tobacco Induced Diseases, 1(1), 8. http://doi.org/10.1186/1617-9625-1-8.
2 The Global Youth Tobacco Survey Collaborating Group. Tobacco use among youth: A cross-country comparison. Tob Control 2002;11:252-70.
3 Auluck A, Hislop G, Poh C, Zhang L, Rosin MP. Areca nut and betel quid chewing among South Asian immigrants to Western countries and its implications for oral cancer screening. Rural Remote Health 2009;9:1118.

premalignant lesions and conditions (such as oral leukoplakia and sub mucous fibrosis), gingival diseases, oral and oropharyngeal cancer, and addiction that lead to poor overall health of an individual. India leads the world in rates of oral cancer, with a high prevalence of tobacco chewing being a prominent risk factor. The WHO predicts that tobacco deaths in India may exceed 1.5 million annually by 2020.[4]

The prevention of use of areca nut, tobacco and *gutkha* could be regarded as the single most important preventive measure that can be taken to bring about impactful change in the occurrence of oral cancer in India. In spite of the known association of major diseases with tobacco, its control continues to be a challenge for health professionals and policy-planners alike.

The most important preventive measure is the prevention of use of areca nut, tobacco, and *gutkha*.

Cultural and Behavioral Influences

India is a country of diverse cultures and multiple religions. The prevalence of tobacco use, which is also based on religious and cultural beliefs, is also variable.

The common age of first experimenting with tobacco is 14 to 15 years. Curiosity and peer pressure are the main reasons for trying tobacco during adolescence.[5] Because of their impressionable, curious minds, adolescents are highly prone to a number of influences within and outside home, leading them to experiment with tobacco. The addictive nature of tobacco is potent enough to turn these experimental users into addicts.

Relationships with peers tend to be more influential than with family members for teenagers and youth, and friends have considerable say on their habits and choices. Tobacco use by family members also influences adolescents. They are more likely to perceive tobacco use as a positive and acceptable behavior if a parent is a tobacco user.

Although majority of adolescents seem to be well informed of the hazards of tobacco on health, the lack of complete knowledge—to some extent—has influenced adolescents experimenting with tobacco. The misconception of using smokeless tobacco as a treatment for toothache, headache and stomachache also promotes tobacco use among youth. Moreover, smokeless tobacco products are convenient to hide from parents and teachers, while also being less expensive, easier to use and easily available.

4 Bala DV, Bodiwala IN, Patel DD, Shah PM. Epidemiological determinants of tobacco use in Gujarat State, India. Indian J Community Med 2006;31:173-6.
5 Factors attributing to initiation of tobacco use in adolescent students of Moradabad, (UP) India, TL Ravishankar, Ramesh Nagarajappa.

Surrogate advertising of *gutkha* and tobacco is rampant in India with little or no regulation from authorities. Youth-targeted media advertisements, endorsements by leading movie actors, and sport sponsorships all play a vital role in youth initiating their first experiment with tobacco or areca nut.

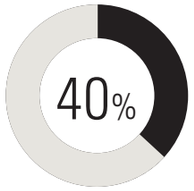
Socio-Economic Impact

Several studies have shown inverse gradients in tobacco use in India—with the exception of cigarette use—with generally greater use among poor, less educated, and disadvantaged caste and tribe groups.[6] The noted patterns may be attributed to differences in the penetration of tobacco control policies, and variations in awareness about the health consequences of tobacco use. Tobacco use disparities have also been linked to differentials in uptake among adolescents, type and quality of products used and patterns in the cessation of use, with education, social norms, and cultural practices being important drivers.[7]

Economic studies have shown that people are losing a significant part of their income to purchasing tobacco products. Studies reveal that poverty-stricken smokers spend up to 40% of their income on tobacco at the cost of their basic needs that in turn lead them them deeper into a cycle of poverty.[8] In a survey conducted in 2004 it was estimated that tobacco consumption pushes approximately 15 million people into poverty in India.[9]

6 Social disparities in tobacco use in Mumbai, India: the roles of occupation, education, and gender. Sorensen G, Gupta PC, Pednekar MS Am J Public Health. 2005 Jun; 95(6):1003-8.
7 Socio-economic patterning of tobacco use in Indian states. Agrawal S, Karan A, Selvaraj S, Bhan N, Subramanian SV, Millett C Int J Tuberc Lung Dis. 2013 Aug; 17(8):1110-7.
8 Efroymsona D, Ahmed S, Townsend J, Mahbubul Alam SM, Dey AR, Saha R, et al. Hungry for tobacco: An analysis of the economic impact of tobacco consumption on the poor in Bangladesh. Tobacco Control 2001;10:212-7.

Poverty-stricken smokers spend up to



of their income on tobacco at the cost of their basic needs.

Tobacco-induced morbidity and mortality cause considerable economic loss, both directly and indirectly. The direct cost is related to the loss of labour productivity and quality of life when ill. The indirect cost is the large healthcare expenses inherent in treating diseases that often contribute to impoverishment. For example, in 2000, three tobacco-related diseases—heart disease, stroke and cancer—caused the Indian government USD 5.8 billion in healthcare expenditure, in contrast to the revenue of USD 1.5 billion that the government collected from the tobacco industry.[10] Apart from the economic costs, the physical and emotional distress caused by morbidity and mortality—to tobacco users as well as their families—cannot be compared to the revenue generated from the industry.

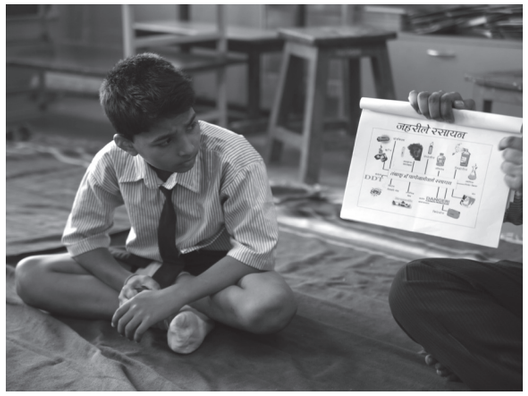
9 http://www.ijph.in/article.asp?issn=0019-557X;year=2011;volume=55;issue=3;spage=161;epage=168;aulast=Kyaing%23ref18
2004, National Sample Survey
10 Madur G. India Finalizes Tobacco Control Legislation. BMJ 2001;322:386.

The WHO predicts that tobacco deaths in India may exceed

1.5 million

annually by 2020.

The main challenge is to formulate effective strategies that motivate young children to not initiate tobacco use.



The Way Forward

In recent years India has taken commendable steps towards tobacco control, but lesser attention has been paid to mechanisms to help people quit. India has implemented newer laws for tobacco control with COTPA (Cigarettes and Other Tobacco Products Act), banning sale of tobacco products, banning sale to minors, and recently introducing 85% pictorial health warnings on cigarette packets. Raising tobacco taxes, banning advertising of tobacco products, smoke-free-environment policies, health education, and mass media campaigns are public health initiatives that increase awareness and decrease accessibility of tobacco products. Cessation and its related therapies, however, are still to receive their due.

Combatting the myth of smokeless tobacco as less harmful than smoked products is a sizable challenge in India. In the current scenario, the main challenges are to formulate effective strategies to motivate young children not to initiate the habit; help child and youth tobacco users quit the habit; and to create awareness among the children, parents and teachers about potential health hazards of these substances.

Young people differ from adults in the way they perceive and interact. Therefore school health education programmes should be adapted to emphasise harmful effects of areca nut, tobacco and *gutkha* on health.

कैंन्सर के प्रारंभिक लक्षण

सलाम
मुंबई

Salaam Mumbai Foundation: Using Community-Based Interventions

Grant: ₹ 2.77 crores.
Sanctioned between December 2011 and March 2016.

SALAAM MUMBAI FOUNDATION

The Salaam Mumbai Foundation was set up with a vision to decrease tobacco use across rural Maharashtra. The foundation believes in empowering communities, especially youth and children, to refuse tobacco and become "change agents" in their respective villages.

The Narotam Sekhsaria Foundation provided Salaam Mumbai Foundation with a three-year grant to make the schools and villages of rural Maharashtra tobacco-free zones. This was mainly done by initiating tobacco control through capacity building programmes that targeted teachers, village health functionaries, local government officials, youth, and like-minded NGOs.

19.9 crore
adults in rural areas use tobacco.

One in three child tobacco users starts before the age of 10.

Goal

To increase awareness of the ill effects of tobacco. Strengthening the enforcement and implementation of COTPA.

Strategy

By training of trainers, health workers and school teachers, the Salaam Mumbai Foundation built capacity at the local level to deliver tobacco control messages. Trained local influencers spread tobacco control messages to target groups across the state. Activities of master trainers included conducting workshops for teachers at the block level, rolling out school programs for tobacco control, conducting sessions with children, implementing tobacco-free schools, and conducting other awareness-building activities within the community.

Achievements

Today, the foundation's work spans 26 districts and 273 blocks in Maharashtra. In 2013–14 alone, it trained 1,241 master trainers, and over 13,000 teachers on the tobacco-free school criteria based on CBSE (Central Board of Secondary Education) guidelines. Similar trainings were conducted annually 2010 onwards. In a period of seven years, the foundation has succeeded in making five villages tobacco-free through community mobilisation, awareness activities, and advocacy at local and regional levels.

"

PRAMOD KHADSE
MANAGER, AMBUJA CEMENT FOUNDATION, CHANDRAPUR

With the combined efforts of health workers, stakeholders, students and teachers, we could make our village tobacco-free. This could happen only by involving villagers and inculcating in them a sense of ownership about the tobacco-free initiative so that they would be motivated to sustain it in the long run. We succeeded in encouraging all stakeholders in the village and can proudly say that our village is now free of tobacco.

MR LAHAMGE
EXTENSION OFFICER, KORAPANA BLOCK, CHANDRAPUR

This is a good programme that encouraged villagers to rid their village of tobacco. This is an example for residents of other villages too. It is possible to make our villages tobacco-free havens if we collectively make efforts to address the addiction problems. The involvement of students and teachers was very necessary as they could spread the message to all the other villagers.

"The Salaam Mumbai Foundation believes in empowering communities, especially youth and children, to refuse tobacco and become 'change-agents' in their villages."

CASE STUDY

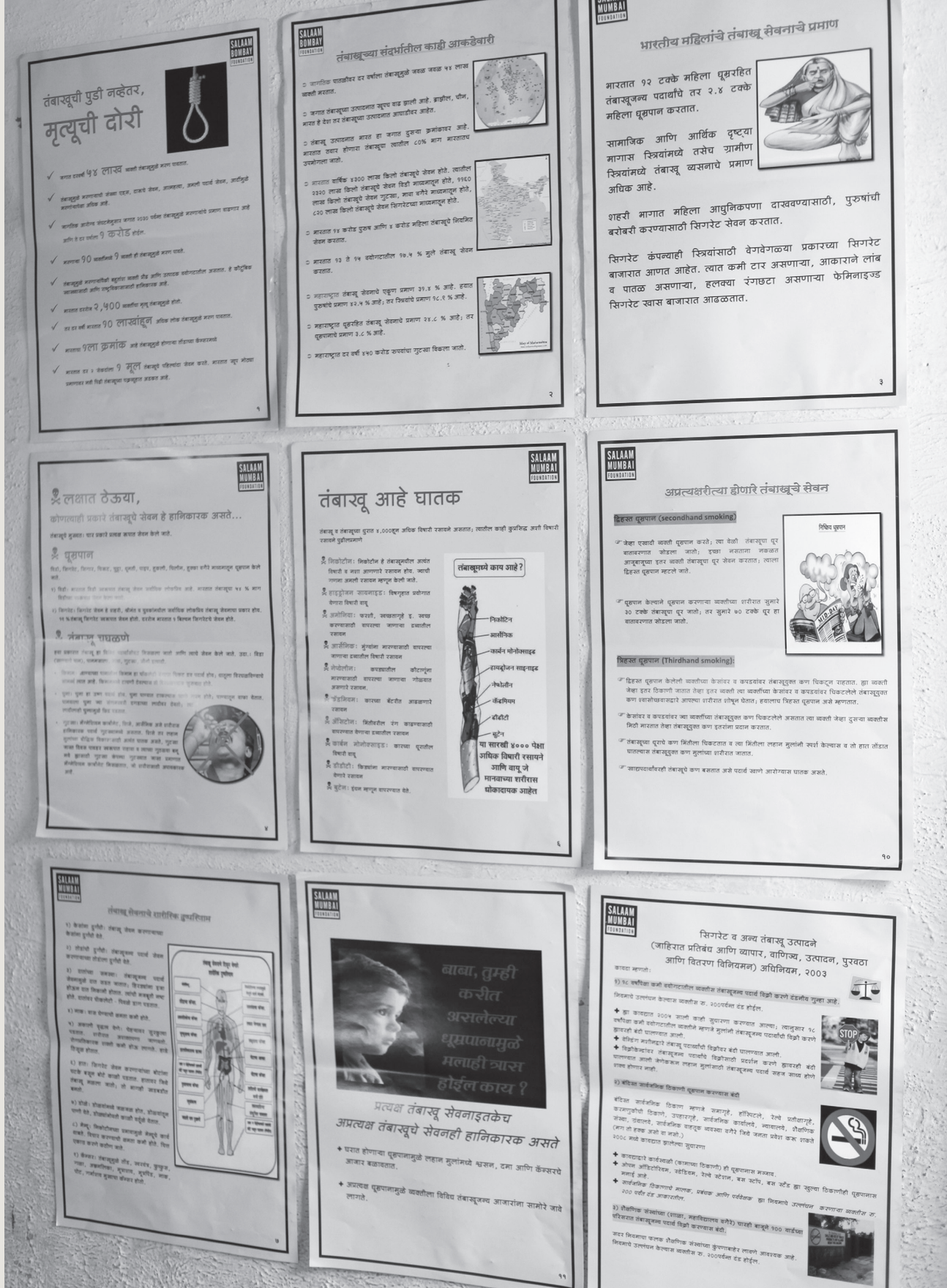
The Making of a Tobacco-Free Village

In 2007, when Salaam Mumbai Foundation first visited Thutra village in Chandrapur district, a very high proportion of villagers (including infants and schoolchildren) consumed tobacco. The addicts ate *gutkha* or *kharra* (chewing tobacco) and unabashedly spat it out. Smokers used bidis or cigarettes openly in the village, and most women used masher (a pyrolysed tobacco product) for oral hygiene and during routine chores.

With the support of Ambuja Cement Foundation (ACF) and its health workers, regular orientation sessions were organized for the villagers. It was conveyed to them that tobacco consumption formed a major proportion of their household expenses, and caused much harm, especially health hazards, in the long run.

Within a year, the vice sarpanch, Mr Vaman Bhivapure, became one of the earliest advocates of the tobacco control programme initiated by the Salaam Mumbai Foundation. Realizing the irreparable damage caused by consumption of tobacco, he proactively campaigned against its use. He first shut down his own tobacco shop, and then encouraged others to follow suit. He organized meetings and discussions among panchayat members and villagers through the gramsabha. He has continued to be an ardent advocate of the tobacco-free movement in his village.

By 2009–10, Mr Bhivapure and ACF health workers were motivated to transform the local school into a tobacco-free zone. Based on the guidelines shared by the Salaam Mumbai Foundation, they asked all tobacco shops within 100 yards of the school premises to shut down. Tobacco vendors in the village could earn up to ₹1,000 per day from sale of tobacco products. Mr Bhivapure spoke widely about how he had chosen to shutdown his primary source of income upon learning about the harmful effects of tobacco.



St Jude India Child Care Centre: A Home Away From Home

Grant: ₹22.7 lakhs.
Sanctioned until 2014.

Around 60,000 children suffer from pediatric cancer in India, but only 1 out of 10 receives full treatment.[1] As cancer care is offered as a super-specialisation only in tertiary care hospitals, over 5,000 children travel to Mumbai annually to get treatment. Treatment costs are often high, leaving families either homeless or hungry during the course of the treatment.

Goal

St Jude Child Care Centre was established with a mission to provide clean, safe and cost-free accommodation to children undergoing treatment for cancer. The aim was to provide holistic care and a home for them (and their immediate family) to recuperate in between treatment sessions.

Strategy

St Jude India Child Care Centre provides counselling, education and entertainment to keep the children and their families engaged. The grant provided by the Narotam Sekhsaria Foundation helped the centre promote academic learning among children, provide counselling for families, and conduct training programmes for its staff. ₹13 lakhs in January–December 2013 also helped the staff update their skills on art-based therapy at the World Centre for Creative Learning Foundation.

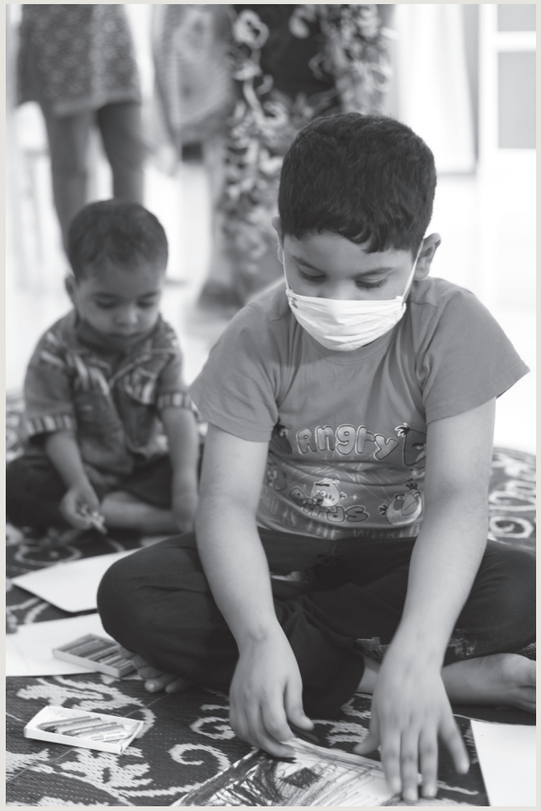
Achievements

So far, 549 children have benefitted through the support provided by the Narotam Sekhsaria Foundation. The staff training promoted teamwork and enhanced communication skills to achieve the goals and mission of St Jude India.

1 http://archive.indianexpress.com/news/only-1-in-10-children-with-cancer-get-complete-treatment-in-india-report/1076733/0

> “The Narotam Sekhsaria Foundation has generously sponsored our educational programme, staff training and capability building. We are very thankful to the foundation for helping and supporting St Jude in providing holistic care to underprivileged children battling chronic illnesses such as cancer.

549 children have benefitted through the support provided by the foundation.



Mahila Sarvangeen Utkarsh Mandal (MASUM): Early Screening For Cancer Prevention

Grant: ₹1.13 crores.
Sanctioned until 2017.

India accounts for almost one-fourth of the world's 5.5 lakh cases of cervical cancer each year. In fact, cancer of the cervix accounts for over 65% of the overall cancer cases in rural India, and it is the most common cause of cancer-related deaths among Indian women. The Mahila Sarvangeen Utkarsh Mandal (MASUM), established in 1989, is a non-profit voluntary organization working on rights and feminist perspectives in the field of health.

Goal

The Narotam Sekhsaria Foundation provided a three-year (March 2013 to March 2016) grant to MASUM to strengthen its advocacy efforts and to integrate in the public health system local-level screening for cervical cancer, reproductive tract infections, and sexually transmitted diseases.

Strategy

Early screening followed by treatment or referral, teaching self-examination techniques, and dietary advice to prevent further regression.

Achievements

In the three-year period, 185 health-screening camps were held where village women were checked for pre-conditions for cervical cancer, uterine prolapse, reproductive tract infections, and anaemia. Over 6,000 women underwent health checks. Of these, 2,340 women also underwent an internal (speculum) examination conducted by trained and experienced health workers.

This was made possible through health awareness and education campaigns held throughout the three-year project. Six training camps, including one exclusively about health rights, were held for adolescent girls and boys, and over 300 adolescents from 20 villages of Purandar taluka near Pune were screened. About 334 adolescent girls were educated on reproductive rights and reproductive health issues to enable them to lead a healthy life.

185

health-screening camps were organised where village women were checked for pre-conditions for cervical cancer, uterine prolapse, reproductive tract infections, and anaemia.

Spotlight

Consider the example of Sindhutai, about 30 years old, from Purandar taluka. Due to cultural biases and financial constraints, it is difficult for women in Sindhutai's community to travel alone for long distances to access healthcare services. Many preventable diseases hence go undiagnosed or get diagnosed so late that multiple complications occur.

However, their collective destiny changed when some among them received 15 months of training from MASUM as health workers. It began with MASUM's trained health staff conducting women's group meetings in villages and creating awareness about cervical cancer. Today most women in the community understand that early diagnosis, especially for gynaecological problems, is imperative to prevent considerable loss of health and money.

Sindhutai, as a trained village health worker at the Sadaphuli centre, uses self-examination techniques to help women understand their own bodies and participate in the process of primary level diagnosis and treatment at a minimal cost. For the first time, women in her community have stepped out of their homes, seeking to link other women to public health services as soon as possible.

"

MS MANISHA GUPTE
CO-FOUNDER OF MASUM

Health is an economic and social asset. By empowering women through awareness and capacity building exercises, two major gaps in our healthcare system have been addressed: first, of demand and timely supply; second, of the prioritising of a woman's health needs by her family and her community as women's health issues don't get the necessary primacy within the household. MASUM's health programme empowers women to speak out and negotiate their health needs and rights in the private as well as the public domains.

Gram Shikshan Charity Foundation: Creating Awareness About Tobacco's Ill Effects

Grant: ₹ 31.8 lakhs.
Sanctioned until 2017.

Gram Shikshan Charity Foundation (GraSCF), established in 2008, works towards creating awareness about the ill-effects of tobacco and undertakes cancer awareness programmes. It is the only NGO in the Hubli-Dharwad-Belgaum region that works in the field of tobacco control. GraSCF received the Narotam Sekhsaria Foundation's Tobacco Award of ₹5 lakhs in 2012–13 for strengthening its ongoing activities by building upon the network created through the award.

Goal

To increase awareness of oral, breast, and cervical cancers in 50 villages of Hubli taluka and 3 corporation wards of Hubli city.

Strategy

GraSCF focuses on early screening and establishing referral linkages with a cancer hospital for treatment of suspected cases. It also builds capacity of link workers, who act as psycho-oncology volunteers by conducting workshops.

Achievements

GraSCF has been active in 50 villages and has reached out to over 3,500 people with its cancer awareness programmes. Around 2,000 villagers have been screened for cervical and breast cancer and over 1,700 for oral cancer. Suspected cases were taken for a second level of screening, and referred to the closest well-equipped cancer hospital for further investigation.

Along with this, 84% of the villagers were identified as tobacco users, and about 63% were imparted cessation advice. Volunteers from 51 villages were trained as psycho-oncology volunteers to conduct future awareness sessions in the villages. Linkages have also been established with SDM Dental College and SDM Medical College's ophthalmology department to conduct joint camps.

"

MR RAVINDRA HOMBAL
TRUSTEE, GRAM SHIKSHAN

Most village women suffer silently, especially when it concerns gynaecological issues. Serious ailments like oral, breast, and cervical cancers go untreated for a long time, creating serious health and financial burden for the families. Our project, supported by the Narotam Sekhsaria Foundation, helped many women understand personal health and hygiene, communicate effectively with their families, and visit city hospitals for chronic symptoms using their health cards. Women understood the ill effects of tobacco, especially the harm it does to health and finances; many of them promised to quit and motivate their husbands to do likewise. The project not only helped women but also their families and their self-help groups. From our trust's perspective, the Narotam Sekhsaria Foundation's support helped implement a scalable, replicable, sustainable, economically viable project. Many institutions have since taken a keen interest in implementing such a health model.

CASE STUDY

Sri Kamakshi Mahila Self-Help Group, Halyal Village, Hubli Taluka, Karnataka

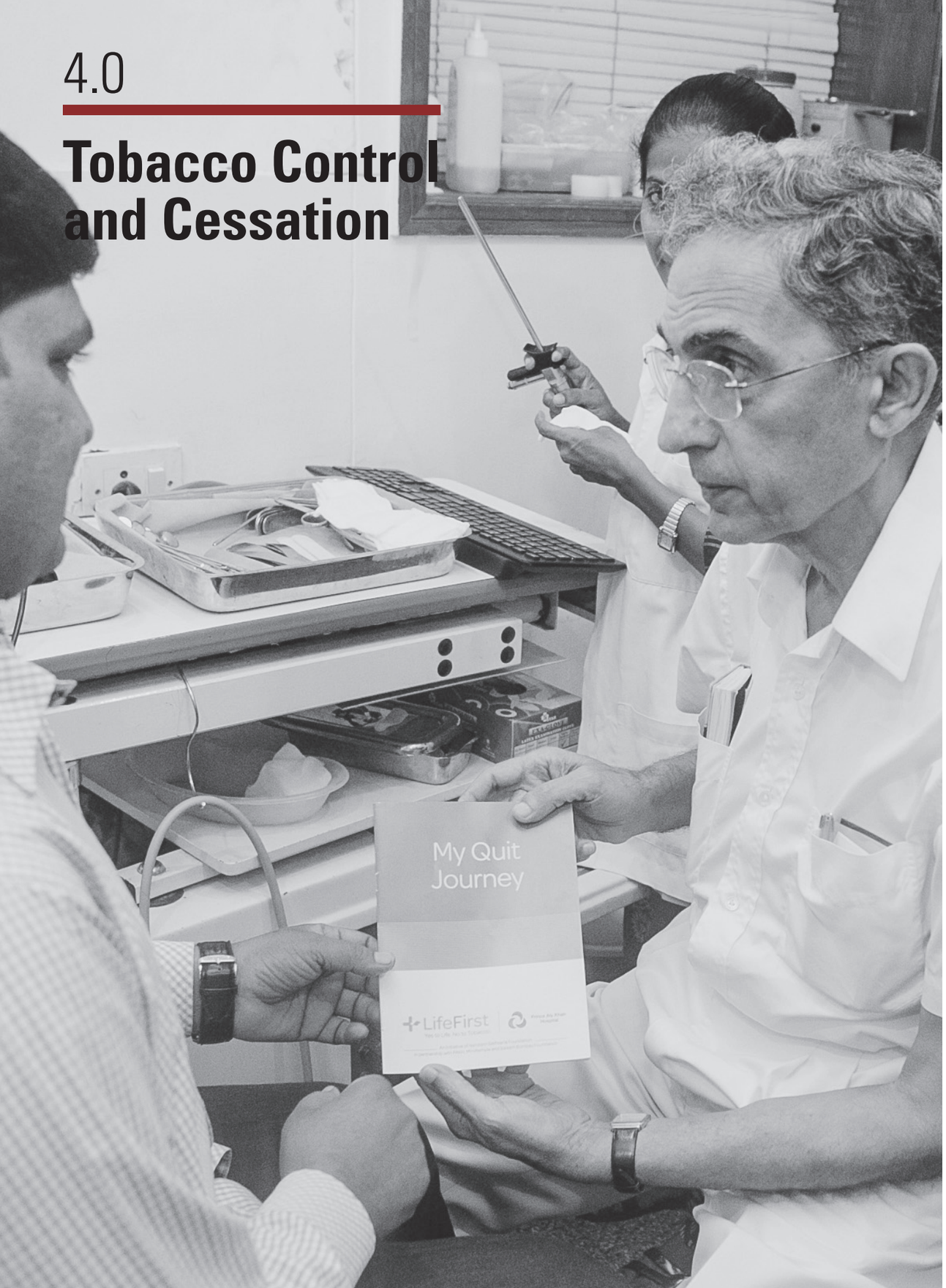
The village self-help group became motivated after a visiting group of Gram Shikshan Foundation's health workers asked its members to attend a health screening camp.

The camp found many women suffering from gynaecological issues that were ignored by them as well as their husbands. The women were too shy to even share it amongst themselves. Their husbands didn't have time to bring them to Hubli city to consult a gynaecologist and the women were unable to explain their gynaecological problems to the male doctors in their villages.

A village screening camp conducted by the Gram Shikshan Foundation ensured that the women underwent a clinical examination by a female doctor. Cervical cancer screening using VIA-VILI methods (visual inspection with acetic acid (VIA) or Lugol's iodine (VILI) resulted in the diagnosis of a few infections and one pre-cancerous case. These were treated at SDM Hospital, the first referral hospital. While many women were also happy to learn about self-breast examination, a few quit the tobacco habit after undergoing an oral examination and getting information on tobacco. The trust's health workers taught them to communicate whenever they experienced serious health problems, use their family health cards such as Sampoorna Suraksha and Vajpayee Arogyashree, and visit gynaecology departments in the city's hospitals whenever required. The telephone helpline also helped them talk and seek counsel whenever needed.

4.0

Tobacco Control and Cessation



4.1 FOREWORD

Highlighting the Dangers of Tobacco to Public

DR P C GUPTA
DIRECTOR
HEALIS SEKHSARIA INSTITUTE FOR PUBLIC HEALTH, MUMBAI

In India, about half of the men and one-fifth of the women over 15 years of age use tobacco in some form. Smokeless tobacco is more than twice as common as smoking across the country.

The Health Burden of Tobacco

As tobacco smoke and tobacco in non-combustible forms contain carcinogens, toxins and other harmful chemicals, they are known to cause cancer of the lung as well as at many other sites in the body. Smoking is also known to cause severe vascular and respiratory diseases that could result in premature deaths, especially among those suffering from tuberculosis.

In India, the use of smokeless tobacco has been proven to be a major cause of oral cancer. Approximately 77,000 cases of oral cancers are diagnosed annually, mostly among middle-aged Indians, many of whom come for treatment at a late stage of the disease. A worrying trend noticed recently suggests that oral cancer is striking younger Indians. Worse, two-thirds of all oral cancer patients die of the disease prematurely.

The use of smokeless tobacco among Indian women has been linked to stillbirths, reduced gestational period, and babies with low birth weight. Not surprisingly, cohort studies conducted across India associate tobacco use, both smoking as well as the smokeless variant, with a higher risk of death. Studies suggest that 1 in 5 deaths of men and 1 in 20 deaths of women are related to tobacco use.

1/5 of Indian women over 15 years of age use tobacco in some form.

Awareness is the Key

There is little knowledge among the masses about the fact that smokeless tobacco products such as *gutkha*, *mawa* or *kharra*, which are commonly used by boys and young men, also contain another proven carcinogen called *supari* (areca nut).

Mass awareness campaigns have to be a part of any public health plans to prevent tobacco-related cancers. Advocacy movements that petition the government to increase the price of tobacco products and their taxation as well as increasing the availability of health services to individuals are other much-needed interventions.

Policies to control tobacco use are encompassed in the Cigarettes and Other Tobacco Products Act (COTPA), 2003, Rule 2.3.4 (2011) under the Foods Safety and Standards Act, 2006, which prohibits tobacco and nicotine in food items, and an amendment (in 1992) to the Drugs & Cosmetics Act, 1940, which prohibits the use of tobacco in toothpowders/ toothpastes. While implementation and enforcement of these laws have been strengthened over the years, the tobacco industry has consistently found ways to circumvent them. Measures such as using surrogate advertising for tobacco products while promoting non-tobacco products; selling a product in two distinct types pf packaging—one with tobacco, one without—that can confuse the customer; or labelling tobacco products as "toothpowder" or "toothpaste."

For increasing general awareness about the dangers of tobacco, mass media communication in the form of print advertisements, audio, and audio-visual spots have been disseminated through newspapers, billboards, radio, and national television channels, especially in the local languages. The Union Ministry of Health and Family Welfare has joined hands with WHO, voluntary organizations, and doctors in a bid to create nationwide impact.

Apart from these mass movements, it is also important to assist individual tobacco users quit the habit. At present, tobacco cessation services are provided through 19 dedicated tobacco cessation centres set up at tertiary care institutions across the country. These cessation centres are staffed with psychologists and social workers. A recent report on their effectiveness in the first five years showed encouraging results on patients quitting tobacco, followed up with for six weeks. Clearly, such services not only need to be provided more widely by healthcare providers but they need to be widely publicised. The existing 19 centres were, in fact, envisioned as regional resource centres that would build capacity for such services at local levels and thus reach a wider population. But the scaling-up process has been slow even though cessation services cost much less than other health services.

"Mass awareness campaigns have to be a part of any public health plans to prevent tobacco-related cancers. Moves for tobacco control prices and availability of health services to individuals are other much-needed interventions."

The Way Ahead

Given the enormity of the need, the Narotam Sekhsaria Foundation has been making an enormous effort to build capacity by training the staff at government health posts for tobacco cessation services. If and when the effectiveness of the model is demonstrated, the foundation would be able to optimise its efforts by reaching out to the state health departments and district level hospitals by scaling up its activities in health posts. In doing so, it may be able to join the efforts of the National Tobacco Control Programme and the National Cancer Control Programme, and also work through Regional Cancer Centres and district hospitals by widening and scaling their work in health posts.

The Narotam Sekhsaria Foundation has been associated with the tobacco control activities of the Salaam Bombay Foundation, which conducts awareness and advocacy programmes in schools across Maharashtra, and with the Healis Sekhsaria Institute for Public Health, which carries out tobacco interventions in schools for teachers and at worksites for factory workers along with conducting epidemiological studies in communities. The considerable experience of these agencies is being harnessed for the Narotam Sekhsaria Foundation's new project on health posts.

Tobacco in India*

26.7 crore

Indian adults use tobacco in some form. This is over a third of the population above the age of 15.

About 1 in 5 male deaths and 1 in 20 female deaths are related to tobacco use.

SMOKELESS TOBACCO

use is twice as common as

SMOKING.

2/3 of all oral cancer patients die of the disease prematurely.

Tobacco use is much more common among rural adults (19.9 crore tobacco users) than urban adults (6.8 crore tobacco users).

3.2 crore

adults use more than one form of tobacco.

Exposure to second-hand smoke:

PUBLIC PLACES: 23%

HOME: 39%

WORKPLACE: 30%

Cigarette smoke contains over

7,000

chemicals,

69 of which are known to cause cancer.

Smoking causes cancer of the lungs as well as cancer at many other sites in the body. Smoking is also a major risk factor in chronic bronchitis, heart disease and stroke, plus other conditions such as slowed healing of wounds, infertility, peptic ulcer disease.

Khaini is the most commonly used tobacco product, followed by *bidi*.

Maharashtra has the highest tobacco use in the country. People prefer smokeless tobacco to smoking.

Smokeless tobacco products commonly used by boys and young men include *gutkha, mawa* or *kharra*, which, besides containing tobacco, also contain areca nut, another proven carcinogen.

In India, tobacco use among women —which is mainly in smokeless forms —is linked to still births, reduced gestational period and babies with low birth weights.

55% smokers

50% smokeless tobacco users

are planning to or thinking of quitting tobacco.

* Global Adult Tobacco Survey (GATS) India report 2016–17 and 2009–10.
https://www.cancer.gov/about-cancer/causes-prevention/risk/tobacco/cessation-fact-sheet

4.2

Hospital-Based Tobacco Cessation Services: Importance and Scope In India

NANCY A RIGOTTI, MD
PROFESSOR OF MEDICINE,
HARVARD MEDICAL SCHOOL.
DIRECTOR, TOBACCO RESEARCH AND
TREATMENT CENTER, MASSACHUSETTS
GENERAL HOSPITAL, BOSTON, USA

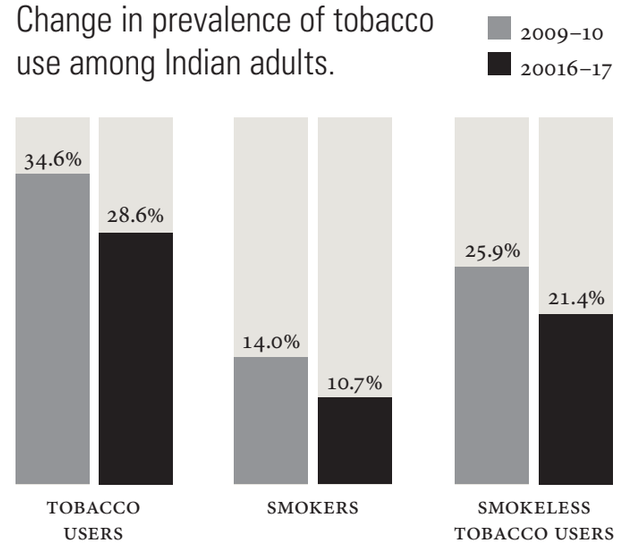
Tobacco use is the leading cause of preventable death worldwide, responsible for nearly 6 million deaths each year.[1] The Global Adult Tobacco Survey of 2016–17 estimates that approximately 267 million adults in India used tobacco, representing 28.6% of the adult population.[2]

Cancer is a major cause of tobacco-related mortality because tobacco use causes cancer at multiple sites throughout the body. Overall, cancer is also a leading contributor to the global burden of disease, accounting for 15% of the world's deaths per year.[3] Although tobacco use and cancer incidence were once highest in high-income countries, they are rising in less affluent countries.[4] Eighty percent of the nearly one billion tobacco users worldwide now live in low- and middle-income countries.[1] In 2013, cancer researchers and policy leaders from 15 countries, including India, identified tobacco use as the most important issue for cancer prevention worldwide.[4]

The World Health Organization's Framework Convention on Tobacco Control (FCTC), which India has ratified, outlines a set of evidence-based steps these countries have agreed to take to reduce the global burden of tobacco-related disease and death by preventing the initiation of tobacco use and helping current tobacco users to quit.[5,6] Article 14 of the FCTC directs countries to implement effective programs to help tobacco users to quit using evidence-based counselling and medication. Guidelines for implementing the article specify that healthcare systems and healthcare workers "should play a central role in promoting tobacco cessation and offering support to tobacco users" through tobacco use screening, brief advice, and referral to specialized treatment services where appropriate.[7]

Incorporating tobacco use treatment into healthcare settings is a challenge worldwide. Most of the efforts have encouraged primary care and specialty

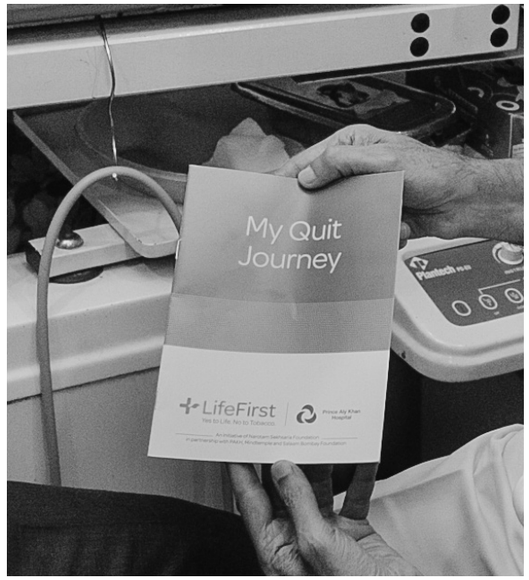
From 2009–10 to 2016–17, the number of tobacco users in India has reduced by about 81 lakhs.[2]



physicians and their staff to deliver tobacco cessation advice, counselling, and medication in ambulatory office practice. They have tended to neglect the powerful opportunity that a hospitalization provides to promote tobacco cessation.[8] The admission may be attributable to a tobacco-related disease, which can strengthen the smoker's awareness of the harms of using tobacco and increase his or her motivation to quit. A hospitalized patient is accessible to medical personnel who can encourage smoking cessation at this teachable moment and guide the smoker to the resources to sustain tobacco cessation after discharge. Hospitals that do not permit tobacco smoking require smokers to abstain temporarily from smoked tobacco, which can start the smoker on the path to quitting.

A substantial body of evidence demonstrates that starting a smoking cessation intervention in the hospital increases the chance that a tobacco user will stop smoking after being discharged.[8] Both counselling and nicotine replacement therapy each improve the odds of cessation but they only have long-lasting effects if they continue for a month or

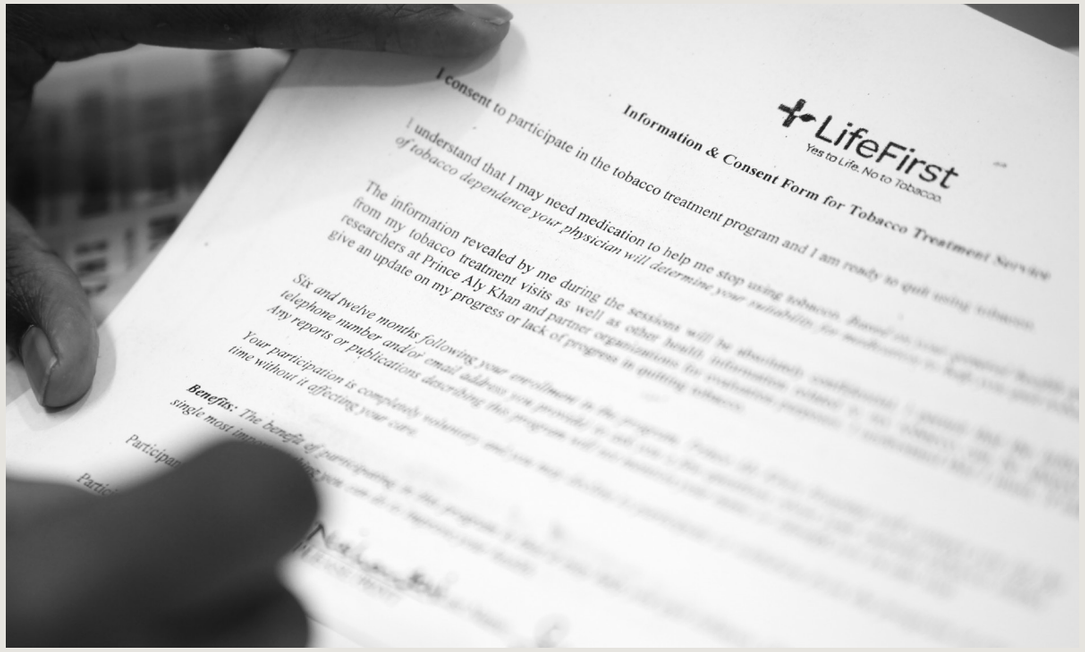
1 WORLD HEALTH Organization. WHO Report on the Global Tobacco Epidemic, 2011: Warning about the dangers of tobacco, Geneva, Switzerland; 2011.
2 Global Adult Tobacco Survey India report 2016–17. Mumbai: International Institute for Population Sciences and New Delhi: Ministry of Health and Family Welfare, 2017.
3 Lozano R1, Naghavi M, Foreman K, et al. Global and regional mortality from 235 causes of death for 20 age groups in 1990 and 2010: a systematic analysis for the Global Burden of Disease Study 2010. Lancet. 2012;380:2095-128.
4 Varmus H, Kumar HS. Addressing the growing international challenge of cancer: a multinational perspective. Sci Transl Med 2013; 5: 175.
5 Asma S., Song Y., Cohen J., Eriksen M., Pechacek T., Cohen N. et al. CDC Grand Rounds: Global Tobacco Control, MMWR Morb Mortal Wkly Rep 2014: 63: 277-280.
6 Parties to the Framework Convention on Tobacco Control. http://www.who.int/fctc/signatories_parties/en/ [Accessed Nov. 19, 2014]
7 WORLD HEALTH Organization. FCTC/COP4(8): Guidelines for Implementation of Article 14 of the WHO Framework Convention on Tobacco Control (Demand Reduction Measures Concerning Tobacco Dependence and Cessation), Geneva, Switzerland; 2010.
8 Rigotti N, Clair C, Munafò MR, Stead LF. Interventions for smoking cessation in hospitalised patients. Cochrane Database of Systematic Reviews 2007 , Issue 3. Art. No.: CD001837. DOI: 10.1002/14651858.CD001837.pub2 .



more after the smoker leaves the hospital. The previous studies were all conducted in high-income countries.[8] To my knowledge, no middle-income country had taken on this challenge until the development of the LifeFirst program, which is described in this monograph. I congratulate the LifeFirst program leaders and the Narotam Sekhsaria Foundation for taking on this important challenge to address tobacco cessation efforts in hospitals and other healthcare settings in India.

It has been my privilege to help the LifeFirst leaders build a program at the Prince Aly Khan Hospital in Mumbai that has the potential to be a model for other hospitals throughout Mumbai and the country. The effort is unique in that it is firmly based on scientific evidence but also tailored to the specific cultural context and distinctive tobacco use patterns of the Indian population. For example, smokeless tobacco is a much larger form of tobacco use in India than it is in most other countries. LifeFirst has incorporated efforts to address both smoked and smokeless tobacco in its programmes. The LifeFirst program is also committed to monitoring and evaluating the results of the new programme in order to learn and improve it.

I am equally delighted to see how LifeFirst is growing, expanding to new hospitals, and beyond hospitals to new sites where tobacco users receive healthcare. Tobacco prevention and cessation treatment needs to be embedded as a standard component of the routine way that healthcare is delivered to the citizens of every country. When that occurs, the healthcare system will be doing its part to reduce the enormous burden of suffering, disease, and death due to tobacco use. LifeFirst is a wonderful pioneering effort that could serve as a model for India and beyond.



"LifeFirst is a unique quit tobacco service in India because not only is it firmly based on scientific evidence but it is also tailored to the specific cultural context and distinctive tobacco use patterns of the Indian population."

4.3

NSF Interventions In Tobacco Control

1 Tobacco Control Interventions In Rural Areas

The Global Adult Tobacco Survey (2016–17) estimates that 26.7 crore adults—almost one-third of India's adult population—use tobacco. According to the survey, 42.4% of men, 14.2% of women and 28.6% of all adults currently either smoke tobacco and/or use smokeless tobacco. Smokeless tobacco predominates and its use is more than twice as common as smoking. Tobacco use in rural areas is more common than in urban areas—19.9 crore adults in rural areas and 6.8 crore adults in urban areas use tobacco. In Maharashtra, the prevalence of tobacco use is higher than the country average, but the tendency to use smokeless tobacco as opposed to smoking is more pronounced (Global Adult Tobacco Survey, 2009–10).

Tobacco-Free India Grants and Awards

Recognising the health hazards of tobacco abuse, the foundation lays equal emphasis on tobacco control initiatives and on cancer prevention. In 2010, the foundation instituted the Tobacco-free India Grants and Awards to provide grants and awards to organisations and individual leaders for their commendable work in the area of tobacco control. NGOs and individuals involved in tobacco control, from different parts of the country, are selected through a rigorous screening process by a group of panelists. This program is geared towards supporting grassroots initiatives in tobacco control and recognizing individuals who have made a pioneering contribution in the area of tobacco control.

Leadership Award These awards are given to individuals who have made their mark in the area of tobacco control. The Narotam Sekhsaria Foundation supports their laudable efforts with a reward of ₹100,000 over two years. Each year, a maximum of five individuals

Recognising the health hazards of tobacco use, the foundation lays equal emphasis on tobacco control initiatives and cancer prevention.

are awarded. Individuals from various backgrounds—teachers, community health workers, dentists, doctors, social workers—have received this award.

NGO Grants The Narotam Sekhsaria Foundation grants an amount of ₹500,000 over two years to nonprofit organisations doing excellent work in the field of tobacco control. This grant focuses on organisations that operate in rural areas and towns with a population of less than 10 lakh people. Each year, a maximum of five grants are awarded to such deserving organisations.

Training and Mentoring The individuals and organisations are supported through training and mentoring by the Salaam Mumbai Foundation. They are supported to increase their scope of work by sensitising local stakeholders like the police department, health department functionaries, school teachers and so on, and by initiating activities at the community level to make schools and villages tobacco-free.

Impact Through the initiative the foundation has extended grant support to 19 organisations and felicitated 21 individuals across 7 states in India. The champions of this programme have made pioneering interventions in the area of tobacco control.

2 Tobacco Cessation

Tobacco use is the leading preventable cause of death across the globe and is responsible for about 9% of all deaths worldwide. Although the relative burden of tobacco is higher in high-income countries, tobacco use is increasing in low- and middle-income countries, which are home to 80% of tobacco-attributable deaths. India faces unique challenges in controlling the tobacco epidemic with high rates of smokeless tobacco use and the availability of a uniquely diverse array of tobacco products.

According to the Global Adult Tobacco Survey (2016–17), India is home to 267 million current tobacco users. This equates to 42.4% of Indian men over the age of 15 being current tobacco users, of which 19% of men are smokers and 29.6% are smokeless tobacco users. Among Indian women over the age of 15 years, 12.8% are smokeless tobacco users and 2% are smokers. The effects of tobacco use are apparent in high rates of head, neck and other cancers as well as heart disease and stroke. According to the survey, 55% of smokers and 50% of smokeless tobacco users are planning to or thinking about quitting tobacco use. Despite growing recognition of the need for tobacco control, few services are available to assist tobacco users in quitting tobacco products.

Approximately

77,000

cases of oral cancer are diagnosed annually in India. The use of smokeless tobacco has been proven to be the major cause for oral cancer in the country.

4.3

Lifefirst: A Tobacco Cessation Service

DR HIMANSHU GUPTE
GENERAL MANAGER
NAROTAM SEKHSARIA FOUNDATION

LifeFirst
Yes to Life. No to Tobacco.

Health is a major area of focus for the Narotam Sekhsaria Foundation and it supports health interventions across various healthcare settings. Right from its inception, the foundation has also supported several projects in cancer prevention and care. As an extension of this support, a tobacco treatment service called LifeFirst was initiated in 2013, with the objective of helping people overcome their dependence on tobacco.

Promoting a widespread usage of treatment for tobacco dependence is one of the primary goals of LifeFirst. The service has been created to catalyse, build capacity of and establish a high-quality, proven tobacco treatment service for individuals from every stratum of society. LifeFirst delivers the service through a range of settings such as hospitals, primary healthcare centres, government health programmes, workplaces, communities, and schools.

LifeFirst is built upon an international research base, as well as standards and protocols from the Mayo Clinic (USA), the Ottawa Model (Canada) and the National Health Service (UK). These have been adapted to Indian sensibilities and environments. The US Public Health Service guideline, "Treating Tobacco Use and Dependence: 2008 Update—Clinical Practice Guidelines" and Massachusetts General Hospital's Tobacco Treatment Service have provided a platform upon which LifeFirst's protocols have been built.

LifeFirst even goes a step beyond counselling service to provide technical support to organisations that wish to set up tobacco treatment services themselves. LifeFirst provides hands-on support to these organisations, providing them with assistance in planning, implementation, and preliminary monitoring of the service. It also provides guidance with regard to the implementation of tobacco-free policies, while also developing information, education and communication (IEC) materials for both providers and patients/clients.

LifeFirst is a high-quality tobacco treatment service for every stratum of society.

Salient Features of LifeFirst

- **Evidence-based**: Builds on best practices, research and approaches for delivery of tobacco treatment services.
- **Dynamic**: Keeps up with the latest scientific evidence and tobacco users' needs .
- **Continuous learning process through monitoring and evaluation**: Ensures the lessons reflect in current practices and future initiatives.

The three components of LifeFirst are service, trainings and research.

Strategy For Counselling Service

- Improve knowledge about the effects of tobacco and benefits of quitting.
- Increase quit attempts at the earliest stage possible.
- Motivate and support users' efforts to quit through behavioural modification and counselling techniques.

Strategy For Training

To build a team of competent healthcare professionals by imparting skills needed to provide evidence-based tobacco dependence treatment in a variety of settings.

Strategy For Research

Developing and establishing robust, context-specific tobacco dependence treatment service models that can then be delivered via diverse settings in India.

Developing a robust resource bank of researchers, relevant materials and an evidence base, for the benefit of all future tobacco treatment initiatives in low- and middle-income countries.

LifeFirst – Project Sites

At present, the service is offered to:

All inpatients of Prince Aly Khan Hospital, a private tertiary care hospital in south Mumbai; tuberculosis patients from 31 TB treatment centres under the Municipal Corporation of Greater Mumbai and the Vasai-Virar Municipal Corporation in collaboration with the Revised National TB Control Programme (RNTCP); and patients visiting two urban health posts for community outreach and patients admitted to a tertiary care hospital in Navi Mumbai (operated as a collaboration between the Navi Mumbai Municipal Corporation (NMMC), and the psychiatry department of a medical college, 2 charitable trust clinics, 27 schools and 9 workplaces.

"LifeFirst services are offered via many sites such as hospitals, workplaces, schools, government DOTS centres and municipal corporations."

1 Hospital Setting

The inpatient service is active in two multispecialty tertiary care hospitals. Patients who use tobacco are identified through personal interaction and offered a combination of tobacco cessation services, including in-person counselling, behavioural interventions, telephone counselling and pharmacotherapy.

The service was initiated for indoor patients, and supported about 1,000 tobacco users who have been enrolled for counselling and provided follow up sessions.

2 Revised National Tuberculosis Control Programme

LifeFirst, in collaboration with three NGOs—Maharashtra Janavikas Kendra (MJK), Peoples' Association for Training and Health (PATH), and Lok Seva Sangam (LSS) that operates TB treatment centres (DOTS centres) in collaboration with the government's Revised National TB Control Program (RNTCP)—rolled out a pilot to provide comprehensive tobacco treatment services (LifeFirst model) through the existing DOTS programme for TB patients.

The pilot project was launched in June 2013, and is active in 31 DOTS centres where tobacco users are provided tobacco-dependence treatment. Over 7,000 TB patients were sensitised about tobacco and 1,040 tobacco users were provided cessation support.

3 Navi Mumbai Municipal Corporation (NMMC)

In collaboration with the NMMC, LifeFirst service was initiated at two urban health posts—Digha and Ilthanpada—for OPD patients in October 2013. All patients (tobacco users) visiting the OPD, the antenatal clinic, and for treatment of tuberculosis are provided help with quitting tobacco. The programme has reached out to over 800 tobacco users by providing detailed counselling sessions to stop tobacco use.

4 Workplaces

Workplaces offer employers a unique opportunity to address employees' health, and influence their decision to quit tobacco. The LifeFirst programme in workplaces helps to create a tobacco-free workplace by creating awareness, supporting tobacco users to quit through counselling, and formulating and implementing tobacco-free workplace policies in coordination with the management.

LifeFirst has worked with nine workplaces till date and sensitised about 14,000 employees and supported about 6,000 of them through their quit journey with counselling.

5 Schools

LifeFirst is implementing school-based cessation programmes for tobacco and *supari* (areca nut, which is known to be a precursor of tobacco use among children). The programme consists of orientation sessions for all children followed by voluntary registration for six group counselling sessions over the academic year. The sessions impart knowledge about the harmful effects of tobacco, benefits of quitting, coping mechanisms, refusal skills, etc.

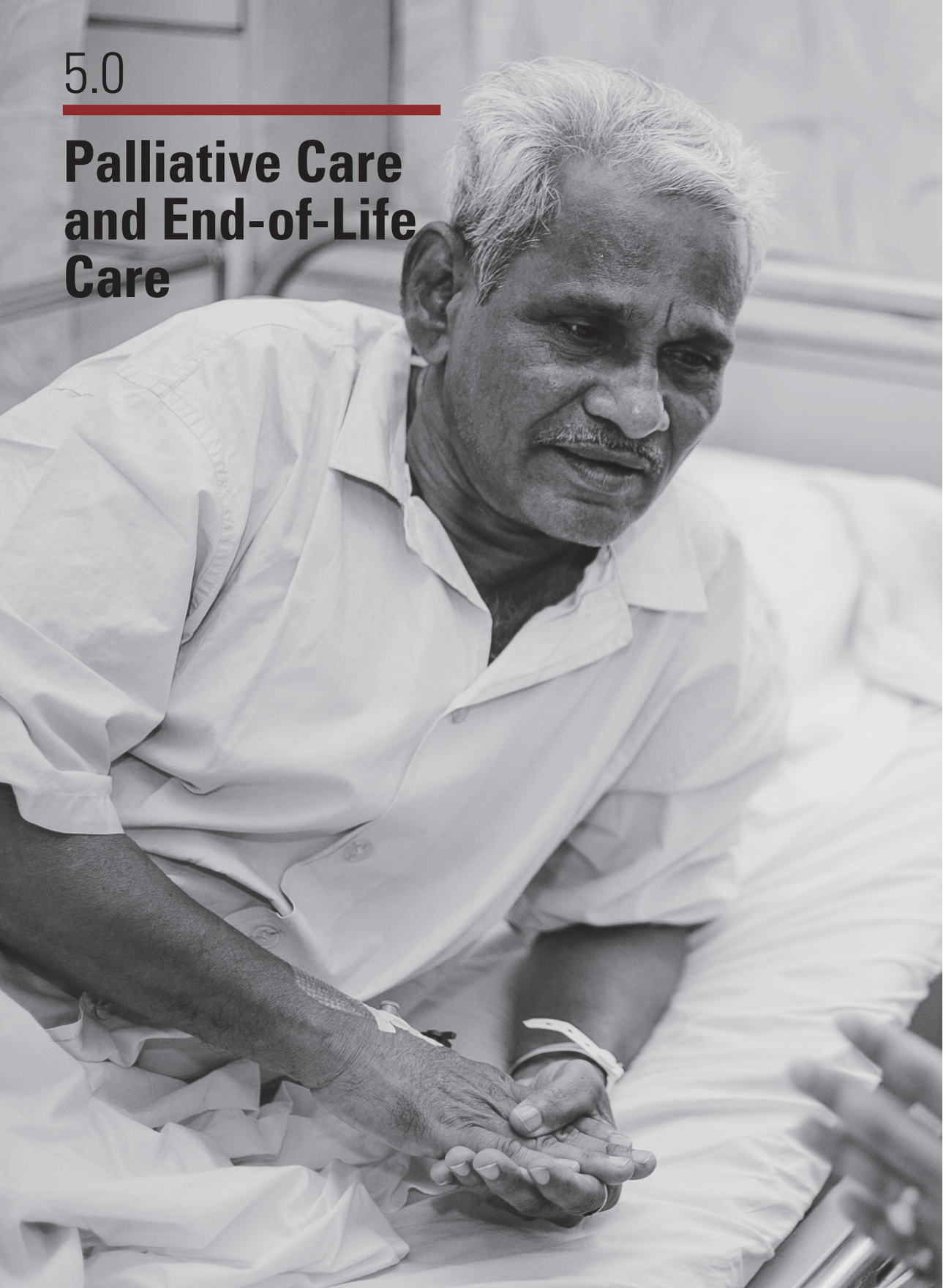
About 10,000 students have been sensitised about tobacco and over 1,500 attended group sessions in 27 schools catering to children from lower socio-economic status in Mumbai.

Tobacco kills

16,000

people every day
around the world.*

* https://www.cdc.gov/tobacco/data_statistics/fact_sheets/fast_facts/index.htm



5.0

Palliative Care and End-of-Life Care

5.1 FOREWORD

Providing Relief From Symptoms and Side Effects Of Disease

DR M R RAJAGOPAL
CHAIRMAN, PALLIUM INDIA
THIRUANANTHAPURAM

A man enduring unbearable, unrelieved pain crawls to the fifth floor window to jump out. He is too weak to climb up to the window and unintentionally makes a noise, and is dragged back to the bed by his shocked family.

A father puts a noose around his only child's neck, hangs him, and then kills his wife and hangs himself, leaving a note that they are doing this because they could not bear to see the child's pain.

A young woman weeping at her cancer-stricken husband's bedside admits in a broken voice that she almost poisoned him and herself the previous night, because she could no longer bear to see his suffering.

None of these instances are exaggerations. These are all real incidents that I personally came across in the course of my practice of palliative care. And these are by no means the rarest of the rare events. In India, 2.4 million people live with cancer. At least 2.1 million live with HIV. 66% of those with cancer and 40% of those with HIV have moderate to severe pain at any point of time.

"In India, 2.4 million people live with cancer. At least 2.1 million live with HIV. Most of their pain is unnecessary. Modern principles of palliative care can take care of them at very low cost."

Most of their pain is unnecessary. Modern principles of palliative care can take care of them at very low cost. Only the ignorance and callousness of society stands in the way of their relief. Two decades of efforts by India's palliative care fraternity have reached a mere 1% of the needy. We all need to be ashamed of the fact that even today, medical students and nursing students in India are not taught modern scientific principles of pain management.

When Pallium India desperately needed support for action steps that would not show immediate results but were essential for long-term success, NSF came forth to help us. When the Indian government, after much persuasion, came out with a National Programme for Palliative Care, but needed a framework for action to make it happen, we approached NSF and they supported us so that we could get together a team of experts to formulate a framework for its implementation. Later, when we needed advocacy to get India's parliament to enact an amendment to its draconian Narcotics Act, we again went to NSF and they helped. When my colleagues and I cheered at 5.30 pm on February 21, 2014, when the Rajya Sabha passed the NDPS Amendment Act as the last item on the last day of the parliamentary session, we had more than enough reasons to thank NSF.

Many donate to help one or several individuals. Very few have the vision to look at the future and to take measures that are most meaningful over the long-term. But that is what NSF chose to do.

Thank you, NSF.

5.2

Setting Up a Palliative Care Programme In the Community

THE EXPERIENCE AT
PRINCE ALY KHAN HOSPITAL

Pain is, unfortunately, a well-documented side effect of cancer. Patients in advanced stages of the disease can barely stand, let alone travel to a hospital for pain relief and care. This was the finding of a survey carried out by the Aga Khan Development Network in Mumbai before setting up mobile palliative and support care services at its Prince Aly Khan Hospital near Mazagaon in April 2016. Identifying a large, unmet need for palliative care in the community, the hospital decided to take its services to patients' homes instead of expecting them to travel to the hospital.

Since its inception, the palliative care team has visited the homes of patients and even performed minor procedures, if required, with adequate consent from the patient or relatives. As a matter of protocol, newly diagnosed cancer patients as well as indoor chemotherapy patients are regularly counselled about palliative treatment. The palliative care team is available on phone and can even be contacted by relatives seeking bereavement support if their patient passes away.

The Narotam Seksaria Foundation supported the training of the palliative care team. Between March 7 and April 2, 2016, the hospital sent a special team comprising a medical doctor, nurse and social worker-cum-counsellor to MNJ Oncology Hospital's Palliative Care Centre in Hyderabad for training.

By January 2017, the centre had counselled 97 outpatient department patients and 51 indoor patients, and conducted 21 home visits and carried out 37 procedures.


SHELIN BABU
PARK

5.3

Care For Patients With Advanced Illnesses: Starting A Dialogue

"Compassion" originates from the Latin *compati*, which means to suffer together, or to share in another's distress and be moved to respond. Palliative care, the branch of medicine that deals with care for the terminally ill, is synonymous with compassion. Palliative care is a relatively new field in India, introduced in the mid-eighties. Since then, the growth in the number of palliative care services and hospices has occurred due to committed individuals who championed the cause with the government.

But despite the good work done, a long road lies ahead. A study has shown that 138 organizations currently provide hospice and palliative care services in 16 states or union territories. These services are usually concentrated in large cities and Regional Cancer Centres, with the exception of Kerala, where services are widespread.

The problem begins with opioid procurement due to the lack of availability of cheap drugs and training among medical professionals. With the rise in chronic illnesses and cancer in India, a large population finds it difficult to access palliative care services.

It is against this backdrop that the Narotam Sekhsaria Foundation decided to take up the cause of palliative care in India. The foundation accepted the challenges of building capacity and training

medical professionals as well as developing sensitisation and knowledge with the urgency that was needed in this sector.

The foundation was keen to generate interest among doctors for specialised training so that they can be seeds of change in their organisations and sensitise colleagues. To widen the reach, it conducted a workshop on the subject of end-of-life care titled "Transitions of Care in Patients With Advanced Illnesses." The workshop was attended by 61 doctors, 2 medical social workers, 2 palliative care nurses, two social workers and nine others.

"Compassion" originates from the Latin *compati*, which means to suffer together, or to share in another's distress. Palliative care is synonymous with compassion.

At the workshop, eminent doctors working in the field of palliative care highlighted issues impeding its growth in India. Dr Mary Ann Muckaden, head of palliative care department and professor of oncology at Tata Memorial Hospital, said that the misconception equating palliative care with euthanasia had stymied the former's growth in India. Dr Shiv Iyer, a professor in the department of critical care at Bharati Vidyapeeth University Medical College, Pune, underlined the need for a dignity-driven decision-making process regarding end-of-life care.

Dr Roop Gursuhani, consultant neurologist at PD Hinduja National Hospital, Mumbai, said there was a need to create awareness about concepts such as advanced care planning, patient-centric communication, including the living will. Dr Nagesh Simha, medical director of Karunashraya, a hospice in Bengaluru, said doctors should provide information that empowers patients to decide, and offers families careful explanations and ample time to comprehend and make decisions. Dr MR Rajagopal, the founding chairperson of Pallium India, Trivandrum Institute of Palliative Care Sciences, advocated that the need for a change in attitude—from death-denying to death-accepting—is important for an effective transition from critical care to palliative care.

Dr R K Mani, group CEO and chairman (critical care and pulmonology) of Nayati Super Speciality Hospital, Mathura and Nayati group of hospitals, discussed how end-of-life care decisions were getting easier across the world in a sharp contrast to India where such decisions have become complicated. He said that there was a misconception that the "Do not Resuscitate" (DNR) option is a form of euthanasia, when it can best be described as the simplest form of treatment limitation; DNR would thus be on the opposite end of the spectrum occupied by euthanasia.

The discussion also touched upon the Kerala model of palliative care, lack of trained physicians, nurses and counsellors for providing palliative care services, and concerns over the availability of oral morphine. The session concluded with a firm commitment from the Narotam Sekhsaria Foundation and the faculty members to work towards facilitating greater access to palliative care for patients with advanced illnesses.

6.0

Looking Ahead: Challenges and Opportunities

The profile of cancer incidence in India has been changing. The most prevalent cancers in India have been head and neck cancers in men (associated with all forms of tobacco use) and, until recently, cervical cancer in women (associated with human papillomavirus infection, sexual hygiene and habits). However, breast cancer has now surpassed cervical cancer as the most prevalent female cancer, and incidence rates of gastrointestinal cancers that have traditionally been low in India have also been rising.

The gap between reported and real incidence, which is primarily due to underdiagnosis of cancer, has resulted in a comparatively late stage of discovery of cancer in the country. Lack of awareness of cancer along with low screening rates for disease have also contributed to late diagnosis, and consequently, low reported cancer incidences in India. As a result, mortality rates are four to six times higher in India than those in developed countries. The baseline cost of cancer treatment (estimated ₹3 to 4 lakhs) is higher than the annual household income for over 80% to 85% of households in India. The problem has worsened due to the lack of adequate infrastructure and an absence of mass screening programmes that are crucial to timely and accurate diagnosis.

The investments made by the Narotam Sekhsaria Foundation in cancer care have been informed by the trends in prevalence of the disease. The foundation has focused on a range of activities to improve the outcomes at both hospital and community level:

- **Prevention**: Preventing common cancers of the head, neck, cervix and breast has been tackled by creating awareness, advocacy for tobacco control, and establishment of tobacco cessation clinics and training health care workers—nurses, pharmacists, paramedics, and undergraduate students—on tobacco and health.
- **Training**: The foundation's efforts in supporting training of community health workers in the VIA/vinegar test for rural population to screen for cervical cancer has shown to have a positive impact in early diagnosis and treatment of cervical cancer.
- **Cancer care**: Establishing cost-effective cancer care facilities, either through infrastructure upgrade or capacity building of human resources, has led to the development of multidisciplinary cancer treatment facilities in tertiary care facilities.
- **Palliative care**: The foundation has recently initiated its programme on palliative care for persons with life-threatening or debilitating illness from diagnosis till death and then into bereavement care for the family. As recommended by the WHO, the foundation's palliative care programme focuses on governmental policy, education, and drug availability.

India's political challenge is to develop convergent health policies that address both communicable and noncommunicable diseases. This will improve the diseases' outcomes significantly. The foundation believes in:

- Political commitment and comprehensive efforts towards reducing and, in the long term, eliminating, the use of tobacco products through the vigorous implementation of the Framework Convention on Tobacco Control.
- Investments in cost-effective vaccination and screening programmes aimed at infection-related cancers, such as cervical cancer (human papillomavirus) and liver cancer (hepatitis B).
- Public health initiatives directed towards improving nutrition.

As mentioned earlier, the landscape of cancer in India has changed in the last two decades. On the

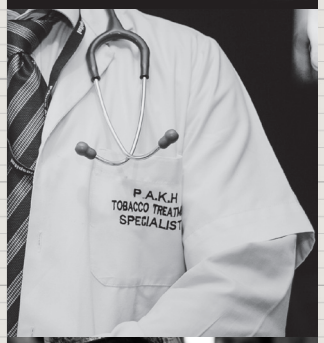
India's political challenge is to develop convergent health policies that address both communicable and noncommunicable diseases.

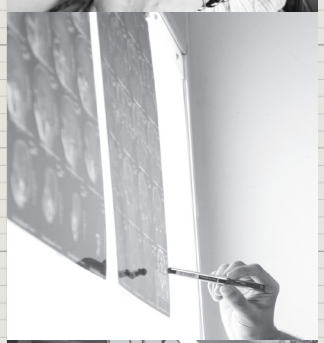
one hand, the incidences of noncommunicable diseases in general and cancer in particular have increased. Lifestyle, environment and genetic factors are responsible for this. On the other hand, the expansion of cancer screening facilities has contributed to an increase in diagnosis, often at an early stage. So the need for cancer treatment facilities has risen manifold. This has contributed to the burden of the already overworked tertiary care system. As a response to this increasing demand, cancer treatment also has to undergo major change. There is a need for treatment to expand in the rural and underserved areas with trained human resources and at modest costs, so that more and more people who are diagnosed with cancer have access to quality treatment.

We at the foundation have been witness to this change in the landscape and have attempted to respond to the need in a limited way. However, we are mindful of the increased demand for trained human resources, scalable and cost-effective models, and comprehensive cancer screening and treatment facilities. Our interventions in the last decade have provided us with a good foundation upon which to build new work. We are aware of the tasks ahead and are committed to move forward.

Over the last decade, we have worked towards transforming cancer care by supporting new approaches for treatment, prevention, and survival. However, scalable and replicable models that enhance survival rates and improve people's access to treatment remain our long-term goals.

Narotam Sekhsaria Foundation





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