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Delivery of affordable and equitable cancer care in India

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The delivery of affordable and equitable cancer care is one of India's greatest public health challenges. Public expenditure on cancer in India remains below US\$10 per person (compared with more than US\$100 per person in high-income countries), and overall public expenditure on health care is still only slightly above 1% of gross domestic product. Out-of-pocket payments, which account for more than three-quarters of cancer expenditures in India, are one of the greatest threats to patients and families, and a cancer diagnosis is increasingly responsible for catastrophic expenditures that negatively affect not only the patient but also the welfare and education of several generations of their family. We explore the complex nature of cancer care systems across India, from state to government levels, and address the crucial issues of infrastructure, manpower shortages, and the pressing need to develop cross-state solutions to prevention and early detection of cancer, in addition to governance of the largely unregulated private sector and the cost of new technologies and drugs. We discuss the role of public insurance schemes, the need to develop new political mandates and authority to set priorities, the necessity to greatly improve the quality of care, and the drive to understand and deliver cost-effective cancer care programmes.

Delivery of affordable cancer care in India: global policy and national reality

To deliver affordable cancer control and care in emerging economies is one of the biggest global health challenges. The range of diseases that constitute cancer; the breadth of systems, pathways, and technologies involved; and the associated costs mean that cancer is a major test of health-care systems in developing countries. As the Institute of Medicine's recent report into the cost of cancer succinctly articulates, "cancer is such a prevalent set of conditions and so costly, it magnifies what we know to be true about the totality of the health care system. It exposes all of its strengths and weaknesses."¹

Following the UN High Level Summit, the global call to embed all non-communicable diseases, including cancer, in the post-2015 development agenda² has been followed rapidly by a plethora of indicators and targets (eg, WHO "25 by 25").³ Unfortunately, there is little insight into the complex economic and structural issues that emerging economies such as India have to deal with to deliver an affordable cancer care and control system. The provision of affordable cancer care in India needs a deep understanding of the substantial differences between spending on health across individual states and union territories, and the gaps in basic health indicators and outcomes (eg, infant mortality rates, health resources, numbers of clinical staff, and physical infrastructure). These data are complex and often difficult to interpret or contradictory. For example, two major studies of the public expenditure on health in individual states provided widely ranging estimates (eg, 235–402 rupees [US\$4–6] per person in Andhra Pradesh and 330–507 rupees [US\$5–8] per person in Kerala).^{4,5} Although trends across all states have mostly been positive and public expenditure has been increasing

gradually over the past 10 years, the underlying strength of each state health system as a foundation to deliver cost-effective pathways and affordable services differs greatly. In particular, the north–south divide in India, with better resources and manpower in the southern states, are a major externality driving patients from the northern states to seek care in the wealthier, better-resourced south. The reasons for this divide are complex, historically rooted, and multifactorial. Whereas states such as Maharashtra, Punjab, and Tamil Nadu enjoy rapid growth under stimulus packages, others, especially those in the north and including Bihar and Rajasthan (two of the most populous states), lag behind. A range of factors have created this situation, including colonial "divide and rule" by the British, caste-based politics and demography, geography (the south has experienced far less political and economic turmoil than the northern regions), and education. Beyond the deep roots of this divide are more recent trends in which southern states have been better prepared to take advantage of globalisation since India's economic liberalisation in the 1990s. Furthermore, the southern states have also benefited from much higher remittances from gulf migrants and non-resident Indians. As part of cancer public policy, exceptional strategies are needed to address this divide through funding and models of care that can deliver quality, affordable care in all areas, even if the north–south gap itself cannot be closed. Intrastate social stratification also is a strong determinant of outcomes, even in socially progressive states such as Kerala.⁶

A key feature of the demographic transition in India is the change in disease epidemiology.⁷ A shift has occurred from a high prevalence of infectious diseases associated with high mortality (especially in infants) to an increasing burden of non-communicable diseases in adults and

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reduced mortality. This ongoing transition and its double disease burden is a consequence of a shift in the contributions of various risk factors, most of which are precursors for chronic diseases in adults.⁸ Individual states and union territories in India are at different stages of the epidemiological transition. Substantial variation in disease profile and risk factor drivers are consequences of disparities in the extent of socioeconomic development and inequalities in health-care access.^{9,10} All these structural, geographic, economic, cultural, and political factors affect the extent to which India can provide affordable cancer care.

The cost of cancer to patients in India

In 2010, the WHO World Health Report emphasised universal health coverage as the key health system goal; the aim was to provide all people with access to affordable, cost-effective health services and to provide financial protection from the costs of ill health to those most in need.^{11,12} In 2011, India spent an estimated 3.9% of its gross domestic product (GDP) on health care (both public and private funding), only 21% of which was contributed by the public sector.¹³ India's public health spending per person remains among the lowest in the world, and although overall public expenditure is growing, it is not doing so at the pace needed to deliver a basic set of cancer care for all cancer patients across India.⁵ The public health expenditure in the country as a percentage of GDP fell from 1.3% in 1990 to 0.9% in 1999, with a marginal increase to 1.1% in 2011.⁵ The central budgetary allocation for health as a percentage of the total central budget, has remained constant during this period at 1.3%, with a slight increase in 2010 to 2%.⁵ Analysis of the Indian National Health Accounts estimates total health expenditure in India, from all sources, to be about

133776×10⁷ rupees (US\$21555 million; roughly 4.25% of total GDP), with nearly 80% of this expenditure in private sector businesses.¹³ Cancer-specific spending has fared little better, with low spending per person, despite the fact that as a percentage of total health-care spending, India's expenditure on cancer is about average in global terms (figure 1).

The Indian health-care system is characterised by high rates of privatisation since the 1960s, with low penetration of voluntary and social health insurance schemes, and a high frequency of out-of-pocket payments,¹⁵ with only around 15% of the country's population covered by some degree of health insurance.¹⁶ Since 2007, several health insurance schemes have been initiated by the central government and individual states. These schemes include Rashtriya Swasthya Bima Yojana (RSBY; a central government initiative that has provided an estimated 302 million Indians with some form of basic health insurance),¹⁷ state-specific schemes (eg, Rajiv Aarogyasri Scheme in Andhra Pradesh, Chief Minister's Comprehensive Health Insurance Scheme in Tamil Nadu, and the Vajpayee Arogyashree Scheme in Karnataka), and community-run initiatives such as Self-Employed Women's Association, and Action for Community Organisation, Rehabilitation and Development.¹⁸ However, most of these initiatives were not designed to address the complexity and cost of cancer care. Many schemes such as RSBY have focused mainly on inpatient care, with low protection from the costs of outpatient expenses.^{17,19} Assessment of RSBY indicates low use of this insurance scheme for cancer patients, and a pressing need remains for insurance schemes that fully cover the financial burden of cancer.

The Vajpayee Arogyashree Scheme is a state insurance scheme that was introduced in Karnataka state in southern India and supports all diseases, including cancer, which now covers about 80% of the population. The scheme was initiated in 2010 with coverage of one district, and has been increased sequentially to cover all districts in the state by 2012. The quality of care is guaranteed by careful selection of the hospitals for insurance cover, which have to fulfil certain quality criteria. 165 hospitals, both public and private, are included, covering about 450 procedures in seven streams, one of which is cancer. The scheme is an assurance scheme and all the facilities are provided through a cashless process. This process is handed over to the third-party organisation, which takes care of all the formalities for the approval of treatment. Funding is provided by the government with the help of the World Bank. A maximum limit of 150000 rupees is set for a family of five per year. The inclusion of district-level hospitals, medical colleges, and tertiary care private hospitals ensures wide distribution of cancer care covered by the scheme, thus increasing the reach of the scheme into even rural and remote areas. 38872 patients have benefited since the scheme's inception, of which cardiology (51%) and oncology (25%) use most of the

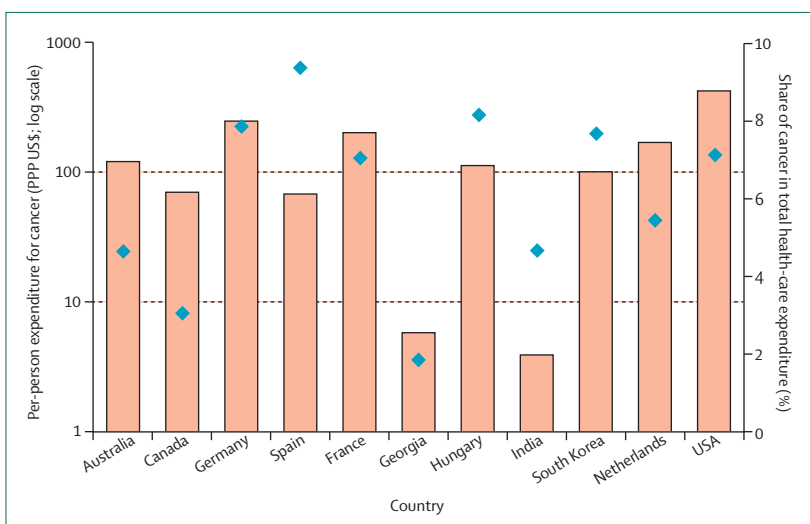


Figure 1: Comparison of per-person expenditures for cancer (red bars; PPP corrected in US\$) and percentage share of cancer in total health-care expenditure (blue diamonds) in different countries
PPP=purchasing power parity. Data are from 2006, extracted from reference 14.

funds. In the next 5 years, the scheme aims to introduce standard treatment guidelines for the major disease and procedure areas. Furthermore, the scheme also intends to include the population living above the poverty line, which will lead to coverage of almost 90% of the population in Karnataka.

The Chief Minister's Comprehensive Health Insurance Scheme in Tamil Nadu was introduced in 2007–08 for the benefit of families living below the poverty line (annual family income of 72 000 rupees) to provide medical help for life-saving procedures. One of the key beneficiaries was the Adyar Cancer Institute in Chennai, which has treated more patients under this scheme than any other medical institutions. During 2010–11, the government introduced more procedures and more than doubled the number of government hospitals providing cancer care under the scheme to make the scheme more comprehensive. The scheme also provides a free ambulance service across Tamil Nadu. For patients living below the poverty line, this scheme provides a maximum of 400 000 rupees for 4 years in a recognised cancer centre. This funding has been very beneficial both to patients and cancer centres, especially charitable, not-for-profit centres such as the Cancer Institute in Chennai.

Despite the introduction of government-funded schemes, for the average patient with cancer in India, health care remains highly privatised, with more than 80% of outpatient care and 40% of inpatient care provided by the private sector.¹⁶ Roughly 71·7% of health care is financed through out-of-pocket payments,^{20,21} with some studies estimating this to be as high as 90% in areas where public health insurance coverage is low.²² These costs in India are among the highest in Asia.²³ Evidence suggests that the high percentage of out-of-pocket payments and low health insurance coverage has resulted in exposure to high financial risk, which pushes patients and their families into catastrophic poverty following a diagnosis of cancer.²⁴ Furthermore, the consequences of high out-of-pocket payments disproportionately affect rural and low-income households.²² Such involuntary expenses are met at the cost of spending on essentials such as food and rent, the selling of assets, use of savings, and the undertaking of greater financial risk through loans from family and landlords.^{25–27} However, it is not only the structure of the health-care system that predisposes individuals and their families to impoverishing cancer care expenses. One also needs to account for disease burden, extent of income distribution, accessibility of public facilities, supply of health-care services (eg, patient to physician ratio), financial coping strategies, and standards of living.²² On a national scale, out-of-pocket health expenditures constitute between 12% and 22% of a rural household's total expenditure.²² Every year, 10% of rural households in less developed states become poorer because of out-of-pocket expenditures for cancer care.²² Supply-side factors were equally relevant—higher health-care costs were

associated with larger patient to physician ratios.²² The 2004 National Sample Survey Organisation's morbidity study estimated that 6·2% of Indian households (63·2 million people) were pushed below the poverty line by health-care expenditures (7% in rural areas and 5% in urban areas) in 2004.^{28,29} The impoverishing effects of out-of-pocket payments were greater for outpatient care (79%) than for inpatient care (21%), despite the greater resource intensity of the latter.^{28,29}

Most (nearly 92%) of patients from rural households first present with cancer to private practitioners, most of whom (79%) are not qualified in allopathic medicine.²⁹ Misinformation, absence of knowledge, and low trust in public cancer care services remain major obstacles to early diagnosis and treatment. Even when patients do present at regional or other qualified cancer centres, waiting times are such that their expenditures (eg, lost income, housing, and food) are substantial.³⁰ Furthermore, the care provided at many cancer centres is often not standard of care but is dictated by the facilities available. For example, many centres across India do not have access to radiotherapy, with on average 2–5 million people per radiotherapy machine (compared with fewer than 250 000 people per machine in high-income countries).³¹

The inability to deliver affordable cancer care is also increasingly having catastrophic effects on both the financial situation of patients and on subsequent generations as health-related poverty drives the family down the social scale. Impoverishment because of health expenditures vary, but one study undertaken in 1999–2000 showed that 3·2% of the population (roughly 32·5 million people) fell below the poverty line because of the cost of health care.³² More recent data from 2004–05 indicated an increase in poverty head count by 3·5% (39·5 million people) because of health-care payments.³³ Although methodological variations might underestimate overall household consumption or cancer-specific expenditures, the message is clear—rural, low-income groups are at serious risk of impoverishing health expenditures caused by cancer, especially in Maharashtra, Andhra Pradesh, Uttar Pradesh, Bihar, Orissa, and West Bengal.³⁴

Cancer is one of the most expensive diseases to treat. In a study of 2204 households in five resource-poor rural settings in India, the cost of chronic illness, especially cancer, was much higher than was that of communicable diseases.²⁹ A study in West Bengal of 3150 households showed that expenditure on chronic diseases by households accessing health services was 5·2% of total health expenditure.³⁵ Patients with chronic illness such as cancer also had a higher risk of incurring catastrophic health expenditure than did those with a diagnosis of a communicable disease.³⁵ Households affected by cancer spent the equivalent of 36–44% of the annual expenditures of control households on inpatient expenses.³⁶ Households with a family member diagnosed with cancer also had 2–3% lower workforce participation rates and higher rates of borrowing and selling of assets to fund

health-care costs (about 50%) than did matched control households (16%).³⁶ Groups with higher socioeconomic status spent more of their household expenditure on health care than did those with lower socioeconomic status and had higher rates of hospital admission, but were less reliant than were lower socioeconomic status groups on asset sales and borrowing to fund their care.³⁷ The complex interplay between sociocultural factors and economic structure typifies cancer care in India. Deficits such as illiteracy, inadequate and inaccessible care, inappropriate initial treatment by traditional healers, myths and stigma surrounding cancer and its treatment, and general misconceptions among family members, society, and even the administrators of general hospitals regarding the prognosis of cancer all have negative effects on affordable cancer treatment.³⁷

Most out-of-pocket payments are channelled into the private sector, which plays a major part in the provision of health services for outpatient visits (78%) and hospital stays (60%).³⁸ Consequently, expenditures on private health, especially on drugs, remain very high,²⁶ exacerbating health inequalities. The absence of governance and regulation around private provision of cancer care is creating serious vertical and horizontal imbalances (eg, higher salaries in the private sector draining health-care professionals away from the public sector; absence of transparency regarding costs and outcomes; inappropriate, non-standardised, and unwanted investigations and treatment, including overuse of expensive diagnostics and treatment modalities, especially radiotherapy; and cherry picking—which is to treat patients until finances have run out and then transferring them to public hospitals).²⁶ A crucial need remains for India to address the governance and regulation of the private provision of cancer care to ensure appropriate standards of treatment and high-quality transparent indicators of quality and outcomes.

The view that cancer costs can be embedded in a broader non-communicable diseases programme fails to understand that cancer care is far more complex and expensive to manage than are diabetes programmes. This situation makes it essential for specific mechanisms to be developed to fund and manage affordable cancer care.

Addressing of political structures to deliver affordable cancer care in India

A major issue in terms of the provision of affordable cancer care in India is the complex nature of government and state budget allocations, fiscal control, and the scarcity of decision-making institutions that can hold cancer care providers to account for the delivery of cost-effective and quality services. Although progress has been made in the delivery of good health at low cost in some states (eg, Kerala and Tamil Nadu), the replication of such success across the country has not been realised.³⁹

Funding of cancer care in India is a complex mixture of state and government accountabilities, with the government shouldering most of the responsibility.⁴⁰ At

the government level, the Ministry of Health and Family Welfare is charged with overall health policy, including cancer care. Within the ministry, a bifurcation exists in terms of the secretariat (health services) and the technical wing (directorate of health services). At the central government level, four other departments are involved in cancer care: Department of Health, Department of Family Welfare, Department of Indian Systems of Medicine and Homeopathy, and the Directorate General of Health Services. The Department of Health deals with health care, including awareness campaigns, immunisation campaigns, preventive medicine, and public health, including all the national health programmes. The Department of Family Welfare is responsible for aspects relating to family welfare, cooperation with non-governmental organisations and international aid groups, and rural health services. The Department of Indian Systems of Medicines and Homoeopathy aims to uphold educational standards in the Indian Systems of Medicines and Homeopathy colleges, strengthen research, promote the cultivation of medicinal plants used, and work on pharmacopoeia standards. The Directorate General of Health Systems provides technical support for the various health programmes. Within each department, secretaries, joint secretaries, deputy secretaries, and under-secretaries oversee different programmes. In some cancer programmes, in addition to the aforementioned personnel, directors, advisers, commissioners, and their deputies also supervise these schemes.

To a large extent, the same administrative structure responsible for cancer expenditures and planning is replicated at the state level. The interaction between the central and state machineries for cancer control is facilitated through the Central Council of Health and Family Welfare. This council also fulfils advisory and policy level functions in the context of health care in the country. Additionally, the Planning Commission of India has a health division, which supports the aforementioned council and provides crucial inputs towards health-care efforts. In the past few decades, several ad-hoc committees and commissions have also been appointed by the government to assess issues and challenges facing the cancer community. Ministers and advisors at both the state and federal levels are in a constant flux, which creates major issues in terms of continuation of public policy for cancer.

The Government of India has continually reiterated its commitment to universal health care for all its citizens through the conceptualisation of national programmes and schemes focused mainly on maternal and child health, communicable diseases, and more recently HIV/AIDS, and endemic diseases that undermined the wellness and productivity of rural communities. However, like many emerging economies, it is catching up in public policy terms in addressing non-communicable diseases such as cancer.⁴¹ Thus, the macroeconomic structures have been geared towards vertical programmes rather than horizontal complex delivery care systems to tackle

diseases like cancer. An emphasis on central government funding through allocated budgets, rather than levies at the state level, exists to support research, education, and training. However, this situation means that little leverage exists to improve quality through fiscal mechanisms, or indeed to relate expenditure in cancer care to outcomes. Furthermore, in terms of health-care financing, the burden of health-care expenditure in India largely falls on individual households (out-of-pocket payments), which means that there is often little leverage from either states or government on institutions to provide quality affordable cancer care.^{20,21} Although one solution is to better educate the Indian public about what constitutes good quality and affordable care, the reality is that this education will be insufficient for many people, and the need to set mandatory quality standards and care pathways needs to be seriously addressed.

Measured amounts of expenditure on health in India continue to provide a sobering picture of stagnant inward investment and even a decline in relation to the disease burden and care and research funding requirements. Investment in the Tenth Five-Year Plan (2002–07) was 31020×10^7 rupees (US\$4998.2 million) for health, 27125×10^7 rupees (US\$4370.6 million) for family welfare, and 775×10^7 rupees (US\$124.9 million) for the Department of Indian Systems of Medicines and Homoeopathy, and increased in the most recent Eleventh 5-Year Plan to a total allocation for health of 140135×10^7 rupees (US\$22579.7 million) (Pramesh C S, unpublished). The hypothecated National Cancer Control Programme in India has also seen a modest rise in spending during the past decade from 48×10^7 rupees (US\$7.7 million) to more than 140×10^7 rupees (US\$22.6 million);²⁰ however, compared with, for example, HIV/AIDS control programme spending of 1400×10^7 rupees (US\$225.6 million), investment in cancer is still very modest²⁰ (table 1). Furthermore, planned health investment rarely represents real disbursements, especially when it comes to revenue expenditures in complex disease care such as that for cancer.⁴² Expenditure by Indian states on health schemes and programmes focuses mainly on delivery of health services. Creation of the National Rural Health Mission in 2005 was a major development in this regard. The Government of India launched this scheme to deliver essential architectural corrections in basic health-care delivery. As far as the services sector is concerned, the proportion of expenditure by the state governments (85%) far exceeds the central government allocation (15%) on health services, including cancer care.²⁰ In some states, a major chunk of the state budgetary allocations goes into maintenance of infrastructure and payment of salaries, with very little funding left to purchase drugs or non-routine health-related services.²⁰ Heterogeneity is substantial, with per person public expenditure on health by states and union territories ranging from 71 rupees in Chandigarh (US\$1.1) to more than 1200 rupees (US\$19.3) in Andaman and Nicobar Islands.⁴³ Increased allocation and funding,

	2002	2003	2004	2005	2006	2007	2008	2009	2010
National AIDS Control Programme	241	231	404	520	905	917	1032	938	1400
National Cancer Control Programme	48	25	62	63	87	106	76	97	140
Control of communicable diseases	27	31	54	81	141	39	47	63	75
Total health budget	1359	1325	1772	2244	3328	2183	3008	3261	5139

Expenditure values are in Rs crore; 1 crore=10⁷ rupees (US\$215 000). Data are from reference 20.

Table 1: Plan expenditures in India by scheme, including total health budget, 2002–10

	Expenditure (rupees)	Percentage of total
Public funds		
Central government	111 552 195	8.34%
State government	183 444 520	12.21%
Local bodies	12 292 886	0.92%
Total public funds	307 289 601	21.47%
Private funds		
Households	951 538 903	71.13%
Social insurance funds	15 073 973	1.13%
Firms	76 643 295	5.73%
Non-governmental organisations	7 217 434	0.54%
Total private funds	1 050 473 605	78.53%
Overall total expenditure	1 357 763 206	100%

Data are from reference 44.

Table 2: Health sector expenditure by the public and private sectors in India, 2010–11

expansion of infrastructure, and improved access through schemes including the National Rural Health Mission has yet to improve the ratio of public and personal expenditure on health, with private funding dominating the cancer care landscape (table 2). In this regard, the gap in expenditure on basic health services has a substantial knock-on effect on the ability and willingness to support essential cancer service delivery.

Delivery of affordable cancer prevention

Tobacco use in India has a complicated pattern of consumption, which means as much as 40% of India's cancer burden is related to this one risk factor.⁴⁵ Unlike many other parts of the world, smokeless tobacco is very common in India. Tobacco or tobacco-containing products are chewed or sucked as a quid, applied to gums, or inhaled. The practice of keeping the quid in the mouth between the cheek and gum causes most cancers of the buccal mucosa, which is the most common mouth cancer in India. Mishri, gudakhu, and toothpastes are popular because people believe that tobacco in the product is a germicidal chemical that helps to clean teeth. Mishri is a smokeless form of tobacco, and gudakhu is a paste of tobacco and sugar molasses. These preparations are used frequently by women and involve direct application of tobacco to the gums, which increases the risk of cancer of the gums. Dry snuff is a mixture of dried tobacco powder

and some scented chemicals, which is inhaled and is used widely in the elderly population of India.

Although the mortality and morbidity associated with poor tobacco control is well documented, the translation into economic effect is equally dramatic. In terms of the financial burden on patients and families, cancer patients with a tobacco-related cancer diagnosis spent on average 17 965 rupees (US\$289, including loss of income) on treatment, with a further 4009 rupees (US\$65) used by the hospital for services.⁴⁶ The loss of productivity because of premature deaths amounts to about 112 475 rupees (US\$1812). Thus, the total individual economic burden attributable to tobacco-related cancer is 134 449 rupees (US\$2166) in 1999 prices (the most recent year in which a major study was done).⁴⁶ Total economic losses to India caused by tobacco-related diseases (eg, cancer and cardiovascular diseases) were first estimated to be 27 760 × 10⁷ rupees (US\$4473 million) per year in 1999.⁴⁶ In the most recent analysis of the total and indirect costs of the three major tobacco-related diseases in India, these estimates increased to 30 833 × 10⁷ rupees (US\$4968) in 2002–03.⁴⁶ This figure represents an increase of more than 11% over a 2-year period without the assumption of any acceleration in either the burden of diseases or the cost of management of such diseases. Notably, the cost of tobacco consumption exceeds the total combined revenue and capital expenditure (budget estimates) by the government and the states on medical and public health, water supply and sanitation, which, according to the Indian Public Finance Statistics, amounted to 29 049 × 10⁷ rupees (US\$4681 million) in the same period.⁴⁶ Tobacco-related mortality is projected to rise to 1.5 million people in India in 2020, which represents 13.3% of total mortality and an increase of 320% within 22 years.⁴⁶ This value gives an arithmetic average increase of 50 500 additional deaths per year because of tobacco-associated diseases, which thus dramatically increases the economic effect of tobacco in India.

Although there is wide political agreement across India that tobacco control needs several public policy approaches, especially higher prices (one of the few effective mechanisms to control consumption), implementation still lags behind rhetoric. In addition to tobacco control, India also faces a range of new prevention challenges, especially in poor and rural areas.⁴⁷ As many parts of India rapidly urbanise and become more affluent, cancer risk factors such as obesity are quickly emerging. Between 1998 and 2005, the proportion of individuals who are overweight increased by 20% in India, with almost one in five men and over one in six women now overweight (although this proportion might be as high as 40% in all people in some urban areas).⁴⁸ This situation presents Indian policy makers with a difficult problem—a prevention paradox requiring policy to address both under-nutrition and over-nutrition.⁴⁹ The funding and organisation of such programmes is also by no means

clear in a country as complex as India, where difficult choices need to be made about priority areas for support.

Although most primary prevention programmes could cost India up to 2700 × 10⁷ rupees (US\$435 million) every year (and with the addition of school-based interventions, this amount could rise to 4934 × 10⁷ rupees [US\$795 million] every year), the resultant reduction in health expenditure has been calculated to be disappointingly low at 639 × 10⁷ rupees (US\$103 million) per year.⁴⁷ These macroeconomic figures are important because the per-person prevention package costs designed to tackle the main risk factors for chronic diseases (tobacco, alcohol, physical activity, high blood pressure, and high cholesterol) and interventions to deal with diet seem to be deceptively cost effective at 93 rupees (US\$1.5) and 22 rupees (US\$0.35) per head, respectively.⁴⁷ In India, many of the prevention programmes assessed have been estimated to be cost effective in the long run. However, some programmes will take a longer to deliver health benefits and will therefore be less cost effective in the short term. Others, such as fiscal measures, virtually pay for themselves after a few years. Beyond the economics of delivering a pan-India cancer prevention programme, which would almost certainly need to be tied into a wider non-communicable disease risk factor programme, the challenge to the government and states is how to deliver joint primary prevention programmes that span several public and political policy domains, such as education, food, mass media, and fiscal measures.

Delivery of affordable cancer screening

Although the National Cancer Control Programme, now integrated with other non-communicable diseases,⁵⁰ was launched almost 40 years ago in 1975 with the aim to reduce cancer-related morbidity and mortality, India still does not have any organised national cancer screening programmes. Opportunistic screening is available in different states, mostly through research or pilot projects. The cancer screening programme in Tamil Nadu state is the only such large-scale programme in the country. It is being implemented for the detection of cervical and breast cancer through cost-effective methods.⁵¹

The existing approaches in India for screening of cervical cancer include exfoliative cytology, visual inspection with acetic acid, and human papillomavirus-based molecular tests. Of these methods, cytology-based Pap smear testing is available only in district-level government hospitals as a free test and in private hospitals on a payment basis. The human papillomavirus test is mainly available through major private centres.⁵² Whereas most developed countries have organised screening programmes for cervical cancer by cytology, human papillomavirus test, and primary prevention through vaccination,⁵³ India, because of its poor infrastructure and scarcity of skilled personnel for the cytology-based Pap smear test and the high costs of human papillomavirus testing, recommends cost-

effective approaches such as visual inspection with acetic acid for screening.⁵⁴

For breast cancer, clinical examination is recommended as a cost-effective approach, by contrast with high-income countries where mammography is the gold standard, since neither the necessary machines nor trained manpower to read the mammograms are available in India.

For oral cancer, available early detection methods include clinical visual examination, supravital staining methods (toluidine blue), cytology, light-based detection tests, and chemiluminescence.⁵⁵ At present, oral cancer screening is not routinely done in high-income countries; however, in India, cost-effective screening for this prevalent cancer by visual examination—the most frequently used approach in India—is recommended for some patients.⁵⁴

The average economic cost of treatment of a typical cancer patient in a government facility in India has been calculated to be about 36812 rupees (US\$593).⁵⁷ India's annual income per person is only US\$1219, and 27.5% of the population live on or below US\$0.4 per day.²⁰ The advanced nature of most cancers and their effect on household finances make cost-effective screening an important part of delivering affordable cancer care in India.⁵⁶ However, for screening to deliver its benefits, India will need to link it with greater capacity and access to cancer treatment centres. Public health at the state level also needs to explore alternative financial models for delivery of screening programmes and India needs to create its own cost-effective screening programmes. In this regard, the experience of high-income countries is a salient lesson in ensuring that screening is affordable and effective. India has already delivered remarkable research around screening programmes⁵⁷ which need to be actioned with truly national public policy. What is good for Tamil Nadu is also good for Bihar or Punjab, and India needs to create a joint commission to drive cost-effective cancer screening programmes across the country.

Public policy solutions for affordable and equitable cancer care

The creation of the National Cancer Grid of India in 2012⁵⁸ (a partnership of all the major regional cancer centres across India) and the drive to improve the quality of services across the public sector provides a major opportunity to improve cancer outcomes. But what are the key areas? Even in the absence of immediate gains in terms of earlier presentation, provision of surgery and radiotherapy remain two of the most important areas for more cost-effective outcomes. Because of volumes and complexity, India has been an innovator in surgical procedures, but research into cost-effective procedures, the setting of national standards, and payment systems has, as is the case in most emerging economies, lagged behind.⁵⁹ The linkage between the research agenda⁵⁷ in cancer drugs focused on repurposing is also a hugely important step in the delivery of cost-effective regimens to patients. India's leadership in, for example, oral metronomic therapy

(prolonged, continuous, or frequently repeated treatment with low doses of chemotherapy with fewer side-effects), increased work on minimum effective dose, and low-cost screening implementation could be crucial not only for Indian patients but also for all other emerging and low-income countries.⁶⁰ India also has a problem that is common to other emerging and high-income economies: the unsustainable prices of cancer drugs.⁶¹ At existing prices, most, if not all, of the newer molecularly targeted drugs from major pharmaceutical companies are priced well beyond what the average citizen in India can afford, and indeed what Indian society can afford as a whole. Global access to new cancer drugs beyond the wealthiest countries remains unattainable unless a radical shift in global pharmaceutical social responsibility takes place.⁶²

India has rightly been heralded as the “pharmacy of the developing world”,⁶³ and further collaborations and research around repurposing of cancer medicines (eg, new indications, formulation enhancements, and generics) would provide a major boost to affordable cancer drugs nationally and internationally.⁶³ Globally, research to inform the affordability debate has been modest at best, and lessons drawn from high-income countries have, on the whole, little applicability to emerging economies.⁶⁴ Some general concepts, such as the impoverishment experienced by families due to out-of-pocket payments, have parallels in high-income countries like the USA,⁶⁵ but the similarities end there. Likewise, previous studies of cancer control in other emerging economies offer little insight or direction for the creation of affordable cancer care and control systems in India.⁶⁶

At both the state and central government levels, a structured assessment of existing health-care policies for delivery of affordable cancer care is urgently needed. Beyond the establishment of funding systems that link payments with outcomes, a national discussion is needed about how to fund the cancer care of the most vulnerable sectors of Indian society.⁶⁷ Although the negative effects of out-of-pocket payments on families is not unique to India—an estimated third of USA families struggle to pay medical bills or default on their payments⁶⁵—the sheer magnitude and extent of these payments urgently needs to be addressed. Although disparities in the wealth distribution between states are obvious, even those with historical poor health outcomes are now experiencing some of the fastest growths in terms of average GDP.⁶⁸ Slower than expected growth (which had slowed to 4.5% in 2012) is nonetheless still growth and some of this wealth needs to be channelled into the development of high-quality, affordable cancer care. Curtailing of catastrophic out-of-pocket payments in cancer care is one of India's most important goals. The development of cancer care packages within insurance schemes is essential, but not sufficient. Insurance must be used as insurance and not entitlement, and it needs to be associated with cost-effective quality care linked to evidence-based guidelines

	Needed	Sanctioned	In position	Vacant (sanctioned minus in position)	Shortfall (needed minus in position)
Andhra Pradesh	1124	578	408	170	716
Bihar	280	280	151	129	129
Gujarat	1220	346	76	270	1144
Karnataka	720	NA	584	NA	136
Madhya Pradesh	1332	778	227	551	1105
Maharashtra	1460	649	600	49	860
Odisha	1508	812	438	374	1070
Rajasthan	1504	1068	569	499	935
Tamil Nadu	1540	0	0	0	1540
Uttar Pradesh	2060	2060	1894	166	166
West Bengal	1392	542	175	367	1217

NA=not available. Data are from reference 72; also see the heatmap available online.

Table 3: Shortfall in specialists and general duty medical officers at community health centres in the 11 most populous states of India (March, 2011)

For the heatmap see <http://www.openheatmap.com/embed.html?map=SupportanceDeputesPlacidities>

	Rural population	Subcentres	Primary health centres	Community health centres
Andhra Pradesh	56 311 788	0	331	207
Bihar	92 075 028	8837	1220	700
Gujarat	34 670 817	660	157	15
Karnataka	37 552 529	0	0	146
Madhya Pradesh	52 537 899	3445	821	161
Maharashtra	61 545 441	2830	380	182
Odisha	34 951 234	1448	80	0
Rajasthan	51 540 236	0	334	86
Tamil Nadu	37 189 229	0	45	0
Uttar Pradesh	155 111 022	10 516	1480	778
West Bengal	62 213 676	2680	1239	189

Data are from reference 73.

Table 4: Shortfall in essential health infrastructure in the 11 most populous states in rural India (March, 2011)

such as those being developed by the National Cancer Grid of India. Other approaches that can directly or indirectly help to make cancer care more reachable and affordable include spreading of cancer awareness in the general population, cancer prevention, training of general practitioners and practitioners in the basic specialties in oncology, and increasing the number of oncologists and other paramedical staff for cancer care.

The existing public–private imbalance is unsustainable if India truly wants to deliver an affordable cancer care system to all its citizens.⁶⁹ Cancer care, like health, is a public good and generally purely market mechanisms are inadequate to deliver such a public good. Moreover, little incentive exists for the private health-care system to engage in cancer prevention—one of the cornerstones of an affordable cancer care system in India. Finally, the effectiveness of market competition depends on the

patient being able to assess the relative value of what they are buying. This situation implies choice and health education, neither of which is available to many patients, and especially not those from poor backgrounds. The large imbalance between private sector and public sector salaries also means that although the public sector essentially trains the workforce and shoulders the bulk of the fiscal risk, the drain to the private sector is very substantial. Previous studies have shown that although cancer, and especially cancer surgery, is a major interest for medical students, the reality is most want to stay in urban areas, and many will be lost to the private sector.⁷⁰

Conclusion

The Indian Government needs to make major policy decisions to ensure that access to health care is available to all people in the country, irrespective of their socioeconomic status. First, we need a strong mandate to strengthen the existing public health system with both improved infrastructure and additional manpower. Most district hospitals and even regional cancer centres do not have the facilities needed to provide quality cancer care to the people who rely on them. Many patients travel long distances to be treated at the handful of major cancer centres, which are mainly located in big cities—a situation that has two undesirable consequences. First, patients spend large sums of money travelling to and staying in these cities, which leaves them with even less to spend on the actual medical care. Second, these major cancer centres are disproportionately overloaded, which creates long waiting times for diagnosis and, subsequently, definitive treatment. However, the government has begun to address this through the Ministry of Railways by providing 100% travel concessions to patients with cancer and 75% concessions to family members.⁷¹ Diagnostic and imaging equipment, optimum surgical and radiotherapy infrastructure and equipment, and palliative care facilities need to be improved in almost all government-funded cancer centres in India. With concerted efforts to upgrade existing infrastructure and trained health-care staff, the regional or tertiary cancer centres will be capable of providing quality treatment for patients diagnosed with cancer. This goal is one of the important mandates of the National Cancer Grid of India.

One of the main problems faced in cost containment in cancer care is the absence of an established system that deliberates and decides what constitutes cost-adjusted effective cancer care, along the lines of the National Institute of Health and Care Excellence guidelines in the UK. Such decisions are especially important in the current era, where a few weeks of extra life in advanced cancers can be bought at disproportionate costs. Without rational use of scarce resources, the prioritisation of resource allocation and justification of additional budgetary requirements for government-funded cancer centres becomes difficult, if not impossible. When health care is subsidised heavily by the government, one of the top priorities should be to establish what will and what

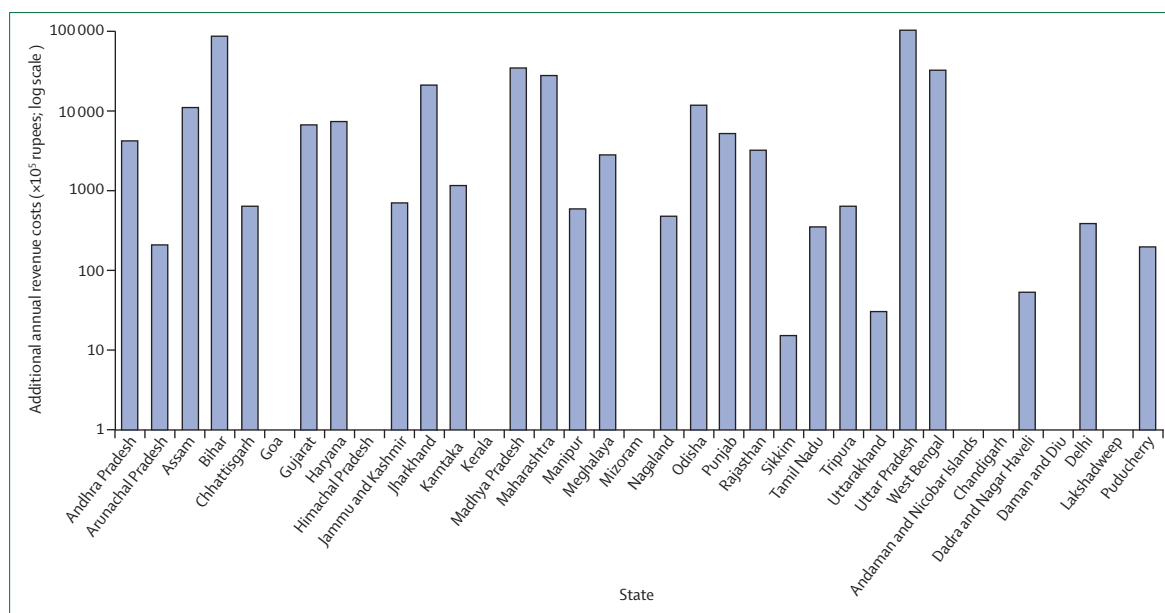


Figure 2: Increased annual expenditure needed to address essential health infrastructure shortfall in rural India, by state
Data are from reference 73.

will not be reimbursed as justifiable health-care costs. The National Cancer Grid has initiated the process of creating evidence-based management guidelines for the treatment of common cancers in India. The next step should be the development of a set of guidelines that can be used to make decisions to offer treatment for free or at a subsidised cost through the government-funded cancer centres, based on economic grounds.

Finally, India needs to look at local, cost-effective solutions to common cancers at all levels—prevention, screening, diagnosis, and treatment. Indian biomedical research should focus on the search for innovative, cost-effective solutions that are unlikely to come from high-income countries. Examples such as visual inspection with acetic acid to screen women for cervical cancer and breast self-examination for breast cancer screening have either shown promise or are being studied in large randomised trials. Recent blockbuster cancer drugs are inaccessible to most patients with cancer and to expect subsidised funding for these expensive treatments from the government would be unrealistic. The National Cancer Grid is initiating research efforts by academic cancer centres to repurpose existing inexpensive drugs, such as aspirin, for cancer treatment. The government has also funded the development of low-cost radiation technology using cobalt-60 (Bhabhatron) and linear accelerators (Siddhartha) through research at the Department of Atomic Energy. These devices, which are available at almost half of the cost of commercially available equipment, are already being deployed in some regional cancer centres.

We further conclude that more robust regulation and governance of the private sector alone is insufficient. Shortfalls in personnel and facilities in the public sector

Panel: Crucial public policy issues for affordable cancer care in India

- The government needs to increase support to regional cancer centres with mandated authority to provide affordable (and free for poor patients) cancer care and prevention services.
- States need to develop public strategies to adapt and address epidemiological migration by increasing the capacity and quality of cancer care, especially to marginalised and rural populations.
- The cost of outpatient cancer care to the patient is substantially higher than that of inpatient management, and this cost is not covered by most of the existing insurance schemes. The bulk of this expenditure is the cost of travel, food, and rent, and is compounded by loss of income from work. Patients, especially those who are poor or living in rural areas, bear these costs from out-of-pocket payments, and new social and economic support mechanisms and schemes are urgently needed.
- Waiting periods at public facilities are a major contributor to the escalating cost of treatment. Enhancement of capacity and increased clinical and allied health-care manpower are essential.
- India needs to invest more of its gross domestic product in health care, which will deliver both health and wealth to the country.
- Cancer needs to be seen and addressed as a public health priority. Improvements in outcomes will come through early detection and presentation, primary prevention (especially through tobacco control), and a greater emphasis on the social determinants of cancer.

mean that patients do not have the option of being treated in the public sector or they face a long waiting list. The most recent Government of India statistics from 2011 show a shortfall of about 12 000 specialists, general medical officers, and radiographers from community health centres, with five states reporting a shortfall of more than 1000 personnel (table 3). The gap between what is needed and what is available is replicated in essential

Search strategy and selection criteria

We searched Medline, Web of Science, and LISTA with medical subject heading (MeSH) terms ("India", "expenditure", "affordable", "cancer", "healthcare", "cost effectiveness", and "costs") between January, 1980, and December, 2013. We also reviewed various Indian Government sources for information about manpower, infrastructure, and health-care expenditure. Papers, reports, and digests published in English only were selected for the relevance to affordable cancer care in India and were reviewed by the drafting committee. For currency conversions we used standard FOREX rates in the UK as of Feb 20, 2014. No corrections for purchasing power parity were made.

health infrastructure, with nearly 45 000 new health facilities needed in rural areas (table 4). However, capital expenditure to address new builds is not the major issue. As we have already discussed in the first paper in this Series,⁷⁴ manpower planning and funding is the central public policy issue. Our analysis shows that to deliver even a basic package of general oncology to rural India, 15 states would need to find an additional 10×10^7 rupees (US\$1.6 million) per year (not taking into account inflation), and eight of these states would need an additional 100×10^7 rupees (US\$16 million) ever year (figure 2). Strategically, India needs to address affordable and equitable cancer care as a national public policy issue if it is to successfully scale-up cost-effective population-based and cancer clinical care packages. To solely rely on private financing is not the solution, since this approach will only drive cost escalation, inequity, and fragmentation. India has a range of public policy options (panel), many of which have already been well articulated by the Commission on Investing in Health,⁷⁵ which it will need to draw on. These options range from policies to stimulate and control health care, to strategic purchasing of more inclusive and comprehensive insurance schemes for India's poorest communities.⁷⁵ At the heart of this approach must be strong commitment to building, reforming, and funding of public sector capacity and quality, both in terms of new facilities and manpower planning, coupled with a renewed commitment to tackle the catastrophic cancer expenditures faced by patients and their families.

Contributors

RAB, CSP, AP, and RS designed this policy analysis with the National Cancer Grid of India. CSP, RS, AA, MV, PS, and AP drafted the framework document. All other authors contributed equally to writing and revision of the final report.

Declaration of interests

We declare that we have no competing interests.

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