Cancer burden and health systems in India 1

The growing burden of cancer in India: epidemiology and social context

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Cancer can have profound social and economic consequences for people in India, often leading to family impoverishment and societal inequity. Reported age-adjusted incidence rates for cancer are still quite low in the demographically young country. Slightly more than 1 million new cases of cancer are diagnosed every year in a population of 1·2 billion. In age-adjusted terms this represents a combined male and female incidence of about a quarter of that recorded in western Europe. However, an estimated 600 000–700 000 deaths in India were caused by cancer in 2012. In age-standardised terms this figure is close to the mortality burden seen in high-income countries. Such figures are partly indicative of low rates of early-stage detection and poor treatment outcomes. Many cancer cases in India are associated with tobacco use, infections, and other avoidable causes. Social factors, especially inequalities, are major determinants of India's cancer burden, with poorer people more likely to die from cancer before the age of 70 years than those who are more affluent. In this first of three papers, we examine the complex epidemiology of cancer, the future burden, and the dominant sociopolitical themes relating to cancer in India.

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This is the first in a Series of three papers about cancer in India

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Introduction to cancer in India

Cancer is a major cause of morbidity and mortality in developing and developed countries alike.[1] In many low-income and middle-income countries, including India, most of the population does not have access to a well organised and well regulated cancer care system. A diagnosis of cancer often leads to catastrophic personal health expenditures.[2] Such expenditures can push entire families below the poverty line and may, especially when combined with an absence of what are seen as acceptable services, threaten social stability.[3,4]

Population ageing is often assumed to be the main factor driving increases in cancer incidence, death rates, and health-care costs.[5] However, the actual picture is more complex. In high-income countries age-standardised cancer mortality is now typically decreasing in all age groups, although more than half of all cancer deaths are people older than 70 years. In India, despite the weakness of data in terms of population coverage, no evidence exists for a decrease in age-standardised cancer mortality rates, and most deaths occur in individuals younger than 70 years.[1] These differences are only partly due to India having a relatively younger population compared with high-income countries. They are also a product of contrasting causal patterns, with infections and unique local patterns of tobacco use playing a much greater part in causing cancer in India than in richer countries. Poor access to screening and early-stage case-finding services also helps to explain the paradox of India's seemingly low cancer incidence rates but relatively high age-specific death rates.

Although improvements in living standards and Human Development Index rankings are typically linked to increases in the occurrence of, for example, sex hormone exposure-related cancers, and cancers epidemiologically associated with reduced average family sizes,[6] the positive gains that economic and social development bring—eg, improved food quality—normally far outweigh any such costs. The International Agency for Research on Cancer GLOBOCAN project[1] has predicted that India's cancer burden will nearly double in the next 20 years, from slightly over a million new cases in 2012 to more than 1·7 million by 2035. These projections indicate that the absolute number of cancer deaths will also rise from about 680 000 to 1·2 million in the same period.[1] Yet the extent to which cancer-related mortality and disability will actually increase partly depends on the investment decisions made in future decades in health care, cancer research, the wider public understanding of cancer harm-reduction, and on other technical or social changes that will affect disease incidence and outcomes.

Here, we review published data on the epidemiology of cancer and the cancer-related burden in India.[1,7] We also briefly discuss the implications of factors that affect patients, health professionals, and state and government policy makers in cancer care[4] from a policy perspective. Additionally, we explore (as a prelude to the third paper in the Series[4]) the social determinants of cancer occurrence in India, and opportunities for improving prevention and treatment through the enhanced application of existing knowledge, coupled with ongoing scientific and health service innovation. The latter will be discussed in greater depth in the second paper in this Series.[8]

Modern India's cancer burden

No national registry exists that provides comprehensive cancer incidence or mortality data for India. However, the

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National Cancer Registry Programme (NCRP, established by the Indian Council of Medical Research in 1981) provides population-based data from a selected network of 28 cancer registries located across the country.[9]

Information from 12 registries deemed to provide reliable data was used to estimate the national statistics presented in relevant GLOBOCAN publications.[1,7] However, the resulting estimates have several limitations. They might, for example, be more representative of urban and south Indian populations than of those populations living in the rest of the country. Under-recording of cancer cases and deaths, especially among older people, is another problem that reduces accuracy. Nevertheless, the aggregated numbers reported through GLOBOCAN are the best available ongoing estimates of the cancer burden in India and are suitable, despite the caveats indicated, for use as the main basis for priority setting and planning of cancer management across the nation.

In addition to this primary source (and the wider NRCP data)[1] the Million Deaths Study[10] is another important data resource. Researchers independently assigned causes to 122 429 deaths in 1·1 million homes in 6671 randomly selected rural and urban areas of India, using a validated verbal autopsy-based method to establish mortality cause. The Million Deaths Study provides additional useful data about the nationwide cancer burden and on regional, state, and rural versus urban variations.

Figures on the distribution of cancer treatment facilities and expertise available were obtained from various sources, including the Medical Council of India and National Board of Examinations websites, and publications issued by the Atomic Energy Regulatory Board (which licenses and monitors radiotherapy centres in India).[11–13]

With regard to population size, data provided via the office of the Registrar General and Census Commissioner of India were used. The most recent (15th) national census was done in two phases in 2011.[14] The census covered all 35 states and union territories, and, within them, 640 districts, 5924 sub-districts, 7933 towns, and 640 930 villages. The total population on March 1, 2011, was slightly more than 1210 million, of which 833·5 million individuals (69%) were classified as living rurally, and just under 500 million were listed as working in agriculture.

Other key findings from the latest census were that rural and urban populations each increased by 91 million people in 2001–11, and that the child (0–6 years) sex ratio (girls per 1000 boys) declined from 934 to 923 in rural India, and from 906 to 905 in urban areas. The literacy rate in the population aged 7 years and older was 68% in rural areas compared with 84% in urban areas, and 81% for males compared with 65% for females nationwide. These data draw attention to the complex sociocultural backdrop of the burden of cancer in India. The Indian situation reinforces the need to view cancer statistics, such as those available on survival (table 1) in the widest possible context to fully inform care and prevention strategies.

	Cervical cancer	Breast cancer	Oral cancer	Rectal cancer	Colon cancer	Non-Hodgkin lymphoma
Barshi 1993–2000; followed up to 2003	35·1%	55·3%	23·6%	13·0%	NA	25·4%
Bhopal 1991–95; followed up to 2000	30·8%	25·3%	33·9%	4·0%	3·2%	8·8%
Chennai 1990–99; followed up to 2001	60·2%	47·1%	35·6%	NA	NA	21·5%
Karunagapalli 1991–97; followed up to 1999	54·8%	44·8%	42·3%	43·6%	NA	36·0%
Mumbai 1992–94, followed up to 1999; and 1995–99, followed up to 2003	48·2%	43·8%	35·0%	26·1%	25·4%	34·2%

Data taken from Sankaranarayanan and Swaminathan.[18] NA=not available.

Table 1: **Age-standardised relative survivals at 5 years for five of the most common treatable cancers in different regional populations of India, with case detection period**

Cancer incidence and mortality

GLOBOCAN estimates that about 14 million new cancer cases were diagnosed worldwide in 2012 and slightly more than 8 million cancer deaths occurred. 1 million of these new cases and nearly 700 000 of the deaths occurred in India, which is home to about 17% of the global population (table 2). Even in age-adjusted terms the recorded incidence for India is, at 94 per 100 000 people, only slightly more than half of the world average of 182 per 100 000, and about a third of that recorded in the more developed countries (268 per 100 000).

All cancers in Indian men other than oral, lung, stomach, colorectal, pharyneal, and oesophageal cancers have an incidence of five per 100 000 men or less. This, according to US and EU definitions, makes such cancers orphan diseases. Women have an age-adjusted incidence rate of 104·5 per 100 000 women. With the exceptions of breast, cervical, and colorectal cancers, all other cancers in Indian women also have a recorded incidence of less than five per 100 000 women.

In 2012, almost 145 000 Indian women were diagnosed with breast cancer. Nearly 400 000 of those who had reportedly been diagnosed with breast cancer in the previous 5 years were still alive. In 2009, breast cancer became the most frequently diagnosed form of neoplastic disease in women in India and is now the most common cause of cancer death in the country, accounting for more than a fifth of all female cancer mortality (figure 1).

Studies of immigrant Indian populations in settings such as the UK and the USA show a growing convergence between their experiences of cancer and those of their surrounding communities.[15,16] However, in India, the burden of disease is still strikingly unlike that in post-industrial nations. In men, the more common cancers are tobacco-related. For Indian women, cervical cancer is the second most common incident cancer (figure 1A). Cervical cancer is also the second most common cause of cancer deaths when both sexes are combined (figure 1B). In childhood cancers, treatment still remains incomplete

and survival in general is lower in India than in more developed countries. However, for children treated in comprehensive cancer centres, survival approaches that in Europe or the USA.[17]

A substantial difference also exists between the ratios of cancer incidence to mortality recorded in economically developed countries compared with emergent economies (table 2). India is no exception to this pattern, which is affected by causal variations, stage at diagnosis, and the availability and use of cancer treatments. The cancer mortality rate in India is high, at 68% of the annual incidence. This ratio indicates that fewer than 30% of Indian patients with cancer survive 5 years or longer after diagnosis. In view of the limitations in the available data, the true proportion could be significantly lower. By contrast, in North America and western Europe overall 5-year survival for all cancers is about 60%. Delayed diagnoses and inadequate, incorrect, or suboptimum treatment (including patient inability to access or complete appropriate therapies) are the chief factors that cause poor cancer survival in India.[18,19]

Similarly, population-based 5-year survival for common childhood cancers is less than 50% of the results reported from developed countries.[20]

Regional variations

The burdens imposed by cancer vary greatly between regions within India.[7] Figure 2 shows differences in the recorded incidence in 12 parts of the country. Cancer incidence and mortality are generally higher in the more affluent states. However, cancer mortality rates are also significant contributors to mortality in rural regions and where cancer treatment facilities are scarce. Poor individuals are also at a higher age-specific mortality risk than are affluent people (table 3).[10] The extent to which these apparently conflicting observations are an artifact associated with variables such as the fact that some cancers occur much more frequently in the rural parts of the north-eastern states than in urban areas or southern and western India is uncertain and hotly debated. It should be remembered that, even allowing for under-recording, cancer causes no more than 10% of annual deaths in India; nevertheless, the rapid growth in absolute numbers of cancer cases is a major public health issue for India which needs better cancer registration and national statistics.

To make cancer a notifiable disease might be one way to improve assessments of the national burden, as would establishment of new and improved registries wherever they are needed. However, such progress will take time. In the interim, results of additional carefully conducted sample survey-based investigations like the Million Deaths Study[10] could provide more insight into issues such as the extent of regional variations, and help to further inform overall cancer policy and care delivery. A final point to emphasise is that the total cancer burden in India is projected to increase substantially from about 1 million new cases in 2012 to

	Incident cases	Deaths	Incidence ASR	Mortality ASR	Mortality to Incidence ratio
Very high HDI	5 780 821	2 606 104	279·2	105·3	37·7
High HDI	2 126 439	1 244 496	180·2	102·3	56·8
Medium HDI	5 232 474	3 656 562	144·2	102·8	70·9
Low HDI	943 102	690 141	112·8	86·7	76·9
India	1 014 934	682 830	94·0	64·5	68·6

HDI=human development index. Data from GLOBOCAN online analysis for 2012.[1] ASR=age-standardised rate, adjusted for world population and in 100 000 population.

Table 2: **Cancer incidence and mortality in India in very high, high, medium, and low development index regions, 2012**

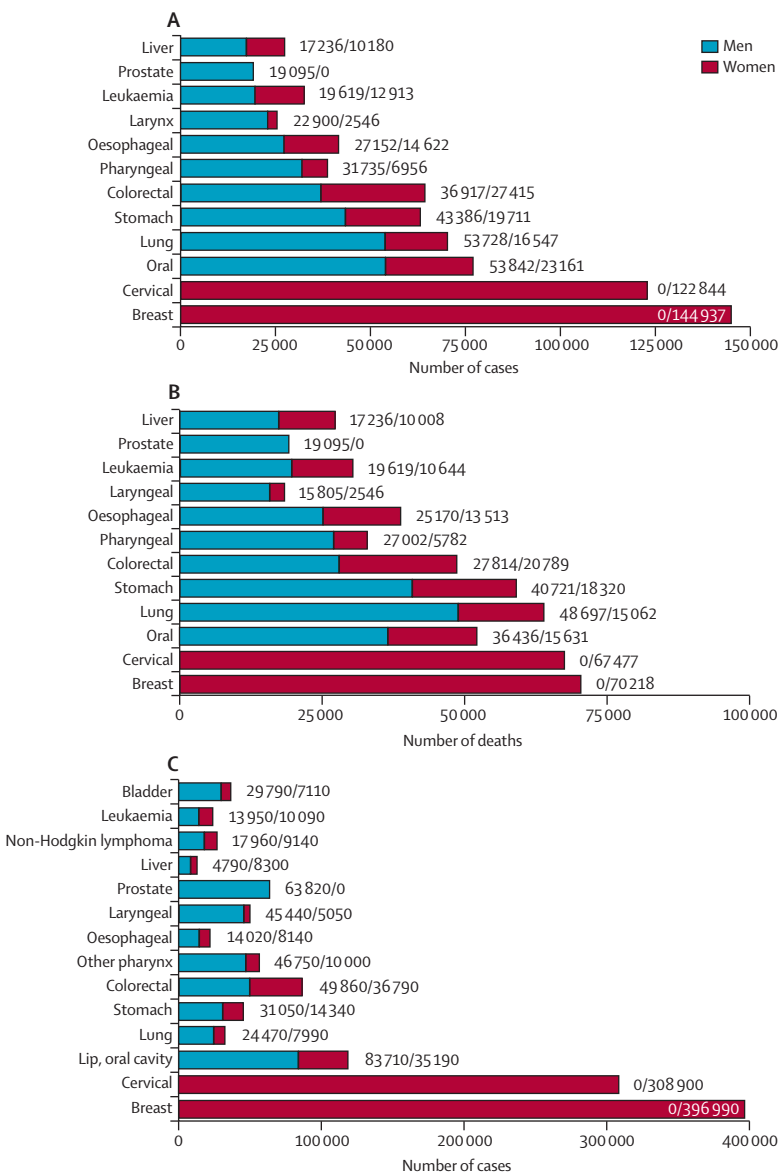

Figure 1: **Incidence (A), mortality (B), and prevalence (C) of the most common cancers in Indian men and women in 2012**
Data from GLOBOCAN 2012.[1]

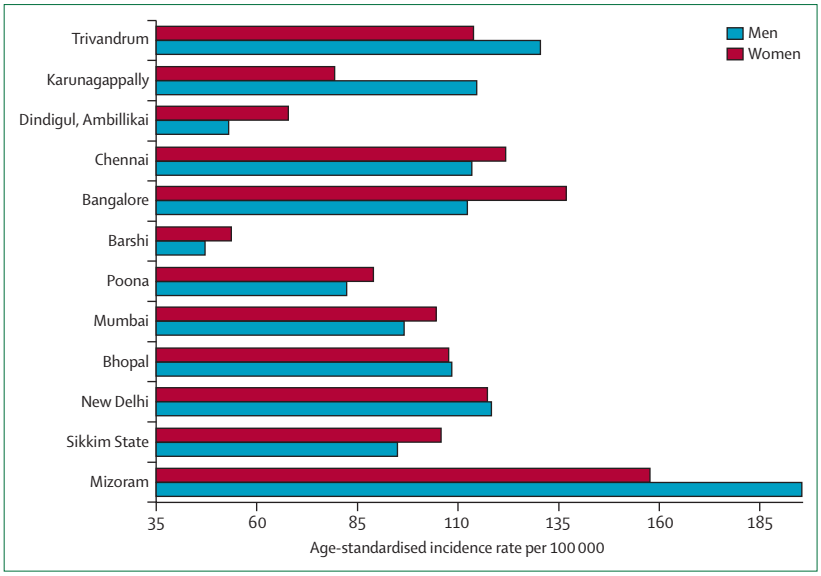

Figure 2: **Regional variations in the age-adjusted incidence rates of cancer in men and women in different regions of India**
Data extracted from Forman and colleagues.[7]

	Illiterate	Primary school	Secondary school and above
Total cancer deaths in men (ASR)	106·6	93·4	45·7
Total cancer deaths in women (ASR)	106·7	64·2	43·4
Tobacco-related cancer in men (ASR)	39·3	37·5	18·2
Tobacco-related cancer in women (ASR)	19·5	10·1	7·2
Infection-related cancer in men (ASR)	24·3	17·8	7·6
Infection-related cancer in women (ASR)	41·2	21·7	10·3
Estimated burden of deaths in men in thousands	79·2	34·3	16·2
Estimated burden of deaths in women in thousands	140·2	15·3	5·4

Data from Dikshit and colleagues.[10] ASR=age-standardised rates per 100 000.

Table 3: **Burden of cancer deaths in Indians by educational status in individuals aged 30–69 years**

more than 1·7 million per year by 2035, primarily because of ageing of the population (figure 3). Additionally, although age-specific incidence and mortality might start to decrease, the prevalence will rise as a consequence of enhanced survival, as and when that is achieved.

India's cancer burden in a social context

Since India regained independence in 1947, its population has quadrupled, from about 300 million to 1·2 billion.[14] In the same period, average life expectancy at birth has increased by about two thirds, from less than 40 years to 65 years for men and women combined. Significant economic growth has also occurred since the early 1980s, with a sharp increase from the start of the 1990s. Such national success deserves recognition; however, in overall terms the gross domestic product (GDP) per person remains low, at about US$1500.

In purchasing-power-adjusted terms, this is equivalent to only about a third of the figure now recorded for China and only 5–10% of that in western Europe and North America. Despite the ability of countries such as Cuba (which has a GDP of about US$5000 per person) and Indian states such as Kerala and Tamil Nadu to achieve relatively good health outcomes, future health developments will be integrally linked to the nation's economic fortunes and collective commitment to equity and universal health-care provision. From a patient perspective the social contract underpinning the country's progress arguably needs a strengthened focus on good quality health-care access generally, rather than on cancer prevention and treatment only.

India's demographic and epidemiological transitions have been slow compared with the progress achieved in the past half century in many other parts of Asia. The population is still fighting relatively high rates of parasitic, bacterial, and viral diseases (which are collectively the direct cause of about a third of all deaths), while encountering increasing levels of illness caused by conditions such as stroke, ischaemic heart disease, type 2 diabetes, and cancer.[20] This double burden (together with that associated with traffic and work-place accidents and hazards such as snake bites) sets a complex health-policy challenge. Effective policies must bridge the continuing public-health task of infection control and the modern goal of non-communicable disease prevention and management. In the case of nutrition, for example, India needs a transition strategy that will both combat malnutrition and guard against the rapidly increasing obesity rates seen in emergent nations such as Mexico and Egypt.

Partly because of continued rapid population growth linked to both enhanced survival and only gradually decreasing birth rates, the proportion of the population aged over 65 years is still little more than 5%. Some commentators regard a young population as a national strength—they believe that, as birth rates continue to decrease, this will eventually release a so-called demographic dividend in India that will generate a major developmental surge. Such observers might see population ageing as a threat, not least because it will increase the overall incidence of cancers that are not infection-linked.

Against this idea, other observers warn that high and still-increasing populations in themselves represent a key challenge to communities trying to escape poverty—they note that, as life expectancies rise, age-specific rates of disabling disease tend to fall in line with mortality. From this perspective, the pursuit of healthy and active ageing should already be as much a priority for modern India as is the continuing reduction of maternal and child deaths.

India is a country traditionally more accustomed to accepting disparities in wealth and health between different community groups than with confrontation of social and gender inequities. Nevertheless, India's low rate of public expenditure on health care is, in some ways, a surprising as well as a serious problem. India

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invests less than 1·5% of its GDP on central government-funded and state-funded health care, out of a total public plus private spend of little more than 4% of GDP. No other comparable nation spends as small a proportion of its national resources on public health care. The situation is further complicated by factors such as poor fiscal governance; sub-optimum (health sector-related) relationships between the federal and state governments; poor public health expertise (compounded by inadequate medical and other health professional education); substantial regional variations; and gross education, caste, and class-related inequalities in income and access to services. Provision of more acceptable standards of cancer care and enhanced preventive services will be very difficult without increased public expenditures on health at both the state and central government levels.

Promotion of cancer patients' interests

From a health-gain standpoint, India's immediate priorities should include improving preventive and primary-care services to reduce the burden of disease linked to factors such as inadequately managed hypertension and, in the case of cancers, tobacco product use, indoor and outdoor pollution, and infections such as human papillomavirus, hepatitis B, and *Helicobacter pylori*.[20] Diagnosis of diseases like oral, cervical, and breast cancers at earlier stages is also needed to save lives and reduce distress, especially when this can be linked to better and more accessible pain management.

Given that the poorest two-thirds of the population is in much greater need of better health-care provision than is the wealthiest third, increased public investment in health services needs to be a public policy priority for India. However, well directed health spending should also benefit all sections of society. Innovations such as the establishment of the National Rural Health Mission (now being rolled out across the country as the National Health Mission) and the introduction of insurance schemes such as the Rashtriya Swasthya Bima Yojna (RSBY) and similar state-level initiatives are examples of positive progress,[21,22] as is the recent publication of a Planning Commission of India-inspired plan for the provision of universal health coverage.[23,24] The development of comprehensive cancer centres in settings such as Ahmedabad, Chennai, Guwahati, Mumbai, and Thiruvananthapuram, with their community-outreach programmes, represent another important step forward in the specific sphere of cancer care.

Nevertheless, improvements in health-care access and delivery have been small so far, and public health improvement in India has (notwithstanding relevant constitutional commitments) been less of a political priority than in other countries at a similar developmental stage. The volume of calls for infrastructural improvements in India in non-health service areas, ranging from energy and clean water supply to improved transport and waste disposal facilities, might partly explain this difference. But, from a sociological and political science perspective, the fact that modern India has retained many of its ancient cultural roots in living forms is also significant.

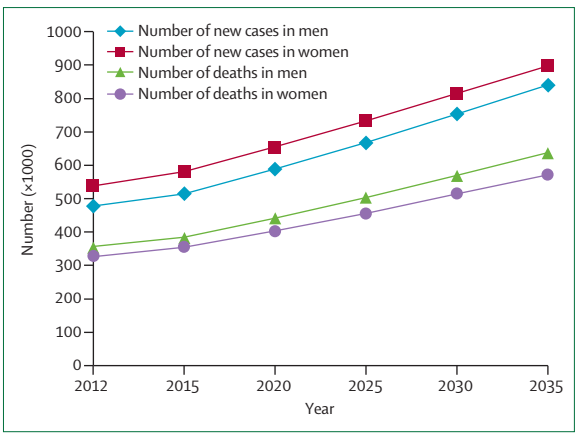

Figure 3: **Estimated projected incidence and mortality burden of all cancers in Indian men and women to 2035**
Data from GLOBOCAN 2012.[1]

India is a highly stratified, ethnically diverse society, with a strong emphasis on family and other kinship-linked responsibilities for provision of personal care. Equally, there has seemed to be a corresponding absence of a commonly perceived need to contribute to universal service funding. With respect to cancer services and all other forms of health-service delivery, this partly explains why costs are largely paid as out-of-pocket expenditures.[4,24]

This expenditure is especially apparent in the case of outlays on drugs. In manufacturers' prices, medicines of all types probably account for about 20% of Indian health spending.[25] But because their costs (which in practice often encompass additional practitioners' fees) are very visible to people who have poor access to other services, outlays on medicines have been a key focus of attention. This focal point might, on occasions—along with an absence of public, professional, and political awareness of the underlying social and allied determinants of public health—have concealed more fundamental policy concerns. In the cancer services context, this has been typified by disputes about the licensing and pricing of patented anticancer treatments.[26]

One core reason why the infrastructure for management of India's cancer burden is insufficient is the severe shortage of appropriately educated medical and other health personnel, and of the training facilities needed to produce them (table 4). Linked to this, factors such as the preferences of doctors and other health professionals for working in more affluent areas, and the effects of a largely unregulated private sector, have resulted in a skewed geographical distribution of cancer treatment facilities.

The available evidence suggests that about 60% of specialist facilities are located in regions to the south and the west of India.[4] However, more than 50% of the

population live in the central and eastern regions, distorting service provision. For example, at least half of patients with cancer will be judged to need radiotherapy at some point. Yet data published by the Atomic Energy Regulatory Board indicate that the 26% of the population living in the eastern region of India have immediate access to only 11% of radiotherapy facilities (figure 4). Cancer surgery and radiotherapy provision are available only on a highly inequitable geographical basis, and radiotherapy is significantly under-resourced (the last systematic analysis in 2007 showed that there were 347 teletherapy units across India against a requirement of 1059).[27] Addressing the social determinants of cancer and cancer-related needs must go hand-in-hand with improvement in cancer care capacity and delivery capability across India.

As early as 1946, the Bhore Committee drew attention to cancer as a problem in India, and made several recommendations for the establishment of accessible services;[28] nevertheless, nearly 70 years later, many Indians with cancer still have to travel long distances for medical care. This situation can exacerbate sex, age, and socioeconomic biases. Women, the frail, elderly people, and those with low incomes are unlikely to have the resources and support they need to travel safely despite the improvements in, for example, rail concessions.

Even when people in need of cancer therapy can reach treatment centres, they typically have to stay in what are often over-crowded and unhygienic dharmashalas, or non-religious lodging houses.[29] Many are at increased risk of contracting infections (including those caused by drug-resistant pathogens), and so might be unable to complete treatment regimens in a timely way or attend follow-up care sessions.[30] This could well be one of the factors that contributes to India's disproportionately high cancer incidence-to-mortality ratios, alongside late diagnosis. To ensure safety and quality of treatments is a difficult area to study. India has a complex set of interlocking legal regulations and regulatory frameworks;[31] however, a major challenge to cancer equity is the fact that poor sectors of society are more likely than are wealthier groups to receive poor quality treatment from less-qualified institutions.[32]

	University-affiliated postgraduate degrees		National Board of Examinations-affiliated postgraduate degrees		Total	
	Colleges	Seats	Colleges	Seats	Colleges	Seats
Medical oncology	14	61	15	26	29	87
Clinical haematology	7	14	2	4	9	18
Radiation oncology	64	196	22	33	86	229
Surgical oncology	13	58	19	31	32	89

Data from Medical Council of India[11] and National Board of Examinations.[12] Number of MBBS seats is 49 918 per year from 381 colleges. Number of colleges running all three courses is nine. Duration of training is 3 years.

Table 4: **Training facilities and yearly intake for formal training of oncology staff in India, by postgraduate course**

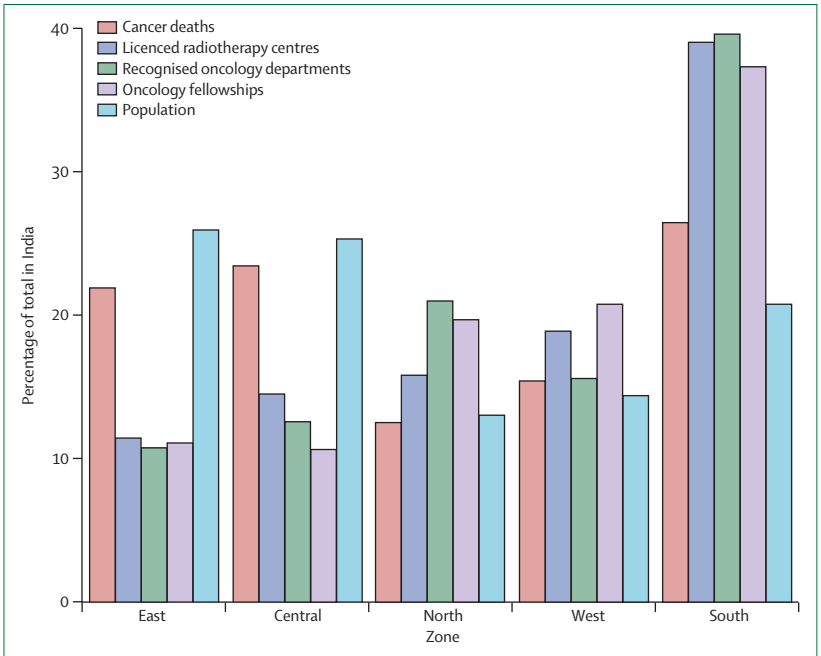

Figure 4: **The distribution of the population (2011) and cancer mortality (2010) in five zones of India compared with the corresponding proportions of radiotherapy centres, oncology departments, and postgraduate oncology training positions**

The 35 states and union territories of India included in the five zones are: East Zone (Bihar, Jharkhand Orissa, West Bengal, Sikkim, Assam, Arunachal Pradesh, Manipur, Mizoram, Meghalaya, Nagaland, Tripura); Central Zone (Chhattisgarh, Madhya Pradesh, Uttar Pradesh, Uttaranchal); North Zone (Jammu and Kashmir, Punjab, Haryana, New Delhi, Rajasthan); West Zone (Goa, Maharashtra, Gujarat, Daman and Diu, Dadara, and Nagar Haveli); and South Zone (Kerala, Tamil Nadu, Karnataka, Andhra Pradesh, Pondicherry, Andaman and Nicobar islands, Lakshadweep).

Conclusion

The burden of cancer in India is intimately linked to the country's major socioeconomic inequalities in access to health care and other areas. Rebalancing of the distribution of power, social goods, and resources[33] will be a crucial determinant of how India will address its cancer burden in the long term. Failure to address social inequalities reduces survival and can needlessly increase the costs of cancer to individuals and Indian society as a whole.

Even greater losses of welfare are associated with long-standing weaknesses in the country's public health system and its capacity to deliver preventive services.[34] These weaknesses have limited India's ability to protect its citizens from the key causes of cancer and treat the disease in a timely and successful way when it occurs. To achieve better outcomes will demand new ways of thinking among individuals and groups at all levels, including political leaders, the medical profession, patient organisations, and the public as a whole.

At the root of the solutions to India's cancer burden is the need for political commitment and action. Measures such as a fully committed effort to reduce, and, in the long term, eliminate, use of tobacco products through the vigorous implementation of the Framework Convention on Tobacco Control, would in time substantially decrease the incidence of, and consequently the mortality caused by,

Search strategy and selection criteria

We identified data sources for this review by searching Medline, PubMed, Google Scholar, and references from relevant articles, using the search terms "cancer", "India", "epidemiology" and "burden". We included only articles published in English and after Jan 1, 2000. We searched the websites of the International Agency for Cancer Research, the Medical Council of India, National Board of Examinations, Atomic Energy Regulatory Board, and Registrar General and Census Commissioner of India for relevant data since 2010.

many common forms of cancer in India.[35] So, too, could 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 at improving nutrition, better urban planning to provide exercise space, and prevention of obesity in India's population would also slow increases in lifestyle-associated cancers. India's political challenge is to develop convergent health policies that address both communicable and non-communicable diseases.[36]

The continuing improvement of cancer outcomes will require changed priorities and strong national, regional, and district leadership.[37] It will also demand increased public spending on both primary health care and specialist facilities in every Indian state[4] and more emphasis on improvement of cancer research in India.[8] Addressing of the cancer burden in India will require continued focus on other major social determinants of good outcomes—particularly education.[38] In view of the acute suffering of people with advanced disease, oncologists and others with patient interests at heart will wish to see the requirements of seriously ill patients met as rapidly and fully as possible, especially when new palliative or curative opportunities become available. But prevention of cancer wherever possible will generate greater long-term benefit. To truly serve public interests, Indian policy makers should be aware of this last reality, along with the importance of focusing rigorously on overcoming the fundamental barriers to provision of affordable, equitable, and universal cancer care for the entire population.

Contributors

MKM and DGT contributed equally to this paper and are joint first authors. MKM, DGT, ADP, CSP, JAG, and RS designed this policy analysis with the National Cancer Grid of India, and drafted the framework document. All other authors contributed equally to writing and revising the final paper.

Declaration of interests

We declare that we have no competing interests.

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Cancer burden and health systems in India 2

Cancer research in India: national priorities, global results

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Over the past 20 years, cancer research in India has grown in size and impact. Clinicians, scientists, and government and state policy makers in India have championed cancer research, from studies to achieve low-tech, large-scale health outcomes to some of the most advanced areas of fundamental cancer science. In this paper, we frame public policy discussions about cancer with use of an in-depth analysis of research publications from India. Cancer research in India is a complex environment that needs to balance public policy across many competing agendas. We identify major needs across these environments such as those for increased research capacity and training and protected time for clinical researchers; for more support from states and enhanced collaborative funding programmes from government; for development of national infrastructures across a range of domains (ie, clinical trials, tissue banking, registries, etc); and for a streamlined and rational regulatory environment. We also discuss improvements that should be made to translate research into improvements in cancer outcomes and public health.

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Cancer research in India compared with that in other countries

The public policy rationale for cancer research—ie, improvement of outcomes for patients in the immediate term, availability of cost-effective solutions matched to the range and burden of disease, creation of national wealth through innovation, and effects on global health—is as relevant for India as it is for high-income countries. However, most of the discourse about cancer control in emerging economies does not mention the need and importance of research[1] or high-income economies set their research agenda.[2] Research needs to be placed at the centre of plans for national cancer control, and cancer should be one of the focuses of national research agendas and priorities.[3] Similar to most of the narrative about global health and universal health coverage in India, the need for a strong research agenda has not yet been recognised in the country.[4] This absence of recognition is a serious gap in public policy. Development of a strong research base substantially improves patient outcomes,[5] in addition to its benefits for human capital and wealth creation.[6] Cancer research could be as useful to the public good in India as programmes to deliver rural health services.[7]

The research agenda for cancer in India is large and diverse, and, increasingly, priorities need to be set.[8] By comparison with high-income countries, challenges to deliver cancer research programmes in India are more complex. Research systems need to cover both modern medicine and traditional medicine such as Ayrurveda, yoga, unani, Sidha and homoeopathy. Programmes need to account for the capacity of individual states and union territories in terms of their economic and human development indicators, and to support research infrastructure including training, and sheer magnitude of patient care to be given. The research agenda also needs to embrace a wide range of domains such as nursing that have been traditionally poorly supported by research funders. Such factors have substantial effects on public policy about cancer research, which are essential to know to create a national research strategy.[9]

The emergence of India as a member of the world cancer research community has taken a different trajectory from that of countries in Europe and North America.[10] For example, during discussion of structural aspects of cancer research networks in high-income countries, there has been the implicit recognition that these networks include secondary centres and outreach into the community, whereas in India, most cancer research so far is concentrated in tertiary cancer centres and specialised institutions of biomedical science. India's lower staff levels and low capacity beyond tertiary cancer centres thus frame the structural and organisational discussions of research networks in a very different way.[11] The rising burden of cancer in India[12] creates a major drain on protected research time, particularly for clinical staff. Institutions in India also have to struggle to develop infrastructure to support cancer research. One important example is the development of The National Cancer Registry Programme created by the Indian Council of Medical Research (ICMR) in 1981, which now has 23 registries across India, supplying data for both the Atlas of Cancer in India, international studies, and the Cancer Incidence in Five Continents series.

As the agenda for cancer research in India has developed, the regulatory environment for clinical research has evolved. The 59th report of the Parliamentary Standing Committee on Health and Family Welfare[13] uncovered many lax standards and regulatory violations in clinical trials and marketing authorisations, including major problems with ethical approvals.[14] Steps were taken in 2007 to create a clinical trials registry for India (based on that from WHO) that required ethics committee and regulatory

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For the **Atlas of Cancer in India** see http://www.ncrpindia.org

For the **Cancer Incidence in Five Continents** see http://ci5.iarc.fr

For the **National Centre for Biological Sciences in Bangalore** see http://www.ncbs.res.in/

disclosures, but this step was not backed up by legislation.[15] After the Indian press published a series of articles about consent failures, the health rights group Swasthya Adhikar Manch filed a public interest litigation petition with the Supreme court, in which it was stated that patients who are poor had been exploited and in many cases had not given informed consent. This move caused sweeping changes in the requirements for compensation after injury in trials, for ethics, and for complex and onerous regulatory approvals. The scale of the new regulatory requirements, absence of transparency, and shifting legal grounds has caused many trial activities to be substantially delayed or suspended. Implications for policy for cancer research have been equally serious, and there is an urgent need to streamline and rationalise regulatory processes to allow essential domestic and international collaborations to continue.

India has been recognised for the diverse nature of cancer research that takes place there, from studies that screen the poorest people in society to those for advanced fundamental research findings (eg, from the National Centre for Biological Sciences in Bangalore).[16,17] However, despite these important contributions, India still does not have developed public health policies to guide implementation of early detection strategies. From other papers in this Series,[12,18] it is clear that issues such as affordability, access, quality of care and symptom awareness, education, and stigma all reinforce late presentation. Our analysis shows that several key states still do not adequately support cancer research; this provision needs to be part of the overall solution to strengthen cancer care in India. Policy for cancer research and development should be embedded within the National Cancer Control Programme and the wider health research policy for India to deliver on the following five key objectives[19,20]—identification of priority areas for research, fostering of intersectoral coordination, strengthening of networks between and within academic organisations and national and international institutions, assessment of the cost-effectiveness and effects of research on individual and population outcomes, and development of human resources for research.

Use of bibliometrics to examine cancer research

Bibliometrics can provide a good method to understand, calibrate, and compare research outputs and activity within and between countries. In 2011, the National Cancer Grid of India (a group of 36 pre-eminent cancer centres across India) commissioned a full analysis of all scientific outputs (publications) that arose from cancer research done in India.[20] Research papers (articles, notes, proceedings papers, and reviews, but not books) processed for the Web of Science over the past 21 years (this time period included indexed Indian medical journals in the past decade). Papers were analysed for their main characteristics, and, in particular, to identify papers for the following features according to previously described methods[21]—the Indian state or union territory from which the works originated; the organ of origin for the cancer with use of the 16 anatomical locations listed by the WHO in its burden of disease data; the type of research from 11 categories (genetics, surgery, etc); the level of research (from clinical to basic, assessed on the basis of the journals in which they were published); and the extent of international collaboration. Specific methods on how the bibliometric analysis was done have been previously published.[21] Briefly, Lewison and Roe[21] extracted details of 12 967 cancer publications from India published between 1990 and 2010. 3115 were published in 2009–10 and had funding data available in the acknowledgments (funding data for papers published earlier than 2009 will become available but has not been added at present). 7490 papers were published between 1990 and 2006 and had citation data available. Lewison and Roe,[21] calculated citations for papers published 1990–2006 for the 5 years after publication with use of Web of Science and downloaded to a separate series of files. A series of analyses was then carried out, each necessitating the creation of a special macro—first, to identify the fractional presence of any authors from other (foreign) countries working on each paper; second, to identify, the fractional presence of each of the 35 Indian states and union territories as representation of the location of the authors; and third, to classify titles of papers as either clinical or basic research with use of two standardised lists of title words and to classify the journals in which they were published as a decimal number on a scale from 1·0 for clinical to 4·0 for basic science. Subfilters were also developed to divide Indian cancer research output both by cancer site and by the type of research. Each subfilter consisted of title words and most also contained strings designed to identify relevant journals. The National Cancer Grid of India used this process to create data for evidence-based policy from bibliometrical analysis at two meetings to establish key public policy issues, solutions, and priorities for cancer research in India.[22]

Outputs of cancer research in India

Outputs of cancer research in Indian have increased from about 300 research publications per year in 1990 to almost 1500 publications in 2010, with nearly 67% of the research led by researchers in India (first or last authors).[21] Less than 5% of this rise was due to increased indexing of Indian medical journals. India's outputs were about 1% of the world's total in the 1990s; this proportion has since increased to about 2% in 2010. The average 5-year citation score for cancer research papers from India has grown by 42% since 1990, but the number is still less than the world mean—14 cites for 2004–05 publications.[23] The immediacy with which Indian papers were cited rose slightly, and the percentage of 5-year cites received in the first 2 years (ie, the year of publication and the following year) rose from 15% to nearly 19% in the 20 year period, with a dip in the mid-1990s. The

five-time rise in output from India over the past 20 years parallels the rise in output from other developing Asian countries and shows that cancer is increasing in importance.

The percentage of review articles from Indian authors rose from 2% in the 1990s to higher than 8% in recent years.[24] These percentages are approaching the world average steadily: they were only 25% of the world value in 1998, but were 44% in 2001 and as high as 69% in 2007. These numbers show that Indian cancer researchers are improving their reputation compared with the rest of the world. This conclusion is supported by the increases in international contribution in Indian cancer research output—only 5% of the total in 1990–94, but 9·6% in 2000–04 and 11·0% in 2010. However, collaboration occurs at a lower rate than might be expected for a country with a relatively small scientific output (1–2% of the world's total) in which international partners could provide complementary skills and experience. Investigators from the USA (4% of the total on a fractional count basis), the UK (0·8%), Germany, Japan, and France (between 0·5% and 0·6%) collaborated on publications with cancer researchers from India most often.

If research is to drive the evidence base for care delivery in India, and if the country is to recruit and retain academics, then overall outputs need to increase. With worldwide evidence showing a correlation between research activity and good outcomes in patients,[5] one of the crucial policy issues in India is how to enhance cancer research across all states and union territories. Outputs by states and union territories correlate closely with their individual gross domestic product (GDP). However, New Delhi and Chandigarh have much more cancer research activity than their overall GDP would indicate because major research centres are based there. A big gap in cancer research activity clearly exists between the nine largest states active in cancer research and others (table 1). Little collaboration has been taking place between different states and union territories in India, although some union territories were better at collaborating than others. The six states with smaller output at the bottom of table 1 have a higher collaboration rate than do other states, however; this finding is to be expected because clinicians in these areas are less likely to find appropriate partners for their work in their own state. Collaboration is an important driver to improve outcomes across national boundaries;[5] however, funding mechanisms to support both interstate and international collaborations are insufficient. The creation of such mechanisms would greatly enhance research outputs.

In the long term, each state should become active in cancer research. For this to occur, several factors should be addressed now—eg, the need for scientific infrastructure and capacity; the need for implementation of research training programmes; the need for development of systems in very busy academic centres, including regional centres, to allow clinicians to spend more time on research proposals (particularly clinical staff in regional cancer centres who are under huge

	Main city	Total output		Collaboration		Mean research level*	5-year actual citation impact of publication
		Integer count	Fractional count	Percentage of total output involving investigators from other Indian states	Percentage of total output involving investigators from foreign countries		
New Delhi	Delhi	2554	2148	7·5%	8·4%	1·99	5·08
Maharashtra	Mumbai	2281	1920	5·0%	10·9%	2·10	5·74
Tamil Nadu	Chennai	1550	1314	4·7%	10·5%	2·35	5·83
Uttar Pradesh	Varanasi	1496	1246	10·2%	6·5%	2·36	4·98
West Bengal	Kolkata	1145	973	4·6%	10·4%	2·73	5·13
Karnataka	Bangalore	1135	922	7·3%	11·5%	2·30	7·53
Kerala	Trivandrum	869	722	6·2%	10·7%	2·14	6·39
Chandigarh	Chandigarh	782	707	5·5%	4·1%	1·82	3·60
Andhra Pradesh	Hyderabad	715	583	8·8%	9·7%	2·84	6·44
Gujarat	Ahmedabad	309	244	9·5%	11·6%	2·21	5·11
Madhya Pradesh	Bhopal	241	194	13·4%	6·0%	2·44	4·34
Rajasthan	Jaipur	172	131	12·6%	11·3%	2·57	4·36
Punjab	Chandigarh	171	125	19·8%	7·1%	2·54	4·28
Jammu and Kashmir	Srinagar	142	104	20·3%	6·7%	2·57	3·82
Haryana	Chandigarh	129	103	16·5%	3·7%	2·15	3·45

For more information about calculation of these bibliometrics see Lewison and Roe.[21] *Papers classified on the basis of title and journal in which they were published with score on a scale running from 1·0 for clinical to 4·0 for basic science. Adapted from reference 21.

Table 1: **Features of research done in the 15 largest Indian states and union territories (1980–2010)**

pressures to deliver care to increasing numbers of patients); and the need for expanded clinical trials. Some differences can be noted in the type of cancer research being done, with researchers in Andhra Pradesh and West Bengal doing, proportionally, the most basic science work, and researchers in Chandigarh and New Delhi doing the most clinical research. Research papers from Karnataka are the most cited, and those from Haryana and Chandigarh the least, with a factor of more than two dividing their citations. Broadly speaking, higher citations are associated with more international collaboration (figure 1) and more fundamental cancer research being done in specific institutions from leading basic research groups. Although strategies to encourage international collaborations and to build focused research institutions will enhance citations of cancer research, stakeholders in India need to support and promote research with outcomes that will have great value to guide national cancer control, not necessarily research that will be highly cited internationally.

Epidemiology and prevention research

Key objectives of India's national cancer control programme (in operation since 1975) are that of a national cancer registry programme and epidemiological research to guide control measures.[25] India is also an important centre for training and education in epidemiology for WHO's southeast Asia region,[26] and hosts the International Agency for Research on Cancer's regional hub for cancer registration. The national cancer registry programme of India is one of the most important initiatives in developing countries worldwide, leading cancer epidemiology and secondary research in India. Although, at present, the volume of high-quality, high-impact research in India to investigate cancer epidemiology is low, a few key institutions are building research capacity.

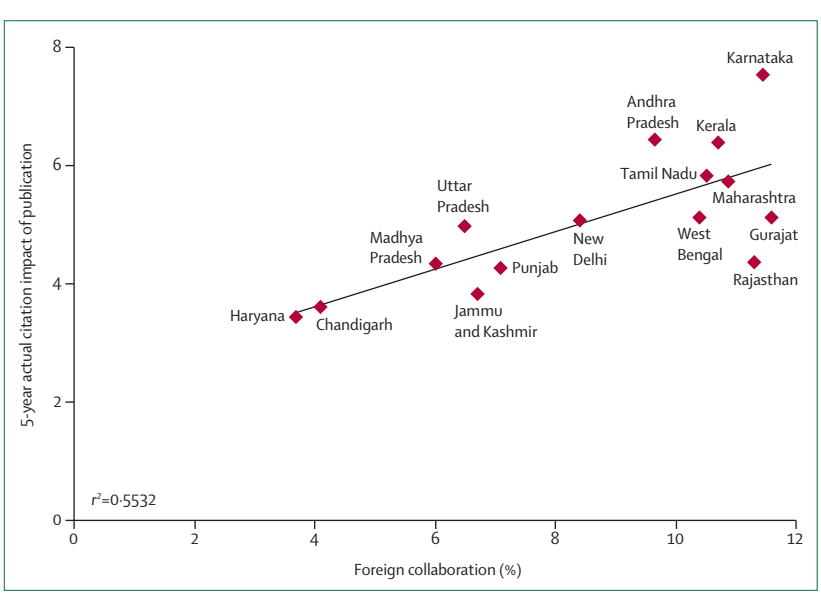

***Figure 1*: Correlation between international collaboration (co-authorship) for papers from the leading 15 states and union territories and the mean citation score of published papers (1980–2006)**
Figure reproduced with permission from reference 21.

Investigators in high-income countries have identified risk factors for common cancers and rigorously assessed these effects in well designed case-control studies and longitudinal cohorts that are heavily phenotyped with biological samples, repeat assessments, and decades-long follow-up. In India, cancer epidemiology has so far largely focused on confirmation of these associations first discovered elsewhere (eg, those for tobacco, alcohol, infections, diet, occupational exposures, and radiation), mainly through case-control studies. However, many of these studies have faced challenges, such as insufficient access to population-based cancer registries, selection bias (eg, family, friend, or benign disease controls), low power (eg, for genetic studies), and measurement error (eg, diet). As a result, many studies from India are excluded from international systematic reviews.

Almost three of five cancer deaths in India are associated with tobacco or infectious diseases.[27] The most common cancer sites are lung (11·0 per 100 000 individuals), lip and oral cavity (10·1), and stomach (8·6) in men, and breast (25·8), cervix (22·0), and colon and rectum (5·1) in women.[28] Studies of tobacco-related cancer in India have yielded data for associations with different types of tobacco and their public health effect, which has led to evidence-based comprehensive regulations in accordance with the Framework Convention for Tobacco Control.[29,30] Regional differences and trends of tobacco-related site-specific cancers suggest that further assessment of local practices is needed to design culturally appropriate interventions and policy (to be implemented at state level). Indian research on infection-related cancers has confirmed the importance of certain viruses on cervical cancer and liver cancer, and particular bacteria on stomach cancer, although few evidence-based interventions or policies have emerged from this work. Despite the well established importance of obesity and physical activity in cancer prevalence,[31] few investigators doing epidemiological studies of these factors in India used standardised, validated instruments or adequately controlled for measurement error. Qualitative work to overcome stigma, barriers to knowledge and access, and pathways for care is scarce compared with the need for it, despite efforts by non-governmental organisations working in these areas. Less than 3% of cancer research in India reports findings in these particular areas. Despite these challenges, research in India has informed cost-effective strategies for cancer detection in resource-constrained settings (eg, visual inspection with acetic acid to screen for cervical cancer and then treatment with cryotherapy[32]) and has the potential to lead to important findings for exposures (eg, for *Helicobacter pylori*, smokeless tobacco, and arsenic), cancer sites (eg, gall bladder, and oropharynx), and subtypes (eg, triple-negative breast cancer) that are less common in high-income

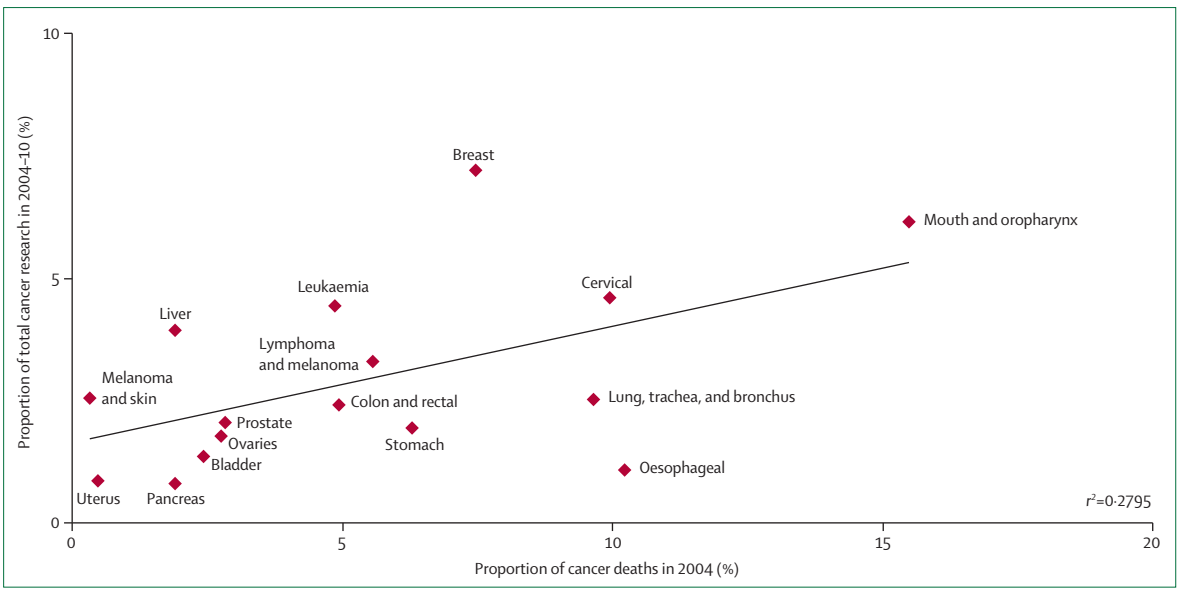

***Figure 2*: Focus of cancer research in India per disease site compared with deaths attributable to that cancer site, 2004–10**
Figure reproduced with permission from reference 21.

countries. Great opportunity exists for India to contribute and improve understanding for all cancers through investment in resources and skills and international collaborations that eventually benefit patients with cancer worldwide.

Need for balance for cancer research in India

A slight correlation exists between India's disease burden and research output, with greater research efforts focused on cancers that occur most frequently in India (figure 2). Although small, the correlation is still more positive than that of many other countries (China is an exception with r^2 of about 0·6). Main outliers of this trend are breast cancer and liver cancer (which have substantial research activity) and oesophageal cancer (which remains very under-researched). The distribution of cancer research done in India by tumour site shows well the burden and range of cancer across the country (table 2) and the biggest cancer burdens (head and neck cancer and cervical cancer) both attract significant attention from Indian cancer researchers. Conversely, colorectal cancer, lung cancer, pancreatic cancer, prostate cancer, and stomach cancer are relatively less burdensome in India than they are worldwide and so do not elicit as much research.

Studies of cancer genetics and medical oncology (chemotherapy) are the dominant work in the Indian cancer research community and receive more than 30% of total research output. Research for surgical oncology, the main method of control and cure of cancer, makes up 9% of the total, and the proportion dedicated to radiotherapy research is even lower (figure 3). The range of research domains correlate with those noted worldwide, with more medical oncology research in India than other fields. The relative positions of these domains in terms of output have changed very little in the past two decades. Several other crucial areas of research such as palliative care and health services and outcomes research are under-researched. Given the importance of development and deliverance of effective public health policies for cancer, more focused and funded programmes in these areas are needed beyond the slight efforts of the Department of Health Research.

Palliative care services have been delivered in India for more than 40 years. Despite this fact, it is still not recognised as a specialty by many health-care professionals.[33,34] Most palliative care in India is based in practice, but in an era of evidence-based medicine, this experience needs to be translated into solid evidence.[35] Country specific research should be developed and promoted in 5-year planning.[36] Progress has already been made at national, international, and state level. Tamil Nadu and Kerala have rapidly developing palliative care services, and international organisations such as the International Network for Cancer Treatment and Research are actively engaged in research protocols. Key issues in public policy continue to be researched,[37,38] but we suggest the following actions to improve palliative care services—promotion of clinical research and demonstration of the need for evidence-based service to palliative care physicians; linkage of existing palliative care services and creation of a joint research programme in which there can be sharing of common protocols, ideas, and resources; development of palliative care departments, with service and research activities, in more medical colleges and involvement of departments in initiatives from the ICMR; involvement of non-governmental organisations,

	World	India	India–world ratio	Disability-adjusted life-years
Bladder	1·11	1·14	1·03	0·77
Cervix	1·72	4·55	2·64	2·43
Colon and rectum	4·85	2·07	0·43	0·60
Leucocytes (leukaemias)	5·79	5·03	0·87	1·54
Liver	4·45	4·09	0·92	0·23
Lung, trachea, and bronchi	4·01	2·05	0·51	0·53
Lymphocytes (lymphoma and myeloma)	4·70	3·21	0·68	1·25
Breast	8·32	6·58	0·79	0·92
Melanocytes and skin	3·23	2·87	0·89	0·34
Mouth and oropharynx	2·38	6·10	2·56	2·87
Oesophagus	0·98	1·17	1·20	1·39
Ovary	2·29	1·57	0·68	1·27
Pancreas	1·54	0·66	0·43	0·58
Prostate	3·52	1·60	0·45	0·59
Stomach	3·83	1·96	0·51	0·57
Uterus	1·29	1·29	1·00	0·41

World data for 1994–96 and 2006–07 and data for India from 1990–2010. DALY data from WHO. For more information about calculation of these bibliometrics see Lewison and Roe.[21] Adapted from reference 20.

Table 2: **Proportion of cancer research, shown for WHO's 16 anatomical sites for cancer, done in India, the world, and per disability-adjusted life-year (DALY)**

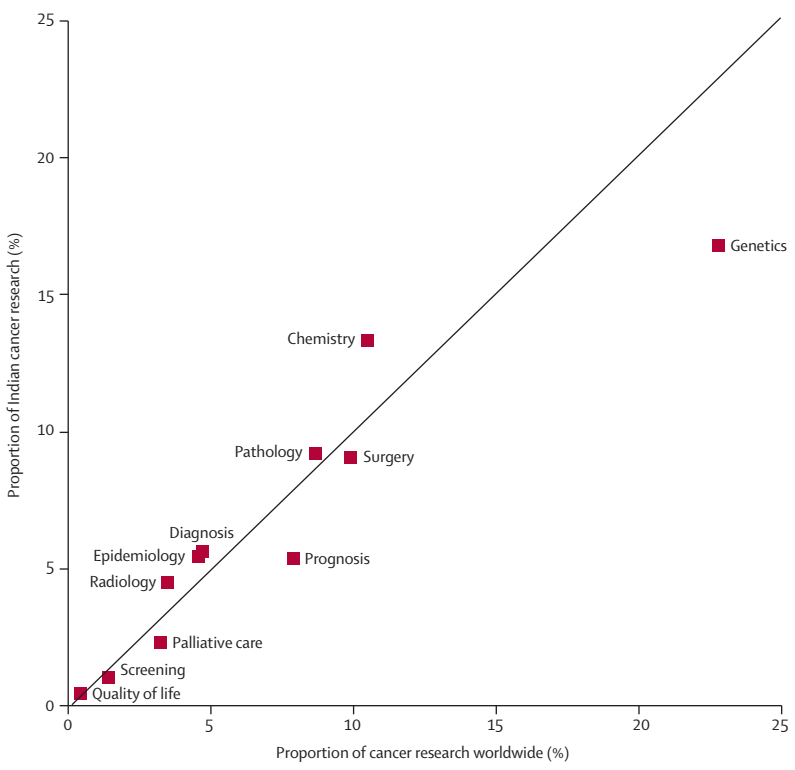

Figure 3: **Focus of cancer research in India (1990–2010) compared with other countries (1994–96 and 2006–07)**
Figure reproduced with permission from reference 21.

government departments, and institutions to participate and promote palliative care service and research; increases in use of the *Indian Journal of Palliative Care*, which is run by the Indian Association of Palliative Care, to coordinate and motivate clinicians to share their research experiences; and introduction of palliative care research fellowships and scholarships to medical graduates.

As with all developing economies, India needs to balance investment in high-technology, often more fundamental, cancer research, with the more immediate needs of a health system that requires context-specific research, often in domains that do not elicit high-impact citations or publication in international journals.[39] India needs more investment and capacity building in several areas—eg, palliative care, childhood cancer, surgery, radiotherapy, health systems and services research, and outcomes research. At present, available population-based survival outcomes, mostly from some urban areas, probably show the best outcomes in the country given development and access to health services. We know from previous analysis of the Indian research system for public health[40] that population-level interventions for cancer are under-represented in the country's cancer research portfolio. Opportunities to improve representation through structures such as the National Cancer Grid of India and through wider institutional partnerships with high-income cancer centres and organisations (eg, those building on already strong linkages with the US National Cancer Institute) are needed. However, alongside continuing analysis of research needs, priority setting, and structural changes, greater state and central government support is needed to develop tertiary research capacity and to create networks within India and internationally.

Global health research in India also directly affects other countries. As the cost of cancer care continues to accelerate, many high-income countries have seen their cancer care budgets contract or stagnate.[41] More cost-effective treatment pathways that will provide good outcomes are needed.[42] Practices that encourage shorter in-patient stays and use of less extensive and expensive cancer drugs (the two key components of direct health-care costs in cancer) provide countries such as India with the potential to lead global research in clinical trials and care.[43] For example, results of clinical research on brachytherapy, hypofractionated radiotherapy schedules, and regular repeating (metronomic) chemotherapy regimens to reduce treatment times can drive down the costs of care and enable more patients to be effectively treated.[44,45] Analysis of the portfolio of cancer research in India also shows the breadth of research with global effects, from next-generation cobalt radiotherapy[46] to highly cost-effective cervical screening programmes using visual inspection and acetic acid.[47] Such research has the potential to be accelerated and, through state and central government programmes for global health diplomacy, could make a far greater contribution to global cancer control than can research done by and for high-income countries.

Support for cancer research: funding, training, and infrastructure

The role of the government

Nearly all departments or agencies of the Indian Government support cancer research, and the government provides the bulk of funding (the US National Institute of Health is the only major external funder). No pharmaceutical company was involved in authoring more than five papers in the 20 years of Indian research publications analysed by Lewison and Roe.[21] Irrespective of perceptions and research funding for clinical trials, the global pharmaceutical industry has played a minor part in cancer research in India, at least in terms of published articles. The poor support by the global pharmaceutical industry could be an opportunity for greater engagement of regional cancer centres with the strong and growing biotechnology and pharmaceutical industries in India, particularly with regards to research into the repurposing of medicines, development of novel formulations, and cost-effective devices.

The most striking difference between the situation in India and most western European countries is that in India, the government has a dominant role and charities and commercial companies have a very minor one. At present, more than 44% of cancer research in India receives funding from one or more government sources. It is clear from policy discussions with the National Cancer Grid (Pramesh CS, National Cancer Grid, unpublished) that although multinational companies are active in India, much of the research that they fund is not published or the Indian investigators are not properly acknowledged in the authorship list. Our more in-depth analysis reveals that direct funding for cancer research in India preferentially supports basic research (mostly genomics), clinical research in medical oncology, and to a lesser extent, epidemiology. Outputs for important areas such as surgery and radiotherapy have very few direct funding acknowledgments, suggesting that they are dependent on so-called soft short-term funding. More than 50% of Indian publications do not cite any external funding support. Most of these studies are probably indirectly funded (salaries for researchers, infrastructure, and consumables) by the core grant to the institutions from the parent funding body (eg, Department of Atomic Energy, ICMR, Department of Science and Technology, and University Grants Commission). Although core funding is an important basis to sustain research, an absence of oversight through peer review is, in the long term, insufficient to keep quality high.

Despite the Indian Government having a department specifically devoted to biotechnology, there is little funding of cancer programmes. This scarcity is partly because the government strategy for science and technology has traditionally focused on chemistry and physics, with biomedical sciences a relatively new addition to the national portfolio.[48] At present, most resources for cancer research are focused in four main states—Maharashtra, Tamil Nadu, Chandigarh, and Kerala—and predominantly from within government-owned academic institutes and hospitals.[49] A greater distribution of funding and research collaboration within India and internationally would encourage cross-state participation. More funding for cancer research from central government and states is also needed. In many countries, the funds available to support research are too low. This is particularly true in India where variation in disease epidemiology and burden exists among states, and local data are needed to ensure optimum treatment strategies are developed.

International collaboration

International collaboration can be an important source of additional funding in India, and a potential way to guide what cancer research takes place. India must be able to review the successes of cancer control programmes in other countries and identify programmes to be evaluated. Similarly, experiences in India have much to teach both high-income countries and other developing countries about key research areas such as radiotherapy, repurposing of cancer medicines, and expertise in cancers, which occur more frequently in India than other parts of the world. The scale of the global burden of cancer also makes clear the importance of scientists and physicians from around the world working closely together to identify new ways to prevent, screen for, diagnose, and treat cancer. One example is the International Cancer Genome Consortium, which brings together scientists from 17 countries in more than 65 project teams. India leads the global International Cancer Genome Consortium efforts for the study of oral cancer. Indian regulatory and fiscal public policy should facilitate international academic collaboration in cancer. Individual research institutions and cancer centres in India could benefit from twinning with research institutions in other parts of the world. Such twinning programmes can strengthen training for cancer research, mentoring, interdisciplinary cancer care and research, and the development of research infrastructure.

New funding arrangements

An initiative supported by the Wellcome Trust could change the funding situation for biomedical research in India, although perhaps not as much for cancer research as for other areas. The organisation have set up a fellowship programme with Department of Biotechnology in India supported by £80 million over 10 years. They also form one of the four partners of the Public Health Foundation of India, along with the World Bank, WHO, and the Bill & Melinda Gates Foundation. Four Indian Institutes of Public Health have been built (in Bhubaneswar, Delhi, Gandhinagar, and Hyderabad; more institutes are planned) to provide education, training, and research for public health. The Australia–India Research Fund has organised a similar initiative to support strategic

For the **Australia-India Research Fund** see http://www.innovation.gov.au/SCIENCE/INTERNATIONAL-COLLABORATION/AISRF/Pages/default.aspx

alliances between Australian and Indian researchers in all sciences, including biomedicine. The Academy of Finland aims to promote high-quality scientific research and has key partners in India, with which it has well established research funding. It has agreements on funding cooperation with the Department of Biotechnology, and the Department of Science and Technology. To cover all areas of science, the Academy has also expressed interest in collaborating with the ICMR and the Indian Council of Social Science Research. Such country-based initiatives should be expanded to drive the funding for cancer research from international sources. However, such initiatives should not distract from the important problems associated with the uneven distribution of well funded government establishments for research in Delhi and Chandigarth, which are better resourced and staffed than are many state-funded institutions. We have not been able to separate out these two funding sources; however, there is a need for better government distribution of funding in addition to greater state support.

For the **Indian Cancer Research Database** see http://www.incredb.org/

The future of funding for cancer research in India

The creation of the Department of Health Research by the Ministry of Health in 2007 was an important step to address the funding challenges for cancer research. Public policy in India envisages devoting at least 2% of the overall budget for health towards research in the next decade. At present, allocation to health-related research is about 4% of the total government expenditure. However, accurate information about funding allocation for health-related research by these agencies is difficult to obtain. The Department of Science and Technology is the largest funding body of extramural research in India, receiving nearly 50% of the national funds. This department has been traditionally more focused on support for basic research through extramural research grants, with relatively moderate levels of budget support towards clinical and public health research.

Departments under different ministries in the Indian Government, particularly the Ministry of Science and Technology, not only engage in research within the research and development institutes of their departments, but also fund wide-ranging research projects (including those for cancer) in academic and industrial organisations. Funding for biomedical research increased from 2002 to 2007 (tenth 5-year plan), with investments in health-related research of, on average, 800 000 000 rupees.

ICMR has been the main agency to carry out and promote biomedical research in India during the different plan periods. ICMR spends about a third of its research budget on extramural grants to other institutions in the country. Its budget for oncology is now 8–10% of its total spending; an allocation that has risen slowly since late 2008. Since the eleventh 5-year plan (2007–12), the ICRM has enhanced support for basic research, improved development of scientific human resources, and built research facilities and centres of excellence with a greater global outlook. To coordinate cancer research and ensure optimisation of resources, the Institute of Bioinformatics developed the Indian Cancer Research Database. This database provides information about scientists and researchers doing cancer research in India to foster collaborations among researchers and provide a real-time view of continuing activities and initiatives in India. However, the usage and awareness of this database has not been established.

The expert working group of the Planning Commission advised that international collaborations should be leveraged and mainly aimed towards complementing and supplementing of national efforts in certain areas of basic research, including in life sciences. Since India now has emerging strength in cancer research, there is opportunity to further support the national and global efforts of the National Cancer Grid. Public policy is replete with policy makers claiming leadership in global non-communicable disease research networks; however, the reality is that most of these initiatives arise from institutions in high-income countries.[50] India is ideally placed in global cancer research, both for the relevance of its research to other developing countries and as an innovator of technologies and care pathways (from financial models to cost-effective early detection methods). However, this innovation can be achieved only when the major funding agencies in India commit to supporting prospective clinical research and trials into all major methods of control and cure from medical oncology to surgery and health-services research.

Identification of national priorities

Work is needed to identify gaps in cancer research and research infrastructure relative to the Indian burden of cancer and across the cancer continuum. Investigators also need to determine whether there are explicit links between the research and public health communities to ensure timely implementation of research results into public health and clinical practice. For example, Maharastra state plans to roll out cervical cancer screening state-wide on the basis of results from a randomised trial[16] done by investigators from Tata Memorial Hospital in poor areas of Mumbai, and in Tamil Nadu and Sikkim the results of research have meant that these states are

Search strategy and selection criteria

We searched Medline, Embase, and Web of Science for relevant policy papers published from Jan 1, 1980, to Dec 31, 2013, with use of the MeSH terms "India", "policy", "cancer", and "research", and did a major bibliometric analysis of all India research outputs. Additionally, we searched national websites (eg that of the Indian Council for Medical Research) for relevant policy documents, and consulted key book databases.

For the **website of the Indian Council for Medical Research** see http://www.icmr.nic.in/

implementing visual screening with acetic acid and physical examination of the breast through primary care services. It is not known whether other states in India are willing to change public health practice on the basis of prospective evidence. Commitment across the broad non-communicable disease research and public health communities to work together on issues as tobacco control and obesity is also not yet known. Whether institutions in India can increase funding for research and provide the protected time that is necessary, especially for clinicians to undertake research, is not certain. The development of the National Cancer Grid of India is a crucial platform upon which to build the public policies and financial support to drive research that can also deliver capability for orphan areas such as palliative care and surgery. India also needs to address some of the important regulatory barriers that are encountered by investigators planning clinical trials and research that use tissues samples for the country to harness the full benefits of increased national investment.

Conclusion

India is on a unique health trajectory. When framing the policy debate, high-quality information provides a strong foundation to engage both political and public support for cancer research in India.[51] In addition to provision of better outcomes for its own cancer patients,[52] cancer research in India also guides cancer care in other emerging economies. Much more value needs to be given to the importance of cancer research by policy makers at state and government levels. Cancer research is also essential to deliver an affordable cancer care system in India; connecting the research and policy agendas is crucial to create effective decision-making institutions for health.[53] Finally, India has the opportunity and capability, with the right support, to be a world leader in cancer research that delivers radical cost-effective solutions to deliver affordable cancer care.

Contributors

RB, CSP, GL, GR, ADP, and RS designed this policy analysis with the National Cancer Grid of India. GL led the bibliometric analysis with input from RS. CSP, RS, GL, and AP drafted the framework document. All authors contributed equally to writing and revising of this paper.

Declaration of interests

We declare that we have no competing interests.

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Cancer burden and health systems in India 3

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.

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This is the third in a Series of three papers about cancer in India

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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 agenda[2] 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 133 776×10⁷ rupees (US$21 555 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).

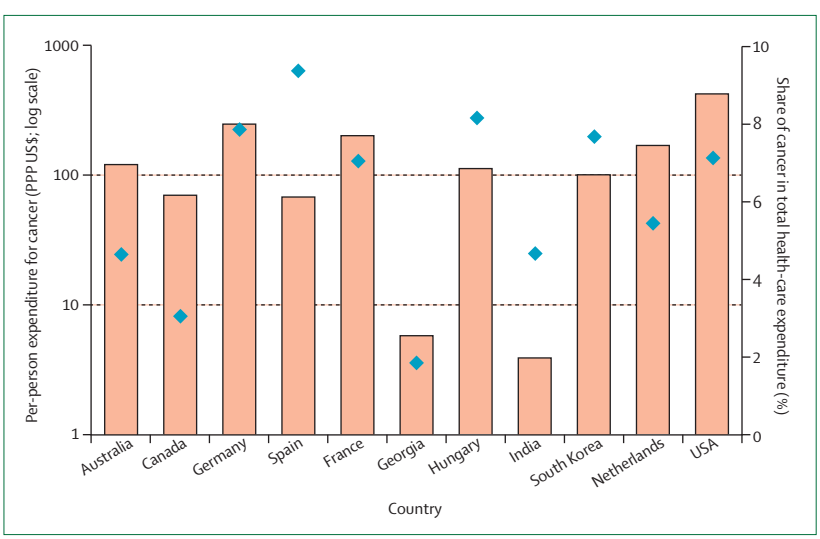

Figure 1: **Comparison of per-person expenditures for cancer (red bars; PPP corrected in US$) and percentage share of cancer in total health-care expenditure (blue diamonds) in different countries**
PPP=purchasing power parity. Data are from 2006, extracted from reference 14.

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 Andra 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 150 000 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. 38 872 patients have benefited since the scheme's inception, of which cardiology (51%) and oncology (25%) use most of the

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 modest[20] (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, 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.

	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=10^7 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**

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 27760×10^7 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 30833×10^7 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 29049×10^7 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 2700×10^7 rupees (US$435 million) every year (and with the addition of school-based interventions, this amount could rise to 4934×10^7 rupees [US$795 million] every year), the resultant reduction in health expenditure has been calculated to be disappointingly low at 639×10^7 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 chemiluminiscence.[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 36 812 rupees (US$593).[37] 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 programmes[57] 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 2012[58] (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 agenda[57] 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 payments[65]—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

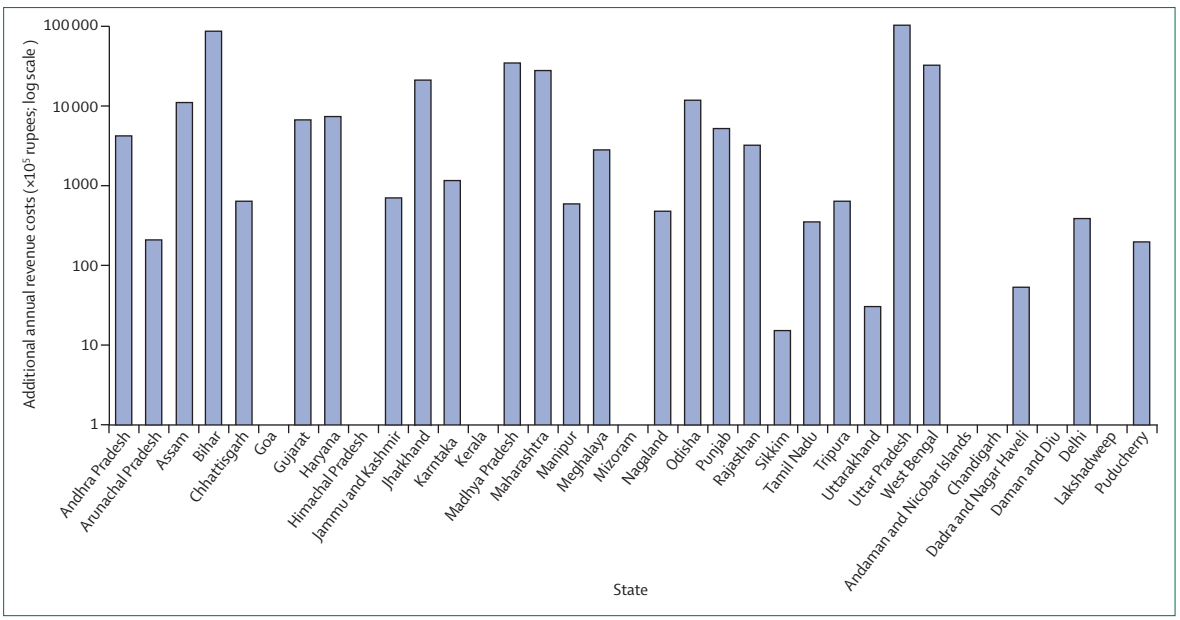

Figure 2: **Increased annual expenditure needed to address essential health infrastructure shortfall in rural India, by state**
Data are from reference 73.

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 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

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.

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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