Cancer burden and health systems in India 2

Cancer research in India: national priorities, global results


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.

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 or high-income economies set their research agenda. 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. 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. This absence of recognition is a serious gap in public policy. Development of a strong research base substantially improves patient outcomes, in addition to its benefits for human capital and wealth creation. Cancer research could be as useful to the public good in India as programmes to deliver rural health services.

The research agenda for cancer in India is large and diverse, and, increasingly, priorities need to be set. 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, Siddha 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.

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. 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. The rising burden of cancer in India 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 uncovered many lax standards and regulatory violations in clinical trials and marketing authorisations, including major problems with ethical approvals. Steps were taken in 2007 to create a clinical trials registry for India (based on that from WHO) that required ethics committee and regulatory
disclaimers, but this step was not backed up by legislation.5 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).6–8 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,9–11 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:9–11—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.12 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— 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.13 Briefly, Lewison and Roe14 extracted details of 12.917 cancer publications from India published between 1990 and 2010. 3.115 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, 7.490 papers were published between 1990 and 2006 and had citation data available. Lewison and Roe15 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—for instance, 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.16

Outputs of cancer research in India

Outputs of cancer research in India 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).17 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.17 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. 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, 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; 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

<table>
<thead>
<tr>
<th>Main city</th>
<th>Total output</th>
<th>Collaboration</th>
<th>Mean research level</th>
<th>5-year actual citation impact of publication</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Integer count</td>
<td>Fractional count</td>
<td>Percentage of total output involving investigators from other Indian states</td>
<td>Percentage of total output involving investigators from foreign countries</td>
</tr>
<tr>
<td>New Delhi</td>
<td>2554</td>
<td>2148</td>
<td>7·5%</td>
<td>8·4%</td>
</tr>
<tr>
<td>Maharashtra</td>
<td>2281</td>
<td>1920</td>
<td>5·0%</td>
<td>10·9%</td>
</tr>
<tr>
<td>Tamil Nadu</td>
<td>1550</td>
<td>1314</td>
<td>4·7%</td>
<td>10·5%</td>
</tr>
<tr>
<td>Uttar Pradesh</td>
<td>1496</td>
<td>1246</td>
<td>10·2%</td>
<td>6·5%</td>
</tr>
<tr>
<td>West Bengal</td>
<td>1145</td>
<td>973</td>
<td>4·6%</td>
<td>10·4%</td>
</tr>
<tr>
<td>Karnataka</td>
<td>1135</td>
<td>922</td>
<td>7·3%</td>
<td>11·5%</td>
</tr>
<tr>
<td>Kerala</td>
<td>869</td>
<td>722</td>
<td>6·2%</td>
<td>10·7%</td>
</tr>
<tr>
<td>Chandigarh</td>
<td>782</td>
<td>707</td>
<td>5·5%</td>
<td>4·1%</td>
</tr>
<tr>
<td>Andhra Pradesh</td>
<td>715</td>
<td>583</td>
<td>8·8%</td>
<td>9·7%</td>
</tr>
<tr>
<td>Gujarat</td>
<td>309</td>
<td>244</td>
<td>9·5%</td>
<td>11·6%</td>
</tr>
<tr>
<td>Madhya Pradesh</td>
<td>241</td>
<td>194</td>
<td>13·4%</td>
<td>6·0%</td>
</tr>
<tr>
<td>Rajasthan</td>
<td>172</td>
<td>131</td>
<td>12·6%</td>
<td>11·3%</td>
</tr>
<tr>
<td>Punjab</td>
<td>171</td>
<td>125</td>
<td>19·8%</td>
<td>7·1%</td>
</tr>
<tr>
<td>Jammu and Kashmir</td>
<td>142</td>
<td>104</td>
<td>20·3%</td>
<td>6·7%</td>
</tr>
<tr>
<td>Haryana</td>
<td>129</td>
<td>103</td>
<td>16·5%</td>
<td>3·7%</td>
</tr>
</tbody>
</table>

For more information about calculation of these bibliometrics see Lewison and Roe. 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. India is also an important centre for training and education in epidemiology for WHO’s southeast Asia region, 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.

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. 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. 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. 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, 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) 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
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. 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. Country specific research should be developed and promoted in 5-year planning. 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, 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,

---

**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.
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. 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 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. More cost-effective treatment pathways that will provide good outcomes are needed. 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. 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. Analysis of the portfolio of cancer research in India also shows the breadth of research with global effects, from next-generation cobalt radiotherapy to highly cost-effective cervical screening programmes using visual inspection and acetic acid. 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.

<table>
<thead>
<tr>
<th></th>
<th>World</th>
<th>India</th>
<th>India-world ratio</th>
<th>Disability-adjusted life-years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bladder</td>
<td>1.11</td>
<td>1.14</td>
<td>1.03</td>
<td>0.77</td>
</tr>
<tr>
<td>Cervix</td>
<td>1.72</td>
<td>4.55</td>
<td>2.64</td>
<td>2.43</td>
</tr>
<tr>
<td>Colon and rectum</td>
<td>4.85</td>
<td>2.07</td>
<td>0.43</td>
<td>0.60</td>
</tr>
<tr>
<td>Leucocytes (leukaemias)</td>
<td>5.79</td>
<td>5.03</td>
<td>0.87</td>
<td>1.54</td>
</tr>
<tr>
<td>Liver</td>
<td>4.45</td>
<td>4.09</td>
<td>0.92</td>
<td>0.23</td>
</tr>
<tr>
<td>Lung, trachea, and bronchi</td>
<td>4.01</td>
<td>2.05</td>
<td>0.51</td>
<td>0.53</td>
</tr>
<tr>
<td>Lymphocytes (lymphoma and myeloma)</td>
<td>4.70</td>
<td>3.21</td>
<td>0.68</td>
<td>1.25</td>
</tr>
<tr>
<td>Breast</td>
<td>8.32</td>
<td>6.58</td>
<td>0.79</td>
<td>0.92</td>
</tr>
<tr>
<td>Melanocytes and skin</td>
<td>3.23</td>
<td>2.87</td>
<td>0.89</td>
<td>0.34</td>
</tr>
<tr>
<td>Mouth and oropharynx</td>
<td>2.38</td>
<td>6.10</td>
<td>2.56</td>
<td>2.87</td>
</tr>
<tr>
<td>Oesophagus</td>
<td>0.98</td>
<td>1.17</td>
<td>1.20</td>
<td>1.39</td>
</tr>
<tr>
<td>Ovary</td>
<td>2.29</td>
<td>1.57</td>
<td>0.68</td>
<td>1.27</td>
</tr>
<tr>
<td>Pancreas</td>
<td>1.54</td>
<td>0.66</td>
<td>0.43</td>
<td>0.58</td>
</tr>
<tr>
<td>Prostate</td>
<td>3.52</td>
<td>1.60</td>
<td>0.45</td>
<td>0.59</td>
</tr>
<tr>
<td>Stomach</td>
<td>3.83</td>
<td>1.96</td>
<td>0.51</td>
<td>0.57</td>
</tr>
<tr>
<td>Uterus</td>
<td>1.29</td>
<td>1.29</td>
<td>1.00</td>
<td>0.41</td>
</tr>
</tbody>
</table>

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)
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. 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. 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. 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
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. 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, Maharashtra state plans to roll out cervical cancer screening state-wide on the basis of results from a randomised trial 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
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. In addition to provision of better outcomes for its own cancer patients, 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. 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.

**Acknowledgments**

We thank members of the National Cancer Grid of India for their engagement and their discussion at meetings and at the first Indian Cancer Congress in 2013. We thank the anonymous reviewers for their considerable diligence and input in providing additions and comments, which strengthened this analysis considerably.

**References**


