Involvement of general public in biomedical research

Biomedical research is crucial for any country’s progress and the health of its ethnic population. This effort needs to be sustained and well supported for it to bear optimum results. The major stakeholders in medical research are the general public, patients, researchers, physicians (and medical institutions), the pharmaceutical industry, regulatory authorities, and the government. Much of the pressure to perform cutting edge research in developed countries is driven by the general public; however, this has been conspicuous by its absence in India. This is largely due to misconceptions that medical research in developing countries is an experimental exercise using human beings as guinea pigs, primarily benefiting only the pharmaceutical industry and a general lack of awareness about the importance of original research within the country. This editorial addresses various issues related to public involvement in biomedical research and suggests the need for solutions and imperative remedial measures.

Key words: Biomedical, clinical research, public

On April 8, 2013, over 8000 people participated in a peaceful march starting from the steps of the Carnegie Library at Washington DC.[1] What makes this march unprecedented and unique is that this was neither a political rally nor were the supporters fighting for increased salaries. This rally for Medical Research was “a unified call to action to raise awareness about the critical need for an increased investment in the National Institutes of Health (NIH) to improve health, spur more progress, inspire more hope, and save more lives.”[1] The purpose of this rally,
which comprised patients, patient advocacy groups, businessmen, and general lay public in addition to clinicians and researchers, was “to call on our nation’s policymakers to make life-saving medical research funding a national priority.” The participants were peacefully expressing their protest against the declining federal funding for medical research, which they felt threatened the future health of Americans. President Obama expressed his support for the rally pointing out that “(to) meet the challenges of the 21st century, we must commit to a serious, sustained effort to advance medical research.”[4] These rallies now have become an annual event, involving hundreds of organizations and millions of people.[5]

On January 30, 2013, the Department of Health and Family Welfare, Government of India, released a gazette notification, which aroused vociferous protests from clinicians, researchers, and the pharmaceutical industry.[6] Without going into the merits or demerits of the gazette notification, there was widespread consternation among these communities about the new regulations for medical research in the country. The collective opinion of these stakeholders was that this would spell the end for clinical research in India, both from an academic research perspective as well as from an industry-funded research viewpoint.[4] Several letters and discussions resulted, expressing outrage and urging the government to reverse their stand. Subsequent data confirmed these dire predictions with a dramatic fall in the number of clinical trials conducted in India, with many reputed international research organizations such as the National Institutes of Health, USA withdrawing several research studies from India.[3] Remarkably, while the general media blanked out sustained and detailed coverage of these regulations and their repercussions, there was virtually no response from patients, patient advocacy groups, and the lay public.

Even a cursory comparison of these two stories speaks volumes about the nature and intensity of patients’ participation in policy matters influencing healthcare. Why are there such stark differences between the responses of the American and Indian public toward medical research policy? Is the Indian lay public not interested in their own health and the impact of these policy decisions on their future health? Or, are they just not bothered by government policy matters, recognizing the futility of protesting against them? Has the medical research community as a whole abjectly failed in engaging them at every step of framing national health research policy? Have the most important stakeholders in the healthcare debate been marginalized from issues that directly impact their lives?

Practicing physicians will acknowledge that the Indian public has never been more aware of health and illness. There is growing knowledge about not ignoring early symptoms of disease, with fewer patients presenting with advanced disease in illnesses such as cancer than a few decades back. There is an increased participation in health-screening camps and routine health checks. There is more informed participation in individual treatment decisions – all these are refreshing changes from the past where healthcare delivery was a unidirectional and passive process and the paternalistic attitude of treating physicians brooked nothing but meek compliance from patients. Clearly, the Indian lay public is not callous toward their health. Mass participation by hundreds and thousands of lay public was seen whenever sensitive issues cropped up in the past, even in situations when there was little hope of influencing the government (the public movement on the Jan Lokpal is a good example). Does this then imply that the reason is a lack of awareness among the general populace about the crucial role of biomedical research as well as the consequences of not pursuing it with sustained enthusiasm? Developing societies are struggling at the nether levels of Maslow’s hierarchy of needs, wherein the basic needs remain unfulfilled and erudite thoughts of cause and effect is a distant cry of the loon. Relating to process changing and impactful aspects such as biomedical research are seldom thought of and little understood.

Research in any field is vital for scientific progress. While commodities have their respective industries driving this research for commercial profits, healthcare research is vastly different. While commercial interests certainly exist with medical research also, much of clinical research is conducted in major hospitals and research institutes. The latter address burning issues in routine clinical care and look for innovative and cost-effective solutions which are likely to be of immediate benefit for patients as well as provide guidance on overall health policy to the government.[6–8] Moreover, the boundaries between pharmaceutical and academic research are getting increasingly blurred due to a symbiotic relationship between the two. While participating in industry-sponsored research leads to new drugs and major treatment breakthroughs, a collateral benefit of doing so is that the academic physician–researcher gets trained in the methods of clinical research which are stringently followed in industry-sponsored trials. In an educational environment wherein systematic training to physicians is lacking with respect to clinical research methods,[9] the importance of participating in pharmaceutical-sponsored research should not be underestimated.

While research in every field is a crucial ingredient for a country’s overall progress, advancements in most other
fields will occur regardless of Indian involvement in the global research process. A more advanced computer or a more sophisticated mobile phone technology is uniformly effective across all nations sans demographic and geographical barriers. Unfortunately, this generalizability quite escapes the medical field where research solutions have to take into account the unique ethnic variations in disease, response to treatment, and affordability of care. This is not, by any means, an argument to deprioritize research in other technological fields – quite to the contrary. However, the fact remains that if we do not drive the biomedical research in our country, we are likely to either not have our unique problems addressed by the Western world (where these issues are irrelevant) or saddled with expensive, cost-ineffective drugs, and products which will be out of reach for the common man.\textsuperscript{[10-12]}

For example, although multi-drug resistant tuberculosis is a problem in several countries, it is observed as a much bigger problem in India; similar is the case for head and neck and gall bladder cancers, which have a much higher prevalence in India.\textsuperscript{[13]} Do we really expect developed countries to conduct research in these areas, when they are relatively minor problems in their own countries? And even if they do, are the treatments likely to be readily applicable in India? What proportion of India’s patients can afford the spiraling costs of healthcare delivery in the West?\textsuperscript{[10]} Given the mutant forms of the tuberculosis bacteria and the genetic variations between patients in different parts of the world, are we not taking major risks by accepting the results of research in ethnically different populations? These risks, by virtue of not being obvious or apparent, are therefore far more dangerous and can cause incalculable harm to our patients. If we adopt new treatment options tested and proven to be effective only in the Caucasian population in our own patients, there is a real danger that we would miss out on highly beneficial treatment for potentially life-threatening diseases; equally, if not, more importantly, we could end up spending huge amounts of money on ineffective treatment strategies which could harm Indian patients’ health as well as impact their families fiscally. Here, we are not even remotely embarking on the philosophical debate about whether it is appropriate for Indian patients to reap the benefits of clinical research done in the West without contributing to the research itself.

By not giving a major thrust to biomedical research in India, we are actively obstructing progress in medical science. We cannot claim to be an emerging power if our research is restricted to information technology and basic sciences. We would be doing an immense disservice to our patients if we do not reverse the trend of decreasing research in India and take active steps to ensure that over the next few years, we reach a trajectory which can see us compete with the best and contribute to improved health worldwide, which brings us back to the original question – where is the common Indian positioned in this situation? Is it apathy that prevents him from promoting or pushing for increased research in India? Or have we (physicians, academic researchers, pharmaceutical industry, research societies, healthcare providers, social groups, patient advocacy groups, and the media) as a community completely failed in raising awareness about this issue to the level it needs? When will the average common man in India prioritize healthcare and medical research? When will the Indian public go on a massive march pushing for an increase in biomedical research and funding in India?

In this paper, we have identified that the lack of concerted public involvement in research is an issue that needs to be addressed in India, and will identify what can be done to correct this. However, equally important is the actual methodology of doing so – who will be involved in effecting this change? How, where and when can these be most effectively done? While these are extremely important (and challenging) aspects, a detailed discussion on this is beyond the purview of the current paper. Awareness of how crucial medical research really is needs to permeate every individual citizen in this country. While most stakeholders listed above could play an important role in this, the two critical groups are the researchers and the media. Medical researchers, whether from industry or academia, need to sustain a mass awareness campaign which debunks several myths of medical research in India, primarily the ones which paint researchers as exploiters of the poor and illiterate. They need to demonstrate with data that just like you have bad politicians, bad lawyers, and bad engineers, you also may bear the burden of bad medical researchers, but that they form a miniscule proportion of the large community of physicians and scientists who soldier on against all odds for the benefit of humankind. Media, while continuing its healthy trend of investigative journalism, should avoid falling into the trap of sensationalism, and report objectively, emphasizing the immense benefits that biomedical research has offered to improve our lives to sensitize the Indian population on this important issue. The resolution would be strategic involvement of media broadcast and information for publishing objective articles on healthcare, defining the processes underlying research, emphasizing its significance, and by demonstrating their transparency of work and accountability. In addition, advocacy by opinion makers, health activists and thinkers specifically highlighting the benefits of medical research would be immensely helpful; this would encourage engagement of the masses, either by way of participation in clinical trials or by virtue of material contributions to biomedical research. While researchers and the media have a major role to play, every single stakeholder listed above needs to work concertedly toward increasing
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awareness and dispelling myths about medical research among India’s public, and ensure that our children live healthier lives than what we do now.

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