

resulted in extremely conformal treatment capabilities. Proton radiotherapy provides the most conformal approach with the lowest likelihood of radiation penetrating unintended regions of the body, and has been used for paediatric cancers, particularly CNS tumours, in centres with a proton facility.¹¹ Children suffer the most severe long-term sequelae from radiation and are the most likely to live decades if cured. Therefore proton facilities should make treating children with cancer a high priority, including young women requiring abdominal or pelvic radiation that might scatter to affect the uterus or ovary. For premenopausal women, potential options for preservation of fertility should be discussed.¹² Should uterine irradiation be unavoidable, parents should be informed that their daughter's offspring might be at risk of stillbirth and neonatal death when their daughter reaches adulthood. For childhood cancer survivors, reproductive counselling and testing in a specialised centre to assess the feasibility and potential risks associated with a pregnancy should be discussed, and a plan implemented to ensure a successful outcome.

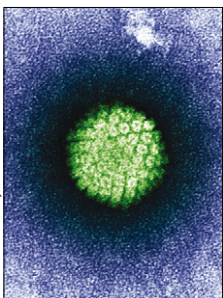
Akila N Viswanathan

Gynecologic Radiation Oncology, Brigham and Women's Hospital/Dana-Farber Cancer Center, Harvard Medical School, Boston, MA 02115, USA
aviswanathan@lroc.harvard.edu

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The India HPV-vaccine suspension



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In response to demands from advocacy groups, the Indian Government has suspended demonstration projects for HPV vaccination in Andhra Pradesh and Gujarat.^{1,2} The episode provides salutary lessons about how a lack of public confidence can amplify if not quickly addressed.

The first lesson is timing. Too often, the response to citizen advocates who question health interventions, programmes, or studies, is too late. The April, 2010, memorandum³ from 68 Indian human rights and women's groups, academics, and individuals sent to the Indian Minister of Health and Family Welfare should not have been a surprise. A similar memo had been sent 6 months earlier.⁴ The April memo called for the immediate halt of the demonstration projects until "concerns relating to safety, efficacy and cost effectiveness

of the planned interventions are re-evaluated".³ It also demanded an inquiry into, and compensation for, the reported side-effects and alleged vaccine-related deaths of four girls who participated in the study. The deaths have since been investigated and confirmed as unrelated to the vaccine.^{2,5} Similarly, the memorandum⁴ sent on Oct 1, 2009, demanded that "all trials and studies be immediately brought to a halt till in an open forum questions relating to safety, efficacy and cost effectiveness of the planned intervention can be justified".

On Dec 28, 2009, the groups continued their unanswered pleas and convened a public meeting that generated more attention than the October memorandum.⁶ By February, GlaxoSmithKline, Merck, and PATH had issued responses on the safety of the vaccine and on the process of the study.⁷⁻⁹

By April 7, 2010, the pressure on the government had reached a tipping point and the demonstration projects were suspended on the day the second memorandum was received;² and a committee was appointed to conduct an inquiry.^{2,5,10} Would a government response to the October memorandum—or even a willingness to hold a public debate—have made a difference? Probably it would.

The second lesson is that there is not one definitive set of evidence that can resolve problems generated by principles and politics. Facts should be clarified and promptly communicated—especially when involving adverse events and study procedures—but alone, they will not resolve deeper issues of public distrust. A different and more sympathetic engagement and dialogue with the public is required.

Globalisation takes many forms; one is the rapid sharing of multiple types of information and evidence. The advocacy groups that pressured the Indian Government to halt and re-evaluate the HPV-vaccine activities drew their information from many sources. They made fact-finding visits to study sites, combined with information from a US-based anti-HPV vaccination group, and additionally researched various public documents.¹¹

As far as these groups were concerned, their arguments were evidence-based. Some of the points made by the advocacy groups and a member of parliament are generally reasonable: calling for increased funds for health, maximising investment in priority health-issues, ensuring the safety of health interventions, communicating clearly and honestly any risks, and conducting ethical processes in research.^{12,13} Beyond these broader demands, there was a mix of facts, misinformation, principles, anger at injustices, and anger at perceived interference by multinational companies, funders, and international non-governmental organisations in local concerns, and a final pointing to the government for its ultimate responsibility to protect people's health and wellbeing.

Consideration that the HPV-vaccine activities were in the interest of women's health could have been more loudly articulated, but that argument would need a different type of evidence and argument than that used by the advocacy groups. Reluctance by public health authorities to respond to issues of public distrust for fear that they will exacerbate the problem

is dangerous.¹³ Experience is increasingly showing that public distrust does not go away if unaddressed and can lead to programme disruptions and even disease outbreaks. We need to find new ways to engage the public, early on, in health research and in the design and delivery of health programmes. That approach includes taking the time to listen to societal concerns, public emotions, and politics that can derail programmes or research. We might not always understand them, but we cannot ignore them.

*Heidi J Larson, Pauline Brocard, Geoffrey Garnett

Institute for Global Health, Imperial College London,
London SW7 1NA, UK
h.larson@imperial.ac.uk

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