**Public communication about CHIMs: what is the role of the media?**

The basic concept behind the Controlled Human Infection Model for research – infecting a healthy person with a disease in order to observe its progression, or in order to test potential treatments for (or vaccines against) that disease – is frightening to the general public.

Of course, we are told that the CHIM model is at present used only in specific circumstances: the disease strain used would not cause more than mild infection. CHIM has been used on diseases that have effective treatments so that the infection would be treated before the volunteer experienced severe disease. Volunteers receive extensive counselling before being admitted into a study, the studies are conducted by highly trained scientists using sophisticated and well run research facilities and carefully monitored (1).

We are also told that CHIM will immensely benefit the research enterprise. Promising vaccine candidates are tested on animals which have been infected, to see which of them – if any – is safe, and effective. Effective candidates are then tested on volunteers for efficacy against naturally acquired infection. But a vaccine candidate effective on a mouse may turn out not to work as well on humans. Using CHIM, if you infect the volunteer before administering the vaccine candidate, you will learn much faster which of the vaccine candidates have some efficacy, so that you can concentrate only on those which have been proved to have some efficacy. You also learn much more about the disease itself. We are also told that most studies using CHIM are conducted in high income countries (2), even those for vaccines more relevant in low income countries. For example, recently, a typhoid vaccine candidate developed by an Indian company was tested in the UK though Indians are more likely to benefit from such a vaccine (1).

And, finally, we are told that CHIM would be of immense value to research in India, to help develop vaccines specific to the local conditions. Currently, CHIM may be considered to test vaccine candidates for malaria (3), a disease which kills hundreds of thousands of people in India every year.

However, before CHIM can be introduced in India, the public may need to be convinced of the necessity for this research model, and assured that it will not harm volunteers or the larger community. The media would play an important role in this activity.

Of course, we should consider if, from the point of view of the research community, why there is a need to engage in public discussion of this particular research technology. What is special about CHIM, when other forms of research have never been taken before the general public? Is there any more need for public communication on CHIM in India than there is on other aspects of research – such as, for example, phase 1 trials of cancer drugs on terminally ill people, or conducting research on patients in intensive care? Or is it time for us to promote public communication on all health research?

**Communication in health**

Communication is an integral part of public health programmes. For example, according to the World Health Organization’s 2017 document *Strategic communications framework for effective communications,* the purpose of such communication is“To provide information, advice, and guidance to decision-makers (key audiences) to prompt action that will protect the health of individuals, families, communities and nations.” The decision makers are: individuals, healthcare providers, policy makers, communities, international organisations and WHO staff. Such communication is often for education, such as on good feeding practices and hygiene, and information and protective action against disease outbreaks (4).

Public communication of science is also a way for (government and private) research institutions to share their work with the general public through the media, to alert them of new information and technologies that could improve their lives. For example, research on how cancerous cells multiply could help in the development of more effective treatments (5). The science journalist, who makes science accessible to the public, is often treated as a key intermediary between the research institution and the reading public. Of course, there is a self-serving aspect to this, as media coverage helps generate more funding as well as a potential market for the commodity developed in this research. Journalists quoting experts’ opinions on new research must ensure that these experts have no hidden conflicts of interest (6) that bias their views.

Good public communication is critical to crisis settings, such as for epidemic preparedness. In India, the H1N1 pandemic is one example of where poor public communication – and to some extent an irresponsible media -- exacerbated the crisis created by an inadequate public health response, and hospitals were overwhelmed by an anxious public while the seriously ill sometimes did not receive life-saving treatment (7). The media has often contributed to the public panic (8, 9). An analysis of media coverage on the H1N1 pandemic notes that this problem is common to such public communication all over the world: “The management of the global response, the conditions under which vaccination campaigns have been launched, alleged conflicts of interest between government agencies and pharmaceutical firms, distrust of official messages, and emergence of recurrent rumors in the media and over the Internet brought to light challenges that health officials at all levels typically have to face during and after such pandemic episodes.” (10)

This has regularly affected vaccination campaigns. For example, a 2000 analysis of the government’s response to illness and deaths following OPV concluded that the government first dismissed cases of diarrhea as common side effects and, in response to a community demand for a medical inquiry, sent a combined police and medical team, treating it as a “law and order” issue (11). Such government responses, and poor public communication in adverse events following vaccination, threaten public trust in all immunization programmes. Zika is another example of deception – health officials tested fever patients’ blood samples for the zika virus without telling them – or the local government officials -- what the test was for, something that could well have had a backlash (12).

In the case of CHIM, the objective of public communication would presumably be to inform the public and allay any fears about its risks. The institution planning to use this model would be expected to develop media briefs on CHIM, with information on what it consists of, what it will be used for, examples of where it is being used currently, and measures that would be taken to prevent harm to individual participants and the community, as well as to dispel any fears about it. Journalists would be contacted to disseminate this information in the media.

**Communication and the role of the media**

In the case of vaccine-related issues, a UNICEF working paper’s suggestions include that the government programme work with communication professionals to answer general questions about vaccine safety, respond fast to any cases of illness or death following immunisation (which would include investigating the incident, making full findings public and taking the appropriate action) have a plan on how to deal with rumours, develop long-term “partnerships” with the media, and overall build public trust in immunisation (13). n

The most important and the best organised programmes will fail if the public does not trust the government.

The journalist will demand more. The media’s role is not to convince the public of the need for CHIM – or any other aspect of research and science but to represent the public’s interests, and enable the public to make informed decisions.

Very little has been written on CHIM in India so far. The starting point for journalists writing about CHIM is the environment in which it would be conducted in India: poor healthcare infrastructure, poverty, vulnerability of various kinds. In medical research, there is extensively documented ethical violations, weak regulation, and industry’s impunity.

Among the questions that journalists will ask are:

What is the scientific necessity of this technique in medical research? Why has it come up for discussion in India now? What exactly does it involve and what are the different uses? Who are the potential participants, and what measures will be taken to protect them? What steps will be taken to ensure that the research is properly regulated? How much of all this will be in the public domain?

There are concerns that research agendas are driven by funding organisations which focus technological solution to complex problems. Such emphasis on technology “can detract attention from the social determinants of health while promoting an approach to health that is heavily dependent on clinical technologies. The support of vertical, disease-based programmes can undermine coherent and long-term development of health systems…” (14) The public-private model for vaccine research has been criticised for developing and promoting unnecessary vaccines and subsidising the private sector vaccine industry (15). Who will be conducting CHIM-related research? Will the design and data from the research be in the public domain? Will vaccines developed using CHIM be made available to the government, for use in the public system, free?

**Challenges to the research community**

For some parts of the public, CHIM is likely to evoke images of experiments by Nazi doctors on prisoners, or the Tuskegee study on poor African Americans. They might also be reminded of horror stories closer home. Like Indian women on whom contraceptives were tested in government studies. Or even more recently, the reports of patients dying in drug trials.

The general public knows almost nothing of what goes on in medical research on humans. They don’t know who participates in these trials, their socioeconomic backgrounds, their motivations. All this is very much a part of what the media should be doing to inform the public on research. So, in a way, for the media to talk about CHIM separately is incomplete. The journalist will write about CHIM within the context of all this research.

When talking about the media and CHIM, the research community will have to be ready to be honest about its plans, transparent in its functioning, and democratic in that it should be ready to admit the possibility that we’re not ready for CHIM today. .

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