Researchers have a moral responsibility to meet participants' immediate health needs

If a project is not willing or able to accommodate such needs, ethics committees should reject it, writes **Allen G P Ross**

My colleagues and I currently coordinate a five year clinical trial investigating the neglected tropical disease schistosomiasis in the remote Philippines. Twenty two villages and almost 20 000 residents in the municipalities of Laoang and Palapag are taking part.

The Northern Samar province is considered the second poorest in the country, with more than half of its rural inhabitants living below the poverty line. The prevalence of malnutrition is high, with stunting, thinness, and wasting seen in 49%, 28%, and 60% of all children respectively (unpublished data). The burden of infectious disease is also high. The prevalence of schistosomiasis was found to be 27.1% (n=10 436; 95% confidence interval 26.3% to 28.0%) and for infection with any soil transmitted helminth (*Ascaris*, *Trichuris*, and hookworm) 77.2% (n=10 434; 76.4% to 78.0%).[1]

While examining participants I am often asked to help with health problems that are beyond the scope of the research that has been funded by the National Health and Medical Research Council of Australia. This presents an ethical dilemma. Do investigators involved in global health research have a responsibility to examine patients in studies for illnesses not being studied—and to treat patients and refer them to specialty care? If so, who should pay the associated expenses? Should national and international ethical review boards take such matters under consideration when reviewing global health research grants? Should global health funding agencies shoulder some of the costs? What role should national and local government have?

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In our study, I believe that we have a moral responsibility to treat patients presenting with other illnesses when they ask, despite no request from an ethics committee that we do so. We treat patients for simple ailments, such as acute respiratory infections, rashes, arthritis, and headache and refer them to specialty care when appropriate.

The local government has provided drugs for primary care. The provincial government has helped with the cost of transporting surgical patients to the capital, Manila, and several charitable public hospitals in Manila have helped with poor patients' costs. The national health insurer, PhilHealth (Philippines Health Insurance Corporation), covers only 20% of medical bills; patients must make up the shortfall, perhaps with the help of national charitable organisations such as the Philippine Charitable Sweepstakes.

To complicate matters further, some patients were referred, transferred, and admitted to hospital but ultimately did not have potentially life-saving operations. To go from small rural villages to Manila, home to more than 22 million people, can be overwhelming, particularly if patients have no family there. Also, taking time off work and raising living expenses while in hospital is simply beyond many people's means. If governments cannot take full care of such patients and their families, what can be done for them?

The developing world has large disparities in healthcare provision. Parts of rural Asia and Africa have as few as one or two doctors for every 100 000 inhabitants.[2] When a global health study is conducted in such an underserved area, local inhabitants may see it as a great opportunity to get the help they so desperately need.

However, it is unethical to conduct such research without meeting participants' immediate health needs. If a global health project is not willing or able to accommodate such needs, ethics committees should reject the application.

I suggest that a small fraction—for example, 5%—of all global health grants should be set aside for the immediate primary care needs of participants. Moreover, care should be provided for patients who need specialty care or surgery. Ethics committees should ensure that this forms part of all grant applications and is implemented. District, state, and national government should be asked to cover any additional expense. And, again, ethics review boards should not approve studies if the government is not willing or able to do this.

Once a study has ethical approval, careful monitoring and evaluation of study participants by licensed doctors with supervision by the ethical review board would be needed. All grants would need annual audit to ensure that the 5% of allocated funds have indeed been spent on primary care. Reprehensibly, at present very few global health studies worldwide provide such a service for the rural poor being studied.

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- News: Revision of Helsinki declaration aims to prevent exploitation of study participants (*BMJ* 2013;347:f6401)
- Editorial: India's new policy to protect research participants (*BMJ* 2013;347:f4841)

Research participants in Northern Samar who presented with health problems beyond the scope of the study funding; from left to right, top to bottom: chin tumour, dermatological disease, neck tumour, neck tumour, abdominal ascites from advanced schistosomiasis, and dermatological disease

FROM THE FRONTLINE **Des Spence**

Lost in translation

The last days of school: shaving foam over teachers' cars, food dye in the pool, running in the corridors, throwing eggs, smoking on school property, ties off, makeup on (boys and girls), and heading off to the pub at lunchtime, embarrassed by the lameness of our pranks. People who have nothing to lose can be dangerous, so with one month to go before I stop writing my weekly column perhaps I should throw caution to the wind and just start offending everyone. However, I thought I should do something different for a change.

Communication between doctors and patients is the subject of many confusing and profoundly dull books full of silly phrases and clunky simplistic constructs. And communication remains obstructed by doublespeak, pompous professional jargon, and coded clichés. What is said in the consultation rarely reflects what is heard by doctors and patients alike. Often neither the doctor nor the patient has any idea what is going on. In an utterly randomised, multicentred, and truly double blinded prospective study conducted over decades, I have managed to decode some of these phrases to disprove the dull hypothesis.

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Consider these common phrases used by doctors and then what the patient really hears: "I think we should do some tests" (you think I've got cancer); "I think we should get a second opinion" (I've got cancer); "Your tests were mainly normal but we should repeat the test" (I've got cancer); "It just a small lump/growth/shadow/mass" (I've definitely got cancer); "I think we could try some chemotherapy" (I'm going to die); "Your cholesterol/blood pressure/sugars are slightly high" (I'm going to have a stroke or amputation, or both); "Do you have any idea about what is causing your condition?" (this guy has no clue what he is doing).

And when patients say these familiar phrases to doctors, what are they really saying? "I read something online" (I think have cancer); "I read in the paper" (I think I have cancer); "I read an official NHS circular" (I think I have cancer); "I have a cough/cold/sore throat" (I need antibiotics now and I don't care what you say); "I have had two sore throats this year" (I want my tonsils out); "My child has a fever/cough/sore throat" (I want to see a paediatrician); "I brought a list" (I'm getting my money's worth, you fat, overpaid public servant); "I want a second opinion" (I have private medical insurance); "A medical friend suggested" (this what I want you to do).

This is original, real world research, and I wonder what other researchers in communication have found.

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BMJ BLOG OF THE WEEK **Richard Smith**

Nourishing the world

About a billion people end the day hungry, another billion are obese, and food prices are steadily rising. Clearly something is very wrong with the world's food system, and the *Economist* recently held a conference on Feeding the World. As several people pointed out, it might better have been called Nourishing the World as it's not just a matter of filling bellies. Some 165 million children are stunted because of malnutrition, and two billion people are deficient in vitamins and minerals.

We are living, said Gordon Conway (professor of international development, Imperial College, London), in a time of crises—financial, food security, water supply, climate change, and strife—most of which are getting worse, and these crises are all connected.

Population growth, he said, is seen by the public as the big problem on the demand side of the food crisis, but a bigger problem is changing food patterns, with many in the developing world adopting diets with more meat, fish, and dairy products. Half of all the pork and pig meat in the world is consumed in China. Another problem is demand for biofuels, with the price of corn undoubtedly being pushed up because it can be fed to humans or animals or used as biofuel.

Low yields are the major problem on the supply side with farmers in Africa producing about one ton per hectare of land, which was the yield in the UK in the days of the Roman Empire. Much of the world's food is produced by 500 million smallholders, 80% of whom are women. They need much more support. The rise in oil prices is

pushing up fertilisers, and climate change is producing both stress and shocks, like the heat wave in Russia or the floods in Pakistan. Stress is shortening growing seasons. Land and water scarcity are also major problems.

The answer to the global food crisis, said Kanayo Nwanze (president of the International Fund for Agricultural Development), is rural development, not just improvements in agriculture but also in education, health, transport, energy supply, finance, insurance, security, and access to markets. Equally important, he added, is to invest in women. A study in the Ivory Coast showed that $1 invested in a woman farmer produced the same yield as $11 invested in a man. Several others at the meeting made the same point, and David Nabarro (special representative of the UN Secretary General for food security and nutrition) later said: "The time of women, especially mothers, is one of the most valuable resources in the world."

Richard Smith was the editor of the *BMJ* until 2004 and is director of the United Health Group's chronic disease initiative

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