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Don't keep your distance

Investigations that involve human subjects always require a close relationship between the researchers and those being studied.

The US Institute of Medicine (IOM) has, in effect, directed researchers who work with human subjects to come down out of their ivory towers. The call is made in a report, issued on 19 September, that addresses the procedures that scientists should follow when they are investigating the health of underprivileged children. But the principles that it espouses apply to a great many of those involved in publicly funded research.

The IOM study was triggered by a court case involving the Kennedy Krieger Institute, a health research centre affiliated with Johns Hopkins University in Baltimore, Maryland. The institute ran into trouble during a study on the efficacy of various techniques for removing toxic lead paint from low-cost housing. Two mothers of children in the study sued the institute, claiming that the researchers never told them that their children's high levels of lead in the blood posed dangerous health risks.

In 2001, a Maryland appeals court ruled in favour of the mothers. The court criticized ethical lapses in the study, which it compared to the infamous Tuskegee experiments on black men with syphilis. It said researchers owed a "duty of care" to the children in the study — and that the parents did not have the right to consent for children to participate, as the study was not going to benefit the children directly and could even cause some harm, through procedures such as blood testing. The institute subsequently reached an undisclosed financial settlement with the children's families.

The IOM report, *Ethical Considerations for Research on Housing-Related Health Hazards Involving Children*, makes no judgement on the Kennedy Krieger episode. But it offers some useful guidelines for managing the delicate relationship between researchers and their subjects. The Kennedy Krieger study was aimed at helping disadvantaged people, but made the subjects' families — who lived in substandard housing and had little chance of relocating — feel exploited instead. The mothers who sued the researchers claimed they were never told that their children might ingest lead, or that high blood lead levels could harm their children. The IOM points out that the signing of a consent form wasn't sufficient to ensure that the parents understood the study.

Researchers working with disadvantaged populations should become much more involved with the communities they study, the IOM report says — the time and effort that it takes to do this will be rewarded by more convincing study outcomes. Partners in the community can help researchers, it points out, by highlighting flaws in study design, recruiting participants, and strengthening the informed-consent process.

The report also suggests that poor people in the United States are becoming more wary of participating in research, after years of involvement in studies and scant indication that the findings have any real impact on their lives.

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The devastation wrought by Hurricane Katrina provided a dramatic illustration of the grounds for this mistrust. Researchers knew before the hurricane that 120,000 people in New Orleans lived in households without cars (see *Nature* **437,** 174–176; 2005). Yet the city's evacuation plans made no provisions for these residents.

The IOM's recommendation that scientists work with communities to promote the translation of their findings into action applies in many different fields of study. Those who do basic research on rare diseases now realize, for example, that they must find unconventional ways to translate it into treatments, as drug companies have little interest in developing products for small numbers of patients.

Engaging communities is more difficult than simply publishing work and hoping that it will be noticed. But it is necessary, because science depends on public support, which in turn depends on the public's belief that research benefits them. If society comes to believe that researchers are operating in another world, divorced from real life, support for science can only be eroded. ■

Value-free nanotech?

Efforts to gauge public attitudes to nanotechnology reveal concerns that can be readily addressed.

A profound question underlying many debates involving science and its publics is "how knowledge comes to be perceived as reliable in political settings, and how scientific claims, more specifically, pattern as authoritative".

That quote comes from *Designs on Nature* by Sheila Jasanoff (Princeton University Press, 2005; reviewed in *Nature* **437,** 193–194; 2005), an overview of how the United States, Britain, Germany and the European Union have sought to deal with the issues brought up by biotechnology. Magisterial in its scope, the book takes for granted the idea, alien to many of *Nature*'s readers, that science is not value-free, and that some members of the public have cultural outlooks that are simply unreceptive to accounts of what science tells us.

A corollary of this is the idea, also shared by many science-studies specialists, that attempts by scientists to communicate their discipline to the public are likely to miss the point. Only by fully engaging at the outset with the cultural preconceptions of those audiences — by being what sociologists call 'reflexive' — can science's institutions do justice to their goal of engaging with citizens. At its

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worst, this agenda descends into relativism — the idea that someone's beliefs have as much weight as the so-called facts — or even Lysenkoism, in which the requirements of the state or of powerful groups take precedence over the facts. At its best, however, it can help scientists recognize how public hostility can be mobilized and consolidated despite the weight of peer-reviewed scientific evidence. This may happen because a culture of disrespect for science helps to reinforce cherished beliefs, or because experience has left individuals feeling betrayed by science or its application.

A major concern, especially in Europe, is to try to prevent such a climate enveloping nanotechnology. Experiences with genetically modified crops have led some governments to move towards being reflexive. At the same time, non-governmental organizations and other citizens' groups, more concerned about an emerging technology's potential disadvantages to their own interests, have welcomed the opportunity to tackle them as far upstream as possible.

It is in this context that two reports of citizens' participation are published this month. One, *Informed Public Perceptions of Nanotechnology and Trust in Government* by Jane Macoubrie of the Woodrow Wilson International Center for Scholars in Washington, is a study in which 177 members of the US public were briefed on nanotechnology and given a chance to explore its opportunities and their concerns. It documents weak public trust in regulatory agencies as a result of previous experiences with asbestos, dioxins, Agent Orange and nuclear power — exactly the type of cultural resistance to which Jasanoff and others would point. It also highlights a need to breed trust through better product labelling and compulsory regulation, and indicates a desire for information about the technology.

Another report, published in Britain this week, takes a less conventional approach. Sponsored by Greenpeace, *The Guardian* newspaper and centres connected to the universities of Cambridge and Newcastle, it represents the outcome of a UK citizens' jury, in which 20 members of the public met repeatedly to hear from a variety of witnesses (see www.nanojury.org). The jury was asked about nanotechnology's benefits for the poor and disadvantaged (weak jury concerns), whether the public should determine when nanoparticles can be used in particular technologies (weak support), and whether it needs to yield more "quality leisure time" to deserve public funds (stronger support). As in the US study, the jury supported labelling, mandatory safety testing and better access to information about which nanotechnologies are being publicly funded.

These two studies reinforce the impression that the public has strong concerns about regulation and a lack of information about nanotechnology, and that nanotechnology is welcomed for its potential benefits. The results of the citizens' jury suggest that nanotechnology is not perceived as a serious threat to the values of anyone but die-hard anti-technologists. But this was a small study, and one that the jurors themselves said is provisional.

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Supporters of full-blown reflexiveness should welcome a transparent citizens' jury that has probed society's assumptions about the need for a technology, and should also acknowledge these appeals for communication and regulation. Meanwhile, governments have received some direct public guidance on citizens' interests that must be protected if nanotechnology is to flourish. ■

Science after Katrina

The hurricane disaster on the Gulf coast will change the federal government's research priorities.

The clean-up operations in the wake of Katrina are a nightmare for all concerned, including scientists at Tulane University and other research institutions on the Gulf coast (see *Nature* **437**, 177; 2005). They need all the help they can get, and other institutions must endeavour to provide it and get them back on their feet.

The ramifications of this tragedy will run deep. There are already signs that national priorities are changing: President George W. Bush, speaking in New Orleans on 16 September, broached some themes that he had previously avoided. "We have a duty to confront poverty with bold action," he said. If that pledge is to be followed through, it will involve changes in research priorities.

For better or for worse, the US federal government — particularly Congress — has a propensity to adjust the government's spending portfolio quickly in response to particular events. After the attacks of 11 September 2001, for example, the government created the Department of Homeland Security, with a large and ill-defined research programme, and diverted resources at the National Institutes of Health towards activities related to bioterrorism. Four years later, there is scant evidence that either shift has achieved much for science or for national security. After that precedent, some would argue that the government should avoid overreacting to Katrina.

Yet Katrina has brought to the surface some critical issues that have been wantonly ignored in Washington in recent years and now deserve some attention. The most significant of these relate to poverty, as Bush has now acknowledged, and racial division. Policy-makers need good information if they are to tackle these issues, and in many instances research can provide it. The aftermath of Katrina will push poverty, at least, up the agendas of agencies such as the National Science Foundation and the National Institutes of Health that support research in the social sciences and environmental health.

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At the same time, the disaster raises the profile of two very different spheres of environmental research — water management and climate change. The former is quite well understood, although a great deal of existing knowledge about rivers and wetlands, for example, is frequently ignored by policy-makers. Despite the Bush administration's scepticism about the latter, it has maintained a powerful climate-change science programme, which in time may shed valuable light on the complex relationship between global warming and extreme weather events, including hurricanes. ■

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