

## Professional responsibilities of biomedical scientists in public discourse

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Minorities who disagree with the “scientific consensus” must be allowed to air their views

I will begin by discussing the example used in Schüklenk’s paper<sup>1</sup> of the self-proclaimed “HIV dissidents” and then discuss whether the recommendations made are useful and could be applied to other examples in science.

Schüklenk’s primary concern according to his title is with the professional responsibilities of biomedical scientists engaging in public discourse. The example given is of the effect that self-proclaimed HIV dissidents have had on the provision of HIV related public health measures in South Africa. Fundamental to the example given is a distinction that both Schüklenk and indeed the general public often fail to make. It is important to recognise the difference between biomedical science and clinical practice. Science and medicine are two distinct fields, each with their own historically founded methods and purposes; they have had little in common with each other until relatively recently. Schüklenk confuses the two when he judges a scientific hypothesis by its clinical utility.

It certainly seemed prudent to me at the time to give support to critics of a hypothesis, the pursuit of which had done little to bring those in need closer to life extending or life saving AIDS drugs.

He later reconsiders his position on the basis of new clinical evidence.

My own conversion to the mainstream view took place roughly when dissident predictions about AIDS deaths resulting from what they believed were highly poisonous drug cocktails—that is, triple therapy, did not occur, and when it became clear that actually the opposite was true; these drugs were at least life extending. I saw people with AIDS, following years of decline, turn the corner after they began using these drugs.

Once we disentangle these once quite separate discourses of science and medicine the answer to the question of government responsibility is I suggest quite simple. The issue here has little to do with science and everything to do with what is considered to be clinical best practice. The measures designed to protect people from developing AIDS and the treatments given to those suffering from AIDS have been clinically proven to be effective and save lives regardless of whether there is any scientific basis for them. In medicine the “gold standard” for treatments is the randomised placebo controlled trial. The only question answered by such trials is: “does the treatment protocol improve outcomes or not”. The biomedical science question of “how does it work” never even enters the picture. In the face of overwhelming clinical evidence as to the effectiveness of treatments for HIV/AIDS, any concern about the biomedical science questions raised is irrelevant. That the focus in clinical medicine is on positive outcomes regardless of any understanding of why or how is neither controversial nor surprising given that our understanding of the human body is still somewhat limited. This is why so many promising pharmaceuticals fail to make the jump from the lab to the clinic and does not imply that the underlying biomedical theories are necessarily wrong, just incomplete. The HIV dissidents’ claims that it has not been proven that HIV is in fact the cause of AIDS are genuine scientific claims worthy of investigation or at least consideration for contestable research funding. The dissident claims that retroviral drugs are not useful in the treatment of AIDS have been proven to be fallacious by multiple clinical trials. Mbeki is morally obliged to do what he can to provide what is internationally proven clinical best practice to the people of South Africa.

Such a simple answer to the situation in South Africa is unlikely to change much. While Schüklenk presents evidence that Mbeki has been convinced by the HIV dissidents, it is difficult to know

who is taking advantage of whom here. As Schüklenk notes, Mbeki previously denied access to retrovirals on the basis of their cost and only when that excuse wore out, switched to using dissident arguments against their effectiveness. Mandisa Mbali<sup>2</sup> argues that Mbeki undoubtedly has his own political motivations as a postcolonial African leader. It is not by chance that the HIV dissidents’ views have been accepted and propagated only by certain social and political groups. The groups who have accepted and promoted the dissident position indubitably have their own reasons for doing so. Fundamental to Schüklenk’s argument is that these reasons all effectively originate in a minority scientific interpretation. I suspect that, as with Mbeki, the real motives are a complex mix of political and social causes, which include, to varying degrees, denial and an unwillingness to alter personal behaviour among at risk groups. In general, minority groups are likely to be more accepting of minority interpretations and possibly even sceptical of a majority consensus by which they feel disempowered, as Schüklenk notes when he states: “Part of the dissidents’ appeal was their claim that the ‘establishment’ was censoring their views”. The suggestion then that professionals who wish to engage in public discourse and present minority views ensure that the public concerned “must understand how exceedingly small the number of professionals is who hold dissident views” is probably not going to improve the situation.

The broader question raised by Schüklenk regarding the professional responsibilities of biomedical scientists in public discourse requires that we consider some more generic examples. Central to the argument is the assumption that there can be consensus agreement within science and that it is unprofessional for those (minorities) who disagree with that consensus to campaign for their views in the public arena. Science, however, is not as uniform as it may first appear. There are deep disagreements between scientists over many important questions that manifest themselves in debates such as that surrounding genetic determinism. The nature/nurture debate essentially comes down to a continuum of positions with no single position able to claim to be the majority. One of the nature/nurture debate’s most famous protagonists, Richard Dawkins, is the Charles Simonyi Professor of the Public Understanding of Science at Oxford University. Professor Dawkins is well known for his relatively extreme position on genetic determinism, which, regardless of its scientific merit is

probably a minority view from the perspective of the wider scientific community. This debate is not simply academic but is fundamental to our understanding of what and perhaps even who we are. There is, however, a long tradition in science of charismatic individuals with novel (minority) views that have had considerable impact on both the public understanding of science and the progress of science. Even Dawkins's adversaries would, I suspect, balk at Schüklenk's suggestion that "Science organisations could consider censoring publicly such publicity seeking scientists".

Schüklenk's example of the situation in South Africa is, however, certainly graphic enough and disturbing enough for us to wish to avoid anything like it happening again. One of Schüklenk's suggestions is that we should encourage professional organisations to develop ethical guidelines for the interaction of their members with the lay public. I am

unsure that science should or even could present a consensus line to the public but even if this were possible it would not seem to solve the problem at hand. Partly due to the historical rift between science and medicine there exist a number of alternative metaphysical foundations for the practice of medicine. Practitioners of alternative or complementary medicine such as homeopaths already have their own professional organisations complete with codes of ethics. Unsurprisingly the homeopaths' code of ethics supports the explanation of homeopathic principles to the lay public who may choose to believe them and/or accept treatment based on them. The basic metaphysical rift between homeopathy and science over the causes of diseases, and between homeopathy and medicine over their treatment effectively places them in competition. The objective of winning the day in this case does seem to be to convince the public audience. In the

light of sincere disagreement both within and between professional groups it would seem that public debate should remain as open as possible. This, however, does not deny the value of randomised controlled trials in determining what constitutes "best practice" in the delivery of health care.

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## ECHO

### The public must decide whether genetic screening is ethical



Please visit the *Journal of Medical Ethics* website [www.jmedethics.com] for a link to the full text of this article.

Decisions about whether prenatal screening is ethical should come from the public, not research ethics committees, argues a study that has shown that UK committees' opinions vary on screening for Down's syndrome. The study raises ethical questions about genetic testing in general, which need to be debated publicly before the advent of screening tests made possible by the Human Genome Project, says its author.

Among 77 members of 28 research ethics committees screening was strongly supported as ethical when Down's syndrome was simply described as a "serious condition with no risk of abortion to unaffected fetuses" but less so for a clinical description (72% v 44%). Only 21% and 14% of them respectively, thought that screening was ethical at current rates of spontaneous abortion—one aborted unaffected fetus for every two affected fetuses identified. Support was strong for screening for a serious condition to permit prompt treatment at birth versus screening for undesirable appearance—red hair and freckles—at the other end of the range (94% v 10%). Responses for screening and termination for a condition with a poor life expectancy were equivocal and support was minimal for mildly (6%) or severely reduced IQ (21%).

This study sought replies of members of 40 randomly chosen UK ethics committees to a questionnaire covering four scenarios: potentially embarrassing traits, cystic fibrosis and premature child death; type 2 diabetes and premature adult death; and Down's syndrome.

This study coincides with the National Screening Committee's harmonisation of screening standards for Down's syndrome, which will extend screening.

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