

risk. These should occur when warranted by preclinical data, and not by public opinion. Without the ability to perform even limited trials, little information can be obtained.

As a member of the XEWG, I support the concept of public consultation pertaining to xenotransplantation. Public consultation is an important mechanism of prioritizing and rationalizing health services in the context of limited funding.^{11,12} It is also potentially a valid way to determine society's reactions to emerging technologies. Therefore, it is appropriate that the public help decide whether xenotransplantation is potentially an appropriate future health care technology. However, a major principle defining useful public consultation is that the "consultees must have sufficient information to make meaningful comment."¹³ Because it is not possible in one weekend to provide lay people with more than superficial knowledge about the science of xenotransplantation, the decisions of "when" and "under what circumstances" xenotransplantation clinical trials should be allowed to go forward cannot be decided by public consultation.

I do not pretend to be an expert in methods of evaluating public opinion; however, I am a scientist and I recognize inconclusive and poorly interpreted data when I see it. In this context, I believe that the Public Advisory Group is bold and self-serving to offer its last recommendation, "that the citizen forum model be strongly considered for future consultations on complex and not widely understood policy issues." Until the methodology used in this current consultation has been fully analyzed and corrected, another experiment like this is both unwarranted and dangerous.

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Dr. Wright is with the Department of Pathology, IWK Health Centre, and the Departments of Pathology, Surgery and Biomedical Engineering, Dalhousie University, Halifax, NS

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Correspondence to: Dr. James R. Wright Jr., Department of Pathology, IWK Health Centre, 5850 University Ave., Halifax NS B3H 1V7; fax 902 470-7215; jim.wright@iwk.nshealth.ca

The xenotransplantation question: public consultation is an important part of the answer

Adrian J. Ivinson, Fritz H. Bach

β See related article page 40

In his commentary in this issue (page 40),¹ James Wright disagrees with the central conclusion of the recent Canadian Public Health Association (CPHA) report on its public consultation on xenotransplantation. Whereas we have some sympathy with some of the concerns he raises, both he and the CPHA are missing the point. They see the public consultation as a voting exercise, the result of which can be used to determine policy. And that is wrong.

The CPHA report summarized the findings of a "comprehensive consultation with Canadians on the complex issue of xenotransplantation" through citizen forums.² Deliv-

ered to the federal minister of health, the report made 7 recommendations. It was the principal recommendation "That Canada not proceed with xenotransplantation involving humans at this time ..." that bothered Wright the most.

Wright takes issue with the consultation process, arguing that on the whole it was poorly designed. And he raises some important concerns. For example, the central question that was repeatedly asked of the lay participants "Should Canada proceed with xenotransplantation and if so, under what conditions?" was indeed vague and difficult to answer simply. The great variation in responses from the different lay panels is also cause for concern, and the suit-

ability of some of the expert witnesses put at the disposal of the lay panels was questionable. That said, judging by the description given in the official report, the public consultation exercise generally was well organized and comprehensive. But it is just that, a consultative exercise, not a vote or recommendation for a particular policy.

The benefits of new technological discoveries must always be weighed against their potential dangers. In the case of xenotransplantation, the medical and scientific communities are familiar with many of the risks³ (with infectious agents⁴ topping the list for most of us). Likewise, the typical stakeholders — industry, patient advocacy groups, animal rights advocates, the legal community and others — are also aware of the issues and know how to make their views heard. The public, in contrast, is rarely consulted, yet is expected to live with the consequences of these decisions. As such, the CPHA and others are to be congratulated on any effort to involve the public in this discussion.

Public consultation on complex biomedical issues (or indeed on any technological development) is not simple. As both the CPHA and Wright stress, there is little value in asking the opinion of an uninformed or misinformed constituency. Great efforts must therefore be made to explain the issues in such a way that the lay audience is given an accurate, comprehensive and objective picture that includes all the major views but is nondirective. In effect, we are aiming for a process similar to that required for fully informed consent in clinical practice.⁵

But the CPHA's public consultation exercise must not be mistaken for a referendum or a national poll. Determining whether most Canadians endorse xenotransplantation would certainly be interesting but is neither possible from this exercise in limited public consultation, nor, we believe, should it have been the aim. Rather, the value of this exercise lies in exploring with a lay group a variety of concerns and options and then feeding this understanding to those who ultimately are charged with setting policy.⁶ Those decision-makers are responsible for considering the positions of all the parties and arriving at a decision that is informed by all parties, including the public.

At first blush, some stakeholder groups may not welcome public consultation, fearing perhaps that the public may not support their aims. Experience suggests that this is not necessarily the case. After the near-wholesale European rejection of their genetically modified foods program,

Monsanto's president, Hendrik Verfaillie, admitted that they had made a mistake and acknowledged the value of public consultation:⁶ "As we tried to understand what had happened, we realized that we needed to hear directly from people about what they thought, what their concerns were and what they thought we ought to do."

From the biological perspective, significant immunological hurdles still need to be overcome before xenotransplantation becomes viable. But with many scientists investigating various solutions to these problems, there is at least reason for optimism that xenotransplantation will become a viable medical option. Between now and then, it is essential that we better understand the public's views on this new technology. The CPHA report is certainly a valuable contribution and should indeed influence the Canadian government's deliberations. But it is not a referendum result that on its own should dictate policy. Rather, it is an essential mechanism for adding the public's voice to those of the traditional stakeholders.

Dr. Ivinson is Director of the Harvard Center for Neurodegeneration and Repair, Harvard Medical School, and Dr. Bach is with the Immunobiology Research Center, Harvard Medical School, Boston, Mass.

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Correspondence to: Dr. Fritz H. Bach, Immunobiology Research Center, 99 Brookline Ave., Boston MA 02215, USA; fax 617 632-1198; fritzbach@aol.com