

Roberta M. Berry  
Question B

(1) Role of public involvement.

I see public involvement as key to sound policymaking about enhancement technologies because, in brief, experts work in silos, people live in fields. The work that experts perform in their silos is valuable only to the extent it serves the needs and interests of the public. And members of the public are in the best position to determine what serves their needs and interests.

By “experts” I mean both those with scientific and technical expertise and those who hold themselves out as experts in ethics or policy. Expertise requires immersion in the work of one’s fellow experts, mastery of a common language and set of concepts, and acceptance of common standards for judging good and bad work. It means working in a silo that is separate and a bit isolated from the lives of people who will be affected by their work.

By “people” I mean members of the public who lead their lives as individuals and as members of families, neighborhoods, political communities, workplaces, religious groups, ethnic or racial groups, disability groups, hobby and other interest groups, and so on. Unlike experts engaged in their work, people live in wide open fields where they must navigate the complex daily demands that arise from their commitments and goals as individuals, parents and children, co-religionists, employees, citizens, and so on. This typically involves cooperating with others to understand and solve problems, achieve goals, and realize the good things in life. We are very good at this—otherwise we would not have survived to this point.

Without scientific and technological expertise, we would not have enjoyed the astonishing benefits of public health measures (clean water, inoculations) that have saved millions of lives over the past couple of centuries or of medical technologies (organ transplantation, heart surgery) that routinely rescue people who would have died prematurely just decades ago. But we also know that experts in science and technology can commit horrific offenses against individuals in pursuit of ends that are not beneficial to humanity—Nazi research on human subjects are an extreme example of this. Short of this, we know that scientific and technological experts sometimes lose sight of what is valuable to the lives of individuals and their families as opposed to what is technologically possible; we have struggled to find the proper place for life-prolonging technologies in a good life and death.

Experts in ethics and policy can and have responded helpfully to abusive exercises of scientific and technological expertise. An example of this is the Nuremberg Code, developed after World War II in response to the Nazi experiments; the principles developed in the Nuremberg Code eventually led to the development and enactment of the U.S. law known as the “Common Rule” regulating the conduct of federally funded research. The Common Rule establishes standards for the ethical treatment of human subjects of research experiments in light of the hoped-for benefits of the experiments for

humanity. But experts in ethics and policy also act in ways that prove misguided at best and horribly wrong at worst. For example, one of America's greatest jurists, Justice Oliver Wendell Holmes, wrote a U.S. Supreme Court opinion in the 1927 case Buck v. Bell upholding a Virginia eugenics law providing for the involuntary sterilization of "mental defectives." Justice Holmes was a brilliant and expert policymaker—who worked in a silo in which the lives of those like him seemed much more important and valuable than the lives of those who were different from him.

I believe that the best—and only—way to ensure that enhancement technologies serve the needs and interests of all of us is to engage the public in directing the course of development and regulation. Of course, the contributions of experts—scientific/technological and ethical/policy—will be important and necessary. But those "living in the fields" are in the best position to determine what serves their needs and interests and to help the political community navigate to sound policy choices. We are very good at this—we do it day in and day out in our families, neighborhoods, workplaces—and, in a democracy, we have a chance to do this at the level of the political community. But this does not mean that achieving the benefits of public involvement will be easy.

(2) How to ensure public involvement and how to disseminate information to support this involvement.

Ensuring public involvement, I believe, will be difficult because of the challenging nature of the questions raised by enhancement technologies. But there are some examples of how we have engaged and are now engaging the public that might help us find good ways to accomplish this.

Public involvement will involve challenges because of the nature of the questions raised: (a) They involve scientific and technological complexity as well as the complexity of the implications of these technologies for the biological and social being and for the community. (b) They challenge our ethical commitments: some of our most deeply held secular and religious ethical beliefs concern procreation and parenting, life and death, and the meaning of liberty, equality, and welfare in a democratic republic. (c) In a pluralistic society, we will disagree about some of these ethical commitments. (d) The questions raised are novel; we cannot draw on previous experience in a straightforward way to guide us in answering the questions. (e) Some of the questions raised are unavoidably public. We cannot resolve them by saying that all are simply matters of individual choice. This is because some of the enhancement technologies would be applied to future children, the development of these technologies typically involves the use of public funds, and there are implications for public values such as liberty, equality, and welfare. (f) The questions cannot be resolved at one point in time and once and for all. Enhancement science and technology will continue to advance and continue to pose novel questions.

We have seen that the policy process can sometimes become polarized and frustrating when questions with similarly challenging characteristics are raised. One example is the

debate surrounding embryonic stem cell research. Another example is the debate surrounding the life and death of Terri Schiavo.

But I believe that wider and deeper public involvement, as opposed to a narrower debate involving primarily experts and dedicated interest groups, offers the best opportunity to cope with the challenges posed by these sorts of questions. At the most basic and concrete level of daily living, we have a lot in common and we have a lot of experience in working together to arrive at good-enough resolutions, seeing one another's perspectives, learning from them, finding common ground.

Previous and ongoing examples of ways to inform and involve the public in policymaking surrounding questions like these include: (a) Ensuring citizen membership on regulatory boards, such as the Recombinant DNA Advisory Committee (RAC), a committee of the National Institutes of Health (NIH) that provides advice about somatic-cell gene therapy (involving inserting genes into living human beings in an attempt to cure diseases). (b) Holding public meetings to provide information and gather input, as when U.S. Food and Drug Administration (FDA) held a series of public meetings regarding genetically modified foods. (c) Charging public advisory councils with preparing reports and recommendations on issues in biotechnology (such as the National Bioethics Advisory Commission (NBAC), established by President Clinton, and the President's Council on Bioethics (PCBE), established by President Bush) and requiring that the councils obtain input from the public and disseminate their results broadly. (d) Incorporating in our K-12 and higher educational systems instruction both in science and technology and about the ethical and policy issues surrounding them. (e) Engaging in participatory projects, such as the one you are involved in.