



Of Metrics, Genomes & Morality: A Conversation with Kathy Hudson

Dr. Kathy Hudson is the founder and Director of the Genetics and Public Policy Center and an Associate Professor in the Berman Bioethics Institute, Institute of Genetic Medicine, and the Department of Pediatrics at The Johns Hopkins University. Hudson founded the Center in 2002 to fill an important niche in the science policy landscape and to focus exclusively on public policy issues raised by advances in human genetics. She leads the Center's efforts to address legal, ethical, and policy issues related to human reproductive genetic technologies, genetic testing quality and oversight, and public engagement in genetic research.

Hudson also testifies frequently on genetics-related issues on Capitol Hill, and is a longtime friend of Knowledge Networks. We recently sat down with Hudson to talk about the importance of research quality to the Center's efforts.

Can you talk about the role research plays in your work today?

Research has been a centerpiece of our efforts since the Center was founded in 2002. We study a number of different genetics-related issues to increase the

knowledge base about where the American public stands, and we publish that in peer-reviewed medical and scientific literature. In our more recent, policy-focused work, we have been able to use KnowledgePanel[®] to get public feedback in record time. Recently, as a piece of legislation that would prohibit genetic discrimination by health insurers and employers started being seriously considered on Capitol Hill, I realized that there was no up-to-date or comprehensive information on how much trust the public has in those people who could be holding their genetic data and using it—to make decisions about who gets health insurance, hiring and firing, and other things. So I was able to write a survey in one afternoon, get IRB approval the following week, and have the data back from KN in time to incorporate it into my testimony before the Energy & Commerce Committee in the House.

What level of scrutiny are your different surveys subjected to, and how does that affect the methodologies and modes that you use?

Whether we are doing a quick survey or a longer one, we use the same sort of rigor in data collection and analysis; we want data

that will withstand the very high scrutiny needed to be published in the peer-reviewed literature.

And does that mean there are certain methodologies or modes that you prefer or are most comfortable with?

The critical thing for our work on public attitudes is to ensure that the sample is representative of the American public; and this is where Knowledge Networks has been really essential—providing representativeness while turning around a survey quickly.

Can you talk about the difficulties of designing a general-population survey about, for example, a complicated bioethical issue?

I think one of the key challenges with ethical and moral issues is that they are never black and white; we need to assess the nuances of people's values and views on ethically complex subjects—both by giving them coherent, concise descriptions of the subject matter and by having categories of responses that are more nuanced than a five-point scale. For example, we worked with Knowledge Networks to create what we call the Moral-o-Meter, which is basically a visual thermometer; for example, people were presented with various stages of development of human life and a definition of what moral status means, and then asked to rate the status of those various stages. A respondent could visually see the differences between the categories, so their answers could be very fine grained.

Do you have a sense of an awareness of research quality among your colleagues or the people you present to?

Our colleagues are both hard scientists, who are very oriented toward evaluating methodologies, and social scientists who know the particular methods really well. They have evaluated our methods—using either KnowledgePanel® or, back in the day, random digit dial telephone—and our work passed the test.

What advantages do on-line surveys bring for addressing the kinds of complicated topics you need to study?

I think the ability to have people refer back to material—whether it's a definition or an image—is really important; the same is true for capturing responses to visual images. For example, in a survey that we did about public attitudes towards embryonic stem cell research, we included in the survey instrument pictures of embryos at different developmental stages and asked people to identify the image of a one-week-old embryo—which is what is used for embryonic stem cells; you certainly would not be able to do that with a voice interview. We are also looking forward to integrating video into the survey instrument as a way to make some information more accessible and more interesting; this is part of a large study on attitudes towards genetic research that we have recently launched.

When you are assessing the reliability of survey data that you might encounter in a newspaper or magazine, what are you looking for?

I look, first of all, at who was surveyed—how do you know that the data are or are not representative of a certain public? Second, I look for the numbers involved—is it a substantial enough number of respondents to actually give some confidence? And probably the most important thing I look at is the survey instrument itself, how the questions were asked; frequently questions are designed to evoke a desired answer. When we were doing our embryonic stem cell survey, we collected all of the surveys that existed on the subject; we found one by a religious organization in which they asked, roughly, "Do you support the use of tax payer dollars to destroy nascent human life?" And, in contrast, the research groups that were advocating for embryonic stem cell research asked, "Do you support federal research funding to find new cures to treat devastating diseases?"; they managed to avoid explicitly using the word "embryo." Not surprisingly, those two surveys got very different results, which did not accord with our own.

What about media attitudes toward survey research—how have they changed, if at all?

What I have found with the media—and, to a lesser extent, with policy makers—is an extraordinary attentiveness to the questions. They are happy to look at your data, but what they really want to see is the survey instrument.

So they have seized on the questionnaire, perhaps to the exclusion of other issues, such as sampling.

For media people in particular, if we tell them it's a representative sample, they believe it's a representative sampling; they will say fine and cross it off their mental check list.

I understand that you and Knowledge Networks are involved in a consultation about a study on genes and environment. Can you describe what the challenge is?

We are at an interesting point in genetics research now, where studies are being designed to understand common complex diseases like type II diabetes, cardiovascular disease, colon cancer. The risk factors for these diseases are complex with a number of genes interacting with one another and with environmental and lifestyle exposures to give you a final risk of a variety of illnesses. Some scientists have proposed that there be a genes/environment research study that would follow half a million people or so over the course of a decade or more, in which detailed information about the participants' genes, environmental exposures, lifestyles and medical experiences are recorded, to understand how each contribute to the overall increased risk for various diseases. For such a study to be successful, it will require a large number of people, perhaps a half a million, who are willing to step up and participate.

We have been asked to explore what the public would think of the burden and benefits of participating in such a study; and about their views and preferences of

how that study is designed. The researchers who are going to design such a study, if it moves forward, are genuinely interested in being responsive to the public's views and concerns. Do participants want only the results back that are clinically relevant and that they can do something about? Or are they information seekers who want to know everything?

We are in the midst right now of doing focus groups around the country in which we are trying to identify key themes that will then be the basis for our development of a very large, population-based survey in the fall.