インタビュー

ナレッジ･マネジメントと「一般人の科学理解（PUS）」

―医学･医療を見据えるソーシャル・エピステモロジー（社会的認識論）の視点―

Knowledge management (KM) and public understanding of science (PUS)

― The view from social epistemology on medicine and medical research ―

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Special contribution：STS and Professor Fuller's visit to ICU
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Interview：Knowledge management and public understanding of science
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Abstract

An interview with Steve Fuller, Professor of Sociology at the University of Warwick in the United Kingdom, and Osamu Kanamori, Professor at the Graduate School of Education, the University of Tokyo, was held at the International Christian University(ICU), to gain insights into the characteristics of medical knowledge and its comprehensibility for the public, from the view of science, technology and social studies（STS）.

This article is in part written by Professor Yoichiro Murakami, founder of the educational field of STS, to describe the process of inviting Professor Fuller as a visiting professor to ICU for the winter term from December 2001 to January 2002.

Professor Fuller is a founder of "social epistemology", an intellectual movement of broad cross-disciplinary provenance that attempts to reconstruct the problems of epistemology once knowledge is regarded as intrinsically social. It is often seen as philosophical science policy or the normative wing of science studies. Professor Kanamori, an up-and-coming scholar of science studies, introduced the situation of STS in Japan. The three interviewers and the observers were from a wide field of Japanese practitioners, researchers, and educators of medicine, pharmacy, bioethics, sociology, and musicology. They were challenged to explore the possibility of interaction between STS and medicine, and held a frank, open, and critical discussion on evidence-based medicine, knowledge management for pharmaceutical companies, public understanding of science, and the possibility of holding consensus conferences, for the new age of progressive technological advances in medicine.

Key words

knowledge management（KM）, public understanding of science（PUS）, social epistemology, science technology and social studies（STS）, evidence-based medicine（EBM）

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TRANSCRIPT OF DISCUSSION / INTERVIEW WITH DR. STEVE FULLER
JANUARY 6, 2002, TOKYO, JAPAN

LECTURES AT I.C.U.

TEI: So I would like to ask this question about you. We understand that you are staying in Japan being invited by Prof. Yoichiro Murakami to have a lecture at I. C. U.. What are you doing here now?
FULLER: I am teaching two courses. One of them is an undergraduate course and the official title of it is "Reimagining Sociology" and what it has to do with is basically what can sociology become in the 21st century. It has actually a lot to do with the changes in the biological sciences and the challenges that they make to what it is to be a human which has always been at the core of sociology but has been challenged quite a lot recently. Then there is another course which is an upper division, graduate course on the philosophical foundations of science and technology studies. I am doing both of those courses for the seven weeks that I am here.
TEI: And you are giving your lecture in the English language?
FULLER: Of course, yes, and the students understand and they are able to have meaningful discussions.
TEI: You told me before that 15 percent of the courses here are taught in English.
FULLER: Yes. Professor Murakami invited me to a faculty senate meeting before the end of the term. So I got to see what was being discussed on this issue. Actually, it was one of the things discussed and it was clear that that was one of the distinctive features of this university.
KURIHARA: Is it the first time for you to visit Japan?
FULLER: But it's the first time I spent this long. The other two occasions, one was in '98 and the other in '99, I was here for about seven to ten days, and did some lectures in the country. But this is the first time I've been here for such a sustained period.

STS SCENE IN THE WORLD/JAPAN

KURIHARA: So how is your impression of Japan especially in your specialized area?
FULLER: Well, one thing I always notice is that the field of science and technology studies has a very large presence in this country. Much larger than, I think, Westerners realize. So large, that if Japanese researchers could vote in block, they would have substantial influence on the world scene. Although science and technology studies is a very research-active field and people in the field make a lot of noise, there are only about 700 or 800 people doing it in the world. If you think of Japan, you have close to a hundred or more. They may not get to the Western world or make talks in the Western world but still we see quite a large presence.
KURIHARA: Even if the number is so many, it seems that there is very few interaction between the specialists in science studies and the scientists.
FULLER: That's common everywhere, not just here. In fact, it's a difficult issue because science and technology studies is, in a sense, trying to become professionalized. Especially in countries where there are quite a large number of people working in science and technology studies, there is a tendency to want to stick together and distinguish oneself from scientists and technologists and so forth. I don't know if the history is the same in this country, but in Europe and in the United States, most science and technology studies programs originated as service teachings for science, engineering schools and medical schools, in some cases, where humanists and social scientists were hired primarily to teach people who train to be scientists.

But then over time, these programs developed into their own entities, began to have their own degree programs and eventually their own Ph.D. programs. And it's at that point, you start to get conflict. The conflict arises because the science and technology studies people wanted to define their own agenda, which is quite different from what the scientists and the technologists want. And now we have these things called the "science wars" which, in a sense, marks a very formal public recognition of science and technology studies as a field. In a sense, it's what we say in English 'baptism by fire' where you're sort of get born into the world in a very conflicted state. I think that's something we feel all over the world. It's difficult to know what one does about that. But I don't find that particularly unusual. I think one measure of the Japanese presence in this field is that there is now a Japanese member of the Council of the Society for Social Studies of Science, which is the world professional society.

SAIO: Then, the numbers you said 700 or 800 in the world and 100 in Japan mean the number of the members of STS, is it right?

FULLER: Yes.

TEI: Are you saying that Japanese researchers in this field should speak louder?

FULLER: Yes. The numbers are certainly there, and there is certainly a very large science and technology base in this country. There is no doubt about that. It seems to me that Japan's moves on the larger global scene of science and technology studies have been already quite prominent, even though a relatively small percentage of the whole Japanese science and technology studies community has been involved. Another thing to keep in mind is that we live in a period when science and technology studies is going nowhere in particular. I mean, there's a lot of it happening and there's a lot of publicity given to it. But if you had to say, where is this field going, it's not going anywhere in particular. In fact it's very much captive, I would say, to particular national situations. Different countries are captive to different kinds of problems and that often explains the way in which the research ends up turning out. So, a lot of the stuff that travels internationally, especially theory, is almost like a mythology because it's very much abstracted from the context in which this stuff originally had some kind of meaning. I have a chapter on this in the book I've written on Thomas Kuhn. Because even though science and technology studies is a field that's supposedly based on the social conditions of science and technology, it all too often abstracts itself from its own social conditions. I think that causes a lot of misunderstanding in terms of what's going on. So I think there is a real role for Japanese researchers here to help define the field. No doubt about it.

TEI: So, Prof. Kanamori, how do you regard the Japanese situation.

KANAMORI: Well, I tell you my opinion on the positional value of science studies researchers in Japan. When I published the book on science wars, it is just a brief introduction of what was happening in the United States. I was hoping that Japanese scientists would have some interest or some reactions, no matter how it might be positive or negative. Unfortunately there were very few reactions. Some said negative, but not so interesting, reactions. And I was really disappointed. I think one of the reasons is that perhaps my presentation was simply bad or I think that there is some difference between the culture of scientists in Europe, Japan and the United States. Generally speaking, Japanese scientists have very specialized point of view so they are very good specialist, but if they go out of their own specialties they don't have many capacities to think through some problems which are in general composed by very hybrid and complex elements. They don't think about sociology, they don't think about the history, etc. So if they speak about something out of their own specialties then they are at a lost. So I think their level of understanding of sociology or history, etc. is very limited. Quite

paradoxically, Japanese scientists cannot be considered as "intelligentsia" in a traditional sense.

FULLER: Let me respond to that. I think it's a mistake to think that scientists in Europe or America actually know all that much about history or philosophy and so forth either. But what they do see is a change in the social conditions for the support of science and technology; that there are questions being asked now that perhaps were not asked before; and certain kind of skepticism, distrust, whatever, being expressed that wasn't expressed before; and see science and technology studies in a way as legitimating that kind of doubt about science and technology. So that even if these guys don't understand what we're writing about, they understand the social conditions that make our writing somewhat prominent. In a sense they can respond at that level. They see it as a symptom, an intellectual version of a larger problem that exists in the society with regard to the legitimation of the natural sciences in our time. And you know, with the Europe and America, it's the post-Cold War thing: The whole idea of state funding for science, which was taken for granted in the past, is now being devolved because there is no longer such a great concern for national security kind. (Though this may change in light of 11 September 2001.) It's worth pointing out, if you don't know, that at the height of the Cold War, in both Europe and America thirty (30) percent of all science funding was from defense sources. Most of that has been liquidated at the end of the Cold War. That is why there is now a greater turn to the private sector. This immediately causes the issue of why fund science? What's the value for money? You see, 'national security' answers that question because we all have to survive in the same country. We're all worried about the Russians or whatever it was back then, and so we're all willing to allow this money to be spent. But once that common threat is no longer there, particular constituencies will want to have more specific kinds of answers. What's in it for me? Why support this science? And this has resulted generally in a decline in physics funding which was the big beneficiary of state-based funding, and the general shift towards medical sciences but in a more diffuse funding environment where there are more players, more constituencies. So there is more money but it is also more diffuse and there are more complicated questions of accountability. It's in that kind of environment that science and technology studies flourishes because science and technology studies says that science is a very complex thing. It means different things to different people. There isn't just one science. There are many sciences, many rationalities, and immediately that causes, especially traditional scientists, real concern. They don't need to understand any of our theories to feel this. We're sort of an intellectual symptom of the Cold War meltdown of government science policy. I think that's fair to say actually. I think that's fair to say if you look at the conditions under which science and technology studies has flourished. It certainly has taken advantage of this kind of change in the way in which science is being understood.

KANAMORI: That is the direction in which Japanese scientists should view this science and technology studies. Perhaps Japanese scientists have very strong social prestige so not many are accustomed to being objectified by some external point of view. I am talking of a different thing because what you said about science and technology studies in Japan is quite a positive thing. But I think that, as you said, the actual state of science and technology studies is really in a critical stage, including Japanese researchers and in the United States also. They have no main trend. Or perhaps, at least in Japan, they are divided principally into two main trends. One is a very technocratic innovation studies which are perhaps in vogue in European science studies context. And the other one is close to what is called the cultural studies or the post-colonial science studies. So there are many differences in the points of view and differences in critical position. They work together. That's true. But there are much

discordant between these two kinds of trends. And perhaps even inside the science and technology studies, these two main trends do not know which is the essential merit on one side and which is the defect on the other side.

FULLER: I agree. I think we certainly do see that kind of thing in the Western countries as well. In a way, a lot has to do with the source of funding. I hate to be kind of a Marxist about everything but there is a sense of political economy which really drives a lot of this story. You know, where is the money coming from for this stuff? It's quite clear that when science and technology studies is driven primarily by academic funding through the state, where you don't have to actually compete in an open marketplace, cultural studies tend to flourish under those circumstances. It tends to be a much more humanistic discipline. But of course, where you have to compete for grants, on the other hand, in an open market where you have a lot of competitors, let's say, economists, people in business schools and stuff of that kind, then of course science studies will tend to be technocratic because the market drives you in that direction. And you see both kinds of things happening. Britain is very interesting in this respect because it is very clearly pulled in both directions at once. The technocratic side is largely the European pull. The continental European pull is toward the technocratic. The European Union is very keen on science and technology studies as part of European science policy, which is very much into strategic research initiatives where you target areas, you try to make things happen in certain areas very deliberately. But there is still a very strong humanistic academic tradition in Britain and that's where the cultural studies side flourishes in science studies, with women studies, post-colonial studies, things of that kind. You could see that very often in the same campus – Lancaster University is a good example, because on the one hand you have a lot of this more cultural studies stuff taking place. For example, actor network theory in Britain is largely a cultural studies thing, whereas in France it's mostly a technocratic thing. The more technocratic stuff in Britain at Lancaster is actually the environment thing. Brian Wynne, the Center for the Study of Environmental Change, gets all the big money, and you get all these contract researchers working there. Yet this doesn't add up to a field. Lancaster is the place that probably has the largest Ph.D. program in science and technology studies in Britain and the reason they have the largest program is because the technocratic side supports Ph.D.'s as contract researchers on large government projects where the interest is usually in bringing state and industry closer together. That's what enabling science and technology studies to reproduce to a younger generation but it doesn't guarantee what kind of department you're going to have. It just says we're going to have this people with Ph.D.'s in science and technology studies who are funded by the state for this kind of technocratic work. But what would they do after they finish their contracts? It doesn't guarantee that there are departments or any particular future. It's all very short term. So while it's flourishing, it's flourishing on a kind of very short term basis.

KANAMORI: As far as these two main trends, this technocratic and this cultural critic trend, remain and coexist in Japan, I would say that that it is good. But I am anxious, as you said, that if the power of funding is greater on one side, on the technocratic side in this case, because it is this technocratic side will be closer to the state decision with many money, many funds, etc., this kind of technocratic side will become bigger and bigger at the expense of the other trend.

FULLER: And I tell you, it's a real problem. For a very important reason, it has to do with the nature of how science and technology studies work. Well, if you know anything about science and technology studies, you know that there is a tendency in this field to be kind of relativistic, post-modernistic. That is the general flavor of the things that people say in this field. When that is combined with the technocratic orientation then what you end up training people who

can basically justify anything because in a sense the post-modern turn makes you open to anything. So whatever decisions are made on political grounds can end up getting justified. You see a version of this with some of the stuff in medical ethics actually. One of the big complaints that arises over having a medical ethics specialist in hospitals, especially a sophisticated ethicist, is that he can basically justify any decision doctors and administrators have got to take, because there is always a reason out there. There is always a context that you can invoke to justify whatever you decide to do, and all you need is to have one of these guys on your staff. In ancient Greece, you had the Sophists. You would pay them, and they would give you whatever argument you wanted. Well, science and technology studies is very much like this. And the problem is, if the field is not independent then it's really, you might say, an 'ideological wild card'. It can justify anything. And it has been used to justify anything.

SOCIAL EPISTEMOLOGY AND NORMATIVENESS

KURIHARA: Many of the persons in the area of science studies seem to have a view point of relativism. But your viewpoint expressed in your book "Social Epistemology" seems to be different.
FULLER: Yes, I'm different.
KURIHARA: Your viewpoint seems to have some normativeness to help in decision-making, isn't it?
FULLER: Okay. Let me give you a little background to this because in a sense, this is where I enter the picture. I'm somewhat younger than most of the people who are major figures in the science studies field. For the people of that older generation -- and when I say older, I really mean people who are in their 50s or at most in their early 60s, because the field is still relatively young. Most of those people, and I would include everyone ranging from the Edinburgh School (David Bloor, Barry Barnes), as well as people like Bruno Latour and Steve Woolgar, who are somewhat younger. The radical gesture made by all of these people was to oppose certain philosophical notions of science that functioned as a kind of dominant ideology for scientists and also for the society at large as a means of thinking about science. So all this stuff about objectivism and rationalism and realism was the enemy originally. They were the things that science and technology studies, in a sense, deconstructed. And the way that they deconstructed was pretty straightforward, namely, they looked empirically at the history and the actual practice of scientists and said "Look, what scientists actually do does not live up to these philosophical standards." In other words, a very straightforward negative argument. This was a very powerful argument, of course, because in a sense it was sort of applying science to itself. In a sense, it was like going into the lab and observing. As if it were using a kind of version of the scientific method on science itself and basically saying that scientists were self-mystified, mainly because they listen to philosophers rather than paying attention to what they were doing. And this is the whole idea of science as practiced. That was one of the big buzzwords "practice" throughout the 80s and 90s. So that was the sense in which science and technology studies was very critical of certain views about science. Now, this was a double-edge sword, this kind of critique. Because on the one hand, it certainly demystified science. But when you demystified science you immediately made it very ordinary. So you can then start to wonder, "Well, okay, if science is just the stuff these people do, why are we funding it?" In other words, you start to ask the kinds of questions you would ask of ordinary social activities. What's the cost versus the benefit? Why are we spending all this money? Are we getting what we want? Here, science and technology studies people say, what happens in

the lab often has nothing to do with what happens outside the lab. So how do we judge the consequences of drugs or whatever they are developing in the lab? All these questions suddenly get opened up. Of course in a period when people are looking for excuses to cut funding, science and technology studies is incredibly useful, because it immediately makes you question things. And that's in fact where the problem starts. When it gets combined with the technocratic approach, science and technology studies is deadly to science, because if nothing else, the traditional philosophical approach protected science from that kind of scrutiny. But science and technology studies seems to say, "The emperor has no clothes". And that's the problem. That is how I enter the story. I learned about science studies as a graduate student, about maybe 15 – 20 years ago. At that point, as someone who's training philosophy of science, I say, "Okay, that's a good opening move to demystify science but now what's the positive story? Are there new norms to science? What are we talking about here? The interesting thing, of course, is that science and technology studies, generally speaking, does not have a normative perspective. Part of this is, I think, the post-modern aspect of science and technology studies. No grand narratives. There are no general stories to be told. It isn't that some general stories are wrong and some other ones are right. It's rather that master narratives are just wrong in general. This seems to me quite a dangerous and maybe even irresponsible move, once it is out there in the public, because there's a sense in which, like it or not, no matter how specialized or professionalized we think of ourselves, our stuff is out there in the public. The science wars are there because people are reading this stuff and they are putting it together with other things they're doing. It seems to me that at that point, if not earlier, we certainly have a responsibility to involve ourselves in this discussion about where science should go from here. For me, the issue is not whether science and technology studies is right or wrong. I pretty much take it for granted that, yes, the demystified picture of science is correct as an empirical picture. The question though is normatively, what do you do with that picture? This is how I think the normative question has to be asked. And I give scientists credit for seeing this. However much I disagree with particular things members of the scientific community say about science and technology studies, the one thing they should be given credit for is realizing that there is a serious normative question here, and it just can't be thrown out or ignored. And the problem is that the people in our community tend to think, "Well sorry, it's not my responsibility. I'm just the bearer of bad news. I'm not responsible for solving the problem." I think that that is really unfortunate. So then the question becomes, okay, normatively what will you do? Well, I think that if you have a science and technology studies perspective, there are a couple of things that are important normatively. One is whatever norms you propose, they have to start from the position of where science is at the moment. It doesn't make sense to say, "Oh, we want perfect rational science. We want perfect models of truth," because that's not going to happen. So there is a sense in which those old notions do have to be put aside, and you have to start from where we are. But then the question is, how do you conceptualize the normative? Well, for me the answer has to do with the kinds of institutions that you design for making decisions about science policy, and science policy has two components. It has a research component obviously, what kind of research ought to be done, but it also has an education component as well. That part of the normative force of science is basically, what is it that people need to know about science, and how should that sort of general curriculum for science be set. Not just curriculum for people training to be scientists, but the people who aren't going to be scientists but who you want to have involved in decision making about science. So there is a sense in which normative questions have to operate at least on these two levels at once. So obviously things like universities are going to be very important as the places where these kinds of normative issues get raised. Once you

get to that point, then there are some decisions to be made about how do you actually constitute these institutions. For example, like a lot of people, I generally believe in the democratization of science.

KURIHARA: Are there any essential philosophical backgrounds you extract from the past days philosophers?

FULLER: Yes. I think that in a sense, the relevant kind philosophy actually comes out more from political philosophy than from traditional epistemology. I mean one of the reasons why I call this 'social epistemology', as opposed to just epistemology, is because I think traditionally the theory of knowledge has been very exclusively focused on individuals. This is especially true, I might add, in the Anglo-American tradition, much more so than in the Continental European tradition. A distinction needs to be made here. In the Anglo-American philosophy, normative issues about the nature of knowledge tend to be discussed quite independently of issues about how to organize society. So politics, ethics, legal philosophy, the people who do these kinds of things in the Anglo-American world, are quite different from the people who do epistemology and philosophy of science.

KURIHARA: Okay, I think Prof. Kanamori has a different standpoint.

KANAMORI: No, no. It's almost the same.

KURIHARA: But you used to study epistemology in France.

FULLER: Oh, but that's different. Continental epistemology is different, that's my point.

KURIHARA: Why did you change your standpoint?

KANAMORI: All right, I tell you. Of course the domain on which I studied during quite a long time is totally different from the works to which Dr.Fuller referred.

KURIHARA: Could you explain the process.

KANAMORI: You know, because as he said, knowledge cannot be constituted by just one or two persons. In Japan unfortunately I work almost 15 years as a specialist in French epistemology. During those 15 years I tried to find other Japanese with whom I can discuss specifically about French epistemology but I only found one or two or three persons. For fifteen years. So I said to myself after 15 years, I cannot continue like this, because knowledge cannot be constituted only by me or by only two or three persons. So I gave up. And in France also, French epistemology is already rather weak tradition. Of course even today, there are some good researchers but there are no more young researchers anymore. So many young researchers now have different orientation already. Beside that, as I have said, my friends in science and technology studies in Japan, are almost exclusively working in the other trend, not French, but the other side such as STS, social philosophy, etc. So I gave up. Totally give up.

MEDICAL SCIENCE AND SCIENCE STUDIES

KURIHARA: Okay. I'd like to ask you how is the situation or interaction of medical science and science studies in Japan.

KANAMORI: I think there were some good researchers who had philosophical formation but who decided to study medicine when they were already 20 or 30 years old. They felt a philosophical necessity to study almost professionally medical sciences, in order to continue their philosophical works. I would say that this tradition is almost equivalent with that of French philosophers such as Goerges Canguilhem or François Dagognet to name but a few. In effect, actually, there is a general course in the university on philosophy of medicine. We have this tradition. But because of the fact that medicine and philosophy are two very different kinds of knowledge and since these two have strong traditions, if you study specifically one

tradition you need 30 years, 40 years. So not many persons can study both medicine and philosophy, especially since the second half of 20th century, the era of outstanding expansion of medical knowledge. So I think that even in France there are already not so many persons like Canguilhem.

FULLER: Well, in America there really has never been anyone like Canguilhem. You see, in America, and this is also true in Britain, if you want to talk about philosophy of medicine, immediately it's ethics. It's not about epistemology. And it's very much in the context of making decisions about particular cases. That's why the bioethics thing has become such a very big deal in the Anglo-American world. But there has never been a general philosophy of medicine of the kind of Canguilhem initiated. In a sense, it's indicative of the problem that we've been speaking of, because the interesting thing about Canguilhem is that his was a very comprehensive philosophy of medicine. He problematized the normal-pathological distinction, whereas in the Anglo-American world, this would be broken down into different issues. Bioethicists unproblematically make decisions about what's normal and pathological, while a philosopher of biology who would look at, say, the conceptual foundations of biomedical science and not consider the normative aspects of that. So in the Anglo-American world, these two things will be treated as quite separate, while someone like Canguilhem would treat them as part of the same philosophical system.

KANAMORI: There is one thing I would like to add. I read last year a book on philosophy of medicine written by a French and this person was a good doctor. But when he was 40 or 45 years old, the state made a decision to make him study the epistemology of medicine. So he began to systematically study the epistemology and history of medicine. This style serves to maintain the good tradition of philosophy of medicine in France. We don't have this.

FULLER: Well, that's very interesting. I mean, that would be the way to do it, wouldn't it?

KURIHARA: So could you explain the necessity of learning social epistemology for medical doctors especially those involved in clinical trials or clinical research?

FULLER: Well, I think what social epistemology primarily brings to any understanding of science is a kind of standpoint. This is a very live issue in medicine, from what standpoint does one set the norms. Obviously one could set the norms from the standpoint of what's best for science, if you want to produce the most reliable valid scientific knowledge regardless of the people that you're dealing with. There's going to be one kind of answer, then. Or you could look at it exclusively from the standpoint of the subjects and be extremely concerned about them and basically orient your science entirely to that. Well, social epistemology, in a way, is a little different, because both of those groups, you might say, are 'stakeholders'. That's the term that's get used. Stakeholder groups have already a well-defined interest in the actual activity. Now there's nothing wrong with that, but if you want to come up with a kind of comprehensive perspective, what the social epistemologist does is basically operate from the standpoint of a sort of interested non-stakeholder. I think that that kind of perspective is really quite important, especially with things involving medicine. You may be today functioning as a scientist but tomorrow you may be a subject or you may be the beneficiary of some kind of drug or treatment that was the result of some kind of clinical trial. So there is a sense in which the normative perspective has to be sufficiently general to enable you to accept what happens under all of those possible descriptions that you yourself might fall under. Now, part of my way of thinking about this is a bit influenced by John Rawls' *A Theory of Justice* – his famous book. Rawls has this idea that if you want to set the principles of justice you have to adopt a certain standpoint which he calls the 'original position'. The original position means that you are basically trying to design the principles for a just society but you don't know where you're going to be in that society. You don't know whether you're

rich or poor, healthy or ill, but nevertheless you want to define principles that would cover regardless.

KANAMORI: Veil of ignorance.

FULLER: Yes, the veil of ignorance. What you're ignorant of is your specific place. You're not ignorant of the general positions that there are in society. So you'd be told, for example, that there are going to be these different characteristics and they have these different interests. You just don't know which ones are yours. So then the question becomes, how do you define the principles of justice under those circumstances. Now, social epistemology adopts that kind of viewpoint. In the case of health policy, we see what are the relevant groups in the construction of medical knowledge: There'll be the scientists interests, there'll be the interests of the people who, let's say, would most directly benefit from some kind of treatment or drug, the people who would be the subjects in experiments, and so forth. All of these are different interests. But you have to operate from the assumption that you don't know in which groups you're going to be, and in part that's because you could be in any one of them over the course of your lifetime. That assumption then becomes the standpoint that you want to adopt when you're setting the norms. What that does is to distance you a bit from actually adopting any particular interest. I stress this because I think we can all agree, more or less, that we want to somehow democratize science, make it more accountable democratically. The problem, however, is that when people put this into practice, the tendency is to reduce it down to stakeholders. So, basically the people who are most clearly identified as having a stake in whatever you're talking about turn out to be the people who exercise the most power in the discussion. This is unfortunate because it's not really democratic, because it doesn't take into account the full range of social interests, many of which will not have a clear stand on a particular issue but who may nevertheless be affected in the long run. Especially if you're talking things like disease, it's not just the people who have it now: One needs to be concerned with those who'll have it in the future. There are all kinds of issues here. I say this in part because the idea of getting stakeholders involved in decisions having to do with biomedical knowledge is very popular now in Germany. In fact, they actually have a National Ethics Advisory Board which brings together, or makes a point of setting up a panel that brings together, stakeholders. So, as it were, the major interest groups decide amongst themselves what will and will not be allowed. Now, I can understand that, in a sense: It's a certain kind of democracy but it's based entirely on the idea that the only people who should be involved are the ones who already have clearly defined interests. But that is going to be always a minority of the population, a very vocal minority. No doubt a very informed minority, but still a minority. So I'd like to move away from that model. One of the things I've been promoting in contrast has been 'consensus conferences.' I am very big on that because in a consensus conference you basically have a clear separation between the stakeholders who function as witnesses -- they're giving testimony – and the people who make the decision, who are like the jurors in a trial. That is, they are ordinary members of the public who do not have vested, well-defined interests. I think that's the way to set the situation up. You see, a social epistemologist, at the end of the day, is interested in the design of the institution more than the actual outcome. So I am not going to tell you whether clinical trials should always be used and all that. What I'm more interested in is the institutional arrangement by which such a decision gets made. In that sense, the issue of the standpoint and the perspective becomes important, and I think that something like consensus conferences that keeps the stakeholders in the position of witnesses is much preferable to just having the stakeholders decide amongst themselves, which is way in which things are going in Germany.

CONSENSUS CONFERENCE AND SOME STRATEGIES

KURIHARA: In the case of Japan, recently, there is some movement that is becoming more popular - to hold some ethics committees, or institutional review board, or advisory committees and sometimes making the public participate in it. But one problem is, these kinds of members are called by authorities, but never called by the public. I observed the Consensus Conference on genetic research experimentally held in Tokyo in 2001. There seemed no strategy or method how they select the members of "public panel", so what they could do seemed to be only trying to understand "what is genetic research". One of the members of "specialist panel", who are engaged in the issue of eugenics and said "I should be a member of public panel, because I have learned with some specialty but stand point is from public". Moreover, Some ethicist engaged in developing guideline of genetic research said that ethicist who has negative opinion against genetic research seemed to be excluded from the "specialist panel". She also said that during developing the guideline, negative or strict opinions against research couldn't be accepted, and staff of regulatory authority proceeded to draft up the guideline without considering such strict opinions. This is the problem in Japan. Would you have some strategy to solve this problem?

FULLER: Well, I'll give you a kind of strategic solution, and I think actually people in this country might be well placed to do it. I noticed that members of the science and technology studies community have organized consensus conferences in this country. That is actually quite unique. I mean there are consensus conferences all over the world. Twenty-five countries have had them. But Japan is the country where the science and technology studies community has actually been actively involved in organizing them. Now what I would suggest in this respect is that members of the science and technology studies community here basically make the argument that there is a kind of expertise that one needs to have to assemble these kinds of boards and bodies; that you just can't leave it to government to just choose people because they're famous or important or they're well known to represent certain groups. That is not an appropriate way of doing it. There is no principle behind that. In fact, one needs to actually know how to organize these things, how to select these things and it involves a kind of expertise. And in a sense, the science and technology studies community, because it's been involved in the design of consensus conferences, has a kind of expertise in institutional design of this kind, and so therefore should be consulted to organize these boards. I think the big problem, at the moment, is that politicians often think they just know how to do it. You know, just get the important people, get the representatives, just bring them together. I mean this happens in Britain and America as well, of course, all the time, so-called blue ribbon panels where you get the great and the good -- I mean, you kind of see why they're there. It's not that arbitrary, but in a way, it's all too predictable. That's the problem. It shows no respect for the idea that there needs to be specific institutions if you actually want to get democratic accountability in science and technology matters. In Britain, we have a specific version of this problem, which you may run across at some point. I don't think you have it yet: The politicians take on board the idea of consensus conference because they supposedly want to broaden participation. But then they basically have so many different consultation procedures beside consensus conferences that in fact none of them count for anything. So the government can end up doing whatever it wants. You see what I mean. So the idea here is instead of having one body that specifically design to set that policy, you say, okay, we're going to have hundreds of bodies or ten different bodies, all of them with public involvement: Some through the internet. Some through consensus conferences. Some through public opinion polling. Some through special panels. And they all come up with

different ideas. That's the big problem. When they come up with different ideas, then the government can pick whichever they want. It's almost as if you had no consultation at all because nothing is binding. That's the problem you face at the other end, when you open up decision-making democratically. You call lots of people. But you have no procedure for resolving the discussion.

KURIHARA: In Britain and in U.S. are there any special strategies to educate the patients and subjects to participate in clinical trials or clinical research.

FULLER: Well, that's the problem. There is no formal education. No.

KURIHARA: Do you make use of the consensus conference?

FULLER: Yes, sometimes. You see, a lot of consensus conferences have been done. The big problem is they're usually done in the spirit of experiments. In other words, you do them to show, as a kind of intellectual proof, that indeed ordinary members of the public can make intelligent decisions about complex matters relating to medicine, technology or science. But that's where it ends. Again this is where institutional design is crucial. Unless consensus conferences are made an integral part of the policy process, where their results are actually fed into something that makes a decision, these experiments are idle. You see, consensus conference always work. They always come up with good decisions, in the sense of being responsible, and serious and so forth. The problem is they're not binding on anything. They're just experiments. They're just sitting there and you can do whatever you want with them. The thing is to make them binding, and the only country where they're binding is Denmark. In Denmark, there is this procedure: The parliament says, okay, we've got to make some decisions about what kind of biomedical research are we going to allow in this country. Denmark is a very interesting country. It's a country with a very sophisticated scientific base but also a small country. And so it can't expect to compete on every front. So it wants to be strategic in what it does. But at the same time there is also an enormous amount of public accountability for science already in the country. This immediately creates an interesting kind of decision-making environment. So the issues are -- where do you specialize, and in a way that's publicly approvable? The parliament says, we're going to discuss this matter. For example, they recently were discussing the issue of these transgenic crops that are resistant to herbicides. Big issue in Germany. Danish were considering this, too. So they say, we're going to have a vote in parliament about this in the next two or three months. In the interim, we're going to convene some consensus conferences, which will then write up reports that will then feed into the legislature. And the function of the consensus conferences, you might say, is to establish the framework within which the legislation is made. So the consensus conference doesn't actually tell the legislators 'Make this law.' It's not like that. But rather it's more like a second order thing, namely, what kinds of issues need to be incorporated in any piece of legislation. You have to make sure that this is taken into account, that's taken into account, this other thing is taken into account. That's what your legislation should have incorporated into it. So it's very much like setting up a constitutional framework within which the laws can be made. That works well. The thing that is really interesting about the Danish situation, which again I think is very important is, that the people participating in consensus conferences actually write up the guidelines. Because in Britain and in America, and Germany too, very often in order to save time and money, the consensus conference results are written up by somebody else. So it gets put into some kind of a neat package and then delivered to policymakers. But in Denmark the point is that, the people in the conference actually draft the guidelines so you actually see the way they are thinking about it. You get to see their language. You get to see how they're framing the categories. And that's really important, it seems to me, for this thing to work. So that would be the way to do it.

You've got to integrate it into the policy process. All these experiments also show that the people involved can learn the amount of science that they need to learn to make these judgments. They listen to the witnesses. They are able to ask questions. And so the kind of technical knowledge that you might need for these things is not hard. You know, you can learn this over the 3-4 weekends of the conference. So I think the issue is just getting it institutionalized. The problem isn't with what people know or anything like that. Rather, the problem, I think, is with politicians -- having the politicians trust the consensus conference process. That's the main problem.

TEI: So you think the case in Denmark is the best so far.

FULLER: It's the only country where that has been institutionalized and it works. But in other countries where they've been tried they've been successful in terms of the results produced. It's just that they don't go anywhere after that. They're just experiments.

HIRAI: In case of Denmark, how do they choose the members of the conference?

FULLER: Well, it's a bit like jury selection, in that people really need to be willing to get on top of things, because a consensus conference isn't easy. It's not just sitting there and waiting for things to happen. You actually have to listen. And so there is the tendency for certain kinds of people -- high school teachers, you know, people of that kind -- to be naturals for this kind of activity. The consensus conference organizers must also check to make sure a prospective juror is not already a member of one of the relevant interest groups, because it's really important that you're relatively neutral to the discussion, in the sense that you are willing to change your mind, in principle, in light of evidence. So just like in a jury, if you have a view that you're not going to change, you get dismissed from the jury. You're not allowed to participate in the jury if you are already coming with very, very strong views. Now Denmark has certain advantages, which are in a way kind of obvious, namely, highly educated population. So you're not struggling really to get people to serve on these things. Also, at least until recently, Denmark has been a relatively homogeneous country. This matters because one issue that does arise with consensus conferences is whether there are enough different sorts of people participating. Do they represent the public generally? Not necessarily in terms of the issue being discussed, but just in terms of the general population. Enough men, enough women, old, young, that kind of thing. That has been an issue raised in Britain about consensus conferences. But in Denmark, that doesn't seem to be a problem. And as I said before, it's institutionalized. They have websites where you can see the results that the consensus conferences come up with. The other thing about consensus conferences is, I think, very important -- and this is why it needs to be put as part of a legislative package -- is they have got to be seen to be reversible. I think, one of the things that people are afraid of with consensus conferences is that whatever decision the consensus conference comes up with will just become fact and it will never change. That's why you need to normalize it. It can't be just seen as kind of special one-off event that's going to decide everything forever. But rather it has to be normalized into the ordinary legislative process so just as laws get changed over time, this gets changed too. By the way, to me, the reversibility of decisions is the key to democracy because you're never going to get everybody's views represented at any given time. But what you can hope for is that bad decisions get reversed over time once you see the consequences. In that sense, democracy is ideally an exercise in collective learning.

KANAMORI: You mentioned that even a layperson who participates in a consensus conference can quite understand the contents or the special scientific knowledge. Do you think that we can say the same thing in the relationship between the doctor and patient because medical knowledge is one of the most specialized knowledge in science?

FULLER: Okay. The issue here has to do with the context in which people have to present their knowledge. I mean the problem with an ordinary doctor-patient relationship is usually the doctor's authority is so taken for granted that the doctor doesn't need to try to persuade the patient. The doctor is under no special burden because there's a sense in which the doctor thinks, "I'm the doctor. I know what's right for you. I'm just going to tell you and you're going to listen and it doesn't matter whether you understand." But you see, the consensus conference is different because if you're a witness in a consensus conference presenting your case, let's say a doctor speaking for the medical profession, you will know there will be other people presenting cases opposed to yours, and so you have to make a persuasive argument. You have to get your point across clearly, and in a way that the ordinary member of the public can relate to. That means you have to open yourself up to questions. That means you have to be able to take the public's position to understand how they think about things in a way that you don't normally do in a doctor-patient interaction. So the consensus conference creates a more competitive epistemological space where you really have to get your point across because your authority is not being taken for granted.

EBM AND PUS

SAIO: Do you know CASP – Critical Appraisal Skills Program? That came from Oxford University. SAIO This is one program to learn EBM, where patients or the public can take part in. There is another program, named DISCERN, developed with NHS subsidy. This is an assessment tool for patients to evaluate credibility of medical information by themselves.: I think that such kind of program can be made use of also as tool to educate the public.
FULLER: Yes. I think that's right. But I think that if we're talking about more systemic decisions about research policy and things, then you're going to need something like a consensus conference arrangement. But I agree with that in terms of individual patient-doctor interaction.
SAIO: One of the aims of CASP program is to educate patients how to read medical papers. But I wonder if such skills for ordinary people to read professional papers is necessary or not. Because medical knowledge would be easily misunderstood.
FULLER: Well, that's an interesting point. I think that if you're talking about real medical research papers, I don't think that developing such expert skills is necessary. In fact, it seems to me that it could be misleading in a way because medical research will tell you what actually got accomplished in certain clinical trials and laboratory experiments, but that those results don't necessarily say how the knowledge relates to your own case. And so there is a sense in which one can have a kind of false sense of understanding. Because the real crucial problem is how exactly do you extrapolate from medical research papers to specific patient cases. I mean you can understand a medical research article perfectly well but still it doesn't necessarily specify what should be done in your case.
SAIO: In Britain and U.S. there are also several kinds of months or years courses for consumers to learn how to read medical papers. Other examples are that consumers take part in such activities as Cochrane Collaboration where they participate in systematic review of reports of randomized controlled clinical trials, or development of Clinical Practice Guidelines. Such activities are useful to get consensus including consumer not only medical specialists. It may help education for lay-person to grow up to lay-experts.
FULLER: Maybe so, but I wonder exactly how valuable that would turn out to be. I mean, I could see how such training would make one more comfortable with medical knowledge – in which case they may become less critical, in a way. But I don't see how that actually helps the

patient understand whether a particular treatment is relevant to their case because one has to know the details of their specific case.
HIRAI: You mean those courses are for patients?
FULLER/OTHERS: Yes, to learn how to read medical articles.
FULLER: I just don't know how helpful that is. I mean a lot depends on what the motivation is for doing this. If part of the motivation is to make laypeople more comfortable with medical knowledge so they're not so critical then it probably will succeed. (So it perhaps serves good public relations for the medical profession!) But whether it actually helps laypeople understand what's relevant to their particular case, I don't think so.
SAIO: That would be a problem of external validity or generalization. This problem often arises during educational programs such like CASP. The patients who learned how to read medical literatures feel they get more comfortable to medical literature, but also feel they cannot ascertain how those skills working for their own cases. On the other hand, in some diseases like diabetes mellitus, patients want to obtain special knowledge of the disease, and then success to obtain it with information technology, for example through internet. I suppose problems of patient oneself evoke more motivation in learning medical knowledge than memorizing medical information as medical students do.
HIRAI: It is very natural for patients to know the progressive results of their disease.
FULLER: I see. So you're imagining that people are kind of relating what they're reading to how they're responding to treatment. Is that the idea?
(Laughs. no audible answer)
FULLER: Maybe, I don't know. It's interesting. I don't know.
KANAMORI: Well, if for example one lay person is unfortunately happening to suffer from a disease of the kidney, this person becomes interested in the study in kidney disease and makes research privately and exclusively on this question. But in this case, because this person is not a doctor, and is not interested in disease in general sense, he voluntarily ignores all the other information on human body. In this sense, one lay person doesn't have to study about general medicine theoretically, but only understand the specific need of specific condition. Do you agree with this kind of thinking?
FULLER: Well, I think it is possible for lay people to understand what they need to understand about their own kidney disorder without learning general medicine. That's correct. I think there's a question of how they actually come to understand that. What's the best way for them to understand it? I don't know if reading the medical articles is necessarily the best way to understand.
SAIO: Don't you see some kind of possibility to relate between specialized knowledge and lay person, some kind of social epistemology in medicine to translate the specialized knowledge to lay person?
FULLER: Sure, that could well happen. In a sense, a consensus conference could bring that about through interrogation, where the lay person starts to ask the specialist specific things and then the knowledge gets formed in the process. Yes.
KURIHARA: So I think consensus conference comes from social science studies and EBM seminor, CASP, DISCERN, and consumers' participation in Cochran Collaboration or developing Clinical Practice Guideline, such things comes from medical area. I think the best way is to conjecture this kind of strategy.
FULLER: Oh yes, that's right. I think that would be fine.

KNOWLEDGE MANAGEMENT FOR DRUG DEVELOPEMENT

KURIHARA: I would like to ask some questions about knowledge management for drug development. Which kinds of companies are making use of knowledge management system in producing drugs in Europe?
FULLER: Glaxo, the major ones.
KURIHARA: There are many companies?
FULLER: Oh, yes.
TEI: Aventis?
FULLER: Yes.
KURIHARA: Pfizer?
FULLER: Yes. In fact, I would say pharmaceutical industry is the prime example of a knowledge management industry. That's why I mentioned in my written response to you that there's even a master's program in Pharmaceutical Information Management.
KURIHARA: Yes, I would like to ask you in detail about that?
FULLER: Yes, that indicates just how widespread the knowledge management mentality is in drugs companies.
KURIHARA: Could you explain more in detail about this Master of Science program. For the regulatory authorities there is the proactive case strategies. Is that for regulatory authorities? You wrote it here. You said that M.S. program and there is some proactive case strategies to serve the public interest.
FULLER: Actually I am saying something different here. The M.Sc. program is administered at the City University of London -- by the way, the City University of London is primarily a business school. That's the first thing to keep in mind about it. It's located in "The City," which is the financial district. If you go to the website for the M.Sc. program, it's clear that it is a kind of a library science program where basically you learn how to go through the scientific literature and be able it to read in a way that enables you to find new biochemical ideas that could be used for drugs that haven't been exploited yet. That's basically what you do. You learn how to "mine the literature." The reason why this is such a valuable degree is because potentially it could actually save a lot of money in R and D expenses by the pharmaceutical firms. So instead of having their own scientists come up with stuff, they could see whether it has already been done in the scientific literature. That's knowledge management. In other words, it's trying to save money on the production of knowledge, on the assumption that the new knowledge will actually give them a competitive advantage in the marketplace. The reason I stress this point is because a lot of people seem to think that knowledge management is pro-knowledge. In other words, that it's a kind of orientation that in a way wants to produce more knowledge. But no, I don't think that's the case at all. I think rather what "KM" wants to do is to exploit knowledge and the more cheaply you can exploit it, the better. Sometimes you have to do your own research but much of the time the research has already been done, but it's been done in a university lab and so the industry doesn't know about it. And that's why you hire these guys with the M.Sc. in Pharmaceutical Information Management, to discover the hidden knowledge. So, it's part of a general business strategy where you come up with the cheapest way of bringing drugs to market, and one of the ways you do that is by finding out what knowledge have already been discovered. So I don't see the knowledge management stuff as really anything more than just management by other means. Only now, instead of looking for cheap labor, instead of looking for cheap raw materials, you look for cheap knowledge and that's why you read the scientific literature -- because it's got knowledge that's already been done and so you don't have to pay for it.
KURIHARA: So there are some specialized staffs in pharmaceutical companies dealing with knowledge management.

FULLER: Yes. There are often people who are called CKOs – Chief Knowledge Officers. They are the specialists doing this kind of thing.
KURIHARA: The economists are also taking part in here.
FULLER: There are economists in this but economists typically have a somewhat different attitude from people who are in knowledge management. In fact, my book *Knowledge Management Foundations* (Butterworth-Heinemann, 2002) talks a lot about this. Economists hold what you might call a traditional view about knowledge. They believe that knowledge is the thing that leads to progress. It's the most necessary part of production. It's also something that in a way is unpredictable. There is a sense in which knowledge can never be determined. In that way knowledge appears like a randomly distributed natural resource. It has that kind of character in economics literature. Knowledge management on the other hand takes this idea of knowledge as a natural resource but interprets it in a very, you might say, negative way -- a natural resource that shouldn't be allowed to run wild. So what you have out there is a jungle of knowledge. So part of what knowledge management does is to tame knowledge by basically going into the literature and finding all the nuggets from all of the stuff that the scientists write. Because scientists write in all of these incomprehensible jargons and they use all these theories and methods, it's often hard to figure out where the nuggets are that can be exploited from their arcane purposes. And that is why you need these people who have master's degrees because they can read the scientific literature and separate what is needed to bring the drugs to market and get rid of all that superfluous scientific stuff.
SAIO: Are there any difference between knowledge manager and librarian?
FULLER: Well, in this case not really except that it's a very strategically minded librarian. It's a librarian who is on a very specific search mission to find the kind of knowledge that can be used and exploited into products. But basically the kinds of skills we're talking about are those kinds of skills. It's just very strategically focused. That's right.
KURIHARA: So the cost-benefit analysis seems to be very important in knowledge management.
FULLER: Oh yes, that's important. In fact that is where knowledge management in a way revolutionizes our thinking about knowledge because we usually think of knowledge as something that's good in itself. In other words, you can never have too much of it. It's always good. Keep on producing it. And the only reason why we can't produce more of it is because we don't have the money or time to do it. But knowledge management basically holds the view that knowledge is necessary evil: The more necessary it is, the more evil it is. In other words, in principle you don't want too much knowledge, you just want just enough to make money. But you don't want so much that it ends up eating up all your profit because you're doing research on everything. So, if you look at what kinds of drugs end up getting developed, it isn't necessarily because they are the most useful drugs to have but rather because they are the drugs that are most competitive for the companies in the marketplace in which they happen to be. And that ends up driving the research.
KURIHARA: Does it work well to shorten the process of development?
FULLER: Only from the standpoint of the company. I think this is one of these things where it obviously serves the company's interest. But I'm not sure who else's interest it serves. You see, it's only if you think of patients as consumers that this looks attractive. In other words, we've got these consumers out there and they want the products as quickly as possible, and so we want to get the products through the system fast. That's the only context in which it would make sense for shortening the development process to be positive, it seems to me.

KURIHARA: In Japanese medical area, the cost-benefit analysis doesn't work well because there are few interactions between the economists and the medical scientists. So I would like to ask, what is the situation in Britain or U.S.?
FULLER: There is now beginning a discipline called "health economics" which actually is much more stronger in Britain than in the United States. But again, it's not really being developed in the context of new knowledge or drugs or anything of that sort, but rather it's in the context of hospital management. So economists are very much involved in managing the resources of hospitals.
SAIO: Some Japanese critiques told that EBM serves only for hospital administration or medical economics of the nation not for curing patients
FULLER: Right, exactly. Health economists tend to be a kind of business administrators for hospitals and so they haven't really gotten into this side of things. If anything, when economists talk about the production of knowledge, as I suggested earlier they still tend to look at it as a very basic research thing.
KURIHARA: Then, which kind of specialized person becomes the top of this knowledge management section, in case of pharmaceutical company? Is it pharmacist? Or doctor?
FULLER: Well, the people who would be involved in knowledge management in a pharmaceutical company would actually tend to be an information scientist.
KURIHARA: An information scientist.
FULLER: Yes, you know, like this librarian work, only of a very strategic, sophisticated kind. Sometimes these people are operations research, systems analysis people who have a kind of very big picture about the whole idea of what it takes to actually develop a drug and bring it to market and all that. You know, I mean, people who often would have a business school background and perhaps spent some time working for government.
SAIO: But I wonder, if knowledge manager works very well, they will develope some sort of database. When their development of database is completed, then they will lose their jobs
FULLER: Well, yes, there are several issues with this. One issue is, yes, there is a tendency to construct computer databases in knowledge management. That, you might say, is knowledge management's own product. But there is a problem with that for two reasons. Like you say, the knowledge managers disappear. This could happen for one of two reasons. One is their services aren't needed anymore. They are hired as consultants in a sense and once they do it, they're gone. They're finished with the contract. The other reason of course is, if they are really good they don't want to stick around with the company. They go somewhere else where they are being offered more money. Now, this latter aspect causes a big problem because one of the big, you might say, meta-problems of knowledge management is how do you deal with the products of knowledge management once a knowledge manager is gone. Who understands the database in your company? This is a serious problem. I mean if you look at a lot of the practical literature of knowledge management, the so-called -- KM gurus, that's what they are called in the trade -- it's often about that. It's often about this issue, namely, mainly how do you manage your databases after the guy you hired to put it together leaves. Because a lot of companies these days that have all these databases and they can't make sense of it, they feel that they're losing the knowledge that they've supposedly invested in. That becomes a real problem with knowledge management. Then you have this sort of second-order knowledge manager who basically tries to teach corporate executives how to codify your knowledge so that you can continue using it after your personnel has left. That's difficult. That is very difficult. But this is part of what the second order job of a knowledge manager is. But you see, at the bottom of all this is the very mobile labor force in knowledge-related industries. I think that a really very important part of the story of

knowledge management is that staff are no longer kept in the companies for very long, either because they are fired or because they voluntarily leave. Both reasons are possible. This is part of what keeps the problem going. In the knowledge management literature, there is sometimes an issue that gets raised called "corporate amnesia". The corporation forgets its identity, that kind of thing. Because the knowledge in corporations traditionally was grounded in certain people who would be around forever or for a long time (often because they belonged to the same family that owned the business), they would be the ones through whom everything went. But now that's lost. So the idea of a collective memory can easily disappear. Knowledge management, in a sense, partly aims to reconstruct the corporate memory or prevent it from completely disappearing as people disappear. But it is very difficult.

HIRAI: I wonder if knowledge management is only for corporations, how about in case of universities or non-profit organizations?

FULLER: Well, my own book on knowledge management deals mostly with universities because, in a sense, universities have what companies lack. In other words, universities are great at fighting corporate amnesia. If nothing else, universities have memory. That is a very important aspect of things. In fact, in Sweden -- I talk about this in my book -- there are executive Ph.D. programs being done through the Stockholm School of Economics that are designed to teach corporate managers high level academic skills -- not just librarian skills but actually how to do research, especially how to integrate traditional forms of knowledge with cutting-edge knowledge. The problem with corporate managers these days -- especially the ones in the knowledge intensive industries – is that they're too short-term oriented. For example, if they're reading a scientific article they are just looking for what they can exploit. They don't think about larger issues of what it says about the long-term theoretical developments in the field, about the methods that would be worth adopting, all that. These issues are what the universities are good at. The executive Ph.D. students learn these skills so that they can cultivate some kind of corporate memory on the model of what academics have. So it's not just enough to be able to read a scientific article, but you have to read it as an academic reads it. An academic is not just interested in the conclusion. He's not just interested in whether it shows if this treatment works or not. He's interested to know the background stuff, the theories, the methods. In a way, it's like in the stock market where there is this thing called the 'fundamentals'. There are lots of different ways to analyze the movement of stocks, and there are certain analysts in the market who are called 'fundamentalists'. They look at the long-term productivity of the company independent of its stock price. What kinds of things does this company produce? Does it have a long track record of doing this? So even if its stock is not too high, nevertheless it may have longevity because it's based on something solid. This is the way academics read research. So the idea with these executive Ph.D. courses is to actually teach corporate managers how to think in terms of fundamentals when they read scientific literature. I don't see evidence-based medicine dealing with this. Evidence-based medicine is very superficial, it seems to me, in terms of the way it treats scientific literature. It just looks for the conclusions. And that is a real problem. You need to actually train people more deeply. That is where universities, as knowledge institutions, are really strong. But you see, at the moment, knowledge managers ignore this. The reason why the executive Ph.D. programme was invented in Sweden is interesting. Partly it has to do with the fact that Sweden is a country that produces many more Ph.D.'s than it has jobs for in academia. So there is a surplus productivity of academically highly qualified people. And so as part of an experiment, the major multinationals – AstraZeneca, Ericsson, Volvo, all those Swedish multinational corporations, got together and said, "Well, you've got all these underemployed Ph.D.'s and we've got these corporate executive, and we're

really worrying about the future of the companies." As you may know, Sweden is a country where until quite recently most of the major companies were family-owned. It was still in the old 19th century model, family-owned corporations. Over the last decade or two, very quickly they've shifted into a much more American style/British style where the companies are no longer actually manufacturing their traditional products, but they're more like holding companies with portfolios investing in different things. This is causing a lot of anxiety because then basically the future of your company has nothing to do with what you're making. It has to do with what other companies are making. So there is a sense of insubstantiality to what's going on here. As a way to stop that tendency, the idea is to go back to fundamentals, to go back to what's solid, what's real. There academic knowledge production provides a model, since that's what we're always concerned about. As a result, we tend to be a bit slower and we're not so cutting-edge in the way that corporations want, but at the same time we're there for the distance; we're there for the long-term. This is the thing that corporations increasingly have to realize themselves. So they've tried this experiment. I've participated as a visiting lecturer on a couple of occasions. Now I have to tell you it's a mixed bag. There is a clash of cultures. I don't want to make it look like it's a complete success. There are problems. Academics and business people are still different people, and there are going to be some clashes, especially when it comes to actually writing up the Executive Ph.D. dissertation. What's the exact form that it takes? Think of how an academic Ph.D. has to look in order to get passed. However, corporations want a document that they can use easily. You start to get some conflict at the level of the outputs. But they're still committed, and I think it's a very instructive example, one that I'd recommend because I do think, if corporations are increasingly worrying about stabilizing their positions in the market -- to have some sense of their identity -- then these more traditional knowledge institutions like the university turn out to be very good models. I think that's a very positive thing. But it's against knowledge management wisdom. I should emphasize that. Knowledge managers hate universities. That's the other point. I've been giving you very positive stories about what goes on in Sweden. But knowledge managers routinely draw a distinction between the 'smart' and 'dumb' organizations. You've probably heard of this. The smart organization is a whole that is greater than the sum of the parts. So McDonald's is a smart organization because you've got a lot of idiot workers, but through managerial genius they are organized so as to produce eight billion hamburgers. That is a smart organization. A dumb organization, according to knowledge managers, is a university because it is a whole much less than the sum of the parts because you've got all these Ph.D.'s running around but what are they all up to? That's the way the knowledge manager looks at this. This has affected university policy quite a lot. For example, the current rector of Imperial College of London, which is Britain's MIT, is the former head of Glaxo. Now, what's going on there? That is scary. What he did Glaxo was to pioneer of the knowledge management mentality in the pharmaceutical industry, and now he is doing it at Imperial College. You know what they did, immediately as soon as he took over? They got rid of all the departments that were not high producers, and then they consolidated the strong ones and made it easier for intellectual property rights to be gained by members of the university. In the past, the university had a policy of being extremely proprietary. So if you patented something the university got the patent. Of course, for better or worse, that discouraged many scientists from wanting to get involved in any patentable research. So now you liberalize the policy. You allow individuals to take out patents within the university as long as they pay rent or some kind of fees to the university for doing their research there. That's what's happening now.

HIRAI: Maybe the musicology would be the first to be cut.

KURIHARA: It seems for me that the works of universities are becoming like a venture business.
FULLER: That's what knowledge management leads to, when it comes to the university. It gives you that kind of move. So there is a real battle here. That is what my book on knowledge management is focused on, and basically it defends the university as not being a dumb organization. If you look at the stuff that the pharmaceutical companies say about knowledge management and about one's ability to bring drugs to market more efficiently, in all of their discussion there is an implicit critique of the universities as being slow, as not being sensitive to market conditions, as just sticking with traditional lines of reasoning. I mean you can tell that the person who writes all that stuff supporting the pharmaceutical knowledge management is basically a disgruntled academic, someone who found the university constraining, and so moved into industry and now thinks it's wonderful. I mean there's a lot to be explained that way. Britain is a very interesting country because it has a nationalized academic system that is increasingly liberalizing its policies with regard to state industry interaction. So it's not surprising, for example, that knowledge management and evidence-based medicine are very strong in Britain. There's a lot of government incentive to get universities involved to make itself more open to industry. It's a very tricky issue.

KNOWLEDGE MANAGEMENT AND EBM

TEI: Don't you think the problem you have mentioned about the knowledge management in drug company can apply to the EBM, replacing the word "knowledge" into "evidence".
FULLER: Oh, yes, definitely. One of the things I mentioned in response to one of your written questions was that's exactly what's going in this evidence-based medicine stuff. What it generally amounts to is, on the one hand, trying to make practitioners dependent on scientific knowledge, but not really in a way that empowers scientists. That is because all the theoretical and methodological stuff is stripped away and is just being presented as brute facts, which are supposedly then made easier to use by practitioners. The practitioners are disempowered because they can't use their own experience. Instead, they're supposed to be using these facts from the evidence-based medicine. So it's like everybody is being disempowered. It's very strange. But we see this in Britain. I'm surprised that there's so much acceptance of it, especially given that there doesn't seem to be any hard evidence that evidence-based medicine actually improves treatment. I would have thought that that should be the bottom line with this: Shouldn't it be that people actually get better as a result of this? If you're going to put people through all this trouble and develop this evidence-based medicine, shouldn't it actually do something? Even the people who support evidence-based medicine admit that it hasn't yet. They just think that in a matter of time it will improve treatment. Well, frankly, anything 'in a matter of time' will have some sort of effect. I mean, there could be a placebo effect of evidence-based medicine, so that if you give it long enough, it will have some positive effect! In Britain, I can tell you why we've got this. It again has to do with a certain interpretation of accountability, where science and medicine can no longer be taken for granted as being public goods. They have to justify themselves. But then public accountability is interpreted in a very particular way. It's interpreted in terms of all sorts of market values. You know, consumer values, you might say, like efficiency and speed and ease of access, and all of that. As if those were the only things. That seems to me to reflect very much a kind of business mentality that has been superimposed on the issue of accountability. In Britain, the effect it's had at least in the short-term, when evidence-based policy is used in the social sciences, it actually discourages social scientists from doing basic research, but

rather orients their research in ways that could easily be used in this context of evidence-based policy. So it distorts the entire academic agenda and in a way it corrupts it. I just don't see it leading to any good either way, from a practitioner side or from a scientific side. I see it as almost a kind of bookkeeping exercise where you are able to prove to people simply that we've got this evidence-based medicine: So many practitioners have access to so many journal articles, and they're using these as a basis for all their decisions and treatments. And that looks like the main context in which this would make a difference. But I don't see this as really helping the actual people involved. I think this is a disaster in the making. Who is doing this kind of stuff here? Who likes evidence-based medicine? (Laughter) I mean other than pharmaceutical companies. I mean who exactly likes this?

SAIO: Government.

FULLER: Government does, of course, yes. Well, it shows just how close the state has gotten to business interests that this turns out to be the way of trying to unify the medical system. Of all ways to do it, this is an amazing way to do it.

TEI: So you think the EBM is not a good idea at large?

FULLER: No. I mean, obviously there is nothing wrong with making medical knowledge easily available through the Internet and all that kind of stuff. Also I do think that more could be done to make public the results of trials, experiments, and also the results of what practitioners do, to consolidate our knowledge of the consequences of using drugs and treatment. Having a more focused and consolidated database of that kind so that people can inspect it: I think that would be excellent. That is great. So there is a need for that kind of record keeping, relating to track record and things like that. That's very important. But this way of doing things, this evidence-based medicine, especially the way it wants to relate the scientists and the practitioners, that seems to me really bad. I'm surprised professional associations aren't against it. I would have thought that both practitioners and scientists would be opposed to this as de-professionalizing.

HIRAI: But in Japan there are some doctors whose treatment is based on no evidence at all.

FULLER: Okay, you have to give me a little more detail. What do they mean when they say that their treatments are based on no evidence? What is it based on then? They just make it up. What do they do?

HIRAI: For example in some cases they use the most profitable drug.

FULLER: I see.

HIRAI: Rather than the best drug.

FULLER: I see. Oh well, there is that. That certainly is a problem. But . . .

SAIO: So EBM may have some advantage in such case.

TEI: Sometimes you just rely on your own experience. Just that.

FULLER: Well, but that raises some issues about exactly what the nature of medical practice is. I mean, a lot of what we often call placebo effect is really, when it gets down to it, the kind of charisma that the doctor has with the patient, which is not trivial. Of course that would never appear in evidence-based medicine. That would never have any role. That would be completely obliterated. But there is some sort of validity in the so-called placebo effect. At least one needs to be open to that, because there is a sense in which even though it is called 'evidence-based medicine', there are a lot of theoretical assumptions about the kind of knowledge that's appropriate to medicine and the way that knowledge bares on practice. There's a lot of assumptions built into this, which nobody seems to have ever been consulted about. They are just imposed. You know, it's interesting, when expert systems are first being developed twenty, thirty years ago, one of the areas where they were developed had to do with psychiatric diagnosis. And there the issue was whether the intuitive judgments of the

clinicians were better or worse than this sort of actuarial inference that the machine can make, where it basically weighs the probabilities that certain kinds of symptoms will be indicative of certain kinds of diseases. Of course, they showed that the machine always does better. That is always the punch line. But even back then, in the old days of expert systems, the way the expert systems were developed usually involved the so-called knowledge engineer interviewing psychiatrists to get a sense of how they actually thought about symptoms of illnesses and such things. So that, in a sense, then becomes the program of the expert system
KURIHARA: It's interesting. How about in Japanese case, did the Japanese specialists who developed expert system do such kind of interview?
SAIO: No, I don't think so.
FULLER: Right. They try to capture the reasoning pattern so that you could update the expert system with new information but you would still have the reasoning pattern in place. At least it was assumed that a clinician had a certain way of thinking that would lead him or her to arrive at certain kinds of things. But this evidence-based medicine stuff seems to lack all of this. In that sense, evidence-based medicine is much worse. It's much worse than what the old expert systems were trying to do. With something like medicine that is so inherently social, where you really want to know what people are thinking and how they're interacting, it's a complete mistake to automatically turn to evidence-based medicine, especially without a formal discussion of the matter. Because at the end of the day, you could imagine through some kind of consensus conference, somebody, that people conclude, okay, evidence-based medicine has a place in this or that situation and we would like it to be developed for this or that purpose. No problem. But it has not been institutionalized in that way, has it?
TEI: No, I don't think so.
FULLER: No. It would be a great thing to have a consensus conference on evidence-based medicine because you have a lot of stakeholders who could testify on what they think about it. Also, ordinary members of the public in principle would be potentially subject to this sort of medical treatment at some point if they ever get sick in any serious way. So I say put it into consensus conference, and pose the following questions to the jury: Are there contexts where evidence-based medicine should be used? Are there contexts where it shouldn't be used?
TEI: That is one thing we are trying to do.
FULLER: Good! The future of medicine is a very interesting issue but evidence-based medicine is not the way to resolve it. So this was a government-led issue in this country? The government started this?
TEI: Yes.
FULLER: Aha. That's what I thought. That's usually how it is.
TEI: But not in the beginning.
KURIHARA: In Japan, there are many believers of evidence-based medicine without knowing what it is.
FULLER: Oh because it says evidence, right?
KURIHARA: Yes, probably. "evidence" is very strong word, and sounds scientific. So in Japan, many books the contents of which have nothing to do with orthodox meaning of evidence-based medicine have titles, including word of "evidence". In Britain, for example in the British Medical Journal, we can findmany articles which is critical onevidence-based medicine but authors of which know very well what evidence-based medicine really is.
FULLER: Well, let's put it this way: There are people who are critical but I don't think they are in the majority. One of the big problems is that evidence-based medicine has money backing it. There is a lot of money supporting research that contributes to evidence-based medicine. I mean like this thing that you've got from Oxford, right? This is not simply state

funding. One of the leading private charities, the Wellcome Trust, puts money into it. So the critics will tend to be those who are not influenced by money. They will be the academics, university people, so forth. But there's a lot of money coming down to this and that keeps the criticisms low.

KURIHARA: There is one paradoxical thing, do you know the name Archibald Cochrane who funded the conception of Cochrane Collaboration. He established this kind of concept to avoid many, many clinical trials. In order to avoid conducting duplicated, repetitive similar kinds of clinical trials, records of randomized controlled trials should be kept in database and made use of. But the paradoxical thing is, if people say that evidence is necessary, researchers start to conduct more clinical trials in order to make evidence.

FULLER: That's interesting. That's an interesting point. It becomes a kind of industry in its own right. It doesn't save effort but it actually creates new effort.

TEI: You wrote in your email, your own view on EBM and knowledge management is quite different, namely that knowledge management should encourage the emergence of disagreements among patients, practitioners and researchers, but these disagreements should be organized in a system of checks and balances produced individually. Could you put that in more specific terms?

FULLER: All right. What I'm reacting to here is this tendency of evidence-based medicine to eliminate the theoretical and methodological differences that patients, practitioners and researchers come to medicine with. Yet, in fact, those differences are in a sense the most interesting and important issues about medicine because they happen to lie with what is medicine about. What we need are forums for articulating and expressing those disagreements. A consensus conference is a good way to begin this kind of discussion because people basically have to present their own viewpoints for purposes of defense and interrogation in an open forum. But the ideal would be, in principle, that even at a setting like a patient going to a doctor's office a doctor would ask a patient, 'Well, what do you want out of this? What are your goals with regard to health? What is it that you want? What do you want to feel like in the end?' And actually take that on board as a serious constraint within which medical practice will occur. Rather than having the doctor say, 'Oh, you've got disease X. When you have disease X we do this to you.' Not like that, but rather get a sense of what are your health goals. What do you want. In other words, make those goals more evident.

TEI: Some people say that's the essence of EBM – the goal.

FULLER: Really.

TEI: Some people misunderstood it, about the EBM.

FULLER: But that doesn't seem to be what is going on.

TEI: You also said that unlike many people in knowledge management, you do not hold that sharp distinction can be drawn between knowledge practitioners and consumers.

FULLER: That's right.

TEI: Could you also put that in more specific terms?

FULLER: If you look at the way EBM is set up, there is a kind of a chain of command, you might say, where you have these researchers who produce this medical knowledge which has to be put in a way that can then be used by these practitioners who don't really produce any knowledge but just use knowledge. They are sort of the first consumer class, and then there is the second consumer class, the patients on whom this knowledge is then used. That seems to me a really strong distinction between who's producing knowledge and who's consuming knowledge. My view is, no, all of these people are producing and consuming simultaneously and the problem is that the production side of the practitioner's knowledge and patient

knowledge is marginalized from EBM. I mean, practitioners really do produce knowledge. They produce knowledge through practice, and hence all this business about 'my experience' as a practitioner. I might not write it down. I might not be able to count it, but it's still knowledge. It's knowledge that I produce through my interaction with patients. And the patients also produce knowledge. They produce knowledge by their living: They eat certain things, and certain things happen to them. They've got all kinds of knowledge. And it's quite clear that doctors implicitly recognize that when they ask patient these things, when they ask what have you been eating lately, what have you been doing lately. Obviously the patients are producing knowledge and the doctors need to know it. So all of that has to be highlighted, and the problem with a lot of this knowledge management stuff is that it's like a very old-fashioned production line model. Like from the early 20th century industry, where you have the producers and consumers clearly separated, so that the production goes through a certain preordained process and then gets consumed in a certain way.

TEI: Some gurus of EBM say we need more and more evidence generating medicine.

FULLER: Well, medicine that can generate medicine.

TEI: That's right.

FULLER: I mean, it seems to me what's important is that whatever treatments are made, there is an adequate record of the effects when it's applied. I think that is a very fundamental problem with medicine -- actually with any kind of policy, to be perfectly honest. Any kind of application of science generally has this problem, namely, there isn't a systematic record kept of consequences. So it's very hard to tell whether things work or not. And it seems to me that you do not have this in evidence-based medicine, either. Evidence-based medicine involves a lot of other assumptions that are very problematic. You see, we don't need evidence-based medicine for public accountability and good record keeping. You just need incentives for people to be more open with the consequences of what they're doing.

PROGRESS OF MEDICINE

KANAMORI: One thing. You said that knowledge is sort of necessary evil, but in saying so, on the other side you said you like to increase the use of human subjects.

FULLER: Yes.

KANAMORI: That can mean a sort of promotion of human experimentations. But why? Because I can say that we have already a lot of knowledge so we can perhaps think that it is almost enough. We actually focus our attention and evaluation too closely on cutting-edge research, which always can implicate doing risky human experimentations. But I think that we should concentrate our energy more on the social aspects of pre-clinical activities, etc.

FULLER: First of all, I don't see that you have to make a choice here. I think that there is a sense in which you can have both. The reason why I would like to encourage human subject experimentation is to change people's attitude towards medicine. I think medicine should be seen as a much more collective kind of enterprise. I think there's too much of a tendency to see human subjects as almost like unfortunate victims. Instead, I believe we should of participation in scientific experiments as a kind of social responsibility because each of us has an interest in the collective health and well-being of everyone. In fact, I would like people to have the attitude toward medicine that they have traditionally had toward going to war with an external foe: I think that would be a much healthier attitude towards medicine. People would think: 'I'm participating in this experiment. It might not do anything for me but the knowledge that it's gained for might be of some use to someone else'.

KANAMORI: I said that because as I've told earlier in this session I am working on history of human experimentation, and I said that because if medical doctors have to choose subjects of human experimentation most often it is children, orphans, "feebleminded persons", prisoners, soldiers etc.

FULLER: Exactly, and that is bad. That is bad. And I think that has put a big stigma on human subject experimentation. You are absolutely right about that. But one of the problems is, of course, it then helps lead to an enormous amount of animal experimentation, much of which has had very misleading results, regardless of what you think about animals. Some people don't want to experiment on animals in principle. But in fact often the experimental results are misleading because the small genetic differences between animals and human beings make a big difference in certain medical contexts. So, it seems that there is a problem there as well. What we need to do is to reconceptualize or repackage what human subject experimentation is about so that it loses its historic stigma. But this is where I think getting people involved in consensus conferences to set the medical agenda become important. Because the more that people are actually involved in setting the agenda, the more they are likely to be willing to participate because these experiments won't then be so 'other' to them. The problem is that biomedical research is still very much 'other', or very much alien to any particular subject. But then, if they're actually involved in participating in formulating the agenda, they'll be more open to participate as subjects. At least that's my belief. Generally speaking, when you open things to participation, people are more willing to take riskier decisions because they feel more involved. They feel they understand it better.

KURIHARA: I basically agree with your idea. But there also is problems. Because if the weak, vulnerable public can take part in such a chance like consensus conference, it works well. But in many cases information doesn't come to these kinds of weak people. That is the problem. What is your strategy?

FULLER: When you say 'weak people', you mean?

KURIHARA: For example, old people or as he said prisoners, children.

FULLER: Well I do think that with those people who are not likely to participate in the conferences on the juror's side that you need representatives as witnesses. In other words, when you think about who are the stakeholders, who need to be represented as witnesses, then you may need to include some of these groups, members of these groups to testify, to give their side of the story to the members of the consensus conference.

KURIHARA: In Japan, problem is that the representative of the public are called to such meeting like consensus conference, or ethics committee, as representatives who are ignorant of medical science. But according to your idea, they should be some lay-experts to have abilities to represent various kinds of public, imaging various situations. The Public Understanding Science would be necessary for educating such kind of representative of public. Then, How do you think about the balance between individual ethics and collective ethics? In many cases, collective ethics overcome the individual ethics. How do you think about it?

FULLER: Well, I think that consensus conferences are quite good at doing are two things. First of all, when you have a consensus conference, typically you end up seeing that there is a lot of disagreement within the jury because of the many different positions that are laid out. If you've got members of a consensus conference who don't come in with very fixed views, there's likely to be lots of changes of opinion along the way. But the key thing is, that members of consensus conferences typically learn to appreciate differences of opinion. I mean, regardless of their view, they often come away thinking, God, I didn't realize that there were these different possibilities out there. So the types of guidelines that consensus conferences have tended to come up with tend to allow the possibility for different ways of doing things. In

other words, it's not a 'consensus' in the sense that 'everybody should do this'. Rather, it's kind of laying out a range of tolerable possibilities. This part of the learning experience, especially since people often come into consensus conferences thinking that there is only one or two ways to understand a situation – especially, with issues relating to, say, transgenic things, where people often start either all for or all against it. People tend to have a very polarized views at the outset. But once they go to the conference, they begin to realize that it's a much subtler matter. That's the kind of thing you want to end up with: a tolerance for variation and with guidelines that enable variation to exist. Of course, the key thing is that the consequences of all of the different allowable treatments be publicly recorded. This may be the core truth of evidence-based medicine, namely that it should be publicly available whatever the people try. But I don't see consensus conferences as leading to some kind of just uniform monolithic viewpoint. No. They usually make people open-minded to different possibilities.

KURIHARA: How about the science shop? Does that make use of it for education?

FULLER: Well, that's a Dutch thing, you know, in the Netherlands. That in effect is one of the big institutional legacies of the 1960s of all the critics of science and technology then. Typically what happens is that ordinary people come off the street, and they are able to go to these shops and get advice relating to science and technology from people who know stuff. It's quite useful and they often help members of the public organize themselves if they have, let's say, a problem with something having to do with their environment, such as if they're worried about some kind of chemical dumping. Often the science shops would be helpful in enabling people to assess the situation, to see how serious it is, and to offer advice as to what kind of, if any, legal action that should be taken. They have been useful, but they have been used pretty much only there. They're not widely used. But they have been successful there.

KURIHARA: I think that basically you have an idea that the progress of medical science is a good thing, is it right?

FULLER: Well, I do. I'm not against medicine. Nevertheless, I think there are always going to be some big issues that have to be decided. Yes, I believe in progress in medical science but it can go in many different directions from this point. In particular, what is the goal of medicine? What kind of lives are we talking about maintaining? Depending on the answers that are given to those questions, the direction of funding of medical research will change. But I certainly don't want to get rid of all of medicine. By the way, I say this as someone who never goes to a doctor! I am not particularly beholden to medical science on a regular basis. Still, I do think that there are issues, like life and death issues about, say, whether life should be extended indefinitely. Well, I do think there are a lot of different answers that can be given. But then again, this is the sort of thing that I would want to turn over to a consensus conference -- namely, the ends of medicine because that's very important for setting the research agenda. But I am, generally speaking, positive.

KANAMORI: At least in Japan, a doctor is one of the strongest person here, very rich, very intellectual person, very socially strong person. So in the context, as you said, that disease is a sort of a collective enemy against mankind, I think it can be contentious. There will be sacrifice in some way between individuals, because the patient is the one who suffers from the disease and is essentially the weak one. On the other hand, the doctor is the one who is intellectual and therefore stronger. It is not quite an equal relationship.

FULLER: This seems to me a stronger argument for having consensus conferences integral to the setting of medical policy, especially in situations where you have this kind of asymmetry in social relations. You've got to have some institutional check then.

KANAMORI: What kind of system can you suggest to check this asymmetric relation between doctor and patient generally or in the social sphere?
FULLER: On an individual level I think that's very difficult. On the systemic level, if you actually had consensus conferences institutionalized every time there was major medical policy decision by the government, like in the Danish system where you would allow certain number of months or whatever for this to happen, it would then become routinized. One thing that happens during a consensus conference is that specialists become more aware of the interests and the needs of laypeople and start to actually try to solicit them more. They don't act simply as unilateral authorities but actually try to come to terms more with lay needs. So, I think in the long term it would have some effect in reorienting specialists. There are other things that can be done, too, of course. Part of the public understanding of science movement in Britain has led to an increase in courses in science communication which are often taught by people in science and technology studies, who basically train people who are training to be scientists or doctors or engineers about how to relate to the public. It becomes a required part of the curriculum. That sort of course could be institutionalized, and that would be something where science and technology studies people could claim some kind of expertise. That's another thing in terms of making doctors more sensitive to those kinds of issues. The whole trick of science communication is to basically teach the scientists that they operate in more than one context. And while they may be in some sense epistemologically superior that doesn't translate into the same thing in every context. That's worked reasonably well actually in Britain. I mean, that as well, to integrate that into the training.
SAIO: As an internist, . I understand well that progress of medical science can generate various diagnoses but in some sense it won't improve the quality of life.
FULLER: Not by itself, I would agree with that. Medicine cannot be seen in isolation. There is a sense in which we use this word 'life' in a very loose way to mean a lot of different things. But medicine cannot address all the different senses of the word 'life'. That's why getting this larger social context is very important -- so that when we start talking about issues concerning life and death, that goes beyond the normal course of medical practice, it seems to me. That's more along the lines of what the ends of medicine are. That is something that definitely requires a larger social context for its understanding.
KURIHARA: Most part of medicine seems to go towards the way to prolong life. For me, as a medical consumer, we don't need such prolonged life. Death is also meaningful for our life. On the other hand, recently several kinds of quantitative measurement or analysis of quality of life have become trend, but I don't think these methods work well.
SAIO: As the debate between J. Habermas and J. Lyotard suggests, in post -modern society, we cannot say that making consensus means first priority, so individual value shouldn't become a victim for collective value. This is the point I cannot believe in consensus for medical progress. To say this in ethical consideration, individual values should not become a victim for collective values. How do you think, in the context of post-modern society?
FULLER: I think post-modernism in this sense has been very good in bringing out the differences and disagreements that exist in the society, not only at the level of available treatments but even in terms of what people want out of medicine. I think that postmodernism can be given some credit for saying that the placebo effect maybe is not such a bad thing. And I agree with all that. But I do think at the same time that there is always a need for a collective front to medicine at the level of people seeing the consequences of what are involved in different treatments because, in a sense, regardless of our different views about medicine and our different attitudes toward health, we all have an interest in learning from each other's experiences of using different kinds of treatments and being involved in

different kinds of medical care. It seems to me that at that level there is a great need to consolidate and unify knowledge.

KURIHARA: The first time we read your comment your opinion is close to Habermas, but now I think your opinion is after Lyotard. It is social epistemology, is it right?

FULLER: Yes, I think that's right. One way to put me in this debate is basically I would like to reinstate the normative parts of Habermas that are possible once you've accepted Lyotard's position as factually correct. In other words, the problem with Habermas is that he acts as if Lyotard never existed. I say, okay, grant Lyotard's point: The postmodern condition is a fact. No argument there. The question is then okay, how do you then get a normative perspective after that. And that's where I come in. That is where my position begins.

KURIHARA: The progress of medicine generates various diagnoses and then variety of pharmaceuticals would be widely extended. It would be one cause of drug disaster. In the field of medicine, pharmacology, or social science, they have tried to prevent drug disaster from view of logical positivism, trying to detect the cause and effect of drug disaster. In view of recent sociology, social constructivism, they only try narrative description, but in order to prevent drug disaster, they seem to have to take actions as a public citizen, but not as a sociologist. How you can deal with the problem of drug disaster from view of social epistemology?

FULLER: The short answer to your question is that the social epistemologist would require some sort of public record keeping for the consequences of various drug treatments, so as to allow the most informed judgements to be made, both by individuals and larger policy bodies. Although everyone always stresses the importance of 'reliability' as a value in science and medicine, we actually have very few ways of demonstrating reliability on a regular basis. Most of our judgements are in fact based on faith in the experts that make claims to reliability. Not surprisingly, then, when disasters happen, people lose their faith. But they are not necessarily better informed once they get disillusioned, because the actual history of the failed treatments is still not known. However, I would also stress that any new treatment or innovation always carries risks that are not fully knowable in advance of their use. There is thus always a sense in which we are 'guinea pigs', even when try new foods, genetically modified or otherwise. There is nothing especially wrong with that, as long as we are informed about the range of things are likely or not likely to happen. Life is always dangerous. There is no getting around that basic fact.

IMPACT OF INFORMATION TECHNOLOGY

KURIHARA: Another thing, about the impact of information technology on science field. You mentioned this cyber-conference. Mr. Tei is an organizer of the F-DRUG, the drug information forum. What is that?

TEI: It's one of the oldest electronic conference on the Internet in Japan, where pharmacists and physicians talk about lots of topics on medicine including EBM. We are going to have a symposium in May on Public Understanding of Science. In Japan, it would be the first time in the field of ordinary, not advanced, medicine to have a symposium on this subject.

KURIHARA: So I would like to ask you what is cyber-conference and how does it work?

FULLER: Okay. I was commissioned by the U.K.'s Economic and Social Research Council, which is the big state social science funding agency, to do two cyberconferences. The first one was on the public understanding of science and took place in 1998. The idea was basically, since this term 'public understanding of science' is so widely used, a lot of people are finding it meaningful but they get different meanings out of it. And it's also a very controversial

expression, too. So I organized what basically turned out to be a sort of electronic bulletin board where there were fifteen statements that laid out positions relating to public understanding of science in its different aspects, from people from different parts of the world from different fields, to which then other people were able to respond over a two-week period. And so, discussions went on in that vein. It was posted on the web for quite a while, so people could look at it. I still have all the texts from it, even though it has been now taken down from the web. The second conference is still on the web. It was another two-week conference that took place in 1999, and it was on peer-review in the social sciences. On that occasion, I myself wrote all the initial statements, thirty of them, and I organized them in a logic so that if people responded to any of them, you could see a kind of general discussion growing out of it. The public understanding of science cyberconference had been very diffuse, going in many different directions. But this one was much more contained. Again, we got a lot of people, people from thirty countries participating. We had about a thousand people hitting on the site for the two-week period and, yes, we had some very interesting results. I mean, one thing that cyberconferences are good for is to bring different perspectives to bear and also to bring information that might not be readily available. Especially with the peer-review issue, that was really interesting -- different aspects, different attitudes toward peer-review. Because peer-review, depending on what field and what country you're in, is either very strongly supported or very strongly opposed. So it was really a very useful experience. However, the one thing I would say about these conferences, because they are conducted on the web, that means a lot of people with very primitive or non-existent email access really can't participate. In fact, that was a bit of a problem even for people from Latin America, where email access is still somewhat limited. There I had to basically manually upload their responses because they can only communicate with me through regular e-mail in a UNIX system, without access to the web. So even though the cyberconference idea looks like a free medium, and you do get views from all over the world, there is still a kind of implicit political economy to this. Not everybody is really an equal player, even now. I think that needs to be kept in mind. But you know, I would do it again. I would also recommend that you purchase the technology for doing cyberconferences. I didn't actually own the technology I used. I always had to borrow it from elsewhere. But if you could actually purchase the technology and be able to run these things on a regular basis, it would be really good, because I do think they are very useful. Cyberconferences also generate an enormous amount of publicity. You can publicize the topic. If you want to really highlight the significance of a topic, this is a great way to do it. What's your experience?

KURIHARA: Is there any possibility in Japan for such kind of cyber-conference on the impact of information technology on medical field?

TEI: I would like to open a same kind of cyber-conference, if I could. So are you planning any other kind of conference on other topics?

FULLER: We'll probably have more in the future. Britain has just begun a new 'Science in Society' initiative through the ESRC, and when I get back I'm going to see what's possible there. My idea would be one day, if I actually had the software on my computer, because it's quite expensive actually, I could just organize cyberconferences whenever I felt like it, because it's not that hard to do -- if you want to take the time to sort out the conference's structure, and invite everybody on board. But the software does costs money. So you need to have a grant for it and getting the grant is always the issue.

TEI: Looks like it's always that mostly money talks, right?

FULLER: Yes. I would have thought that if you were to say to a medical foundation, "Look we'll have these things on a regular basis. You could even to commission us to do them. But

we need to have the software planted on our computer." Because that is really the major expense.

PHARMACISTS AND PUS

KURIHARA: Do you have any view on pharmacist's value?
FULLER: Pharmacist?
KURIHARA: Yes, because there are many pharmacist who are members of this symposium. Mr. Tei's FDRUG held in 2000 a symposium titled "Where is the evidence of value of existence of pharmacists?: An Analysis by Medical Economics.
(laughter)
TEI: So what can pharmacists do on this field?
FULLER: When you say pharmacists, you mean the people who dispense drugs? Or do you mean the researchers?
TEI: Both, in my opinion.
KURIHARA: And sometimes I think the pharmacists can work as an interpreter between doctors and patients.
TEI: Or information provider.
SAIO: Otherwise,pharmacists as information coordinators between patients and other medical professionals.
FULLER: Well I think that's certainly possible if they are sufficiently independent as a profession. They can't be beholden to any of the groups that they happen to be mediating. I think that's very important.

TRANSCRIPT OF DR. FULLER'S VIDEO PRESENTATION

(This part is not included in the article of Clinical Evaluation, but Japanese translation would be provided at the time of Mr. Tei's symposium in May, with video presentation.)

Konnichiwa. Hi, I'm Steve Fuller. I'm Professor of Sociology at the University of Warwick in the United Kingdom, and I'm speaking here from International Christian University of Tokyo where I am Visiting Professor of Science and Technology Studies, Winter 2001-2002.

I want to say a little bit about public understanding of science and its relationship to issues having to do with knowledge management and evidence-based medicine. I've written quite a lot on areas relating to this topic and I ran a cyber-conference on public understanding of science in the U.K. in 1998. This is a very controversial issue, especially in the case of medicine where it seems to me, more than ever, we need greater public participation in setting not only the research agenda but also issues of a more basic kind concerning the relationship between practitioners and patients.

Now, in terms of how one goes about doing this, it seems to me that a very good institutional model is the consensus conference. Consensus conferences have been now tried in about 25 countries. It's institutionalized in Denmark. The idea is to introduce a measure of public participation in setting the scientific research agenda but doing so in a rather specific way. It goes beyond having merely stakeholders participate in setting the agenda. That is to say, more than just having the doctors and the patients and the various interest groups involved. Rather, it attempts to expand the picture and to involve ordinary members of the public who, at some point in the future, may be involved in issues having to do with medicine, where their lives depend on it and so forth, but at the moment are not.

A consensus conference is set up very much like a jury hearing a trial, in this case the 'trial' is over the direction that medical or science policy should take. The participants in the jury are ordinary members of the public, not necessarily members of any particular interest group. But the witnesses that the jurors hear are the members of the different interest groups. These witnesses present testimony about how medicine should be represented, how their particular interests should be served. And then the members of the consensus conference set policy guidelines on the basis of this testimony, on the basis of which then legislation can be drafted and put into law.

As I said, this has been tried in 25 different countries with a considerable success. Yet, it's only been institutionalized in Denmark. It's also been tried in Japan and the results have been very encouraging and I am happy to say they had been very much spearheaded by the science and technology studies community in this country.

Now it seems to me that there are some features of consensus conferences that are essential to the public understanding of science. One very important one is the fact that there are different interest groups involved in medical knowledge – researchers, practitioners, different sorts of members of the public. There is no way in which these things can simply be homogenized or wished away. In this respect, I have many reservations about the turn to evidence-based medicine.

Evidence-based medicine, it seems to me, while the goal is to make medical knowledge more transparent and available to practitioners and patients, nevertheless seems to erase a lot of the fundamental disagreements that exist with regard to the nature of healthcare that researchers and practitioners and patients have. These things do need to be voiced and need to be made clearer. At the moment, what I see evidence-based medicine is doing primarily is serving certain kinds of business interests. We have evidence-based medicine in the United Kingdom. There is a very strong state initiative behind it. And I see its overall thrust as basically de-professionalizing the medical science community, since the evidence has to be presented in a way that is short on methodological and theoretical approaches. It also de-professionalizes the practitioner community, since the practitioners are not to rely on their own experience but rather to rely on this database that evidence-based medicine produces. Also, it is not at all clear that patients are empowered since there is very little evidence that evidence-based medicine actually improves treatment.

But then who is served by evidence-based medicine? Well, it seems to me that business values are certainly served, in a sense, they emphasize values of efficiency, of utility, and the pharmaceutical industry not surprisingly has been very strongly behind evidence-based medicine as a way of improving its techniques of getting drugs to market. But it is not at all clear that medicine itself improves in the process.

I understand the turn to evidence-based medicine, why we have it today. There is a greater need for public accountability of science, and medicine as a branch of science is subject to this. But unfortunately the forms of accountability that evidence-based medicine encourages are those of the marketplace, and those do not necessarily encourage either the democratization of science or scientific values, more generally speaking. So in this respect, it seems to me, while there is a great need for medical knowledge to be more publicly available and a great need to improve the keeping of records about the results of medical treatments, evidence-based medicine is not the way to go on this matter. It's not likely to improve public understanding of science. Thank you.

(END)