



Presidential Commission
for the Study of Bioethical Issues

TRANSCRIPT
Nuffield Council

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Jim Wagner:

Let's ask folks to take their seats. There's quite a bit of chatter in the intermission, which is wonderful. Hugh, you want to come up, so I can have an opportunity to introduce you.

Our speaker at this session is Hugh Whittall. Hugh is a scholar of philosophy and politics, graduating from the University of Warrick in 1983, but since 2007, he had been with the London-based Nuffield Council on Bioethics and director of that center. He spent years prior to that working for the European Commission in Brussels where he was responsible for funding and promotion of multi-disciplinary research in Bioethics and Biomedicine and Health Research Programs. The Nuffield Council is independent of the government there, Nuffield Council on Bioethics. It's among a number of organizations and committees that are complimentary to the British government and advise or at least provide information on ethical issues. I guess, in about twenty years of existence, you've addressed about forty topics, in the neighborhood of about twenty reports that are coming out of those and they go from A-Z, from agriculture to xenotransplantation, so at least A-X. Y and Z need to be addressed yet.

In the most recent report published last month, it focused on the issues raised by online medicine and medical profiling such as commercial genetic testing and body imaging. He will be discussing that report with us. Although, he's been telling me that he's been scratching furiously, based on some of the comments today, so I think that's something we want to hear broadly from you and welcome to you to the deliberations of this Commission.

Hugh Whittall:

I pushed the microphone up to enhance the applause. Thank you very much, indeed, I really ..., I will say just a few things. First, if I may, before I start ... first, is thanks. Thank you very much indeed for the invitation to come here — the privilege that it is; the pleasure that it has been; the welcome that you've given me already. And the opportunity that it presents for us — and I know I speak on behalf of my council — to start a conversation. This isn't an event as far as we're concerned, but really the beginning of what hopefully will be a fruitful conversation with you. I would also just like to say how impressed I've been just over the last day and a half with how far you have traveled in a short space of time with your work on synthetic biology, which we know is one of the trickiest problems of the day. To have traveled so far, to have put it together, with the approach that you have and to have articulated it and present it the way that you have over the past

day and a half, I've been very impressed. So I congratulate you already on what you've done, and I'm really looking forward to the final report.

I would just also like to say that the difficulty with being last up in a meeting like this is that I've had the chance to listen to a lot of things, very interesting things. I've seen a lot of connections with the work that we do, that we have done, that we will do, and all of the things that I intended to say are kind of affected by that, and I'm kind of scrambling to fit in some additional observations. So, what I will do, if you will permit me, is give a brief introduction to the Nuffield Council and give a brief overview of our report on medical profiling and online medicine. You should have available to you short copies of the report and access to the full report, but we'll just touch briefly on it for now. An outline of our future plans, because I think that could be very interesting in terms of some of the things that you'll be thinking of, but also ways that we might continue to talk into the future. So, there's loads of things that I would like to say, loads of reasons I'd like to turn this into a conversation, so if I speak very quickly, that's deliberate.

So, the Council was established in 1991, that's almost 20 years now. It was a cluster of people, scientists, medics, philosophers, lawyers, together who actually identified the need for a critical evaluation of developments in science and medicine; and they actually took the idea to government at the time, which felt that it did not wish to establish a national commission for the study of bioethics but encouraged them to go to other agencies to see if there were any external means of developing this. And so it was that in 1991, the Nuffield Foundation initially supported the Council and they were joined shortly afterwards by the Medical Research Council and the Wellcome Trust. So, we do operate independently, and we are funded by these three agencies. They don't exert any influence over the Council in terms of what it chooses to study or what it chooses to say. So we do operate entirely independently which is a phenomenal strength together with sustained quality; I think these are the two planks on which it's built. The question of whether there might be a national commission on bioethics has been revisited on a couple of occasions — most recently just two years ago, 2008, during a passage of some related legislation. And the government Minister, Baroness Royall in the House of Lords, name checked the Council amongst other bodies stating that the current in the UK, what she called a “distributed system of bioethical advice” works well. It remains our view that the national human bioethics commission would not bring sufficient benefits in comparison.

So we have a place in the system that is recognized, it's not a national commission, it's not constitutional statutory basis, and here I've set down what that system consists of. The government does have advisory bodies, the Human Genetics Commission and others. There are a couple of statutory authorities that also provide advice in bioethical areas and independent bodies, ourselves amongst one or two others. I don't know how familiar you are with the term "Bonfire of the Quangos" it's a term that's very prominent in the UK at the moment; Quangos being semi-autonomous advisory government bodies and they are about to be — the bonfire is to say — many of them are about to be disbanded. This includes the Human Genetics Commission and the Gene Therapy Advisory Commission, both of which are statutory bodies working in the area of human fertilization and human tissue. And so it's kind of an interesting time ahead of us that one could say there's a space opening up into which we might move; however, we need to take care it doesn't draw us, if you like, closer to advising government in a direct sense. Nevertheless, it's an interesting time, and I think that the task that lies ahead of us is probably greater, even, than it might have been otherwise.

The terms of reference that we work with, and I just pause very briefly on this, because I think it's worth noting this, that there are three distinct parts to this. One is that we are asked to identify and define issues that are of concern raised by biological scientists. Second is to promote public understanding and discussion. We struggled to achieve this, you will do the same, we talked to other bodies that do the same but nevertheless, an important part of what we do is to use our work to promote public discussion of these issues. And the third is to publish reports and make recommendations, and we take this to mean that it's important that our work is policy-focused.

We are looking for outcomes, we are looking to deliver policy recommendations that have meaning and that can be implemented. This is not Academic work. It is not work to be left on a shelf. And we've followed through on that. I just think important noting that and having that in mind as we work through this.

The Council itself consists of members who are range from basic and applied scientists, clinicians, philosophers, anthropologists, sociologists, lawyers, ethicists, we have a great range and as you will see from this, the Council is greater in number than your commission. Probably a good deal more unattractive... The Secretariat, on the other hand ... I show you this for an important reason: the Council has that much expertise among it, the

Secretariat carries out a hugely important function — I would say that, wouldn't I? — but we have amongst our Secretariat staff, people who have sound experience in policy — my area — medicine, science, law, ethics, but also communications as well.

And, so, I think it's important to note that the strength of the Secretariat is something that the Council recognizes as an important part of its work as well. The way that we work, which is where we really, I think, there is a point of distinction here between what we do and the way that you are working up to now, is that I should preface this by saying that topic selection, the way we select our topics, is actually quite an extended process. We work up from a long list to a short list, we crush it out in a seminar, we've invited experts, then we'll run the potential topic through a workshop.

Again with the group of experts, and then, once we've clearly defined the topic, and that's an important part of preparing the ground if you like, for an effective piece of work, we establish a working party. This is where we draw in experts from relevant fields to work on this with us, supported by the members of the Secretariat, but we tie them in to the Council as well. So probably, usually, two members of the Council will be members of the working party and the chair of the working party will for the duration of usually about two years, become an ex officio member of the Council.

So there's an interaction between the Council and its working parties. The process is critical, this is again something that you would've talked about, I think again we could fruitfully talk about some of these things. The process of fact-finding; of having meetings with relevant parties, with expert academics, with industry, with NGOs, with patients and consumer groups; so these will be face-to-face meetings as well as a public consultation in which people are invited to submit their views and opinions around the topic. This is promoted as wide a media promotion as we can.

The draft report. The kind of stage you're at, at the moment, is the stage that we would put this out to peer review. So, we will identify probably ten or twelve experts across a range of disciplines in connection with any particular report, and we would ask them: Have we missed anything? Are we way off beam? Is this coherent? Is it comprehensive? Is it realistic? And it is implementable? So we would challenge ourselves, if you like, by inviting people to critically review the report at that point and on publication we promote it publicly but also with the policy makers

and we will follow that through to try and have meetings with them face-to-face and to try to promote that.

Jim Wagner:

What would you ask of peer reviewers?

Hugh Whittall:

We will ask them whether any holes were in it, that it's complete in sense of the territory that it's trying to cover, whether we've missed any particular arguments; so whether there are aspects of the issue that we have failed to address properly, whether our report is coherent? That is to say that it works its way through and arrives at its conclusions in a sufficiently logical and persuasive manner and that we are not off beam; we were trying to make sure we're on the right track and we've got an argument that is sound. We don't ask them to agree with us, but at least to identify, if they don't agree, that we've addressed those kinds of arguments, much in the way that you were talking about a little earlier: if they're issues of principle, let's take them head-on rather than take them out of the picture. We've got notes about this that I can, that are kind of briefing notes that we give to peer-reviews. It's okay.

There's another important part of this, and the way we work and if we've had some success we're sticking to our model because it seems to be doing the job, but there's an important relationship between the Council and its working parties. The Council is invited to adopt into a report when it is completed and has done so in every case so far, but it doesn't do so simply at the end of the process. At each stage that the working progress, the draft report comes to the Council, the proposed ethical framework comes to the Council and the Council critically examines that. It has a subgroup of Council members who specifically take that task on. And what my chairman describes as a dialectical struggle takes place, whereby there is a kind of iteration of arguments between the Council and its working party. And this is really about challenging people if claims are made, about making sure that arguments are transparent, that they are properly argued and that they have been properly challenged.

And, so, I said again, an important feature, I think, of how our work progresses. The elements of this — this starts to kind of break up a little bit now. I'll go through this a bit quickly but we can stop and talk about any particular thing. It's important to see some of this. We work in the UK — I quite like this word: *ad hoc*cracy. Things come together simply by chance in certain moments and we're part of that. We're also part of an environment in which the separation of government from the

administration is something that we're all familiar with, so to be able to operate as we do, independently, within this kind of dissipated set of bodies and advisory structures is a comfortable place for us to be.

We operate independently, set our own agenda, we choose our own topics, we look for topics that are timely, that are policy relevant and so this is, again, an important part of our environment. The members of Council in working parties are chosen because of their individual qualities, their skills, their experience, they're not there to represent their profession, or to represent their point of view or to represent some logical position. They are aware of this, and it means that the Council is not, itself, bound by particular principles. It doesn't declare itself of a particular philosophical standing *ab initio*, as it were. But it rather applies itself to each particular question in the way that that particular question demands.

So, the influence that it has is based, not because of its constitutional position or because it has a particular authority, but because of its independence and because of the quality of its work. We do work to see that recommendations are taken up, but, at the same time, we recognize that we're part of a process. We're not giving the definitive last word on anything.

We have a unique history. I don't think if you try to set this up now, you could replicate it. I don't think you would necessarily do the same thing today as happened then. I don't think you could transplant it into another environment. We can't simply say that if France needs a bioethical commission that we have something ready-made. I don't think it could work like that.

We occupy this space of practical public reasoning I think, and I think your discussion about the democratic reasoning as well, touches very closely on this. My chairman, he's got a way of coming up with these phrases. He describes what we do as "civilized contestation," and the common purpose is also important, that we gather people who are prepared to be engaged in that kind of process; prepared to put their argument on the table, to have them challenged and to do so in a way that they expect to be fruitful. It can exclude people who are at extreme positions to some extent, but again, one has to recognize the arguments, be prepared to listen to them, and our process ensures there was the opportunity for those positions to be made known. But they have to be addressed even if they're ultimately not satisfied.

The phrases are often used around the kind of thing that we do about “striking a balance” or “bridge-building” whether it’s between academia and policy or between different positions, and we tend to use these words a lot. I’m a bit skeptical about them, because I think it suggests, as you talked about not setting up us-and-them situations, this underestimates the complexity of the positions that people hold. And so bridges aren’t just between two places. Balance isn’t simply between two things. We’re working in a much more complex environment that increasingly is global. The implications of the work that we’re doing — obviously, which is very far through many of the reports that we’ve worked on and expect to work on — it’s complex, it’s dynamic, and we can’t expect to give a definitive position, but we can hope to contribute significantly.

That’s very rapid. I enjoy talking about the Council, I have to say, and there are an enormous number of things that you could tease out from amongst that, maybe we’ll have the chance to do that. But I would just like to spend a little time on our most recent report published just a couple of months ago, “Medical Profiling and Online Medicine.”

We struggled with actually defining this topic. What is it about? Why did we do this? And really the way I find it easiest to describe is that we arrived at a time when two things came together, broadly speaking. One was a cluster of technologies, largely based around digital technologies and internet-based technologies, that were making claims about offering to people a more personalized approach to their healthcare, an approach that would give them more predictive abilities, better preventative options, and this was a set of claims and technologies that needed some scrutiny to test those kinds of claims.

At the same time, there was a kind of more social and cultural environment developing and political environment developing, which was about choice, which was a political question providing choice, raising the questions about the extent to which people, should take personal responsibility for their health and an increasing consumerization in healthcare. Now this is set against the UK backdrop, where we have of course a universal public healthcare system, which I think makes this whole question different in its context to the way that it might play out in the States. But for us it did raise questions.

When these two broad areas of technological advance and claims and the societal changes about choice, responsiblization, consumerization, were coming together, what was this going to

mean for our health systems? What would it mean for our doctor and patient relationships? What was the future of this question of individual responsibility, or risk pooling, that the health service represents?

So this was the broad environment that we were trying to examine, we went through. So, the report talks about this social context. It proposes an ethical framework, looks at the kind of interventions that we might contemplate, and then has these half a dozen case studies around what actually is a thread of how an individual now could actually manage their own healthcare without seeing a doctor at all.

I'm a guy reaching a certain age, I've got the usual aches, pains, and creaks that I might have. I could look stuff up online. I would diagnose myself. I could order drugs online without seeing a doctor, so I could prescribe it to myself, I could then go down and get my genome profiled, and I could get my body scanned, and I could go round the whole circle again and still get no medical advice. So this was the threat, in a sense, of what we were looking at.

If we look at all of those types of technologies, the types of circumstance, we identify then the ethical values that commonly arose in the context of this, and these are: protection of private information, the individual's right to pursue their own interest in their own way, the state's responsibility to reduce harm, the efficient and fair use of public resources and the belief that public policy should be informed by the principle of social solidarity; and that is the main principle underpinning the public healthcare system in the UK, and in large parts of Europe and ...

Amy Gutmann:

Can you say something about, perhaps not individually, but what you mean by social solidarity — which may be a common term for you, but is not a term that is commonly used here

Hugh Whittall:

Well, I think there are probably a number of different dimensions to it. One is in this context, about the pooling of risk. We recognize that we all have differential risks, we can't necessarily identify them at the outset. And so there's a kind of social agreement for what we will do, is we will share the risk equally as it were, and be willing to pick up the bill for others if that turns out to be greater. It also engages the question of protecting those who are vulnerable. So that as a society we recognize our responsibility to other people. In a previous report, people who

one might describe as fellow travelers, so we recognize the affinity that we have with fellow travelers.

And another dimension to this; we're starting to talk about this concept in several of our reports, so this is not just here. We've talked about it in our report on dementia; it will also arise in our forthcoming report on biofuels, interestingly. But the other aspect to it is what you might call the common good. That is to say, that it represents the good that is shared, that can be more than the sum of its individual parts. Whilst there are individual goods that one can put together, there is something more than that which is the common good that we share. So solidarity, I think, represents a complex set of ideas that —

Amy Gutmann:

[Inaudible-microphone not turned on] [These are concerns that we have tried to capture in our principles as well ...] Public Beneficence to protect the vulnerable, Responsible Stewardship to advance the common good, really all of that.

Hugh Whittall:

Indeed. I think that's right. One of the — I said earlier that the Council doesn't kind of declare itself to be attached to particular principles, they're in appliance to every different situation. But in each particular topic it approaches, it identifies those ethical values that are at stake and constructs them into the kind of framework that you've done here, which I think works extremely well.

It's important that those values are things that people can understand, that people can sign up to. The definitions that we use tend to be quite fluid, and I think one has to be careful about one uses, but also ready to explain it. So, our reports will explain the thinking that's gone into it and the meaning that we're attaching to it in this particular context as well. Partly why our reports are so long, if you pick up a big version, but we've boiled it down for easy consumption.

What often, of course, happens is that values can be in conflict. Now, it's interesting I think, that you said yesterday that you felt that the five principles in your ethical framework were quite consistent with each other. I think that there are, well I don't want to doubt you, but it would be interesting to examine whether that is truly the case, because I think that often they do come into conflict with one another, and one has to find a mechanism for resolving that conflict.

Amy Gutmann:

Just to be clear, I think it's true that the five are not in inherent conflict with one another, but within each of them, there are conflicts such as balancing benefits and risks under public beneficence. In each one, you would find conflicts internal to them.

Hugh Whittall:

Yes. And then when you look at any particular situation, you may find that, for example, if I have the right to pursue my own interest in my own way, and that means gathering certain information about my health stages and that then leads me into making demands of the health service. There's a conflict, then between my private interest being pursued, and the burden that it might place on the public health system. So this is the kind of conflict that one has to resolve.

And what we say here is, we don't think that there is one single value that trumps the others, that is always the primary value, but what we try to do is identify where those conflicts arise and rather than decide one way or the other — rather to soften the dilemma, which is the way that we put it the conflicts of this report. Because we're not looking for hard-edged regulatory measures, but ways of diminishing the conflicts that arise if there are tensions between these values. So we will expect to see intervention only if it is feasible, if it's effective, and it will have to be based on good evidence, if the harm is serious. And the intervention should be the minimum necessary to achieve its effect and should be generalized rather than specific where possible.

So, for example, on the question of information that is given by the genome analysis companies or by body scanning companies, we would want the industry to find its own standards, rather than immediately regulate with central directives. So you come in at that level. If we look at the way they advertise the claims that they make, we would expect the general advertising standards regulations to apply rather than creating specific noble standards for this particular situation. So that's the general approach that we've taken on this.

Very briefly, what we see here with this cluster of technologies, are ways that can potentially offer benefits in the way that people approach their healthcare as consumer goods and get more choices and more benefit from them. But to make use of those, people need to be guided toward where to get good information, how to make use of that information and sometimes, this is going to involve an intervention. For example: with government

websites, with help to direct people to websites that may be type-marked or accredited; with support, maybe, from the general practitioner so maybe need to be trained in how to deal with genome-wide analysis where people are looking at information or scans that are complex and, as was pointed out earlier, may vary in terms of their specificity and applicability in different types of circumstance. So if people are going to make use of this, we need to create an environment in which they can arrive confidently at good information and know how to use that information. So that's the broad approach that's been taken so we make various recommendations.

I won't stop on this because we can look them up or we can talk about them later, but I'd like to just — so for health information, government should provide information or direct people to sites that are well-grounded and are kept up to date. Online drug purchasing, there is a system in the UK of accreditation of online pharmacies. That's a system that would be good if we could apply it worldwide because people are getting their stuff from outside the UK. Genetic profiling and body imaging — we know well that these are not well-founded in terms of their research base. They're making claims that are dubious, so people need to be very careful and to be helped to manage this information — although at the moment we have not seen sufficient harms coming from these to warrant more serious intervention or banning them other than whole-body CT scanning.

So, technologies are still developing, there are potential benefits and harms, but we need to keep an eye on them if they are to deliver goods and people do need support in approaching them.

So if I may just take another 5 minutes, I'm not quite sure what the timing is supposed to be here. I really want to just have a brief word about the future issues that we're looking at.

We look for topics that are novel, they're timely, they're complex, and where we can make a unique contribution. There are some topics in the UK where everybody's been around them enough times that it's difficult to see that we're going to add anything else, so we tend to look at things that are quite intractable but where we can do something new.

We're working on a report on new approaches on biofuels, that's queued to be published early next year, and on the human body. The donations of bits of the body or the whole of the body for therapeutic research purposes and kind of the potential for commercialization in that area — this is a report that's creating a

lot of excitement around on our continent. We're then queued to move on early next year through emerging biotechnologies, and it's the first reason I took so many notes over the last day and a half.

We started to kind of nibble away at synthetic biology and also nanotechnology and I couldn't quite find the shape of the project that we wanted to work on here. And actually what the Council concluded is that there's something common here about emerging the biotechnologies and we need to know what the anxieties are and where they lie and how we manage them — upstream, with the public, etc. So, it's not specifically about what is the problem with syn-bio or nano, but could we use some of those examples of synthetic biology, of something that's on the verge, nanotech, which is kind of out there but hasn't really been appraised fully. Or even going backwards to look at technologies whether it's about vaccinations or antibiotics where we've been through it and taken it forward. So we really wanted to see if there's a way of handling emerging biotechnologies in a broader way.

We're on the stocks and waiting to go, and in fact I've missed the preparatory workshop that took place yesterday on model neurotechnologies — where we will look at the potential for interventions in the brain that are arising through current neurotechnologies.

We've got a short list of topics that we will go through next spring as potential issues for the future. Genes and parenting, which may look at the disconnect between genetic parenting and social parenting that has been, if you like, exacerbated by certain types of fertility treatment and how important it is to have a genetic connection. Many issues in there. Genome-wide associations, the potential that they give for data mining, for the linking of databases and the implications of privacy. Pandemics, hugely expensive new therapies and germline therapies which are, we're kind of at the starting point here as the potential for treating mitochondrial disease by nuclear transfer and whether that kind of opens up a new question of germline changes.

So this is what we may be doing in the relatively near future.

Finally, we may come around to a conversation here, broadly speaking, we've seen over these twenty years quite a change in the way bioethics have been working. Starting from twenty years ago when people were still kind of fixated on four principles of medical bioethics, which were really centered around individual relationships between doctor and patient. And that has broadened

out so much now into wider ways, so that we're now talking about intergenerational justice, for example, as some of the important principles that we're working with.

And so, the way that we put these frameworks together in the context of each specific topic is increasingly interesting but increasingly complex as well. The globalization of science, medicine, training, and everything else, and of the issues that we're looking at is having a huge impact on the way that we've worked. One of the topics that the Council has been keen to try and break into, but hasn't yet found the root into it, is about global health and the equalities. And here, we need to have some discussion, we plan to do that next year, start a discussion with representatives from a number of developing countries from across all continents — about how we can start to approach this in a way that will be fruitful from their point of view more so than from ours.

And so this international agenda, I think, is an important one. It's a growing one, and hopefully it's part of the conversation that we can start to have amongst ourselves. A certainly aiming those is happening amongst groups around the world. We have a European forum of advisory committees, we have a global forum supported by WHO as well and a number of bilaterals too. So, this is a fascinating time to be getting into this. Thank you. That's taken far too long, I apologize for that.

Jim Wagner:

Hugh, as I said, we started a little bit late and I think we're pleased that you're up to all the material and took the time to do it in the pace that you did. But I have suspicions that there are a few questions for you from the group. Nelson.

Nelson Michael:

I was reading some of your materials — I'll admit I did it earlier this morning — and I noticed that you had some discussion about how you interdigitate with other international bodies to include not just WHO but the World Medical Association, UNESCO and other international bodies. Which is something that we discussed in our own deliberations yesterday that perhaps we need to expand some of our deliberations on that; so from a practical standpoint, how do you implement that outreach to the global community when you yourself said that the Nuffield model, as an example, might not fit directly if you went across the channel?

Hugh Whittall:

Well I think there are two things to preface this. That's true, I don't think we could simply export our model and say "This would work for you." But we can explain how we do it, how we think it works, what elements we think are important and then people can take advantage of that if they think it's helpful. Certainly it's helpful to us to see how other people work. I think some interesting discussion to be had about how you have taken your draft proposals out to the public at this stage; I think we can examine for ourselves whether that would be a fruitful way of working. So I think we can share those experiences quite helpfully.

The second point is, in that international dialogue, I think that there were some thoughts some years ago that it might be possible to get groups of advisory committees together and find a common position or common opinions. I don't think that's realistic, frankly. Not because necessarily because we're at such different points philosophically or in terms of where we might arrive at, but also because constitutionally I think some committees have great difficulty in committing in that way when their relationship with their governments or departments are of a different nature. So there were some discussions around that that I think that didn't get very far. So what tends to happen is that we get drawn into sharing information, sharing ideas, understanding different positions and increasingly as we are tackling issues that are of a global nature and all of their dimensions, it's just increasingly important to hear those perspectives. You know, if we're going to try and make recommendations to WHO about programs that they should implement, let's know what people are thinking about these issues in other parts of the world so that we're not simply setting up an unrealistic expectation.

Jim Wagner:

Dan?

Daniel Sulmasy:

Thanks, that was terrific; very informative for us, I think, which is wonderful. Part of the dialogue I hope we will continue to have. I have two questions, one relating to a question Tom Murray put to us yesterday that I'll put back to you and the question is: Who do you think your audience is for your reports and work? And then the second question of topic, of all the ones to talked, they were very centered on technology. I wondered if you ever consider looking at questions related to the ethics of the delivery of healthcare services; the ethics, for instance, of comparative effectiveness research, controversies around what NICE does, etc.,

which are probably more controversial in the US, perhaps, than the UK but maybe that's helpful.

Hugh Whittall:

Okay, on the first question: our audience. We've got various audiences and to some extent one does have to separate them. So we certainly interest policy makers, whether it's in government, international organizations, professional bodies, and as was discussed this morning, it's most helpful if our recommendations are very specific, very targeted, very practical, so that we can initiate conversations that are based on something tangible.

We have a responsibility within our terms of reference to promote public discussion and understanding, so we have a public audience. We have to make sure our work is accessible and that we use mechanisms for promoting that discussion, whether it's through the media — we have a group that addresses young people in particular, and so we develop, for example educational materials that we feed out through partner organizations into schools — not to promote our conclusions, but to promote discussion of the topics — and produce this short version of the report that is much more readable for people who are just on a 20-minute bus ride. We also produce a one page and four page version, which we send to members of parliament because we reckon that's about the extent of their attention span, ordinarily. They're not — do they listen to this?

But it's a very important question and we have to vary our message depending on our audiences, but it bothers us all the time — how are we going to achieve this we can't talk to 60 million people individually. We are too small and we just don't have the resources. We can work with other people to try and promote that, for example, we worked with a touring theatre company who take things out on the road.

Again, talking to other councils, the Danish Council on ethics put up some fabulous work, the French Council on Bioethics had a kind of public day where they have hundreds of people and school kids in for the day. You know, these are the kinds of things people are doing that we also will try to look at, but on pretty limited resource.

Jim Wagner:

Oh right, on the technology?

Hugh Whittall:

Oh, sorry, yeah. I've given you kind of a short list of topics things that we're thinking about, but there's a long list of other things that we could think about.

The question about delivery — we struggle with that because we talked about, a few years ago, about whether we should get into the question of allocation of healthcare resources, for example, tough question. Two reasons why it was difficult, first it was difficult for us to see why we should be able to crack that when no one else has been able to over the last thirty years. So this was about a unique contribution that would want to identify that we could bring.

The second list is about terms of reference. I mean, our terms of reference are based on examining questions arising from new developments on biomedical sciences — in research, sorry, research in biomedical sciences. So we need to anchor our work at some point. Now our trustees of our funding agencies are quite happy about us being free and loose around the boundaries, but I think there is, nevertheless an anchor there which is about developments arising from research and biosciences.

Jim Wagner:

John, and then Anita, I think you'll have the last question.

John Arras:

So Hugh, thanks for a really engaging and very informative presentation. Thanks very much, and I also want to thank you for all these years of work with the Nuffield Council. I'm a long time consumer of your product and —

Hugh Whittall:

I'm standing on the shoulders of many other people.

John Arras:

I think it's absolutely first rate, so thank you. So you mentioned quite correctly that bioethics has been expanding its reach in recent decades. So indeed, bioethics began with a very narrow focus on doctor-patient relationships, the four principles, which I kid my colleague, Jim Childress as being the "Georgetown mantra" of bioethics. So, now you're looking at issues of much wider scope, including global health disparities and so forth. So what I'm wondering is whether and to what extent your working groups have been able to develop an alternative ethical framework that can really encompass the sorts of issues that arise and say public health or global health frontiers. Do you intend to try to

make some headway on that issue in a frontal assault, you know, by trying to self-consciously develop an alternative way of doing things or do you expect that to sort of bubble up from the individual projects that you undertake?

Hugh Whittall:

First, I think it's highly unlikely that the Council will wish to, or try to set down an ethical framework that it will, if you like, use in different contexts. It's very much, I think, certainly for the time being, committed to the notion that, I think, it's something that Tom Murray said that bears repeating and that's "Good ethics start with good facts." And that's where the Council starts. Examination of the facts, of looking at a situation, identifying then which of the ethical considerations that are in play and then setting down within a framework that is applicable there. So I think that the first answer to that question is that it will, I don't think it will look for an ethical framework.

We had a report commissioned by John Harris and Sarah Chan a few years ago to look at the work that the Council has done over the years in working up these ethical frameworks, and what they identified is that the Council has become more systematic about developing its frameworks, but nevertheless, puts up an individual framework for each case. There were some common things, and this is where I think we move on a little bit and this is where we do see some common things. And this question about social solidarity is one that is emerging as a common factor and we've certainly seen it in our dementia reports, in our medical profiling report, we will see it coming through — we talked about it to some extent in our public health report as well, when we talked about community. So some things will emerge and some things will evolve. I think we'll just let that process take its course.

Jim Wagner:

Finally, Anita.

Anita Allen:

Thanks, this has been incredibly helpful. The UK is a multi-national state, multi-cultural society, you have people who are immigrants, whose parents and grandparents are immigrants from Africa, south Asia, India, people who come in from the European off-island continent. So, you have structures or procedures within your council that enable you to take into account the inevitable diversity of opinion and perspective that must come from being in that kind of society. And we're also that kind of society so I'm very curious about whether you've adopted certain strategies for your work that enable you to take into

account these diversities and how that might also bear on social solidarity as a principle within your framework.

Hugh Whittall:

Yes. Thank you; you have saved the really toughest question for last. You saw the photograph of our Council members.

Anita Allen:

Yes, that sparked my question.

Hugh Whittall:

And they are of a certain age and ethnicity and gender-wise it's kind of a little better than it was, but it's still predominantly male. The Council is quite conscious of this and in fact, so to take several aspects of it — I'll try and be brief — in recruiting new members, the Council has a subcommittee that is chaired externally by an independent person who challenges the Council on this very point in terms of its social, professional, ethnic and gender mix. So the Council — but the Council does not want to engage in a tokenistic way of fine quotas and it's working in an environment where there is already a certain imbalance. So I think all I can say in terms of the Council itself: it worries away at it, but with only modest degrees of success. And the same is true if it's working parties.

In terms of gathering up views externally in the course of its work, all I can say is that we do what we can. The Council is certainly committed to being as transparent and inclusive as it can be in trying to reach to get people engaged in its work. Whether it's through our program and work with young people, whether it's through our public consultations where we go out to the media, we try and reach into community groups where we're struggling with questions about how to find representativeness in the opinions we take in. So for example, we've started to have deliberative meetings of members of the public where a representative group, to the extent that we can, will be brought together, but we can't claim that this represents public opinion. That is absolutely not what that can do.

So again, we worry away at that and we do what we can to make sure we reach as wide a community as we can, but I think that we've got a hell of a battle still to go before we can be satisfied with how far we've actually managed to do that.

Jim Wagner:

Hugh, thank you for taking your time to be with us for these two days, we especially appreciate your presentation today and

knowing that we have a new comrade that we can communicate with our continuing work. So thank you again on behalf of all of us ...