

**The Rt Hon Baroness Hayman GBE, Chair of the UK Biobank Ethics and Governance Council
JUNE 2017**

Next up is Baroness Hayman. Baroness Hayman has been a member of the House of Commons. She's currently member of the House of Lords, and she was the very first Lord Speaker of the House of Lords, but her most important job now, the most important one she's ever had in her life is as Chairman of the Ethics and Governance Council. Helene, come to the Platform.

Thank you very much. Thank you Mike. None of that qualifies me for the role of Chair of the Ethics and Governance Council as much as the fact that I too am a participant, and when I went into one of those recruitment centres ten years ago, I did so with a sense that this was something of value, otherwise I wouldn't have done it. Not sure how absolutely clear in my own mind I was that it was going to be of absolutely no value to me myself at that time. I just thought it was an exciting project, and something important to do. I was a blood donor, I was interested in research and medical issues, so this was something to get involved with, and it's quite extraordinary to me that I had no sense whatsoever of what we've just heard, of what actually would be achieved in the ten years since that time. And of course, no sense that I would end up here in this temple to municipal achievement and local accountability as part of the accountability framework for the enterprise that is UK Biobank.

So two years ago I came in as I think the third Chair of the Ethics and Governance Council of UK Biobank. Set up as an independent body, peopled by research ethics experts, by lawyers, by social scientists, by public policy people, by a whole range of different experiences and expertise. And also I'm glad to say that we also create a little bit of a focus group of participants, because I think four of us are participants ourselves, five of us have partners who are participants as well. So every time it must drive Rory and everyone else completely mad, because in 500,000 people the communication is never going to be 100 per cent perfect with everybody. So we're told that something has gone out to everyone, and that someone round the EGC table will always say, 'But I didn't get it'. But that is I think one of our functions. We are there as an assurance mechanism for those with an interest in Biobank's work, whether they are participants, whether they are the research community, or whether they are the public at large who are potential beneficiaries of the work that is done with the resource that is Biobank.

We are there to provide some assurance, so our work in many ways mirrors what you've just heard about the year's activities of UK Biobank. So we're there to monitor in a sense, a sense of being a regulator, of seeing what is happening, assuring ourselves on behalf of all those stakeholders within the potential interest, the interest groups around Biobank that, whether it's data security, the proper scrutiny of applications, all those things are going on, we're also there as a resource for advice, particularly on some of the knottier and more nuanced ethical issues that present themselves. So issues like re-contact applications, issues like third party re-contact applications, issues like the use of tumour samples. I was going to start off this short contribution by saying I'm not going to go through our annual report, because each one of you has got one on your seats. Now as you know the SNAFU as Mike called it, meant that you haven't. I hope that we can find someone, one of those magic bits of money. I thought at one point

that Rory had actually discovered the magic money tree, and was going to ask him about it, because back at the ranch we could do with some advice, but I think we try and make sure that you get the annual report of the EGC, and you'll see the sort of work that we have been doing.

I think all organisations that are charities, that are not for profits, that are public interest organisations, have to try and find their own forms of accountability. Have to reach out to their 'shareholders' and create forms of accountability. So we've been very interested in issues like communications with participants. How do you take soundings from people about what their view would be at a new set of circumstances, a new set of challenges, a new set of opportunities that are presented by developments? And I hope that we perform a useful role as that slightly detached, critical friend, absolutely committed to the success of the enterprise, but also willing to challenge and to ask some of the difficult questions, and some of the idiot questions because they're very smart people at the top of Biobank. And sometimes the idiot questions are the important ones to ask as well. So that's basically how we have operated. There is a document called *The Ethics and Governance Framework of Biobank*, which is very much owned by UK Biobank, and the responsibility for behaving in an ethical way with good governance is that of Mike and the board and the staff of UK Biobank. It's got to be part of their DNA.

We're there, if you like, as second line of defence. We're not there to do that job for them, because that's essential to everything they do and the way that they operate. I think this year, for us, there was a review carried out by the funders last year, and we're appointed by the funders through open appointments applications, public appointment protocols. That after that review we've had a year working slightly differently from how the council did in the past. And I think we're very conscious that just as UK Biobank is evolving, as the challenges and the issues change for them, we too need to look at how we work, how we translate our core functions, what we do that adds some value to the work of Biobank, how we operate in relation to the Ethics and Governance Framework. How we can do that in the most appropriate way for an organisation that is dynamic, that is changing, that is ten years on and different from how it was set up. So I think we'll be doing a lot of that sort of thinking during the next year.

But I would just like to end by congratulating I think those who had the vision, those who had the altruism, and those who've had the sheer grit and determination to make UK Biobank what it is today. Thank you very much.

[Applause]

[END OF TRANSCRIPT]