

Informed consent for: "The ethos and effects of data-sharing rules: Examining the history of the 'Bermuda principles' and their effects on 21st century science"

**University of Adelaide
Duke University**

Researchers at the University of Adelaide, Australia, and the IGSP Center for Genome Ethics, Law & Policy, Duke University, are engaged in research on the **Bermuda Principles** for sharing DNA sequence data from high-volume sequencing centers. You have been selected for an interview because we believe that the recollections you may have of your experiences with the International Strategy Meetings for Human Genome Sequencing (1996-1998) will be interesting and helpful for our project.

We expect that interviews will last from 30 minutes to much longer, but you may stop your interview at any time. Your participation is strictly voluntary, and you do not have to answer every question asked.

Your interview is being recorded and we may take written notes during the interview. After your interview, we may prepare a typed transcript of the interview. If we prepare a transcript, you will have an opportunity to review it and to make deletions and corrections.

Unless you indicate otherwise, the *information* that you provide in this interview will be "on the record"—that is, it can be attributed to you in the various articles and chapters that we plan to write, and thus could become public through these channels. If, however, at some point in the interview you want to provide us with information that might be useful for us to know, but which you do not want to have attributed to you, you should tell us that you wish to go "off the record" and we will stop the recording. We will, however, take notes for our own use. When you are ready to go back "on the record," we will resume recording. Anything you say while "off the record" will not be on the audio recording and therefore will not appear in the transcript.

All *materials* from your interview (audio recording; transcript; interviewer's notes) will be available only to members of the research team affiliated with this project, unless you consent to their wider use, as described in the paragraph below. The digital materials will be maintained in a secure, HIPPA-compliant drive at Duke University. The paper materials will be stored in a locked cabinet.

In addition to the scholarly articles and chapters that we plan to write, we also hope to create a resource for other scholars and members of the public. We plan to post some of our research data to online digital archives. While we will use your "on the record" comments to inform and write our articles, we will not post your interview transcript or audio recording online unless you give us permission to do so, in a separate agreement. At the time we send your transcript to you for review, we will also provide a consent form asking your permission to post your interview transcript and/or audio recording online. The form will provide you with different options for how, when, and with whom the materials may be shared. You will, of course, also have the option not to share the materials beyond the Duke and Adelaide researchers.

One risk of this study is that you may voluntarily disclose identifiable information that later could be requested for legal proceedings, or otherwise be used against you. Please take this into consideration when you are speaking. There may be other risks associated with your "on the record" views being made publicly available, such as having your views mischaracterized or misunderstood.

The main benefit of participating in this study is ensuring that your side of the story is properly portrayed in this history of the Bermuda Principles, which have become a model for open and collaborative research in genomics and other fields.

To help us protect the privacy of those parts of your interview that are not public, we have obtained a Certificate of Confidentiality from the U.S. National Institutes of Health. With this Certificate, we investigators cannot be forced to disclose information that may identify you, even by a court subpoena, in any U.S. federal, state, or local civil, criminal, administrative, legislative, or other proceedings. We researchers can use the Certificate to resist any demands for information that would identify you.

The Certificate cannot be used, however, to resist a demand for information from personnel of the United States Government that is used for auditing or evaluation of federally funded projects or for information that must be disclosed in order to meet the requirements of the federal Food and Drug Administration (FDA).

A Certificate of Confidentiality does not prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research. If an insurer, employer, or other person or institution obtains your written consent to receive research information, the researchers may not use the Certificate to withhold that information.

Signature Francis S. Collins

Printed Name Francis S. Collins

Date 12 April 2012

If you have read this form in its entirety and agree to the interview and its terms, please sign and date above.

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If you have any questions about your rights as a research subject, you may contact the **Duke University Institutional Review Board** at 919-684-3030 or ors-info@duke.edu.

PLEASE FILL OUT AND RETURN THIS FORM TO: Center for Public Genomics, Duke University; c/o Susan Brooks; Center for Genome Ethics, Law, and Policy; 304 Research Drive, Box 90141; Durham, NC, 27708. **OR:** You may fax it to us at (U.S.) 1-919-668-0799.

Interviewee Information. Please list an address where we can contact you.

Full name: Francis S. Collins Date of interview: 4/12/2012
Current institutional affiliation: National Institutes of Health
Street Address: One Center Drive, Bldg. 1, Room 126, Bethesda, MD 20892
Phone: 301-496-2433 Email address: collinsf@od.nih.gov

Interviewer Information.

Full name(s): Robert Cook-Deegan
Affiliations(s): Duke University

I, the undersigned, have read the above, and I **AGREE** to release my interview materials, subject to any restrictions listed below:

(A) I place **no restrictions** on my interview materials.

OR

(B) My interview materials may be reviewed, used, and quoted by the researchers affiliated with the Center for Public Genomics, Duke University; *and in addition* (check all that apply):

- Researchers unaffiliated with the Center for Public Genomics may **read** the interview transcript and any related documents only after obtaining my permission.
- Researchers unaffiliated with the Center for Public Genomics may **quote** from the interview only after obtaining my permission.
- Researchers unaffiliated with the Center for Public Genomics **DO NOT HAVE** my permission to **read or quote** from the interview.

Posting interview materials to public digital archives: In spite of any restrictions listed above, I give permission for my interview materials to be made publicly available on the Internet by deposit in an institutionally affiliated archive:

- 1 year from the date of this form
- 5 years from the date of this form
- 10 years from the date of this form
- 25 years from the date of this form
- After my death
- Other: _____ (please specify a date or condition)
- NEVER: MAY NOT BE DEPOSITED IN A PUBLIC ARCHIVE

Please specify any further restrictions in the space below:

Signature: [Handwritten Signature]

Date: 5/29/2013

Interviewee: Francis Collins

Date, location, method: 12 April 2012, Bethesda, MD, in person

Interviewers: Kathryn Maxson, Robert Cook-Deegan

KM: All right, we are on the record with [FCollins] and we have [BCD] and [KM] and Calvin Jackson here. And we are in Washington, D.C. Well we're not really in Washington, D.C.; we're a little bit outside. How do we want to get started?

BCD: So just for the record, [FCollins] signed and gave us the informed consent. We went over the ground rules for disposition of the transcripts and the interview will now start.

KM: We have several questions for you. We are writing a history about the Bermuda Principles for rapid release of DNA sequence data for the human genome project, as you know. And we're looking into the social, political, and scientific history of those meetings in Bermuda from 1996 to 1998. And how they've been interpreted in retrospect and applied to other areas outside of genomics. So we have four questions for you. And the first one is, Michael Morgan was the planner of these meetings for the Wellcome Trust, and we were wondering how much the two of you discussed what became the rapid release norms before that first meeting, if at all, and to what extent you did.

BCD: Or how you were thinking about that part of the issue, because we have this long agenda about everybody's going to report how much sequencing they're doing, what are the standards, the mapping stuff. Then there's this segment at the end that's set aside for data sharing principles. What were you thinking was going to be the discussion going into the meeting?

FCollins: Of course there are parts of this that I'm pretty clear in my mind about, especially because I found my own notes from the meeting. They're all here because when I left the role as director of the Genome Institute I spent the month after I had actually ceased being a government employee going through all the files and trying to archive the things that I thought someday people might find interesting. And this was certainly on that list. And so I was able to retrieve those. For things that I have my own notes to that occurred at the time I'm pretty clear by looking back at those exactly what happened. Things where I don't have notes it's much harder to recall. And of course one always wants to put oneself in the best possible light so you have to factor that into anybody's recollection of those times.

In 1996 I had been director of the National Center for Human Genome Research at that point for three years. Clearly a lot of the activity that had gone on in those three years was trying to get human genome sequencing ramped up a bit. But a lot of it was focused on model organisms, anxieties about whether the technology was up to the task and then building genetic and physical maps of the human genome. But certainly Michael Morgan and I had gotten to know each other quite well by then and had frequent interactions about this or that issue. A lot of the issues at that point were perhaps more about who was going to be responsible for which part of the territory, and that certainly was a major topic of conversation at all three of the Bermuda meetings. It always seemed a little silly in the first

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meeting that people were worried about colliding with each other. I was fond of telling the story about an African country where there were exactly two automobiles in the entire country and they managed to crash into each other. Which sort of seemed like the kind of circumstance that was being proposed. But I think it's fair to say there was from the beginning as human sequence was starting to be produced this issue about who gets to play with it and how long does that playing get to go on before others who might want to see this information get access to it. And there were opinions about that. And so I can't recall exactly what was the conversation about having this session, about the possibility of some data access debates. But I'm quite sure there was one and that that was part of the plan for the agenda. And the agenda was established jointly between Michael and myself, in my case depending a lot on Mark Guyer, who was a critical part of this. I don't know if you've talked to Mark.

BCD: We did a joint interview with Mark and Jane.

FCollins: Good, good, because they may have recollections about details that have left my mind. So yeah, it was intended to be a discussion. I don't recall expecting though that in that first Bermuda meeting, 1996, we would actually arrive at a conclusion that people would sign onto. That very much seemed to happen on-site. Something that I was delighted about but I don't think had quite expected would get that far.

BCD: So you have this really interesting background because you got into this as a human geneticist who was used to doing the old human genetics, which meant building pedigrees and mining them for years and years and years, and that's your valuable research resource. And you know better than I do what the norms of sharing in that community were, compared to this other seeming extreme of the nematode community. And we should mention that Rachel Ankeny from the University of Adelaide would love to be here. She's working with us on this. And her work as a historian of science and philosopher of science has been in the nematode research community.

KM: The history of that at the LMB and Sydney Brenner, yeah.

BCD: So that's why she's working with us on this because it seems like there's this other community that becomes kind of the model for how the human genome should be as opposed to how human medical genetics had been done. And of course you're in this intermediate space where you're using tools of molecular biology and whiz-bang high tech DNA stuff that is somewhere between those two communities and is borrowing from both of them. So your sympathies seem to be over here with the, get the data out there, let people play with it. But what's your perspective on that?

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FCollins: That was an evolutionary process for me. In that regard I think one of those defining moments for me was as part of the search for the Huntington's disease gene. I was part of that group of seven laboratories that labored over the course of ten years to try to track down the cause of that dominantly inherited degenerative neurological condition. And as we got to the point in Huntington's of having a pretty good idea of where the likely mutation was located, at least within a couple of megabases, there was a need to begin to do sequencing. And one of the collaborations broached was with John Sulston. The Huntington's group had developed something of a cosmid contig and this could now be turned into a sequencing project that would help identify candidate genes.

And John's very clear statement was, yeah, but we have to make the data available to everybody. There was quite a debate about that amongst the group. And I have to say that was the first time for me as a gene hunter in the human genetics community that this immediate access had been proposed as a requirement of collaboration. I was a little taken aback by it because we had other competitors who were out there in the big world. But ultimately it, with a bit of pain and suffering on the part of everybody, seemed like the right thing to do. That was maybe for me then a sort of transition point of saying, okay, you do want to encourage people to do research and you don't want to therefore take away their sense of joy and passion about the search and dilute it in a way that they begin to feel it's no longer worth it because anybody else could do this too. But at the same time the sequence data alone is probably not a sufficient reason to say that dilution has occurred. Then certainly as you begin to talk about sequencing—not just a few cosmids that might contain the Huntington's mutation, but large swaths of DNA about which you know very little and want to know more—the argument about delayed release completely seems indefensible. But even in a circumstance where you care a lot it seemed to me by about 1991, 1992 the pendulum was swinging strongly in the direction of there's no justification for holding onto this.

BCD: So what's a world look like that's built on the rules of ... so you're involved in all these incredible races, right? You're in CF ...

FCollins: I did seem to be in the middle of them.

BCD: ... Huntington's, BRCA ...

FCollins: Neurofibromatosis.

BCD: So what's the world like if instead of the John Sulston and Bob Waterston view of data management it evolves in some other way that's coming more out of the mainstream of medical genetics? What do you think the world would have looked like without this set of pretty strong norms of prepublication data release?

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FCollins: Oh, I think that would have been a really unfortunate outcome. It would have slowed things enormously because I think we, at that point, overvalued the sequence information and undervalued the interpretation of it. And now in hindsight of course we can see that. It's a click of a mouse to get that sequence and that's what it should be. And the idea that the sequence itself was the most important part of a biological experiment now seems sort of indefensible. But at the time because it was what you did, it was what you spent your time on, focusing on your cosmid contig and your reads and trying to get your gel-based sequencing machine to produce something you could actually interpret that didn't have a lot of mistakes, it loomed large as a big part of the science. When in fact it was kind of maybe not so large after all. It was a technical hurdle you had to overcome but it was not the thinking part. It was not the biologically important part. It was a means to an end. And we got maybe too focused on the means because it was what we spent our time on.

KM: So how did the process work going from the 1996 Bermuda meeting to around 1997 when rapid release became both formal policy for NHGRI and also for a condition on grants, sequencing grants for the human genome project for releasing data? How did that happen?

FCollins: Well let's talk a minute about 1996 itself. Again having that conversation, and probably others have walked you through this, it was on the schedule to be discussed at the end of the day, but it actually got brought up in the middle of the day in a fashion that wasn't quite planned for. And John and Bob wanted to have an initial sort of, let's see how we think about this. Interestingly, I'm pretty clear my memory is right here, at that point there was a general sort of favoring of the idea. But there was not a complete unanimity, in part because Craig Venter was still there. He left in the middle of the afternoon and that may be why John and Bob felt they needed to bring it up before anybody departed. And then when we returned to it again, that's when the actual language got put together. That's when it was up on the whiteboard. The picture of that you've seen in John Sulston's book. That's when this ...

BCD: I have actually used the photograph of [FCollins] pointing to it [the white board] at the GenBank 20th anniversary meeting. It's a great profile, pointing up to it.

FCollins: Well it is cool. I mean I've gone back to my notes. I have my own handwriting here, "aim to have all", and there's various scratches here as we were revising on the fly, "all human primary genomics sequence from large-scale sequencing centers freely available and in the public domain" ... that part added ... "for both research and development in order to maximize its benefit to society. Primary means in the absence of additional experimental information about function or diagnostic utility. We endorse the principle"... I'm not sure this got attention ... "the genomic sequence in the absence of any experiment, any additional experimental information about functional or diagnostic significance is not an

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appropriate subject for patent protection”. All of that endorsed unanimously, I say here. And I remember at that time realizing looking around the room that most of us in the room had no authority to make this decision on part of whoever it was that was actually pulling the strings. I maybe did, although I'm not sure I did. But there were, for instance, the Japanese. The scientists were there but their funding agency wasn't. And their funding agency had trouble with this, as you may know, and ended up having to be chastised in a letter that Ari Patrinos and I wrote.

KM: Oh, so that was another question. Was, if there was pressure put on the scientists from particularly France, Germany and Japan? If there was, how did that happen?

FCollins: Well in some instances it happened rather explicitly. I think it was particularly with the Japanese. By the time we got to the third meeting where there was ... yes ... Dear Professor Matsubara.

BCD: Oh, it was Kenichi Matsubara?

FCollins: Kenichi was the person that Ari and Michael Morgan and I wrote to, and reminding them that there was a re-endorsement of the Bermuda Principles in the third meeting in 1998. And yet it was clear that there were Japanese groups that were not adhering. Only Professor Sakaki appeared to be adhering to the policy of rapid release of unfinished DNA sequence contigs. The other three centers apparently did not do this. “As representatives of three major funding agencies involved in the human genome project we would like to take this opportunity to urge you to use your influence, Kenichi, in the Japanese scientific and government communities to encourage large-scale Japanese genome research to come into compliance with current international guidelines.” So that was about as heavy-handed as one could be in what was supposed to be a friendly ...

KM: Right, right. So that was only to the Japanese.

BCD: And was this to Matsubara in his role at Osaka U or ...

FCollins: There was a big debate about whether he was the right person to write to. Yeah, it's addressed to him at the Institute for Molecular and Cellular Biology at Osaka University, I think because he was considered to be the most influential.

BCD: So this is actually helpful to us because we didn't know that he was even in the loop. And we have not interviewed Kenichi. So maybe that's an addition. That's one of the questions we were going to ask you.

KM: Yeah, we have interviewed Professor Sakaki, and Professor Hattori is speaking with us via email. But we haven't interviewed ...

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BCD: Well he wasn't at any of the meetings so he wasn't on our list. But he was certainly the maven of their human genome project in the early days. I didn't know he was still doing that in '98.

FCollins: One had the sense that he had a lot of influence.

BCD: So that's something for us to follow up on.

FCollins: Yeah, so my notes from the data release discussion in 1998, going through center-by-center, there were also tensions with the Germans with Andre Rosenthal.

KM: In 1998.

FCollins: And with the French, and with the French. Fifty percent of the French data was adhering to Bermuda: their work on chromosome 14 and 3. But then they said, '50 percent of what we're doing are collaborations where projects are submitted, [but] there's a scientific community that evaluates and prioritizes,' [and] they do not necessarily feel bound for that purpose. Oh, yeah.

BCD: So are you having informal discussions with the folks who are at these meetings in your role as NHGRI director?

FCollins: Absolutely, yeah. I think the letter was sort of a last resort. You wouldn't want to put something like that down on paper, especially in a way that might embarrass a group of scientists who are particularly sensitive to embarrassment, namely Japanese, unless you had failed otherwise to get attention.

BCD: So now you alluded to the patent clause. So in the air at that time we've had these incredibly public discoveries of BRCA 1 and 2 linked to probably the biggest gene patent controversy there has ever been. Still is.

FCollins: Still is; ain't over.

BCD: Is that what's in the air, or is it the legacy of the EST patent controversy and Craig is in the room? Do you know if during that discussion about patent stuff, Craig was in the room? Or was it just Mark Adams?

FCollins: Let me see whether the first conversation even had comments about patents or that was the second one. It does, yeah, okay ... so I've just marked as interlude, Bob and John, "timing of data release immediate in 1 kilobase contigs." Two, "no patenting of genomic sequence without functional information." There's a little bit of a caveat there. Three, "genes should be freely available for research work." That was a Tom Caskey interposition and I'm not quite sure what that meant. And then in a margin in my handwriting I have, "I think we agreed." Which is another reason, again, I have to be careful not to overstate my role, but I'm pretty sure that

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because of my uneasiness about whether we had actually agreed to something that's why when we came back to it we made sure it got written down and everybody had a chance to say, yes, I agree to this or no, I do not. And maybe I talked to Bob and John about the need to be more explicit about the agreement. Yeah, you're right, by the time we got to the second discussion Craig had left and Mark Adams was, I assume, still there. I don't recall.

BCD: Yeah, he was there. He remembers that. What he doesn't know is what Craig knew when he left. So Craig's going to be one of our last interviews.

FCollins: That'll be interesting.

BCD: Yeah, assuming it happens at all.

KM: So you're having these discussions with the French and the Germans from '96 to '97 through to '98. And you send this formal letter to the Japanese, but there wasn't a letter sent to the French or the Germans as far as you can recall?

FCollins: You know, if there were would I have had it in this collection? I mean, I didn't remember the letter to the Japanese until I pulled all this stuff out. And there might be other letters that didn't make it into this particular set of files.

KM: And Ari Patrinos read this?

FCollins: Oh wait a minute, wait a minute. Dr. Frank Laplace, Germany.

KM: Yes, he's the guy from their research ministry.

FCollins: Right, FMRT, so, yeah, Federal Ministry for Research and Technology. So yeah, this is a letter. This one's signed by me and Ari Patrinos, not by Michael Morgan ... don't know why ... dated March 21, 1997.

KM: And that's to Frank Laplace?

FCollins: Right. So this is following up on the second meeting, the 1997 Bermuda meeting, reiterating that attendees reaffirmed how critical it is to the integrity and success of the international human genome project that human genomic sequence be rapidly released without prior exclusive access to it on the part of anyone. "We are writing to confirm that the National Human Genome Research Institute and the human genome program of the Department of Energy agree with this principle and have adopted policies to implement appropriate rapid data release practices." It goes through what the arguments are for this. "For this reason we are disturbed that the policy of the German human genome program and the BMBF, as we understand from its description at the international strategy meeting, allows German industry restricted access to the pre-finished sequence data for a three-

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month period before the finished data are released to the public nucleotide sequence databases. We are convinced the support enjoyed by the human genome project in the United State and elsewhere in the world is predicated on the assumption that no one will have access to the sequence until it is publicly released for all to work with. We are concerned that the BMBF decision to limit access to the sequence produced by the German genome program may lead to erosion of that support and potentially to subsequent calls for protection of the sequence produced in this country and perhaps elsewhere.” It's I guess fairly strong language here.

BCD: This is activist [FCollins], isn't it?

FCollins: Yeah, that's my name there. So yeah, and I don't have a response nor do I think there was one. But it does seem that ultimately the principle was accepted. Otherwise the genome project would not have succeeded in the form that it did.

KM: Right, right. So then going back to the period after that first meeting, here in the U.S. how did that work in terms of policy translation here at NIH?

FCollins: Well it was pretty clear we were an example of a funding agency supporting researchers who were also present and who all agreed. So having agreed that this was going to be the policy, we felt it was pretty obvious what to do, namely implement it as a condition of our grant awards and make it clear to our grantees that this was the expected outcome. And again Mark and Jane probably could tell you more about exactly the steps that were involved in making that a reality. But I think at that point since the people we were imposing upon had all been part of the decision there was not a lot of objection.

KM: Was there any complication due to Bayh-Dole?

FCollins: Oh, goodness, did we have to get a declaration [DEC] of exceptional circumstances for this? I don't recall it. That would be what you would have to do if somebody raised a ruckus.

BCD: I think I know the answer to that.

FCollins: There was a DEC?

BCD: No, I think Becky looked into it when she wrote her piece with Arti Rai and I think they concluded there never was a DEC. And if anybody had pushed back they both know what would have happened.

KM: So this is Becky Eisenberg?

BCD: Becky Eisenberg ...

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KM: In 2000?

BCD: ... wrote a paper on this ...

KM: That's their 2000 paper? Okay, and so there never was ...

BCD: They didn't find one. There's a written record when you do one of these.

FCollins: Yeah, if there had been one you should be able to unearth it, and I don't recall it. So I think at that point it was a voluntary agreement amongst the funding agency and the grantees and there was no need therefore to go to some legal efforts. And apparently the institutions where the centers were located didn't object either.

KM: Right, right. Craig question?

BCD: Yeah, so one of the other questions that you're probably uniquely in a position to answer is by 1998, the last of these three meetings that happens in Bermuda, the discussions have begun to happen between Tony White and Mike Hunkapiller and Craig about the possibility of what becomes Celera. But nothing's agreed. As far as I know, the public announcement happens in May.

FCollins: In May, right.

KM: Yes.

BCD: Is there any inkling going into this last meeting that any of this is going on, or is this ...

FCollins: No. I have to say I remember being puzzled that TIGR focused on chromosome 16. They had always made noises that they were going to be very bold and they would sort of outrun everybody else in terms of their development of sequence capabilities, but they had been very sleepy in their contributions for six months or so before that Bermuda meeting. And they were clearly missing milestones and not adopting some of the newer ideas that some of the other centers were following. It was like, what's going on here? And now in retrospect, it was pretty clear they weren't paying that much attention to their NIH grant anymore because their focus was on this next big thing. But nobody knew that. I don't think there were even rumors about that at that point. And yeah, I have to say, when I got that particular phone call that Craig would like to meet me on a certain Friday because he had something he wanted to tell me about and he had a surprise guest, I really didn't know what I was walking into in the Red Carpet Club at Dulles Airport. The surprise guest was Mike Hunkapiller.

BCD: And this was while they were doing their exclusive with Nick Wade and before that's happened?

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FCollins: Well presumably Nick Wade knew all about it because the published story was that Sunday morning and this was Friday. And I was on the way to California to give a talk at some scientific meeting. And I ended up riding all the way out to California with Mike Hunkapiller sitting side by side trying to figure out, oh what the hell is going to happen here with this new development? And that was interesting.

BCD: A memorable plane trip.

FCollins: It was. That was, yeah, unexpected.

BCD: So back to this patent thing, do you have a sense of what was it that was driving it? Is it the EST thing or is it the shadow of BRCA? Or is it all these things?

FCollins: I think it was all of that. Certainly ESTs at that point were pretty hot. In '96, my gosh, by that point Bill Haseltine was saying, I own all the expressed sequences, and the Merck effort to try to produce public domain ESTs was getting going. So all of us had been embroiled in trying to wrestle with the consequences of the land grabs. And certainly those who were on this side of it felt this had been a big mistake and let's not make that mistake again.

BCD: So what was our other specific question? There's one that I'm missing out on.

KM: Well those are all four. But I'm interested in your perception of the Bermuda Principles and how they've been interpreted in retrospect. Do you think that these principles changed science kind of from the inside out? Are they changing science? What is your perception?

FCollins: Fundamentally and irreversibly, yes. This was a signature moment. In fact I think in many ways when people look back at what was the most significant contribution of the public human genome project they might well conclude it wasn't just the data. The data would have come out eventually. It was this change in the ethics of how you do this kind of project. The idea that if what you're generating is intended to be a resource for the community then there's no excuse for holding the data back for any longer than it takes to be sure that it's not full of errors. That was pretty radical. And this was not just at publication because there were plenty of people who weren't even living up to that. But it was wildly prepublication, years in this case, prepublication. That set the standard for what many people probably now take for granted—that if you are involved in the 1000 Genomes project or you're involved in the ENCODE project or the Cancer Genome Atlas project, all of which are examples of projects that generate data for a broad community to use, that if you're holding your data back you're a bad guy. That this is no longer acceptable. That the only pathway to justify such a program because you're spending taxpayers' dollars on it, is to make the data available.

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Interviewers: Kathryn Maxson, Robert Cook-Deegan

That is a profound change, and the Bermuda Principles really started that, and I think continues to ripple through many communities now.

Because of its profound difference here in terms of the private effort to sequence the human genome, the Bermuda decision also made it possible for people to understand that business plans going forward that produced that kind of data and restricted access to it were not going to be scientifically acceptable or financially viable. That whole category of mischief essentially got wiped away by this. And again, I think when people were talking about what's the difference between the public project and the private project during that awkward couple of years about the race for the human genome and lot of focus was happening about who had a yacht and who had a motorcycle ...

BCD: Who was that, I can't remember. [Laughter]

FCollins: ...and other silly things about whether there was a profound difference in the shotgun approach versus the map as you go. The real difference was, is the data accessible or not? That was the profound difference between the two programs. And oftentimes that was missed by the people commenting on it. I think history would say the right decision was immediate public access. And it is pretty striking that that decision was arrived at so early. You could imagine another scenario where maybe in a defensive mode the public project was forced to public release in order to distinguish themselves from a commercial challenge. And there may even be people who think that's what happened. But you all know in 1996 ... at that point there was no expectation that a commercial challenge would happen. There had been of course Rick Bourke back there a few years earlier, but that had gone away. There had been Wally Gilbert; that had gone away. Everybody assumed that nobody in the commercial world was going to do this. It's just too painful unless they're supported by public funds. And yet the Bermuda decision was made because it was the right thing to do. And it has set the stage for everything that's followed now for some 16 years, is it? Maybe more? And more to come.

BCD: So I gave you kind of a simpleminded historical thread that says the nematode is the model that becomes projected onto the human genome. Is that too simpleminded? Or ...

FCollins: I think it was a very important pilot of this idea of immediate public access. And it fit particularly well with the community that had that attitude already. So it was a factor I think in supporting the importance of following that same pathway for the human, but I don't think it was sufficient. I think there had to be other factors driving this as well, which came from other directions. And some of it was the sense of anti-patent fervor because of the concerns that that was tying up the future and a sense that the best way ... it was probably a little naïve but it wasn't too bad ... the best way to fight off claiming everything as intellectual property is

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to put it in the public domain right away, and then it's prior art. So that was clearly a motivator that didn't come from *C. elegans*. That came from not wanting to have our shared inheritance owned by some patent holder.

BCD: So in this EST patent ...

FCollins: And I am going to have to break off in just a couple minutes to do something.

BCD: My question is not ... it's actually just an embellishment.

KM: So just very quickly, we're writing both a history paper and I'm writing also a history of policy paper, which is why so many of my questions focused on that. And we've submitted several FOIA requests for notes and other correspondence. But we don't have ... I think we have seen your notes from 1996, but not from the other two meetings, and we certainly haven't seen the letters that you mentioned. Are those fair game?

FCollins: I would think they are.

KM: Yeah, and so what's in there are your notes and also the scans of the letters, things like that?

FCollins: Uh-huh.

BCD: That would be really, really helpful. This is what's going to get [KM] into graduate school.

KM: You have all now been inducted, just so you know, against your better judgment, into the get [KM] into graduate school club. It's a very exclusive club.

FCollins: I hope it works. You should have thought more wisely about whom you asked to help you. [Laughter.]

BCD: She knows that part already.

KM: Well he's not in the club. You, however, are expressly invited to the club. And I'll have you know that I have an entire cadre of friends who say hello, even though you've never met any of them. But they knew that we were coming here to talk to you.

BCD: In fact, we have a Tar Heel who works with us who is absolutely dying to meet you.

FCollins: At Duke?

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BCD: She's going to go to medical school and she may go to UNC. She's our other researcher, Lane Baldwin. At some point I'll get you guys in a room together. Because she is totally in awe. She's so envious that we're here.

KM: Well wonderful, thank you so much.

End of recording.