

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 Mark S. Fey Jane L. Peterson
Printed Name MARK S. FEY Jane L. Peterson
Date 8/18/11

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.*

From: Kathryn Maxson [<mailto:kat.maxson@duke.edu>]

Sent: Thursday, July 11, 2013 4:45 AM

To: Peterson, Jane (NIH/NHGRI) [E]

Cc: Guyer, Mark (NIH/NHGRI) [E]; Cook-Deegan, Robert

Subject: Re: Bermuda Principles interviews

Dear all,

The last bit of work for this is clarifying any restrictions you would like to place on the transcript outside of our immediate research group.

We're creating a public archive of our research materials for this project: <http://dukespace.lib.duke.edu/dspace/handle/10161/7407>.

Would you mind letting us know by email the following things:

A) Whether you would allow this transcript (in your edited form, cleaned up by me) to be posted in our digital archive?

B) And if so, what types of restrictions you would like placed upon it? (I.e., available immediately, available after any number of years, available immediately but no direct quotes, any combination of these things, etc.)

Thank you so much,
Kathryn

On Jul 11, 2013, at 4:32 AM, Kathryn Maxson <kat.maxson@duke.edu> wrote:

July 11, 2013 at 7:37 AM

MG

Mark Guyer <guyerm@exchange.nih.gov>

To: Jane Peterson <petersoj@exchange.nih.gov>, [and 2 more...](#)

RE: Bermuda Principles interviews

Same with me, no restrictions, go ahead and release it.

From: Peterson, Jane (NIH/NHGRI) [E]

Sent: Thursday, July 11, 2013 4:58 AM

To: Kathryn Maxson

Cc: Guyer, Mark (NIH/NHGRI) [E]; Cook-Deegan, Robert

Subject: RE: Bermuda Principles interviews

Fine with me to release it. No restrictions

Jane L Peterson, PhD

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Interviewees: Mark Guyer (A) and Jane Peterson (B)

Date, location, method: 18 August 2011, Rockville, MD (NIH campus), in person

Interviewers: Kathryn Maxson and Robert Cook-Deegan

BCD: Just to mark on the tape, we have the signed informed consent statement from [Interviewee A] and [Interviewee B]. And what I'll do is I'll ask Employee Number Four and Employee tied for Number Five, Six, Seven to explain a little bit about their background and how they came to work at the Office for Human Genome Research before it was the Center, before it was the Institute. And then we'll turn to interview questions about the Bermuda Principles.

Interviewee A: Okay, are we going in numerical order? [Laughter].

BCD: And age before beauty, right?

Interviewee A: Right. So I don't know where you want to start. I'm trained as a bacterial geneticist, did post-docs here at NIH working in bacterial genetics, went to a biotech company in 1980 ...

BCD: Genex?

Interviewee A: Genex. Worked there until late 1985 ... that was all bacterial genetics ... worked there until late 1985 when I was laid off. A few months later got a position at NIGMS as a program officer, starting in spring of 1986. And sometime later, I don't remember the timing, discussions about the nascent human genome project started. The responsibility for that within NIH was assigned to NIGMS. And the first person in GM to work on it was Irene Eckstrand, who had a program in population genetics at that point. Shortly after that Irene went on maternity leave. And so I took over for a while. She came back from maternity leave after a few months, this is between the period of '86 and '88, and reasonably shortly after she came back from maternity leave she was then detailed up to DOE to help them develop their program in human genome. And so after she ... so when she came back from maternity leave she took up the genome activities again, then when she went up to DOE, I was put back on them. And then in 1988 the Office of Human Genome Research was initiated. Elke [Jordan] was hired as the Deputy Director and then they advertised for staff, and I applied and was selected. So that's where I came from.

BCD: And, [Interviewee B], you were right behind ...

Interviewee B: I was right behind him. So I trained at molecular biology in Colorado and then post-doced at Yale and NIH in chromosomal proteins doing 2D gels and things like that.

KM: I like post-doced as a verb. [Laughter].

BCD: With the O'Farrells?

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Interviewee B: Pat was there in my class, yes, at Colorado. And at Yale I worked on viruses as well as continued my work on chromosomes. So at NIH I worked with Wes McBride and we were doing some cloning on genes. And I decided I didn't want to be in the lab anymore and took a job at NSF for three or four years as an associate program director in developmental biology. I learned a whole lot about things I didn't know about before, which is mind-broadening. And then came back and was hired by NIGMS to work as a program director, again in chromosomal ... my portfolio was chromosomal biology, and I had the one sequencing grant, probably at NIH; it was Fred Blattner doing E. coli. So I saw sequencing at its most primitive [Laughter] ... large scale sequencing ... I saw sequencing at its most primitive I suppose too when they were slab gels. And so while [Interviewee A] was doing the genomic portfolio, such as it was, I guess it was genetic mapping probably mostly.

Interviewee A: There were no grants at the time; this was just planning.

Interviewee B: I had the one sequencing grant and I applied for the ... they needed a person to be head of the center [program], a person to be head of review ... and I can't remember what Bettie was head of. Not training ... training, maybe?

Interviewee A: Maybe.

BCD: Yeah, it might have been training.

Interviewee B: And I applied for the centers job ... mapping center and was selected.

BCD: So at NSF were you ... you were a program officer doing both program planning and the peer review?

Interviewee B: Yeah, yeah.

BCD: So you did that for three years?

Interviewee B: Yeah.

BCD: Oh, I didn't know that.

Interviewee B: Which I really liked because I think at NIH you come in and you only get one experience and it's hard to go and get that other experience without interrupting your career sort of. And at NSF it gave me a chance to do both, and I knew I didn't want to do review.

BCD: So and Linda did the review initially?

Interviewee B: Uh-huh.

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BCD: Okay.

Interviewee B: She was head of review for a long time ... ten years, 15 years ... a long time.

BCD: So thank you for giving us some background. So we're trying to understand the context in which the meetings took place in '96, '97 and '98 in Bermuda. So if you could just ... I don't want to put words in your mouth, so if you guys could just ... and it doesn't matter who takes the lead here or whatever makes sense. Why did it happen? What problems were being solved? What was the whole purpose of having the Bermuda meeting in the first place? And what was the state of the human genome project, particularly the sequencing part of it, at that time as you're looking back on it now?

Interviewee B: I would say that sequencing was really not that much of it. It really was mapping when we started. The Bermuda Principles applied to mapping as well as sequencing. Didn't they?

Interviewee A: I don't think so.

Interviewee B: You think it was just sequencing?

Interviewee A: I think it was just sequencing. And it's hard to remember exactly.

Interviewee B: I guess it had to be because Venter was involved and he wasn't doing mapping at all.

Interviewee A: So let me see if I can try and piece it back together. During the mapping phase, say from 1989 to probably '94, there was a lot of attention paid to the organization of the effort, and that ended up being in terms of mapping centers, each of which were responsible for the physical mapping at least of [one] individual chromosomes. There was a whole series of specific chromosome workshops and so forth. So the idea and even culture of this effort as an interactive collaborative activity among groups, none of which had the capacity or ability to do the whole thing developed. And layered on top of that ... when I say none of which had the capacity to do the whole thing, I immediately thought that wasn't true for genetic mapping because Genethon had started to develop its whole genome approaches to genetic mapping.

Interviewee B: I have to say mapping was very hard to get your arms around because there were really never developed any standards.

Interviewee A: no.

Interviewee B: And it never ... the way sequencing eventually came together where there were standards and there were data release policy, and maybe we learned and didn't

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really think about it from the mapping, that we needed to be more [Inaudible - another speaking] about sequence.

Interviewee A: Well certainly, but what I was going to say was that there was a discussion in maybe 1991, 1992 about release of mapping data and NIH and DOE came to an agreement on what was then a relatively radical notion of early data release of mapping data where the data were to be released within six months of generation. So as far as I recall, that was the earliest example, the initiating event of ...

BCD: Where did that happen? Did that happen at those meetings that were happening in conjunction with Cold Spring Harbor meetings?

Interviewee A: No, that happened here. I have a fairly clear mental image of a conference room and I think one of the primary, at least primary discussants in my mental image, is Tony Carrano. But I think that came about because there was this very clear mandate from the beginning of the human genome project that it was for the public benefit that the data were being produced as a public resource and so getting the data to the scientific community was inherent in that.

Interviewee B: It was almost impossible to police. We just never had a good way to know what people released. It was really ...

BCD: Rumor mill.

Interviewee B: ... yeah, and other than what they presented at the meetings, and everyone accused everybody else of claiming they'd done more than was in the databases.

Interviewee A: In late '94 I guess, I mean our plans at NIH had sequencing still.

Interviewee B: That's to say that [Interviewee A] was the foot dragger on sequencing I would say. And I ...

Interviewee A: As I've been on just about everything. [Laughter].

Interviewee B: And I was starting to deal with Venter and his lab, which was at NIH, and they had sequencing machines. And he was, much to [Interviewee A's] irritation, was claiming we could ... maybe this was a little bit later ... claiming we could line up all of these machines and do the human genome. And I just remember how frustrated that made [Interviewee A] because it was so unimaginative. But I don't remember if that was before or after Bermuda. That could have been after Bermuda. Was Bermuda before or after Sulston and Waterston?

Interviewee A: It was after.

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Interviewee B: It was after, okay.

Interviewee A: I think it was in late '94 that Sulston and Waterston came to talk to Watson.

BCD: Is that when the Bourke Initiative ... I'm trying to remember. Bourke was earlier than that, right?

Interviewee B: Oh, the [handbag] guy. Was he sequencing?

BCD: Well he was going to have them sequence the [Inaudible - another speaking] ...

Interviewee B: Oh, that's right, he tried to hire them, that's right.

BCD: That must have happened a couple of years before.

Interviewee B: I think it's about the same time. I think it scared us that they were going to be lured away into industry.

Interviewee A: And I think part of ... and clearly you need to talk to John and Bob about this ... but I think part of their decision making was wanting to know what the NIH was going to do, NIH and MRC-Wellcome was going to do, because this was toward the end of '94. They were convinced that it was time to start serious large scale sequencing that wasn't in our plans at the time before they came to talk to Jim, so I would guess that if the NIH and other funders hadn't agreed that they would start supporting this that they might have gone there.

Interviewee B: Wouldn't that have been weird.

Interviewee A: But they came and talked to Jim and published a paper in *Science* ...

Interviewee B: When they came and talked to our council.

Interviewee A: Did they?

Interviewee B: Oh, yeah, that to me was the big turning point is when the council actually listened and I think they advised ...

Interviewee A: Didn't we do a workshop?

Interviewee B: After they talked to council.

Interviewee A: After they talked to council?

Interviewee B: I think so.

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Interviewee A: We can't remember.

BCD: Yeah, so we should look that up.

Interviewee A: Yeah, so but I think the events that need to be ordered are them coming to talk to Jim and the rest of us ...

Interviewee B: This is Bob and John.

Interviewee A: ... this is Bob and John. We organized a workshop to discuss that and then the presentation was made to council either by Bob and John beforehand, or the results of the workshop or whatever. And that led to the issuance of the first RFA, the first solicitation for large scale sequencing.

Interviewee B: With the understanding ... people were still dead set against it, and this is probably where Venter was lining up his machines, is probably in this context. But no one would have undertaken it if it hadn't been ... especially [Interviewee A] ... if it hadn't been in the context of doing all these model organisms first. We would not do anything on human until the model organisms were well in hand and we had learned how to do them. And of course Frank disagreed with that. What a surprise.

Interviewee A: So that was in 1995, it must have been.

Interviewee B: When was the first Bermuda meeting?

BCD: The first Bermuda meeting is early '96, February of '96. So they happened every year thereafter.

Interviewee B: For four years?

BCD: For three years, '96, '97 and '98.

Interviewee B: I do remember the last one that [Interviewee A] and I decided that this is enough of being in this hotel. We actually hired some of those little bikes and went to see the pink sand. I was sure I was going to kill myself on that little ... they're motor bikes. At one point you started the motor bike with the brake on or something and it goes flying. [Laughter]. We actually got out of the hotel the last time because we knew it was going to be the last meeting. So I remember that.

BCD: Somebody has told us that the weather was apparently always miserable there, right?

Interviewee B: It was never great.

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KM: Well it was February.

Interviewee B: And the sands weren't all that pink.

BCD: But do you remember what problems you were trying to solve or what was the ... why would you have had meetings ... was it trying to get the sequencing part organized?

Interviewee A: I think it was.

Interviewee B: Oh, yeah.

Interviewee A: It was, yeah.

Interviewee B: Because it was international. Was this around the time ... I think we still had mapping centers.

Interviewee A: Yeah.

Interviewee B: When was the big debate of whether the mapping centers were going to be able to transition in the sequencing centers?

Interviewee A: I think that must have been about '97, '98.

Interviewee B: Yeah, that was a big debate for a while, so I guess Lander was in the genometron era and still not sequencing. The sequencers were ...

Interviewee A: Wash U.

Interviewee B: Wash U didn't map at all. Not after Maynard left. Maynard was there for a while. Who else was on the sequencers?

Interviewee A: [Inaudible]

Interviewee B: Gibbs and [Inaudible] and then the Europeans and they wanted to make it international. It was more international than that I would say.

Interviewee A: Gibbs was not the leader of the Baylor effort; it was still Caskey.

BCD: Was it still Tom?

Interviewee A: Yeah. Was Glen Evans sequencing? Bruce Roe.

Interviewee B: Bruce Roe, oh, yes. No, Glen was mapping.

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KM: So where were the mapping centers?

Interviewee B: There were like 15.

KM: Many, many?

Interviewee A: Yeah.

Interviewee B: You'd have to look them up.

KM: Yeah, sure.

Interviewee A: And that's easy to ...

Interviewee B: And the first big automation was the genometron I would say. Wouldn't you? It was this huge PCR water bath and a huge thing that picked the things up and put them from one water bath to another which was a different temperature and you could do I don't know ... Tom Hudson was the man who ran it, so you could find out from him exactly how many samples he could do at a time. I imagine it got completely disassembled and used for something else, but it should have been kept in the museum.

BCD: Yeah, yeah, you should ask Elbert Branscomb about that.

Interviewee A: But I really don't remember where the idea for a meeting like this happened.

Interviewee B: When did Francis come on?

BCD: Well Francis was hired in '93?

Interviewee A: Ninety-three, yeah.

Interviewee B: But Watson was at the meetings.

BCD: Yeah, he was the chair of the first meeting, so he was probably brought back out, I'm assuming, I mean I don't know.

Interviewee B: He was always into international. We went to St. Petersburg in '93 and that was all his doing. And he got ... I actually know when he got fired because he got fired before we went and Francis led that delegation.

BCD: To St. Petersburg?

Interviewee B: Yeah.

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BCD: So Francis stepped in?

Interviewee B: Yep, yep, Jim asked him to take it on, which is interesting.

Interviewee A: Yeah, I would guess that Jim was heavily involved in that as was Michael Morgan. And I don't know, I mean the people that Jim talked to at that point, the Walter Bodmers and those people. I mean they were not at the meeting, but I wouldn't be surprised if discussions among those people were really the genesis of it. But it was definitely on the basis of the semi-chaotic organization of the mapping effort, and sort of each group claiming territory and so forth. This was an attempt to get that under control.

BCD: One thing that that reminds me of that it might be worth also talking about for just a second is I mentioned the Cold Spring Harbor meetings, and I remember very graphically one of the meetings, it must have been the first or the second of those Cold Spring Harbor annual meetings in May, where the genetic linkage map wasn't quite happening. And in typical ... it was probably NCHGR rather than NHGRI at that point ... this ends up in your lap, right, get it organized, get these people talking to each other, let's figure out who is going to do which chromosome. Could you talk a little bit about that process, about coordination and what was doing about genomics compared to other things that you had done at NIGMS or ...

Interviewee B: Well the chromosomes got carved up by grants really, what was funded, except for the ones that were already claimed abroad I would say. But most of them were claimed in the U.S., weren't they? I think there were a couple being done at Sanger?

Interviewee A: Sure.

Interviewee B: Yeah. But I think the chromosome workshops anointed people for particular chromosomes. And certainly initially our centers were formed around chromosomes, not all the chromosomes, but a lot of chromosomes. And then as time went on we saw that that was not benefiting anybody. It was too slow and too cumbersome and too much rivalry.

Interviewee A: And there was also ...

Interviewee B: The failure to release data [Laughter].

Interviewee A: But also the outside driver ... quote/unquote outside driver ... CEPH and then Généthon.

Interviewee B: Yes, yes.

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Interviewee A: Généthon was probably the first automation rather than the genomtron.

Interviewee B: Which I actually ... in NIGMS, what was his name?

Interviewee A: Who are you talking about?

Interviewee B: Who was the driver behind ...

BCD: Cohen?

Interviewee B: Yeah.

BCD: Daniel Cohen?

Interviewee B: What's his first name?

BCD: Daniel Cohen.

Interviewee B: Daniel. He put in a grant to NIGMS to do large scale genetic mapping. And I fought for it. And maybe I shouldn't say this ... this is confidential, right?

BCD: Well we can ... so if we're going to do that, we can do that, but what we should do, just to explain ... we'll zap out that part of the tape, but just so you understand, the stuff that we're trying to record we're going to turn it into a transcript.

Interviewee B: So maybe that should ...

BCD: So let me just put this on pause.

KM: Should I pause?

BCD: Yeah, pause that one ...

Part B

Interviewee B: ... council, not on the NIGMS council, but I fought for that grant. I visited Cohen either before or after, I don't remember which, but I was convinced that they were going to be more automated. This is in GM though, so I can't remember how this all fits in to why you didn't have that grant or Irene didn't have that grant. Maybe it was sequencing. Anyway, Lee Hood said to me a couple of years later, when Genethon was getting ahead of us, that NIGMS gave him, Cohen, a grant several years ago and whoever gave him that grant, whoever fought for that grant, should be assassinated. [Laughter]. And I just kind of went ... [Laughter] ... that it was me. But in hindsight, competition was

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good for the Genome Project all along, no question about it. And so I guess in the end I probably did something good. That's kind of off-subject, sorry.

BCD: No, but that's really interesting.

Interviewee A: So I don't remember enough to answer your question about what were we thinking. I remember in the pre-sequencing days, in the mapping days, I remember spending a lot of time trying to track progress, compiling regular reports that tried to ...

Interviewee B: We were getting lots of criticism. Advisors were saying, You have to have regular reports. You have to be able to track this data or no one is going to be accountable. Everybody was terrified our centers were going to be around forever and not be accountable.

BCD: Because of the dollars?

Interviewee B: And because there's so many centers from institutes I won't mention that have been going on for years and years and years.

Interviewee A: We're not ... [Laughter] no, I mean but Phil Sharp was a particularly strong voice about this issue and was really opposed to NCHGR going into centers on the grounds that once a center got started you couldn't turn it off.

Interviewee B: We proved him wrong.

Interviewee A: Yeah. But Jim's attitude was that you needed the scale of activity and he was perfectly prepared for even the majority of what we funded to fail.

Interviewee B: That was such a different attitude than what I had been brought up in, in NSF and NIGMS. That was a fundamental change. I don't think that we talk about that now in genome anymore, but it was really important to know that your reputation as an administrator was not going to rise and fall on the success or failure of the individual projects, but really success and failure of the overall project.

BCD: So how did that work? How do you make that norm shift? Is it by saying in staff meetings ...

Interviewee B: We started that way.

Interviewee A: No, it started I think Jim Watson said it and all of the sudden it made a lot of sense. If you start ten centers and eight of them fail, but two of them accomplish your goal, you've been successful.

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KM: That's really interesting.

Interviewee B: That was very important. And I don't think we have that going on anymore. That was just really the human genome project for the most part.

Interviewee A: I'm not sure about that.

Interviewee B: Well we don't need to sit here and disagree. [Laughter]. We need to get back ...

Interviewee A: But, no, seriously, I do think we're still thinking in project level terms rather than individual grant.

Interviewee B: Yes, oh, I agree with that. I agree with that. And I agree that reputations aren't made on individual grant bases, but I don't think the idea that failure is okay is something the rest of the staff think about anymore.

Interviewee A: No.

BCD: So again going back, so you get there to Bermuda ... and just from the outside because neither of us was there, all we're doing now is trying to piece this together from the outside.

Interviewee B: I'm surprised you weren't there.

BCD: No, but by then I was gone. I wasn't doing genomics at all at that point. I'd moved on to I was doing mental health policy at that point.

Interviewee B: Which we all should have been doing. [Laughter].

BCD: Well you were actually, you just didn't know it. But it looks like there was a lot of time spent talking about, this is what our center has produced and this is what we're doing.

KM: Yes, yeah, these are our resources, this is what we have.

Interviewee B: Dog and pony shows, right, yes. I remember sort of, especially the Bermuda Agreements, or the first Bermuda Agreement ... which meeting did that happen at?

BCD: That happened at the '96 meeting.

Interviewee B: I remember it happened towards the end of the meeting. Do you remember that?

Interviewee A: Uh-huh.

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Interviewee B: And it happened pretty fast. And I don't know why people thought Craig wasn't going to agree.

Interviewee A: He argued against it.

Interviewee B: He had already shown his cards maybe. But I do remember him grumbling about it and I remember people leaving very quickly. Do you remember that, that ...

Interviewee A: Yeah.

Interviewee B: ... and that was part of the unhappiness is that we agreed to something and left very quickly and didn't have time to talk about the ramifications.

Interviewee A: But it wasn't that somebody tried to ... that we'd agreed to something and then left because we were all running away from it. It was the meeting was scheduled to be adjourned at 12 or whatever it was, and this topic, or this proposal, didn't come up until the end. So it was a sort of race against time.

Interviewee B: But that was because so much time was spent on dog and pony shows.

Interviewee A: But if I recall, the purpose of the so-called dog and pony shows ... I mean obviously there was competitive element too, but it was really to try and grasp what capabilities were, what the landscape was. What really are the realistic opportunities? There's one table I noticed in the text which lists what everybody had done in one column and in the next column what they had said they were going to do. And so a lot of it was to try and get that kind of ...

BCD: The impression from the outside is that it looks like maybe the agenda for this meeting was really trying to get things organized to go upscale, to get serious about sequencing ...

Interviewee B: Serious about not accounting ...

BCD: ... and allocate who was doing what and how much they were actually going to be able to produce compared to what they were going to say they were going to produce ...

Interviewee B: Yeah.

BCD: ... and stuff like that.

Interviewee A: And then there was this tension between agreeing, people said they were going to do something, you have to credit that, you had to say, okay, we'll set that aside for you. But on the other hand, what happens if you don't get it? And how

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long a grace period do you have before it gets taken back and thrown back into the pile?

BCD: So this idea of depositing the data where everybody can see it has multiple functions, one of which is access, but one of which is accountability and signaling the world of what you're doing in your lab so that everybody else can know that so it reduces duplication also, right? So it's got a pragmatic part but it's also got this aspirational, everybody has access to it. How did this idea about very rapid ... so you talked about the precedent of within six months ... this is a pretty big leap ...

Interviewee A: Right.

BCD: ... to the next stage.

KM: So I had a question about that. So you had this precedent that came from mapping and there was this really obvious realization that we need different standards for sequencing and the release needs to be a lot faster than six months. So that was the precedent you were working with was this six month data release for the mapping?

Interviewee A: Yes.

Interviewee B: But it was Waterston and Sulston.

Interviewee A: Yeah. I credit it totally to John and Bob. And so one of the roots of that is the worm community and the culture of the worm community. Another that I remember very distinctly that I don't hear talked about very much is I remember John being up in front of the group and saying, We are going to be given all of this money and that is going to create animosity essentially. People will think you're being given a franchise and you're going to have all this information that you're going to be able to ... and that almost as a defensive position he was saying, we need to release the data so that we're not being accused of hoarding, that we're not being accused of trying to ... what's the British term ... ring off ... create a ring around the area and that if we really want to accomplish this, let's just try and get as much of that noise put aside by releasing the data as possible.

BCD: And how did people react to that? How did that sound to you guys as NIH staff?

Interviewee A: I was happy.

Interviewee B: I probably worried about how I was going to [Inaudible – laughter] because it wasn't clear [GenBank?] was going to help us, but they did, thank heavens. We had no indication coming into that meeting that this was going to happen. We

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did not know about it, so it was completely ... they had been thinking about it behind the scenes. And I don't think Francis knew either, do you?

Interviewee A: I don't. And it didn't come up until the end. I think there had been a reasonable amount of discussion about what was going to be done with the data.

Interviewee B: It would be interesting to know from John and Bob if they had come up with this idea all along and chose to bring it up at the end, or if [Inaudible - another speaking] to them as they were going along.

BCD: Yeah, did it feel like that at all? Was it kind of oh, they're trying to railroad us?

Interviewee A: No, no.

Interviewee B: No. You couldn't tell if they had just thought of it. But they both were so behind it, it kind of felt like they had talked.

Interviewee A: There was another situation in which something like that happened where more in saying that it arose as a result of the discussions, and that was at the Fort Lauderdale meeting, where the notion of community resource came out. That I very distinctly remember there was an ad hoc group that came together the night before the meeting was scheduled to end, trying to resolve this question of credit and ownership of data and things, not legal ownership, but scientific. And that group sat down and out of that discussion emerged ... I don't know anybody who went into the discussion with the idea of community resource, but Geoff Duyk was the one who articulated it in the course of that discussion. I don't know in Bermuda whether it was that kind of process.

Interviewee B: I don't remember any breakout groups in Bermuda at all.

Interviewee A: No, I don't remember any breakout meetings.

BCD: But on that point, I mean it's nice that you raised the Fort Lauderdale, was the Bermuda Principles, Agreement, Rules, whatever, was that cited as a precedent?

Interviewee A: In Fort Lauderdale?

BCD: Yeah.

Interviewee A: Absolutely, absolutely. Fort Lauderdale was essentially considered a follow-on to Bermuda to deal with the newly emergent at that point problem of dealing with whole genome sequences. That hadn't been part of the sequence assemblies, I should say.

Interviewee B: So was it Fort Lauderdale where the two Kb assemblies came out?

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Interviewee A: No, that was Bermuda.

Interviewee B: Yeah, because we had to keep revisiting it as the data changed.

Interviewee A: I think the original [Inaudible - another speaking] ...

Interviewee B: The original was [Inaudible - another speaking] ...

Interviewee A: They were arguing about should it be one kb or two kb, but the idea was that over the course of the discussion the minimal releasable unit kept decreasing and finally it got to the point where people were saying, you're getting so small that you're really talking about releasing individual reads and then they backed off and said there has to be some assembly involved, but maybe not more than a couple of reads.

BCD: So two reads basically is what you had to catch the edges?

Interviewee A: Right.

Interviewee B: Right.

BCD: And that's how you came up with [Inaudible - another speaking] ...

Interviewee B: ... Fort Lauderdale?

Interviewee A: In first Bermuda.

Interviewee B: First Bermuda I mean.

Interviewee A: Yeah, I think so.

Interviewee B: Oh, I thought it was just the single reads and then everyone agreed it was ridiculous and we went to the 2 kb.

Interviewee A: I don't think ... that may have been in the trajectory of the discussion. I don't think it was ever a conclusion that individual reads should be released.

BCD: So just to summarize where we are, from your perspective, number one, do you know how it was decided who was going to chair it? I mean Jim was the chair, but was NIH heavily involved in planning this?

Interviewee A: Oh, yeah. We were, but I think we have to say that the driver in the organization of the whole thing was Wellcome. It was Michael ...

KM: Michael Morgan, yeah.

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Interviewee A: ... but Michael was very conscious of the need and the appropriateness and the value of partnering with NIH. So all of the planning the agenda, all of the logistics of the meeting, except paying for it, were done in collaboration.

Interviewee B: And they paid for the whole thing.

Interviewee A: They paid for the whole thing.

Interviewee B: And the reason it was in Bermuda, you probably know this, is that they didn't want to have it on American soil. Elke didn't want us to be flying off to exotic places. In fact I think the Bermuda meeting stopped because Elke was so concerned that the ...

BCD: It sounded too exotic.

Interviewee B: ... it sounded too exotic. It wasn't. Fort Lauderdale sounded less.

Interviewee A: And Fort Lauderdale actually was less.

Interviewee B: I didn't go to that meeting. I planned the whole thing, but my daughter was ill, so I had to do that instead.

BCD: And what was the feeling of that first meeting? Was it, we're getting down to work here?

Interviewee A: Yeah.

Interviewee B: Yeah, yeah.

Interviewee A: And I remember being in the airport on the way out and the buzz was just palpable. People thought we'd really accomplished something, and that it was a major step that needed to be achieved in order to get this thing going. But the discussion, if I recall correctly, the people who were going back to Washington were continuing the discussion, and Craig and David Lipman were both in the group and were both unhappy about the ...

Interviewee B: I had forgotten that David was unhappy.

Interviewee A: Yeah.

Interviewee B: It doesn't surprise me.

BCD: About the data sharing agreement?

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Interviewee A: Yeah, yeah. And you remember there was the pair of papers in *Science*, Craig and David Bentley, and that was directly derivative of the ongoing unhappiness.

BCD: And when you say there was a feeling of accomplishment, was that more in the way of planning, we're going to get going on the science, or was it a feeling of disagreement about data sharing? Did that seem very significant at the time? Or is that just something that happened and seemed more important in retrospect than it felt at the time?

Interviewee A: I think the major sense of accomplishment was about the organizational aspect of it. But the idea of this 24-hour data release was very energizing.

Interviewee B: Well people were worried how they were going to do it. That was the ...

Interviewee A: But it was not a throw-away.

Interviewee B: No, it wasn't a throw-away, but I don't think the significance was as obvious right there after the meeting. I think the significance grew as time went by.

Interviewee A: And people found they could actually do it.

Interviewee B: Yeah, yeah.

BCD: And so let's fast forward a little bit to so there were two more meetings and it's clear from the agenda on the '97 meeting that there was some pushback on the data sharing, and specifically, for example, from the Germans. And conspicuous silence from the Japanese.

Interviewee B: I was going to say the Japanese must have ...

BCD: So was there any back room politics? Can you say anything about what was going on in terms of the political dynamics or the organizational aspects of ...

Interviewee B: I'm sure Francis put pressure on them. I don't remember any specific conversations, but he was very concerned about it.

Interviewee A: But the genesis was that the Germans were trying to raise money within Germany and were heavily involved in industry as a source of funding and a source of support. And industry wanted first look at the data.

Interviewee B: You still run into that in Europe, with European Union, they will negotiate it away, but the first take on any agreement has that in it.

Interviewee A: The sequencing ...

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Interviewee B: Or the whatever.

Interviewee A: ... genomics as sequencing as a driver of economic development, economic advantage. As you say, the Germans are going to say that and try to stand strongly and at best, the people who were there, Ursula ...

Interviewee B: What was the name of the guy? He had a heart attack later ...

KM: Hans Lehrach?

Interviewee B: No.

Interviewee A: One of the ... oh, the sequencer?

Interviewee B: Yeah.

Interviewee A: Oh, no, I was thinking of the administrators, the people from ...

Interviewee B: Oh, but the sequencer was ... he's a really nice guy, I still see him.

BCD: Not Ansorge?

Interviewee B: No.

BCD: Not the sequencing machine guy.

Interviewee B: No.

Interviewee A: No. But the people from the ministry [Inaudible - another speaking] yeah, yeah, most of the ministries had representatives.

Interviewee B: Did Japan?

Interviewee A: I think, yeah, there were people from Japan at each of the meetings. I believe it was a different person from each meeting as their staff, the ministry ...

Interviewee B: And in China it's always hard to get a consistent one on one between administrators.

Interviewee A: But I think that the two German representatives personally were sympathetic, but were thinking about what they were going to have to do when they got back to say that the rest of these people don't want to go along with what we do. And so I noticed in the minutes that didn't get resolved at the meeting, and Michael Morgan was charged with working with the Germans to find some kind of appropriate language. But correct me if I'm wrong, I think that the group was

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prepared to go ahead with a human genome project with data release and not include the Germans, if they couldn't accept this.

Interviewee B: I mean certainly at some point, and I don't know if it was that point, because I think nobody had the confidence that we could run over parts that people had already claimed, but at some point it became, well if you're not going to do this, someone else is going to do it. And eventually that happened, because a lot of the sequence, as you know, that came out wasn't the quality that was needed.

BCD: Right. So in retrospect, did this feel like it was ... it sounds like it did feel like it was a fairly significant milestone, even at the time.

Interviewee B: The meeting felt like a milestone. And certainly, I mean yeah, the data release, it was ... again, I just don't think that we appreciated how important it was going to be, how it was going to change the field.

Interviewee A: But by the time of the second meeting ...

Interviewee B: I think we appreciated it more.

Interviewee A: ... it was, because that's when I wrote the piece that appeared in *Genome Research* because it was the thought that this needed to have much more widespread publicity and be a very positive statement on the part of this international ...

BCD: And by '97, aside from the Germans, did it feel like it was a well-established norm, the data sharing?

Interviewee A: On paper, yes.

Interviewee B: Yes. Yeah, and getting people ... yeah, getting people to be able to accurately predict what they're going to be able to do, getting them to actually do that and release it all was a continual headache. And when you're dealing with 14 or 15 centers it was really awful. So the simplification in the number of centers made that a lot more ... and the centralization of sequencing was really ...

BCD: That didn't happen until what? Ninety-eight, after ...

Interviewee B: That was another review. Yeah, there was a review ... I can't ...

Interviewee A: I'm sorry, what was the question?

Interviewee B: Probably, we had an awful lot of ... I remember that meeting at Cold Spring Harbor, the day that Jerry Rubin and Craig walked in to tell us they were going to do it. It was in Plimpton and ... oh, what an awful meeting. And there were a

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lot of grantees around that table, so we obviously still had a lot of grant people at that point. And there must have been a competition coming up, because that was when it got simplified a lot. It was an awful meeting.

Interviewee A: Because wasn't TIGR an applicant in that second round of competition?

Interviewee B: We can't tell you all about that. [Laughter]. We should write the confidential history and then when everybody's dead it can be released.

Interviewee A: That's a good idea, good idea.

KM: So what about patenting? Was that an issue?

Interviewee B: You know, when you said something about it at lunch, I was wondering, yeah, it was ... that was more ... came up more when we got to ... well it was certainly coming up because of the patent office patenting sequences.

Interviewee A: And Human Genome Sciences and ...

Interviewee B: But that was later.

Interviewee A: ESTs?

Interviewee B: ESTs ... they were getting patented.

BCD: Yeah, ESTs started in '91.

Interviewee B: Ninety-one, was it really?

BCD: Yeah, that decision was made. The provisional rejection happened in '92.

Interviewee B: Then all the low hanging fruit.

BCD: And it was banded in '94.

Interviewee B: Well certainly Venter's attitude at that point was to only sequence the genes, and that was a big fight as well. And that was probably discussed in the first Fort Lauderdale meeting whether to do the whole genome or not.

Interviewee A: But it definitely in the first Bermuda meeting, the idea of rapid release as a form of an offensive approach to preventing patenting was another major component.

Interviewee B: I know that's part of all this, but I don't remember that it was brought up then.

Interviewee A: I think it was.

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Interviewee B: But HapMap was when they first really made a real legal attempt to prevent patenting and turned out not to be necessary.

Interviewee A: But John ...

Interviewee B: John was so ... yes.

Interviewee A: It was definitely ...

Interviewee B: That's part of his DNA.

KM: So was it explicit?

Interviewee A: Uh-huh.

KM: Yeah, okay.

Interviewee B: It was clearly they wanted to keep it free to public.

BCD: So as you guys are ... I mean you are professional managers of science programs ... are there lessons that kind of come out of this whole process of planning this stage of the human genome project? And how did the Bermuda Principles strike you as being important/unimportant? So both the meetings and the Principles themselves, any lessons to learn?

Interviewee B: Well for that program it was critical. But different programs are going to have different critical decisions that have to be made.

Interviewee A: And the notion of the center ... Genome Institute and other responsible agencies being wedded to the notion of rapid prepublication data release has been a bedrock ever since Bermuda.

Interviewee B: Without the Wellcome Trust coming along with us, it would have been a lot harder. NIH has been the only one that wanted to get it released. But John Sulston being there made it more important.

Interviewee A: And it still is. It's getting harder and harder to figure out what the right equation is at this time between getting data released and ... between the value of data that's released, what kind of data you should release, I mean that's an ongoing discussion. And I think it has osmosed out to a lot of other areas.

KM: It definitely has. My next question was, would you be surprised to note, we've done this really extensive literature search and in a lot of places, way far out of genomics, like weather surveillance and like nanotechnology, where scientists are discussing sharing their data and models for doing so, they always cite the

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Bermuda Principles. I mean I have about 30 papers from the past three or four years.

Interviewee B: And do they adopt them? That's more important.

KM: Yeah, yeah, you know, I'm not sure because a lot of these papers are proposals and ideas...oh, this is an issue for something in chemistry and, look, here are some good models. This is what they did in genomics in the 1990s.

Interviewee B: Definitely revolutionized human genetics. [Interviewee A] and I, as he's saying, it's hard to know when to apply it, where and how to apply it. [Interviewee A] and I are probably the ... well you're in the middle and I think I'm on the far left, but ...

BCD: Far left in terms of open data access?

Interviewee B: Making sure data is released. I've tried to modify my view based on individual investigator's rights to have ... the definition of community resource versus the individual investigator's rights to publish his own data, but I still, I just really worry that with us eventually retiring ...

BCD: That's not going to happen. [Laughter].

Interviewee B: We're going to die with our boots on ... that people are not going to be as concerned about data release and this may have been a bubble that goes away. And it just seems so incredibly important that the less we allow it to filter into individual investigator's research projects, the more it's going to disappear. So I think that I am always pushing that, okay, maybe it doesn't have to be immediate, but let's call it rapid, and say they can have six months. The standard is at publication. A lot of people don't even release it at publication. So I really worry about the slippery slope I think we're on. [Interviewee A] is much more, I believe ... he can speak for himself ... this is an individual investigator's right and it's not a community resource. Why don't you speak for yourself?

Interviewee A: I hate the term individual investigator's rights. This is not a right. And the policy that was elaborated at the Bermuda meetings was very consciously stated to pertain only to large scale sequencing. It wasn't intended to apply to individual investigator initiated RO1 size research grants. And over the course of the years in discussion of policy and things, and certainly in the community, there is the impression that anything genomic, any genomic data, has to be released. And so my foot dragging on that has been to try and remind people that it was a defined policy to apply to certain circumstances where it was eminently appropriate and valuable and things like that, and that as we go along, the balance between how to define the public good of data has to be taken into

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account. Do the data that are produced by an individual who is working on the identification of a specific disease, does that really constitute a public resource in the sense that those data are going to be used by others to advance the whole scientific effort? And in some cases I don't really see the overriding value of getting those data released. I mean I definitely agree with [Interviewee B] that it is desirable for data release to be as rapid as possible. I just don't know that it's something that we can mandate in every situation.

BCD: You have this balance within your own staff of attitudes towards data release, so you're having these debates internally all the time.

Interviewee B: Oh, continually, yeah.

BCD: One issue that comes up, and surely must have come up in this context, was the allocation of credit and reputation and how people advance within science, and that one of the fears of open data release is publication is the way that you get credit, right? So how do you think that actually worked and how did the post-docs and the folks who were running the machines and ... how does it work? Did they do badly by the fact that there was early ...

Interviewee B: Oh, no, look at the post-docs who made their names, oh, my God. Tom Hudson, lots of luminaries came out of that first ...

BCD: And how did that work? How did they get credit?

Interviewee B: Their name is on the paper but I don't think that has ...

Interviewee A: I think in the same way that the initial policy was driven by some of the leaders in the field, those people were well aware of the career needs of the people that were working with them. And I think a lot of it was promoting those individuals who really were contributing in all kinds of ways within the institution. And that having one's name on a paper with hundreds of authors somehow had the effect of having everybody be seen to be a contributor as opposed to ... because this is such a group effort and because it became clear that this would not have happened without a well functioning team, and clearly the groups that were most successful in genomics were the ones that were well managed and well organized and really did function as synergistic teams. I think that participation in that kind of effort was seen to be different than having your name as one of six or eight authors in the middle of a list of six or eight authors on some paper where you don't really have any idea what the ...

BCD: So somehow, just to paraphrase and make sure that I understand, you're basically saying that people kind of know who is doing a good job, which of these centers is well managed, somehow the community knows who is good and

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who is part of a well functioning team and your reputation goes by that as opposed to where your name is listed on this publication. Is that accurate?

Interviewee A: And I think the team leaders did a really good job of making sure that the people in their groups who were making significant contributions of various sorts got the recognition within the community.

Interviewee B: You know what I think would be a really interesting exercise, would be to take the author list and go through it and see where those people are today because I've forgotten a lot of the names but I would be really interested to know how many of them are still in science. I bet a lot, and I bet a lot have done very well. There's probably going to be some dropouts too, but it would be an interesting exercise to see. That was definitely a criticism of the project, these poor flunkies are just monkeys ... isn't that what Watson called Venter? [Laughter].

Interviewee A: And [Interviewee B] mentioned Tom, he's a great example. Rick Wilson, Elaine Mardis, John McPherson.

Interviewee B: Now Gibbs was a post-doc I think.

BCD: Yeah, Gibbs probably started as a post-doc for Tom.

Interviewee A: Right.

BCD: I don't know where he was ... maybe a grad student, probably post-doc.

...

BCD: We will eventually loop back to Francis. We haven't ... he's on our list, but we wanted to do you guys early. We want to do David Cox early because he was chair of ... I don't remember which one of the meetings ... Jim was the chair of the first one, right?

KM: Was it Jim?

BCD: Or maybe it was David Cox. Jim was at the first one, right?

KM: Was Michael chair or just organizer?

BCD: I think Michael is just the organizer.

KM: Just the organizer. So maybe Jim was chair of the first one.

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Interviewee B: David was definitely trying to help me get standards and standard reporting for especially genetic mapping. And the centers just ... they just wouldn't cooperate. They just didn't want to have standards.

BCD: So we're going to try to do David fairly early. We're going to do Ari, although he didn't come in until after the first meeting.

KM: We need to do an official interview with Michael Morgan.

BCD: Yeah, we didn't ...

KM: We met with him in London informally and spoke for like two hours, but it wasn't an interview; it was just information.

BCD: Yeah, and he's probably going to write something up himself. They're trying to do an internal history and create some archival stuff at Wellcome as well. So well thank you so much, guys. This is terrific.

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