

**Informed consent for: “The ethos and effects of data-sharing rules: Examining the history of the ‘Bermuda principles’ and their effects on 21<sup>st</sup> 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 Maynard V. Olson  
Printed Name Maynard V. Olson  
Date 2/28/12

*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](mailto:ors-info@duke.edu).*

**Archiving Permissions Form: “The ethos and effects of data-sharing rules: Examining the history of the ‘Bermuda principles’ and their effects on 21<sup>st</sup> century science”**  
**University of Adelaide**  
**Duke University**

A short while ago, you participated in an interview with investigators engaged in a research project exploring the history and consequences of the Bermuda Principles for DNA sequence data sharing. We have prepared a transcript of your recorded interview. As indicated in the Informed Consent statement for this project, you now have the opportunity to review this transcript and make deletions and corrections.

Your transcript has been sent to you in either electronic format (via Dropbox.com or e-mail communication) or hard copy format (via postal service). Please follow the instructions provided with your transcript when making any changes and when returning the document to us. These instructions are specific to the format in which you received your transcript. If you do not want to make any changes to the transcript, please let us know at the time you return this permission form to us.

In addition to the use of your interview materials in our research, we seek your permission (subject to any restrictions you impose) to place the edited, written transcript of your interview, and any related documents, on the Internet in institutionally affiliated, digital archives.

These archives may include:

- Archives affiliated with the **Institute for Genome Sciences & Policy**, Duke University.
- Archives affiliated with the **Duke University Libraries**.
- Archives affiliated with the **Genentech Center for the History of Molecular Biology and Biotechnology**, a part of the Cold Spring Harbor Laboratory (CSHL) Archives,<sup>1</sup> or
- Archives associated with the **Human Genome Archive** at Georgetown University.<sup>2</sup>

Members of the Duke University community, students, faculty and staff at other institutions, or members of the general public may access these digital archives for purposes unrelated to this research project on the Bermuda Principles. Typical research uses of interview materials include scholarly or other publications, visual presentations (i.e., powerpoint presentations), exhibits, class projects, or websites. However there may be other uses made as well, since the materials will be available to the general public. Investigative reporters and lawyers engaged in or contemplating litigation have, for example, used the Human Genome Archive at Georgetown.

Your permission to post the edited, written transcript of your interview, and any related documents, to a digital archive is completely voluntary. Unless you consent to their wider use, all materials from your interview will be available only to members of the research team affiliated with this project.

The form below provides you with different options for how, when, and with whom your interview materials will be shared. You also have the option, of course, not to share the materials beyond the Duke and Adelaide researchers. In the meantime, all digital materials are maintained in a secure, HIPPA-compliant drive at Duke University; paper materials are stored in a locked cabinet; and steps are being taken (i.e., via layers of electronic password protection of documents) to maintain the security of your materials during exchanges amongst the Bermuda research team and between researchers and interview subjects.

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<sup>1</sup> The Genentech Center at Cold Spring Harbor Laboratories was established in 2006 with a gift of \$2.5 million from Genentech, commemorating the 30th anniversary of the company’s founding. The mission of the Genentech Center is to identify, acquire, preserve, promote, and provide centralized access to the original papers, correspondence, and research materials of the individuals and institutions that were crucial to the development of molecular biology and biotechnology.

<sup>2</sup> The Human Genome Archive at Georgetown University was established in 1988 under a grant from the National Science Foundation, and was long associated with the National Reference Center for Bioethics Literature and other international resources supported by the National Library of Medicine and other components of the National Institutes of Health.

**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: \_\_\_\_\_ Date of interview: \_\_\_\_\_

Current institutional affiliation: \_\_\_\_\_

Street Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Email address: \_\_\_\_\_

**Interviewer Information.**

Full name(s): \_\_\_\_\_

Affiliations(s): \_\_\_\_\_

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: \_\_\_\_\_

Date: \_\_\_\_\_



MOlson: Maynard Olson

Date, location, method: 28 February 2012, Durham, NC, in person

Interviewers: Kathryn Maxson, Robert Cook-Deegan, Rachel Ankeny (via Skype)

KM: We are now recording. And this is [MOlson] we have here, and we've just talked about the informed consent and he's going to sign it and give it to us. And now [RA] is going to introduce herself. We have [RA] and [BCD] and [KM] here.

RA: So, [MOlson], my background is basically in history and philosophy of biological sciences, particularly molecular biology. And I got interested in the topic, this particular topic, in part because I've done a lot of work looking at the *C. elegans* community. And so not surprisingly that brings up all sorts of questions about what makes a scientific community, how do they communicate, what are sort of the explicit and implicit rules under which they function. And Bermuda Principles obviously would be part of, in a way, related to that, not in the least part because some of the actors are the same people, but I think a lot of the motivations people often associate with the Bermuda Principles come out the various organism-based research communities, not only *C. elegans* but some of the others. And so it's a topic I've been interested in a long time. [BCD] and I over the years have talked about needing to do a little more in this domain. And so in the last year or two I decided to pursue this pretty small scale, pretty delimited project. But as [BCD] was saying, I think it's important because there's lots of mists and issues floating around about what went on, how it impacted the research or didn't in that period and then subsequently whether the Bermuda rules have had influence more generally on the ethos of science and the relationship to everything from the open science movement to methods for data curating and credit attribution, specifically in genetics and genomics. So that's how I come to this project. [BCD], is that the kind of thing you had in mind?

BCD: Well yeah, and the other thing [MOlson] should know about you is, [RA] went to St. John's and read great books.

RA: So why is that relevant?

BCD: And then went to ... her training was in history and philosophy of science and technology at the University of Pittsburgh, which is one of the very best academic programs in the world in that area. And the book that she was working on at one time is called *The Conqueror Worm*, and it was the origins of this model organism and why it was significant. And of course you know that story quite well.

MOlson: So the worm sounds like a good topic.

RA: Yeah, it's a better topic with some distance, to be frank. When I first started working on it in the '90s I think it was all a bit too fresh and close and a lot of the actors probably were a bit hesitant to be straightforward about the range of things that had gone on in the whole process. There was a little bit of an upbeat fatherhood kind of story. And I think there's a whole mix. As in any scientific community there's a mixture of things that happened and how they happened and a lot of serendipity and so on. And so probably it's a story that can be told a little

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bit more clearly. I was saying that to John Sulston and Bob Waterston when we saw them. Probably it's a story one can tell with a little bit more accuracy and honesty and probably more interesting with distance. So we will see. That's still in the cards.

So, [MOlson], the script we usually use is for people who actually were at the Bermuda meetings, but we thought it was important to interview you because obviously you were in the mix at the time. There are a few people we're interviewing who are in those sorts of circumstances. And so I just apologize in advance if some of the things I ask aren't quite as relevant as they might be. But I guess the place to start would be, at the time of the Bermuda meetings, say 1996, 1997, just for the record, can you say what your connection was to human genome projects and perhaps then segue into what your awareness was at the time of the Bermuda meetings. What was going on, what was likely to go on and how it might impact your work. So that's a big question.

MOlson: So I guess I was wearing two hats at that time that are relevant. I was an investigator, was director of the genome center at the University of Washington and we were participating in the human genome project and involved in endless rounds of grant applications to support the work. And so I was acutely aware of the investigator's perspective. We were not, neither were nor aspired to be, a really major industrial force in data production. And I think there was kind of a division in viewpoint between what evolved into the G5 centers, the really large data production operations, and the smaller ones. I think we were the largest of the non-G5 centers so it was not a trivial level of data acquisition we were involved in but nothing like what went on at the Sanger or St. Louis or the Broad or those places. So that was one hat.

The other hat, which was in conflict, of course, with the first one, related to my service on a whole series of advisory committees at the NCHGR and NHGRI ... in any event I would have to look deep into my records to tell you exactly what committee I was on at that time. But I was involved either in grant review or in the central advisory committee. In any event I'd had a lot of exposure to the discussion of these issues in the Beltway and was also affected by them in Seattle. That's pretty much a typical story. A little later in the human genome project a few people that were knowledgeable about human genomics, but not in such direct conflict, started to emerge as important advisors. But at that time there just wasn't any pool of expertise to tap into, outside the rather modest number of places that were really trying to scale up DNA sequencing.

BCD: So, [MOlson], just one other context thing that I thought we might inject for this particular interview is, one of the reasons that we wanted to interview you is you're probably the single most cited person who people say, oh you ought to talk to [MOlson] about ... so obviously you had some views that folks who were at Bermuda thought were relevant to the discussions that were going on in Bermuda

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and many of them are a little bit puzzled about why you weren't there. So do you have any insight into that?

MOlson: Yeah, well I think my views were fairly well known. I was an active participant in the genomics community at that time and went to nearly all of the major meetings, and there was a lot of discussion of data release, amongst other things. I didn't go to Bermuda by choice. I didn't like the process that led up to the Bermuda meeting, and I thought that the conclusions were forgone and didn't really see the point in going to Bermuda to engage in futile arguments when the content of what I would have had to say was already well known to all the participants. So that's why I was invited to both of the ... there were two Bermuda meetings?

KM: There were three.

MOlson: Three? I remember being invited to the first one and I thought there was one more. In any event, I just chose not to go because I thought that ... I don't believe still that there was a good-faith intent to discuss these issues at Bermuda. It was a forgone conclusion what would be recommended.

KM: So when you said you didn't like the process leading up to Bermuda, could you explain a little more about what you mean and why you felt this was a forgone conclusion, what was going to happen?

MOlson: Yeah, so it is a little hard to reconstruct. What historians would like you to do, which is to reconstruct with great accuracy things that happened a long time ago, is difficult. And my main point, I suppose, is that these issues were being discussed very actively and had been actually for a long time, certainly several years leading up to the Bermuda meetings. And there I don't think was a lot of uncertainty about where key players stood or even what their major concerns were. And I think it was clear that there was a coalescence of views, perhaps for somewhat different reasons, between Francis Collins and John Sulston and Bob Waterston. And they made it pretty clear what they wanted to happen. Collins will have to speak for himself as to what his motives were, but because he basically controlled the funding in the U.S. it was a forgone conclusion that things were going to develop along the lines he advocated. I think that it was a political alliance between particularly Sulston and Collins. They had very different interests in the issues but they agreed on the data release policies. So I just didn't think that it made much sense to have a meeting out in the middle of the Atlantic Ocean to discuss some issues where we knew what was going to happen and where the positions of the principals were all well known. So I wasn't there and can't speak for whether I would have been surprised at the nature of the discussion, but I was not encouraged by the report that there had been this unanimous endorsement of the so-called Bermuda Principles because I had reason to believe that most of the people there didn't agree with them. So this is a

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suggestive that it was not a discussion that was really aimed at exploring the issues and getting them out on the table.

RA: And as you saw it, what were the issues? Again, I'm asking you to do the rational reconstruction, but in advance, what was your understanding of what was likely to be discussed? There are political issues but then also obviously some practical ones about particular mechanisms for data release, divvying up who was going to do what, and so on. So what particular ... I guess my question is, the process obviously bothered you, and it sounds like for good reason; the substance was also a worry?

MOlson: Yes. As far as the motivations of the key players, and that's what your study is about--and I was not a key player and so my motivations are not so central as I wasn't pushing to make some exceptional set of rules about data release--I think my perception was that what I took to be rather naïve intellectual property concerns were probably the preeminent driver, that there was a lot of concern about gene patenting. I was no fan of gene patents and certainly had no intention of patenting anything, but I thought it was naïve to try to preempt gene patenting by some data release policy that was worked out for the HGP participants. Gene patenting was largely driven by biotech interest in cDNA patents and EST patents and that wasn't what we were going to do. Our strategy for sequencing the human genome would have been the worst possible technical strategy for preempting gene patenting if that was actually our goal because we weren't targeting genes, we were laying a broad infrastructure for producing a high-quality genomic sequence many years in the future. So I thought it was naïve to think that what we did was relevant to the gene patenting issue. And I also actually didn't think it should be relevant. There are laws about patents and we don't make the laws. I didn't happen to like the laws, but I just thought this was kind of a quixotic, almost utopian kind of exercise to imagine that some group of scientific investigators and people funding them could change the rules about well-settled aspects of law. And so that was one thing I didn't like.

RA: So it was not likely to be effective because the law was still going to remain whatever it was and no amount of self-regulation was going to really accomplish the kind of goals that they were hoping to accomplish. Is that ...

MOlson: Particularly by this group, because as I said, what we were setting out to do was about as disjointed as any DNA sequencing project could be from the effort to get cDNA and EST patents. You can argue that maybe the genome project should have had that as a focus, and indeed many people did. But it wasn't the focus. The focus was to sequence the genome and to go about it in a rather cautious way, and of course the cautiousness eventually caught up with the program with the Celera challenge. But that was a post-Bermuda development, and I do think from a policy point of view it's interesting to envision what shape the Celera challenge would have taken if it hadn't been for the Bermuda Principles. But we're out of

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chronological order now. We're talking about 1996, is that right? Or fall of '95? And Celera was still far in the future. There was a lot of concern about EST patents but we weren't doing EST sequencing.

Today, the way I would frame this issue-- and I think it actually captures a lot of what I felt, I just didn't generalize it in this way at the time--relates to the whole idea about genetic exceptionalism, a concept that was articulated later and one that I have adopted in much of my rhetoric. I think that Bermuda can be looked at as a rather extraordinary exercise in genetic exceptionalism. The idea was that there was something really unique and different about what was going on in the human genome project compared to data-intensive science occurring in many other fields and during the hundreds of years of experience in dealing with tensions associated with data release. Here was this little group of utopians who thought that what they were doing was just so different from these other facets of contemporary and historical science that the ordinary rules didn't apply. So that's a casting of my views in a more contemporary rhetoric, but I don't think that it much misrepresents what I thought at the time. I don't know if [BCD] sent you, an email I dug out of my archives that I wrote in the spring of '96 that says more or less the same thing. When I looked at it I was surprised at how little my views have changed since then.

RA: Well we love actually having contemporaneous documents so bless you for doing that. What's interesting, I mean there's a bit of it in the email but just kind of for the record and you might not be comfortable, you might not be positioned, but these are not stupid people. They know there are laws that exist. They know there are structures. Is it really then just a political point of carving out territory, trying to promote a particular vision of science? Is it big picture? Or was it as much a little picture thing about also carving up territory in terms of who was going to do what and how it was going to be done and so on? Why bother, given what you say?

MOlson: I most assuredly did not intend to say any of these people were stupid.

RA: No, no, not at all, but then ...

MOlson: I said that they were utopians. And some more than others. I mean I think John would acknowledge that he's a utopian and a very appealing one. He's a friend of mine and I greatly admire his utopianism. But that's still what it is. And so what was going on at the time, why bother? I actually, if I were going to put my stake in one cause or one set of causal events, it would really be the intellectual property. I'm personally convinced that this was what was actually driving the key players. And they felt an urgency about it. And I just thought this was naïve for the reasons I already explained. I don't think Bermuda had much to do with carving up the turf and so forth. That was driven by the funding processes and was complicated, of course, because the U.S. investigators were dependent on

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U.S. funding, which had its own elaborate way of doing business. John had a funding arrangement that we all envied but couldn't hope to emulate. And I did have ... this is a more minor comment but it is another issue I had with Bermuda: I thought that it was unfair. I could defend myself; I wasn't really too concerned, actually. But I thought it was unfair to some of the international players, the second-tier international players, which would mostly mean the Germans, the French and the Japanese. I've always been a very strong supporter of international science and I think the record will show that. It had been a major hope of mine, utopian as that may have been, that the human genome project would be as international a project as possible. And I played a significant role in getting the Chinese to do their one percent, which as token as it may have been, it sort of ...

BCD: Turned out to be pretty good, though.

MOlson: ... it sent a message. So I was sympathetic that most of my colleagues were not in the positions of particularly the Germans, the French and the Japanese at that time. These scientists brought in still another whole set of funding systems and expectations and patent laws and so forth. I just thought it was wrong for the dominant players, meaning basically the U.S. and the Wellcome Trust, to try to -- not just to try but in fact they rather succeeded --in kind of ramming down the throats of these other international players the way things were going to be done. So that was another concern of mine. Now, let me get a better--I'm happy to say more things--but let me get a better idea of kind of where you'd like to focus.

RA: So do you think then, against that backdrop, whether the principles or Bermuda rules in any sense had any implications for the way research was done and for researchers? Setting aside the political for a moment, were they actually in any way an influence on what people did or felt they were being forced to do on an ongoing basis? It's a bit counter-factual, but did it actually change the direction of the way in which people practiced their sequencing, did their sequencing and what they were able to do?

MOlson: Well I think what I would put the focus on--here I'll really just speak for myself--is that Bermuda aggravated a fairly substantial irritation I had with the way that the NHGRI was operating. And it was an indicator of worse to come but already was irritating. So this doesn't directly answer your question. Did it affect what I did scientifically? Probably not. I felt, and I think many other investigators also felt--especially the smaller players--that it was hard to get anything done because of the level of micromanagement that we were receiving from Bethesda. And we had no choice but to play because they had the money. I noticed when I reread the Elliott Marshall article in *Science* that had precipitated the email that I dug up that I had evidently complained to him that I had to rewrite several times my data release policy. In fact, I felt as though I was doing little else besides rewrite data release policies at the time. It's a historian's job to figure out how the Bermuda Principles took what is now thought to have been their final form ... but my

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recollection of the period after the first Bermuda meeting is that these unanimously endorsed principles were never written down anywhere, and it was actually quite unclear what they were. But it was clear that we were supposed to release data extremely rapidly and to come as close as--in fact, some would argue go a little beyond--what our institutions could legally allow us to do in the way of forswearing any intent of patenting the sequences. So, as I already said, I had absolutely no intention of patenting anything. I'm an academic. But I was not only having to constantly rewrite policies in response to a moving target in Bethesda, but whatever I wrote was never aggressive enough.

KM: These are policies for your ...

MOlson: For my center. Before we would get the money we needed to do anything. So the same time that this was going on I was involved in awkward negotiations with my institution. Grants are not given to investigators in the United States: they're given to institutions. And so the University of Washington had to accept this grant. And I think it was again in the Elliott Marshall piece that an intellectual property official at MIT was quoted as expressing concern about the precedent that was being set. Certainly there was substantial concern at the University of Washington about the precedent. And so I had to try to reassure institutional officials because they would have to sign off on my data-release policy before I'd get my money. They were reluctant to sign—and for good reasons. I couldn't reassure them that the NHGRI was going to do something reasonable in this area because in my opinion they were already behaving unreasonably. So it was really, as far as the effect it had on me, a major distraction from the technical challenge of actually scaling up sequencing and producing a high-quality product. And I do think as far as politics go--Collins can speak to the Beltway politics that he was engaged in--but in the field you were starting to see this schism, a divergence of interest between the smaller and bigger players. The rules, as they were finally formalized, called for release within 24 hours of every contig that was bigger than 1,000 base pairs or something like that. It was actually impossible for a small center like ours to be in full compliance with this policy. It's one thing for a place like the Sanger Center with its 100-person IT staff to be doing this. But when I went and told my two guys to spend all this time funneling data to some repository every morning, day and night, that meant one of my guys was no longer available to help us actually set up a working system. So that was another problem. These were just early skirmishes in what finally became a really bifurcated system; the G5 eventually adopted all sorts of policies that were to their advantage just because they were big. But this was a first indication of what life would be like in this kind of a world. So it was at those fairly practical levels that it affected me.

But I was also, if one can say philosophically, simply opposed to the whole thing. I didn't like the way it was being done and I didn't like the substance. And now I would phrase that in terms of genetic exceptionalism. At the time I just said that,

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look, scientists have been gathering data systematically for several hundred years, and there's a lot of history to the issue of what data is private, what data is public, how the transition is made from the one to the other and so forth. And all of this was just being cast aside. I didn't actually care about the intellectual property precedents, although I could certainly see my institution's point of view but I did care about the data release precedents, and I'm actually still concerned about them. So when we get to that subject of what the future policy implications are we can discuss that. One of my points in my email, which I have here in front of me, is that I do not believe that any scientist should ever be forced into what amounts to real-time release of raw data. I believe that it undercuts a core compact that scientists have with the scientific community, and that is that they will take some responsibility for the data that they release. And what this provided was a carte blanche excuse to just churn out garbage and say, well what else was I supposed to do? I had to have it in GenBank within the hour. And that precedent concerned me at the time and still concerns me. I believe that the human genome project would have been better off if there had been a stronger sense of traditional scientific responsibility. And we can discuss how long it takes for scientists to determine whether or not some big volume of DNA sequence they've got is something they're willing to put their name on, as at least a valid raw-data set. It certainly takes more than 24 hours. It would take more than 24 hours today and took a lot more time and effort then. So anyway, I think you get the drift of my views. As I say, they were well known at the time of the Bermuda meetings.

Let me say one thing, though, that is really on the other side of the argument. There was an element of good politics in the Bermuda accords, and I have come to appreciate more now than I did then the importance of politics in science. And here I'm actually using politics in a relatively positive sense. That it's sort of big politics.

KM: You mean politics within the scientific community?

MOlson: Just brand development. It made a strong statement that this was a kind of utopian venture. That it wasn't something that was about gaining commercial advantage or even narrow scientific advantage. That this was an idealistic venture. I under-appreciated at the time, the importance of this way of branding of the human genome project. And of course this runs counter to my distaste for genetic exceptionalism because that's what the brand was.

KM: I was just going to ask that question.

MOlson: The brand was that we're doing something that's so special that new rules need to be developed and they're going to be very altruistic rules. So just because substantively I think there were a lot of difficulties with that approach, that's always the case with politics and brand building and so forth. There's a tradeoff. I'm more sympathetic now than I was then to the need to make such tradeoffs.

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And so I will concede the point that Bermuda was good politics. I think it was terrible policy and it was terrible process, but it was good politics.

BCD: So, [MOlson], sometimes we hear ... you've focused on the patent rationale and you just came very close to one of the other two rationales that sometimes we hear as why the rules seemed important at the time. The other two reasons that we hear in addition to the IP and kind of defeating ...

MOlson: The forces of evil.

BCD: [Laughter] and InCyte, right. One was simple accountability, which was you're trying to get people to get started with sequencing and everybody's spouting vaporware about how much they can do in their lab. And unless you have sharing of actual outputs you don't have any credible way to say, this group's actually capable of doing X number of megabases.

MOlson: This was absolutely essential but I don't see what it had to do with 24 hours. I said at the end of my email that I was in favor of rapid data release and agreed that past performance of most large-scale sequencing projects had been unacceptable. So I was quite open to discussion. I don't know where I would have come down if this discussion had ever happened in a serious way. But let's say three months, something like that, just to pull a number out of a hat. A year is too long for accountability purposes. A year actually would have had only the slightest effects on the great course of science. I actually didn't like the sense that these data were going to be --I thought it fed into the hype that I'd always tried to curtail--so valuable that everyone needed to see them within much less than a year, which would have been a more standard data release policy. But accountability was a big issue. And so if you start making investigators report much more often than quarterly to headquarters then you're into the morass I already described in which I spent all my time talking to staffers at the NHGRI. And so anyway, we needed fast enough data release that one could actually count the bases and one needed time to do some basic computational assessments of what kind of data one was releasing. But if this was going to be part of your report card you need more than 24 hours to figure out whether or not the machine was running properly or the technician had any idea what he or she was doing.

BCD: So fair enough. That was one of the other justifications and your argument there is quite ... you've made a very coherent point. The other argument we hear is that there was a politics of big lab/small lab and you're kind of intermediate stage.

KM: You're a U.S. lab but you're not a small European or Japanese lab.

MOlson: Well we were getting millions of dollars a year and so we shouldn't cry too much that we were just a tiny little cottage place.

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BCD: So part of this was, it wasn't just pure branding. Some of the arguments that are made is, basically the only way to get support from all of the scientific community was to have a set of rules that basically lashed the big centers to the mast and said, we won't touch these valuable data as they come out of our centers because that would not be fair because we've already got all these resources to generate them. This is really a public works project to create data for science writ large.

KM: For infrastructure building.

MOlson: Yeah, and so I mean I guess my response to that would not be too different from what I said about accountability. I agree with that basic proposition. I believe that it was after Bermuda that the idea of distinguishing between a data resource project and a more conventional scientific project aimed at answering some scientific question took hold. It's not a perfect distinction but I think it's a reasonable one. And I agree that the human genome project was a data resource project. If big centers--and here I would include myself because I was getting heavily funded compared to a typical human genetics lab--were using all this money to carry out aggressive positional cloning projects, and so forth, the community would have had a good right to complain. That's not why I was getting millions of dollars. I was getting millions of dollars to help create a public resource. And so, again it's an issue of time scale and also just plain behavior. So let's suppose that something like a three-month rule had been enforced. Well sure, a very aggressive center could be skimming some publishable content out of their sequence in three months and rushing into print. But it's not as though this would be very easily disguised behavior. I mean, I think there did have to be a general agreement that we were doing data resource work and if people behaved badly there are plenty of tools for reining them in. But I just didn't see what it had to do with being online to GenBank all the time.

RA: So can you just spell out then what kind of tools you think are actually more effective kinds of mechanisms on something like this?

MOlson: Overwhelmingly the most powerful is peer approval. Scientists actually don't like to be thought of as really bad guys. And they tend to be thought of as really bad guys when there are widely accepted rules in some particular community that they're violating. So that's the strongest. But the funding agencies could also ask questions: for example, they could say "it says here your specific aims are to produce 10 million base pairs of sequence, and we don't see any line items for positional cloning or whatever else is going on to exploit the pre-release data." And funding agencies can ask whether or not resources are being diverted from this project to some other project. But peer approval is the biggest enforcer. I mean, look at your specialty, the *C. elegans* community with its unique patriarchal structure. So just as in the mafia crossing the godfather was not a great idea, it was not a good one in the *C. elegans* community either. If you waited

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three years before sending someone a mutant he had asked for, claiming you couldn't find it in your refrigerator, that was not acceptable behavior. And sure enough, the community worked on those principles. Which by the way, I think are wonderful principles. It sometimes got a little cultish for my tastes, but nonetheless, they're wonderful principles. And you couldn't have a better patriarch or even second tier of village elders—really, it's a wonderful community that worked, worked across international and other boundaries. It didn't matter who your funding agency was, didn't matter whether you had a big lab or a small lab—you were just expected to behave in certain ways. So the human genome project definitely needed, as any group will, to develop its own culture. And Bermuda was just a relatively extreme solution to that problem. But it was a solution, and as I said, I've come to appreciate the politics of the Bermuda principles. Bermuda was good politics.

RA: So do you think if those hadn't been ... the principles were at least effective politically even if they weren't effective in any practical sense, are they relevant?

MOlson: I didn't say they were ineffective practically. They actually worked better than I thought they would, mostly because information technology was improving so rapidly. When I went to the University of Washington in 1992 it was the first time that I had pretty good Internet access. So I went to the bookstore, the university bookstore, to find a book about the Internet in order to understand a little better what it was. And I found one 100-page book about the Internet in the whole bookstore. Now they've expanded up and down the street just to house all of the DOS for Dummies kinds of books. So the information technology got a lot better, and the logistical problems that loomed fairly large for me in 1996 were attenuated more rapidly than I anticipated as time went by. So for that reason they proved to be more practical than they looked to be in 1996 for any but the largest centers. And let's see, there was another branch to your question...?

RA: Practicality and then relevance. Have they seen their day or is there some nugget of it that now is still relevant and valid? And I guess then the other branch would be if the principles are in any way, either in spirit or detail, relevant beyond their initial domain? You've talked a lot about genetic exceptionalism but I'm sure you've seen people invoke the Bermuda Principles as general guiding principles about sharing in science.

MOlson: I don't want to overstate my case. Obviously, the Bermuda legacy is a mixed bag. It has probably led to more openness in science, particularly with respect to large data sets. And that's good--that's a positive legacy. And that happened as result of the branding and politics behind the principles. The human genome project, in general, was viewed as a successful, large, top-down project and has spawned a lot of emulators. I think that both with respect to Bermuda and with respect to this larger question of whether the human genome project is actually a good model for doing science, these issues are actually catching up to us. There's always a price

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to pay. To the extent that my effort at logical analysis has some validity, there's always a price to pay when you abandon a more rational approach for essentially political reasons or as a utopian exercise. And I think we are seeing those effects now because the issues surrounding release of large data sets are only getting more complicated. I'm particularly interested, for example, at present in how we're actually going to get medical benefits, major medical benefits, from the human genome project. I served last year on a National Research Council committee that laid out one game plan for trying to organize genomics, medicine and a few other large parts of the research enterprise in ways that are better aligned with what we're going to have to do to get major medical benefits. Well if you look at the data release issues there, they are so complex compared to the ones that we faced in 1996 in the HGP that looking to Bermuda as a standard is a hindrance, not a help. But Bermuda is still there. The problem, of course, with utopianism is that it leads to dichotomous positions...oh, it says connection lost...

KM: That held out for a surprisingly long amount of time.

MOlson: But the quality is good, of the connection.

KM: Hello.

RA: Hi, can you hear me?

KM: Yes.

RA: Okay, good.

MOlson: Good, we're back. Well, so the basic point was just that the basic cost of taking what I refer to as a utopian approach to a problem is that it dichotomizes everything. So the good guys are in favor of Bermuda-style data release and the bad guys want to hoard the data. The real world mostly operates somewhere in the middle of this spectrum. And just to take my example of genomically informed medicine, it's obviously going to have to operate in an incredibly complex environment between these extremes. If everyone continues to hoard data at the level they presently do--often hiding behind patient confidentiality as an all-purpose excuse for the hoarding--we're not going to get very far. But it just isn't going to happen--and shouldn't happen--that data are all going to be released instantly everywhere. I would never enroll in a clinical trial or research study that had my electronic medical record, my genome sequence, all sorts of information about me, if I thought the data were going to be released instantly. I actually would be willing to waive most of the confidentiality that's traditionally associated with those kinds of data, but only if I had confidence that I was dealing with serious people that understood the need to handle those data responsibly and to have carefully worked out policies about how they're released, how access is to be stratified access, and so forth. That's the real world.

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And so I still see this dichotomy when I go to meetings where data release issues are discussed. I believe the whole discussion is more polarized than it would be if it weren't for this '96 exercise. So that remains a concern of mine. I don't think that the Bermuda principles provided a precedent for the hard cases in data release. So we're starting a bit from scratch. But everything is a mixed bag. And I'll give this initiative credit for having tilted science toward more openness, and that's a good thing. There are tradeoffs. I may be the true utopian in having had the expectation that something more rational was going to be done in 1996, with all the pressures that were accumulating. At the time, I thought we needed more rational discussion.

BCD: So these principles come out, you're not at these meetings, you're at a center that's big enough to matter but not so big that it ...

MOlson: Can set the rules.

BCD: ... can set the rules. You haven't been party to this. So what do you do with these principles?

MOlson: Even six months later, as I kept rewriting my data release policies, I was improvising because there weren't absolutely clear guidelines. What happened was that over quite a period of time they gradually got objectified by the NHGRI and became a requirement for participation in the HGP. And so I did what I could to comply.

BCD: So how were you writing those data sharing agreements in the first place?

MOlson: Well that would be interesting to look at. I'm sure there's a long paper trail there. I could dig all these up where I found this email.

KM: That would be wonderful.

MOlson: I tried to get one draft after another approved—more interesting than my drafts were the instructions I was responding to. About them, I could look and see what I could find. It was a little early—some of this correspondence may unfortunately be hard copy as opposed to electronic. But we were required to have a data release policy and we knew it should involve aggressive release of data. But the instructions just weren't very specific, but my data release policy had to be specific. What was I going to agree that our center would actually do? I'd have to look at what I wrote, but I think the core contention was that my proposal wasn't fast enough for the NHGRI staff. But as of the spring of '96 they weren't telling me how fast it had to be. Eventually, I think, 24 hours became the rule for contig sizes exceeding 1 Kb. This is a ridiculous level of micromanagement of any scientific project.

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BCD: Could you actually do that?

MOlson: Could I do it? Oh, I think we were probably in moderate compliance. My instructions to my IT staff were to try to comply. But did I check every morning to make sure that every 1-kb contig had actually been emailed? No, of course not. I don't remember any major breakdowns. I'm sure there were times when for a week or two or three we just couldn't do it because we were having trouble. But we'd recover and keep this stuff flowing. Maybe utopian is slightly the wrong word—it was a sort of platonic exercise. There was this platonic world of ideal forms of 1-kb contigs and smoothly flowing data. Then in the lab, we had technicians getting sick. We had computers breaking down. I was constantly scouring around to find more cooling for my server room because it had been designed to be a janitor's closet, and so forth. On the ground it was not quite such a platonic world. But we were in reasonable compliance. There was certainly no willful noncompliance. And I'm sure if you looked even at the holier-than-thou-players you would find that they were in reasonable compliance but not perfect compliance.

KM: So could you just elaborate a little bit more on the science? So the data, right, what sorts of errors did you risk introducing in the data?

MOlson: By not screening?

KM: By not screening.

MOlson: Massive errors.

KM: Just, yeah, types ...

MOlson: Just for starters, sample confusion is probably the most serious and still most common error. So this actually wasn't the human sequence that you thought it was. It was some bacterial project. Look, we were making all the DNA from *E. coli* clones and so there was already tons of *E. coli* DNA going into GenBank as human. There was not a complete sequence of the *E. coli* genome at that time that would allow you to do a simple screen. And the biology wasn't even entirely favorable. For example, you passage these clones through *E. coli* and transposons insert into them. And so that's biological, that's genetic contamination. Eventually we set up pretty good filters for all of these things. And the NCBI did an excellent job of implementing industrial-scale filters that everyone could use. But none of this stuff was in place in '96 and we knew that a lot of our data was junk. Later, things got a lot easier. There were PHRED scores and PHRAP scores and fancy statistics. There had been technological convergence so everyone was doing everything the same way. And it was pretty easy to do cross-checks on the validity of the raw data. In '96 we were just submitting a bunch of data files, a lot of data files, and many of them were un-interpretable. That's what the 1-kb contig

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filter was supposed to be about. If you couldn't make a 1-kb contig out of raw sequences then you were allowed to consider it potential garbage. But anyone with any experience in this area will confirm that that's an exceedingly crude rule. There are a lot of ways of making contigs. As recently as 2007, we discovered 100-kb contigs in assembled human sequence that weren't human data. So it's science. The raw data are messy.

So, in '96 we had all these things going on. The true information technology surge that made the whole endeavor possible was still on its rising tide. Computing infrastructure was still expensive. There were a lot of incompatibilities and whatnot. The technology was still unstable, and the instrumentation was turning over quite rapidly. We were often working on several different platforms that behaved differently and so forth. It was challenging. And I just didn't need someone telling me that I needed to have all these data flowing instantly into GenBank.

BCD: Was there ever any enforcement?

MOlson: That's a good question.

RA: How would we know? I mean what it would look like?

MOlson: Well it would look like one of these NHGRI staffers calling you up and saying that we've been checking your submissions and there's a discrepancy between your goals or your progress report or something and the data that are actually there in GenBank. I used to run into that later actually, which just again illustrates the precedent-setting issues. I remember having all of these documents rejected, but I don't actually remember once I finally said what they wanted me to, or close enough, the NHGRI ever complaining that I wasn't complying. I do remember conflict later. We had a grant after what was generally considered the finished sequence was published in 2004 to keep trying to finish the sequence. I think we were one of the only places that was explicitly funded in this area. That work was hard because we were working on the parts that had been refractory to standard methods.

So we collected lots of data that proved to be irrelevant to the problem we were addressing, some gap or other problem in the sequence. And I do remember our program officer complaining that we weren't depositing all the data according to the Bermuda Principles. We would work for months on one of these gaps and collect all kinds of data, alternate chemistries, special cloning vectors, and so forth. If we had tried to submit all those data we really would have been unable to work at the same time because even minimally documenting what all these reads were would have required us to have electronic lab notebooks that were online at GenBank. This was very complex data. That's what scientists deal with. But I just

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remember telling the staff member that I wasn't going to do it, that we couldn't do it.

KM: Were you involved in any of the other discussions that affirmed, so to speak, the Bermuda Principles in Fort Lauderdale and Toronto?

MOlson: No, no, no. That was pretty much a G5 thing. Didn't that mostly have to do with diversifying post-HGP projects?

KM: Yes.

MOlson: I read some of that stuff and I thought actually, perhaps not surprisingly, that it got better. In all fairness to some of the players who I disagreed with, Bermuda was their way of dealing with a pioneering situation. The communities and individuals do learn things as time goes by. And I think I remember reading one of those Fort Lauderdale documents, and it seemed a more sophisticated approach than Bermuda. I don't remember whether it still had 24-hour raw data release in it, but the gist of it, the overall impression it gave was that it was trying to address the actual problem, which is that if people are going to get a lot of money to develop community data resources that they should not be exploiting them for narrow scientific advantage. And that's a reasonable principle. I never challenged that principle.

RA: And so, I guess sort of the last sets of things we typically ask people is, I mean you avoided participating for all the reasons that you've recounted. Were there others that you think shared your skepticism? People we might not think to talk to because we don't realize they actually were in the mix but they weren't actively involved in Bermuda? Or anyone a little less obvious that you think it might be interesting for us to talk to about Bermuda?

MOlson: That's an interesting question. It doesn't ...

RA: It's hard to find people who weren't ...

MOlson: I don't think the problem was so much that key people were being excluded because they were not viewed as important. The problem was that people were rolled over. I think that's clear. And so the place I would start would be with people that you're already interviewing. I do not believe that there was even majority support at Bermuda for these principles that were unanimously adopted. And if somebody told me that they had talked to all these people and determined that there was, I'd want to go around and talk to them myself because I know these people and I don't believe that there was even majority support. I think it was a highly coerced discussion, and it would be hard to convince me otherwise.

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RA: I think so far what we've been finding is the devil's in the details. People agreed with some part of it or they agreed perhaps politically it was necessary, but the technical ... a whole range of things that is much more complex, not surprisingly, than everyone unanimously supporting every detail. There is a transcript of the meeting that would actually tell us exactly what happened. But for all sorts of reasons we can't actually get our hands on it at the moment because it belongs to the Wellcome Trust and they have to release it. They want to get everyone's agreement because of the Chatham House rule business, among other issues.

MOlson: I would be quite interested in knowing exactly what happened that was later described as unanimous agreement. And you would probably need a transcript because I don't think Roberts Rules of Order were enforced. I doubt that there was a written statement because months later I was still trying to figure out ...

RA: What had been agreed to.

BCD: Actually, we do have a written document because John's handwriting was put on a blackboard. And we have a picture of it. And so that is available.

RA: People [Inaudible] that was there and that is what people think they agreed to. And that was done ... it was printed kind of in very abbreviated form not long after, sort of in various places.

KM: So there was a summary of the first international strategy meeting, and then there was the statement online.

BCD: But the ratification process we actually don't know. Some people don't even remember if there was one.

MOlson: This included 24 hours and 1kb contigs?

RA: Yeah, [Inaudible - another speaking] it wasn't as big a deal as it has become. It was discussed but it was a relatively minor point in the whole thing and then became the take-home message.

MOlson: Did John's scrawl about this 24-hour thing and 1kb contigs and so forth?

RA: Yeah, [BCD] can get it for you.

KM: Yes, it's in the kind of ... there's ...

RA: Actually, just ...

MOlson: The environment was ...

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RA: ... and thereafter it was actually reprinted.

MOlson: ... the environment was even worse than I thought if people there unanimously agreed to that. This was not what I heard.

KM: Well I don't know. Does not saying anything after John Sulston writes it on the board count as unanimous agreement?

RA: That's the issue, right?

KM: Right, exactly.

BCD: Something, I think it's automatic ...

KM: Automatic ...

BCD: ... release sequence ...

KM: ... release of sequence assemblies greater than 1kb, preferably daily. Immediate ...

BCD: Submission ...

KM: ... submission, finished annotated sequence. Aim to have all sequence freely available and to public domain for both research and development in order to ...

BCD: Maximize ...

KM: ... maximize its benefit to society.

MOlson: Yeah, so I'm all in favor of the statement of principle there, but it is interesting and I'm surprised ...

KM: Preferably daily.

MOlson: ... I'm surprised that it was so specific because my recollection is that it was still wallowing around months later, and it wasn't because I wasn't at Bermuda. Everyone was wallowing around with what the actual implementation was going to be.

RA: Yeah, and I think the devil's in the details as to what it means. It's a pretty vague statement. It's not surprising, it just resulted to a certain extent in a lot of confusion. Even if a copy of the blackboard's released, well that's not very meaningful anyway.

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MOlson: I said in my email to Bob Waterston in May that I had not yet seen a proposal that was well enough specified that I could take a meaningful position on it. The most specific proposals that I had seen were too close to real-time release of raw data for me to support. So it must be that at least my impression in May was that daily release of data was one possible implementation of this very broad principle. And I supported the broad principle. I still do.

RA: I think that's all I've got on my list. [BCD] and [KM]?

BCD: Yeah, I think the only other relevant thing, [MOlson], would be to see if we could get some of the documentation.

KM: That's what I'm looking for right now, because the best that we would have gotten ... second international strategy meeting. There was a report from the first international strategy meeting.

BCD: I'd actually be interested in what you were trying to do by way of data release policy.

KM: Oh, I see, right.

MOlson: I will dig into my archives. I'm sure I've got this stuff. I've got it here if it's electronic. If it's not, it's in my ...

BCD: But if I understand your story you actually feel like you actually got some pushback from your tech licensing office about ...

MOlson: I did, but that might be harder to document. Because what I remember was that I had several discussions with them. And I doubt that there was any written record. They ultimately agreed to sign off on the grant. They were sympathetic to my position, and I was sympathetic to theirs.

BCD: Is that Jerry Barnett?

MOlson: I think it was. I could easily identify from my email records whom I was dealing with. There was one point person, he was an older guy, and he was very helpful. He didn't like the NIH position, but universities typically try to help their faculty, and he concentrated on helping me get a good outcome.

KM: Here's the agenda of the session. I'm looking for a copy of the report. Anyway, sorry.

MOlson: I'll take a look at what I can find of my correspondences with ... I'm sure they were electronic, that I was emailing back and forth with these staff members and they just didn't ever like what I said.

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BCD: Well, cool. [MOlson], thank you so much.

RA: Fabulous and really helpful. Thank you.

KM: This is wonderful, thank you so much.

MOlson: Oh, it's a pleasure and I look forward to this magnum opus. [Laughter].

RA: Hopefully it's not going to be a magnum opus. [Inaudible - another speaking] ... we just keep finding more out, so [Inaudible - another speaking].

MOlson: Trying to get the history right is certainly worthwhile, and I also like the idea of trying to look at the longer-term consequences because we need more policy discussion of this general type. Science policy is a messy business and high-level discussion is always welcome. This is an issue that's not going to disappear.

RA: No, and it's kind of amazing it's so recent and yet there's so many different versions of what happened, what should have happened, what events and so on. It is a good time to try and capture and at least understand because it's not going to go away, as you said.

MOlson: And we're in the deep end of the data-mining era and it's likely to be a long era.

KM: We should have a reunite party, everyone in Bermuda we think. Would you come to this one?

MOlson: No, I don't think so. [Laughter].

BCD: Well, [MOlson], thank you.

END OF RECORDING