

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 Ledean W. Hillier

Printed Name Ledean W. Hillier

Date April 4, 2012

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

Contact information:

Rachel Ankeny, Ph.D. (University of Adelaide)

rachel.ankeney@adelaide.edu.au

+61-8-8303-5570

Kathryn Maxson, B.S. (Duke University)

kat.maxson@duke.edu

(919) 668-0791

Robert Cook-Deegan, MD (Duke University)

bob.cd@duke.edu

(919) 668-0790

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

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

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

Full name: LaDeana W. Hillier Date of interview: April 5, 2012

Current institutional affiliation: University of Washington Genome Sciences

Street Address: Foege Building S-250, Box 355065 3720 15th Ave NE, Seattle WA 98195-5065

Phone: (206) 221-7377 Email address: lhillier@uw.edu

Interviewer Information.

Full name(s): Robert Cook-Deegan and Kathryn Maxson

Affiliations(s): Duke University

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

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

OR

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

Researchers unaffiliated with the Center for Public Genomics may read the interview transcript and any related documents only after obtaining my permission.

Researchers unaffiliated with the Center for Public Genomics may quote from the interview only after obtaining my permission.

Researchers unaffiliated with the Center for Public Genomics DO NOT HAVE my permission to read or quote from the interview.

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

1 year from the date of this form

5 years from the date of this form

10 years from the date of this form

25 years from the date of this form

After my death

Other: _____ (please specify a date or condition)

NEVER: MAY NOT BE DEPOSITED IN A PUBLIC ARCHIVE

Please specify any further restrictions in the space below:

Signature: LaDeana W. Hillier

Date: 10/15/2012

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Interviewers: Kathryn Maxson, Robert Cook-Deegan

KM: So we are on the record, and this is [LHillier] here. And we have [KM] and [BCD] and we're recording this. And just for the record you have received and signed and sent back the informed consent.

LHillier: Correct.

KM: Thanks so much for that. And we just explained it off the tape and answered her questions. So just to start out here, we have on record that you were at all three of the Bermuda meetings. Is that correct?

LHillier: That's correct. Yes, I was there. Obviously this was a very exciting thing to be a part of and I was honored to be included.

KM: Yeah. And so would you mind just maybe starting us off with your recollections of what you were doing at the time, why you think you were invited and what you thought the purpose of the meetings was in advance of attending? Particularly going into the 1996 meeting.

LHillier: Okay. Well of course at Washington University Genome Sequencing Center (WUGSC) we, along with what became the Sanger Center in Hinxton, UK, had sequenced the *C. elegans* genome, a model organism. And we at WUGSC had been sequencing worm Expressed Sequence Tags (ESTs) around the time when Craig Venter had decided that he would try to patent ESTs. So that was kind of a big lead-up to this. At the time we were sequencing some worm ESTs as well to help in annotating our worm genomic sequence at the time when Craig Venter decided that ESTs should be patentable. And so then obviously that possibility of patenting ESTs led to Merck choosing us (Washington University School of Medicine Genome Center) for the big EST sequencing project for mouse and human in late '94. And then we knew things were getting pretty exciting. Basically from 1994 on things were moving at an incredibly high pace. But, like I say, I think in part this was because things were going very well for our sequencing of *C. elegans* and because we had already seen the potential for people wanting to try to patent data.

And so in 1995 I especially remember the Cold Spring Harbor meeting because at the Saturday evening session where they always had the major keynote speakers Maynard Olson got up and talked about how the map was ready for the human genome and John Sulston got up and said that he and Bob Waterston had made the plan for sequencing the human genome. So that was pretty incredibly spine-tingling.

At Washington University, we wrote a grant for participation in the human genome sequencing project, and I think we already knew by that February of '96 that we were supposed to receive funding. And actually we had just been in Cambridge for a big kind of a summit with John Sulston's group at the end of

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January in '96 where we were coming up with our plans for all aspects of sequencing and analyzing the human genome. We had a history of having across-the-water meetings as well as weekly conference calls between our group at WUGSC and the group in Cambridge to keep the *C. elegans* project on track.

And once the human got started we continued working with Cambridge in the same vein. And so, like I say, at the end of January I went over to Cambridge for a meeting and we discussed human analysis, human annotation, human sequence production, and human mapping. I have all the notes from that meeting. It was really setting out what we were going to do. And I think that would have been done regardless of the Bermuda meeting coming in February because I think in the Bermuda meeting it wasn't just specifically about how it was going to be done. But that was a big part of it. I mean they brought me in, I think, because at the time our lab and John Sulston's group in Cambridge were the largest sequencing labs. And so I think Richard Durbin, head of informatics in Cambridge, and I were recognized as key informatics people. So at the various genome-oriented meetings we'd be the ones that would chair the informatics sessions, etc.

So, as director of informatics for the Washington University Genome Center, I was really representing the entire range of informatics from sequence production, lab notebooks and databases and tracking to software for mapping, finger printing, clone organization, sequence assembly, finishing, and all aspects of sequence analysis. I had been in charge of the whole realm of things for the worm and now into the human. I had been responsible for all of the informatics for the Merck EST project. I was responsible for getting all those data immediately into the public databases, which was kind of a big deal. So I think that's why I was invited. I was working for Wash U all those years. I started working there in 1989 working with the whole genetics department at the beginning and then as soon as the first *C. elegans* genome grant came in I transitioned to taking care of informatics for all aspects of that project. Even to this day, I still work for Washington University. I work at University of Washington now but I still have 50 percent of my time subcontracted back to Wash U.

BCD: So how did you get into this business?

LHillier: Well I was working at Central Institute for the Deaf at Washington University and I was doing some really basic research ... and the funding wasn't outstanding. And Washington University has a big biomedical engineering program and my degree was in biomedical engineering. So I went over to talk to Barry Cox, head of that department, and he said, you know, the genome project is really starting to go and the genetics department really needs some people. So I went over and met with Phil Green, Maynard Olson, David Schlessinger, Helen Donis-Keller and Buddy Brownstein, a huge interview day. And that's how it started.

BCD: And what was your background?

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LHillier: My background was engineering physics at the undergraduate level and then biomedical engineering at the graduate level.

BCD: Had you done informatics stuff before?

LHillier: Well most of what I had done in my graduate work was computational, so ... and actually engineering physics as well. I'd done a senior project that was all computational. So that was what I had come from.

KM: And where were your undergraduate and graduate degrees from?

LHillier: My undergraduate was at Northwest Nazarene University in Nampa, Idaho. And my graduate work was done at Northwestern University in Evanston, Illinois.

KM: Cool, cool. I like you. [Laughter]. So you said that this meeting in January of '96 was in Cambridge, right?

LHillier: Yes.

KM: And that was about mapping and organizing mapping?

LHillier: Well, no, it was everything. I mean it was the whole range of sequence assembly, sequence production and sequence analysis. Because we had just started ... like we were sequencing the *BRCA1* region right at the very beginning as a pilot project and so we were talking about exactly what to annotate and what to submit to the databases. Gos Micklem was kind of in charge of analysis and annotation at Cambridge and so I'd spent a lot of time at the computer with him deciding exactly how we were going to annotate tRNAs and repeats, for example, and of course the genes themselves. It was just a really specific meeting about how we were going to go forward with the human.

KM: Right, right. And you said you have those notes.

LHillier: I do.

KM: Would you mind sharing them with us?

LHillier: I wouldn't think there's a reason not to--do you? You would know better.

KM: Not that I can think of.

BCD: You might take a look, scan through them and make sure there's nothing that you don't want the rest of the world to see.

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LHillier: Yeah, I mean there's not like a lot of people's names. It's just a lot of technical details. It's in outline form though so it's not so disorganized. But I'm not absolutely certain how interesting it is to you.

BCD: Actually, it would probably be really interesting to us although we would be looking through for what was going on technically at the time and kind of what it felt like in the day.

LHillier: Sure.

BCD: And if you don't want to digitize it yourself you can ship it to us and we'll ship it back. We've done that for a couple people.

KM: Yeah, that would be wonderful. And you mentioned the public databases. Did you mean that after the first Bermuda meeting you were putting things in the public databases, or how was sharing data working amongst the mapping communities at this time?

LHillier: Well that discussion was more related to the analysis of the sequence rather than the mapping data at that time, at that meeting.

BCD: [LHillier], just so I'm full disclosure: There is one thing that can come up with these notes that has happened in the past. And that's if there was anything that would be involved in patent litigation of one sort or another.

LHillier: I see, yes. Yes, I can't imagine, but I'm not ...

BCD: If this is just sequence data that's probably not going to be the case. But that is the one sort of thing you might think about.

LHillier: Okay, thanks.

BCD: And what can happen is, lawyers are users of these databases and so are investigative reporters. So if somebody wants to dig up a story notes like this can be used by those ...

LHillier: I see. Okay, well, I'll look at them. Look at mine. Thanks.

KM: Yeah, yeah. So thank you, that would be extremely helpful.

BCD: Our eyes kind of popped open when you said you had notes from that meeting.

LHillier: I'm a note person.

KM: Color codes and tabs and all that, anyway.

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BCD: Anyone who ever sues [KM] is in trouble.

KM: So you are going into Bermuda in February of '96 on the heels of this other very technical meeting. And what would you expect to be discussed in Bermuda?

LHillier: Well I mean I really thought of it primarily as a scientific meeting, kind of a continuation of this meeting that we had just had in Cambridge, but on a larger scale. I understood that also the funding agencies would be there and the database people ... the public database people were going to be there. And I understood that all the different people that had ever sequenced the human genome basically, a reasonable amount, were going to be there. So I saw it as an opportunity to get input from everyone to choose the best path forward because all of the plans and methods were totally not set yet. We really were of course the big, huge advocates for the clone-by-clone strategy but Weber was there ... James Weber and Gene Myers ... who were presenting whole genome shotgun, which we were against at the time in part being Luddites, and mainly based on our understanding that the clone-by-clone approach was the most reasonable way to get high accuracy, validated sequence. And also it made it easiest to share the work amongst multiple centers. But I guess my point being that nothing was set yet. And so we were just looking for input as to how best to go ahead with it.

I think the other big thing was to avoid duplication of effort. We wanted to make sure that we weren't duplicating effort. There was so much to be done that we couldn't afford duplication. And in the human community people were possessive of their data and possessive of their little region (understandably so since it could mean their grants and career). We just wanted to make clear our intent was to be systematic genome-wide. We weren't interested in just sequencing *BRCA1* or just sequencing all the disease gene areas. We wanted to get all of chromosome 7, for example. We were on our way to the kind of noble, white horse pathway of being systematic. And I guess we wanted to make sure that everyone else was on board with that. Obviously, because of the background of the *C. elegans* project and setting the precedent there for immediate data release, Bob Waterston and John Sulston were huge into immediate data release and all the things that came out of the meeting. I think it had all been set up by this wonderful collegial atmosphere that the worm group had all these years; not just between Bob and our group but just all the worm labs. If you go to the big worm meetings in Wisconsin, it's just a different community. And I think this was the opportunity. It was a different community meaning just so sharing, and people didn't feel so tied to losing their career if they lost their one gene. So I think this was an opportunity to try to share the community or the collegiality that we had enjoyed on the worm level to try to propagate that to the human community, which we understood was kind of a big, difficult thing.

But I actually have my invitation letters for the meeting, for the '96 and the '97 meetings, and the letter reads, "to facilitate the coordination of research groups

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involved in large-scale genome mapping and sequencing.” So that's exactly what they wanted, right? “The meeting will include discussion about different strategies, potential mechanisms for coordination, new technologies, informatics and data release policies.” And that's exactly what the meeting was. But it was a very scientific meeting with people standing up and presenting details about how they were making their YACs or how they were making their BACs, for example.

We had done yeast with a bunch of other groups and that was done in a very different style, coordination among many small labs. And that was a really difficult project because there were so many labs involved. So we knew what that was like. And then the worm project, which was done with just two major centers, and we benefited from the intimate coordination between just our two groups. And so I think we felt like we had some insight from where we had been. But we weren't trying to be exclusive; the meeting from my perspective was very inclusive, as I said. So many people were invited from all the different groups. And actually they'd all been at Cold Spring Harbor for years. We knew everyone. But it was a scientific meeting and a meeting of coordination.

BCD: So, [LHillier], were you part of the yeast sequencing consortium?

LHillier: Yes.

BCD: The one that was organized out of Europe?

LHillier: Yes, I worked primarily with Mark Johnson. Mark Johnson was the leader for our particular portion of it. But we sequenced and annotated a couple of yeast chromosomes.

BCD: So, wow, so this is actually really ... if you don't mind, let me draw on that for just a second.

KM: Yeah, definitely. We haven't talked very much about yeast with anyone.

BCD: So this is really interesting because you just made a distinction between yeast, the nematode community and then there's this transition, and you're doing work on the human genome at the same time as you're doing yeast; worked on both yeast and nematode, is that right?

LHillier: Exactly, exactly.

BCD: And so one of the things we're trying to establish is this historical transition from the sociology of science. How the science was done. It's very community specific from different collections of scientists who were working on different kinds of organisms and different problems and things like that. And what we seem to be hearing from a lot of people is that basically the nematode model, the sociology of

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science as it was practiced in nematode, became the primary model for the human genome project in this transition to high-throughput sequencing and as the mapping was beginning to get consolidated. Does that seem right to you?

LHillier: Yeah, absolutely.

KM: Which totally wasn't a forgone conclusion, right?

LHillier: No.

KM: Because if this had come out of the human genetics community, I mean, goodness, the human genome project would probably have looked a lot different, don't you think?

LHillier: Absolutely. I mean exactly that's what I think was the purpose, was to kind of bring this more collegial atmosphere into the human world, which was a huge thing to try to do.

BCD: And the main distinction between nematode and yeast was how the community was organized. You're saying it was much more atomized and smaller labs and more labs.

LHillier: Yeah, exactly. In yeast, it was many, many small labs, and the coordination was more difficult, although it was done well. It was done well. But I think the nematode project was much easier just because it was two labs rather than all these individual labs. Which was great too.

KM: So [BCD] and I are over here about to ask the same question. So just picking up that thread it seems like that atomization is something that you felt probably couldn't be scaled up to something as ambitious as the human, so you wanted to also be sure that the human genome was coordinated very well in terms of the people who were involved. But it's almost like this is a, I don't want to say a negative example, but just something you wanted to be careful to guard against in the human genome, what happened in yeast?

LHillier: I guess I wouldn't go that far as guarding against it actually, because I mean I think that had value too, and for a smaller genome it worked. And it got lots of people to ... I mean one of the big problems with like only smaller numbers of groups doing the sequencing is then user education is an issue. Whereas in yeast the user education was taken care of because the sequencing was done at so many different places that everybody kind of understood the limits of the data, et cetera. And I think that was perfect for yeast.

So I don't think I want to say guard against, but I just think in terms of scalability and in terms of cost it would be a totally different question today because

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sequencing can be done in little teeny labs for a really low cost, right? But at that time it was very expensive to do sequencing and to do it well. And the human genome was such a humongous project. But I don't think that upfront there was any plan that it would be a very small number of labs. As I said, that's why they brought in all these different groups. It wasn't just two groups or three groups. I think there could have been ... I don't know, how many were there at the first meeting? A dozen? Twenty? I don't know. Even from the U.S. I mean there were that many. So I want to be careful about guarding against. It just needed a different approach, I guess. But once we had the map, I mean theoretically if it would have been cheap to do it individual labs it could have been done in lots of individual labs. We were so focused on the quality, making sure that we did restriction digests on every clone and comparing the restriction digest to the finished sequence to make sure everything was accurate. We wanted to be sure that anyone that participated would be held to those same standards. And I guess even just traveling to meetings to bring in too many people, to travel to meetings would have been too expensive just at the scale of the human genome.

BCD: So you did remind us of a previous interview that we did with someone where they referred to a yeast controversy, and it sounded like it was about either the sharing of data or the coordination of who got to do what or some mix of those things.

LHillier: Yeah. I mean, I think in human too that happened as well. That's kind of inevitable.

BCD: So when does that emerge? Does that emerge in the end game when you're trying out how to finish? Or do you even know what the...I actually don't know what the, quote, yeast controversy really referred to.

LHillier: I don't recall the details of who that was.

KM: Yeah, we just thought we'd ask because it came up. So were you at that session, the last session of the 1996 meeting where John Sulston got up and wrote on the whiteboard what ended up becoming the Bermuda Principles? Do you remember that?

LHillier: Yeah, yeah, I remember that. We were sitting in kind of a big U and I remember exactly where everyone was sitting. It was a big day.

KM: Really? So how were people sitting?

LHillier: Kind of along the U, if you call it a U, and at the open part of the U is where the people were standing to talk. At the bottom of the U, Francis Collins and Michael Morgan were sitting. And then kind of on the right side of the U from them was Mark Adams, and the Japanese I think were on that side. And over on the left side

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of the U like I think Michael Ashburner and Richard Durbin and I. It was a little bit divided, interestingly. But I mean that whole meeting, it was a lot like the United Nations. I'm sure other people have called it that. It was so interesting basically going around the group and asking each, okay, are you willing to agree to the principles? And if you are then you stay in the group. Otherwise we won't be seeing you next year. So it was a fascinating meeting.

KM: And could you double-click a little bit on how that worked and what people's responses were?

LHillier: Well what I recall is, I mean I have read other places that it was a raising of hands but I don't remember a raising of hands. What I remember is specifically asking each individual person, each individual group, so the French, the Germans, the Japanese, our lab, whoever else was there, Richard Gibbs and his lab. I don't know if they asked all the small U.S. labs. I think the U.S. labs were kind of basically represented in general. Like Elson Chen was there, Bruce Roe, several small labs. I think it was mainly kind of asked country by country, which is why it felt so much like the United Nations. I don't know if I'm allowed to say what people answered. Isn't that kind of under ...

BCD: Well yeah, so we actually aren't sure what the rules were, and it seems like most people think they were under Chatham House rule.

LHillier: That's what I'm concerned about, yeah. I don't remember that and I don't have that written down. And so I don't recall there being any hesitation about what people said at the meeting. I think it was totally open. But now in retrospect I don't know what I'm supposed to reveal and what I'm not supposed to reveal.

BCD: Yeah, and I don't think it matters too much. It's just ... actually the part that is most interesting is the stuff you've already covered, which is kind of how it felt.

LHillier: Okay, good.

BCD: And what it seemed like was happening at the time.

KM: Did it feel tense in the room?

LHillier: Yeah, it was tense because especially for a couple of the countries that really did not want to adhere to the open-release policy. I think it wasn't the scientists so much as the funding agencies and the countries. Yeah, I think other countries have more difficult situations than the United States in terms of protection of intellectual property or something that made it more difficult for them to be able to say, sure, we're happy to put our data right out immediately into the public domain.

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BCD: So, [LHillier], from your perspective does this feel like ... did you know going into this meeting that there was going to be ... the thing that most people remember about the Bermuda meetings is the Bermuda Principles. But from your reading, the purpose of the meeting from your invitation letter it's the final clause after five or six other functions that are being listed as what was going to happen at that meeting.

LHillier: Right, and I don't think I saw it that way. Yeah, I wasn't expecting that to be the big ... I mean, I knew we were going to talk about immediate release, but I was more thinking of it as a scientific meeting to exchange information and to coordinate efforts and make sure that we didn't duplicate effort and make sure we were doing the best job we could do using the best possible approach. I had no idea it was going to become such a gigantic step forward in terms of philosophy.

BCD: Did it feel like that when you were doing this going around the room and agreeing to these principles?

LHillier: Yeah, that felt ... once we were there and we were in this room and the people were agreeing, it felt weightier. Although I still wouldn't have anticipated how far it's ended up reaching. To us (as a part of the worm project) it was so totally natural. To us it was so totally natural. It was so perfect the way the Internet really grew at the right time for the worm project, because we were barely doing FTP at all in 1989, 1990 when I started the project. FTP was kind of a brand-new thing. And it just came at the right time. Everything just developed so well. And so for us in our lab it was just so natural. I think that was part of the reason that we thought it wasn't going to be as big of a deal as it turned out to be, because we had come from the worm world.

BCD: So could you walk us through what happens for a project as you're doing sequencing? And pick whichever one, whichever of these organisms you're sequencing. So what's the flow of data into the public databases that you're talking about here? And what did public release mean and how did that work in kind of a detailed operational way?

LHillier: Well for instance, talk about the worm. So worms were sequenced in cosmids that are 40,000 base sequences. And we did shotguns of the cosmids, so we'd do, whatever, 8X or 10X coverage of the cosmid. So a whole bunch of reads to cover the cosmid. And then we'd do an assembly, and the assembly would be then released within 24 hours directly onto our website at the time. In our implementation it wasn't submitting to the public database. At that point the public databases were only supporting final, finished, totally perfect data. So at that time we were just releasing everything basically as it was coming out of our various processes (vector trimming, assembly, etc). Actually I'm not sure what year. Maybe by then we were already starting to submit stuff to GenBank that was unfinished. But certainly in the initial implementation for the worm community,

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the 24-hour release policy was simply the assemblies of the individual clones. And that was similar for the human data as well.

BCD: So you're doing cosmid-by-cosmid release into a Washington University public server?

LHillier: Exactly. Because I don't think the release to the public databases came until ... I don't remember what year. I would have to look. But the public databases weren't ready to receive unfinished data early on; it was a whole philosophy shift for the public databases.

KM: And so with the human sequencing you were doing, how did the process work for the immediate release? Was it the same?

LHillier: I think we did everything equally the same. Yeast, whatever it was, we'd sequence, get the sequence enough for the clone, make our first assembly and put it out there.

KM: But you'd send it to GenBank then for the human.

LHillier: Well again with the human I don't remember what year we started. It took a while for the databases to begin to be willing to accept unfinished data, and I just don't remember. I can look back, but I don't remember what year they started expecting...then they developed that whole thing of phase one, phase two, phase three data. But that probably was around this time.

BCD: So, [LHillier], could you also tell us a little bit about the EST project that was coming out of Merck? And so you're doing segments or cDNAs there.

LHillier: Right.

BCD: And how does that flow? Where are the samples coming from? You sequence them and then what happens to the data?

LHillier: Yeah, so those were, that was a huge deal. That was a really incredibly intense moment because even the methods weren't fully worked out. So before we got the money we started by developing methods doing *C. briggsae* ESTs (*C. briggsae* is another nematode related to *C. elegans*). Marco Marra was responsible for working up the methods, so we did a bunch of *C. briggsae* ESTs in preparation. And then we started getting the clones from wherever we got them from, Merck and the I.M.A.G.E. Consortium, I think in January '95. And we only had a couple weeks until we were supposed to start submitting data. And that was when dbEST was developed, which was at the NCBI, and we worked with Mark Boguski, who was the database person, and Caroline to work out the format of exactly what we'd be submitting. So I think all during that beginning of January '95 we worked

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that out. And then just as soon as the reads were off the machines, these were individual reads that were meaningful (so the ESTs were just little pieces of cDNA off each end of the cDNA), in this case basically every night the new cDNA data would be submitted because we weren't waiting for a clone to be assembled or something. Just every night we'd submit to dbEST the sequence data for every clone.

BCD: So you have a direct channel from Wash U, your sequencing machines. You do a certain degree of some sort of annotation and error correction in checking. And then you submit ...

LHillier: Yeah, we do vector trimming and contamination checks, etc., and then submit immediately.

BCD: And that then becomes part of an NCBI-maintained public database?

LHillier: Yes, the dbEST. That's what they call for all the EST data.

BCD: But the equivalent for that didn't exist for the human genome until sometime ... that's what you can't remember exactly.

LHillier: Well I mean, like I said, the unfinished data part, yeah, that was ... yeah, I'm not absolutely certain. It was probably around that time when they worked on these, this phased submission where you could submit a phase one clone, which meant it wasn't ordered and oriented, had no gaps closed. Phase two, it had been partly ordered. They made this really sophisticated plan. I think that was around that time.

KM: Yeah, OK.

BCD: So we've heard several reasons for why sharing early was really important. One of those is in order to coordinate projects because you can't know who's going to do what unless you see what they're actually capable of doing. Partly it was to make sure that the quality standards were being met. Partly it was a political problem of, this was a public works project and the small labs weren't going to support the big centralized, high-throughput, very expensive sequencing centers unless they had equal access to the data. And then there was this kind of what John Sulston ... I can use his thing because he said no restrictions on his ... basically kind of spiritual open science. So of those possible reasons, I guess they're all in alignment, but did one of those feel like it was driving this more than the others?

LHillier: I feel like it's been to the more ... I guess spiritual sounds a little funny, but I think just a greater good, the highest road, because we were just hoping that the most people could get access to the data ... having more brains looking at the data obviously then, you have more possibilities for after discoveries being useful. I

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mean we were doing the basic science of putting the sequence out there. There's so much to be done with the data. And we wanted to make that available. I mean also I guess to save money overall too. I think that was a big thing at the time is individual labs would pay so much to sequence an individual clone because they really needed an individual clone. Or they'd know their gene was in a megabase region but in order for them to sequence that that was so expensive. And so we were saving tons of money and speeding up the pace of research by getting sequence out there. So that's another reason. But I think it's really ... I really do think; I mean, it sounds so really cliché-ish, but I think it's just a 'greater good of humankind' was the primary thing that was driving it.

BCD: Since you've got your foot, it sounds like, planted in both the biology and the informatics side of this, are you listening to ... is some of what's going on in open-source software, the sharing norms, the whole idea of copyleft and all that, was any of that thinking driving this? Or is this just growing straight out of the nematode community ethos?

LHillier: Yeah, I think it was totally growing. I mean I totally thought of it all from the background of coming from the worm community, just this huge spirit of camaraderie and sharing and the ability to get better science done more quickly.

KM: And to what extent do you think the EST data release norm was a precedent for what became the Bermuda Principles?

LHillier: Oh, I'm sure that helped. I think Craig hurt himself by trying to patent the ESTs at the very beginning. So then it really helped us to have had a company (Merck) even back us to put data into the public domain immediately so that it was, so no one owned a particular gene. So yeah, I think that was critical.

KM: Yeah, and going into the '96 meeting did you expect patents to come up?

LHillier: Oh, yes, I'm sure we kind of ... I mean like I said, I still mainly thought of it as a scientific meeting and a chance to ... but again, I guess there was some expectation that we ... I mean that was why we wanted to put the data in the public domain was so that it wasn't patent-able. So it's kind of implied. While there wasn't a lot of patent discussion I think it's just basically implied by immediate release.

KM: Right, right. So you come back then in 1997 and again in 1998. How did that process work? It seems as if there was ratification or reaffirmation process of the Bermuda Principles where folks from other countries also came back. What did that feel like?

LHillier: Well I think a lot of it was continued coordination too. Even at that time, even after the first meeting, we still didn't realize that the Bermuda Principles were

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going to be this huge. Even in '97, '98 I don't think we had an idea of how long, far-reaching it was going to be. It was basically trying to make collaboration amongst our groups work. That's all we were doing.

And so at the second meeting I think there was some discussion of extending the principles to other genomes for example. And then at the third meeting I think we talked a lot ... well actually I think at the second meeting too I think we talked a lot about quality, data quality and accuracy rates. Maybe actually it wasn't until the third meeting that we talked more about extending the principles to other organisms. I think the second meeting was mostly about accuracy and quality. But again we were trying to do a lot of standardization. And we were still having problems with people stepping in other people's territories, and so we were saying, okay, you're really going to do 14. How much have you done, can you really say you're going to be able to do this much? And everybody had to actually write up exactly how much sequence they'd generated. And people had to then say, yes, I truly can do this much more this year so if we leave this portion for you, you truly will be able to ... a lot of it was coordination. I think the first meeting was really the biggest in terms of philosophical commitment.

BCD: So one other thing that would change of course is from the first meeting to the second meeting you've now got a set of principles that were agreed to at the first meeting. What happens if you don't abide by them?

LHillier: You don't come back. I mean that was my total understanding even at the first meeting, right? They said if you don't abide you're not invited next time. I think the second meeting was smaller too. Like I say, the first meeting was super-all-inclusive. But I think by the second meeting it was only the people that were still funded and had agreed to the principles.

BCD: And so how do you guys know whether somebody's abiding by the norms that have been stated?

KM: Yeah, what was the enforcement?

LHillier: Well that's a good question. Enforcing is difficult and partly relies on individuals being people with integrity. For example, I developed a database to coordinate the clone selection for the different labs in the U.S. And so what I would do was I took all the sequence data labs were submitting, as long as they were submitting. I guess you're right. If they weren't submitting their data we wouldn't be able to tell. But if they were submitting their data I immediately would pull it off and compare it to everything we had and use the restriction digest and alignments primarily to make sure I didn't choose any more clones that would enter the pipeline and step on territory someone else had already sequenced. We theoretically could have used it to make sure that they weren't in a region they weren't supposed to be in. So we could have checked them on that kind of level. I guess another way we

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could notice is if a group had a huge influx of data at one point and that would suggest they'd been holding onto data. But you're right, it's difficult to enforce except just appealing to people's integrity. We were primarily just trying to make sure that every new clone that was entering the pipeline was really something that had not already been sequenced and also that it had as little overlap as possible with something already sequenced (although also requiring there be enough overlap so we could be confident of the overlap).

BCD: And one of the other things some folks have talked about is an agreement to kind of cross-check each other's work and a certain fraction of things would be shared with other labs to see if they got the same results and stuff like that?

LHillier: Yes, that was a quality checking exercise we participated in. I felt like it was motivated by the NHGRI, but I could be wrong. They were wanting to make sure that everybody was reaching a similar standard so we all would ship off clones to one another and then sequence and assembly them at each of our labs and then compare. I think the results, I don't recall specifically, but I think the results were all reasonably ... I guess there was an article written about it, wasn't there? I think there was a paper written about the comparisons.

KM: Yeah. So what do you think was most important to include in the Bermuda Principles? Was it the timing, the 24 hours, or was it the length of the reads? Or what aspects felt most important to you?

LHillier: Well I think just being freely available. I think the 24 hours wasn't absolutely critical. I think it could have been a week or something. It was basically trying to protect people from being super-interested in a disease gene and only wanting to sequence that area and do all their analysis. It was just basically letting the whole world know that we were really serious about sequencing systematically the whole genome. So I think it was just ... obviously accuracy was really important too because we didn't...because that was actually a big debate too. A lot of people didn't want to truly finish the entire genome. There was a little bit of discussion at the very beginning of the pilot project that all we would finish would be the genes, especially because of the time pressure that was introduced. We'd just do a draft and just finish the genes. And then that kind of evolved, and then it actually went backwards again right when Craig said he could finish the genome. There was, okay, well we'll just shotgun everything and not finish for a while. So I think the accuracy was a really big deal because otherwise long term maybe it wouldn't have gotten finished to the level of accuracy it reached.

BCD: So you have this model of *C. elegans* where you've got a couple of big central labs that are producing data as a kind of a public service for everybody. How well did it feel like that worked when it was scaled up to the human?

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LHillier: I mean I think it was just the only way it could be done, like we discussed earlier. Even for example, the finishing, which is the final stage of after the draft has been done when you're closing gaps, other labs even in the U.S. had a lot of difficulty with that. We really were the key people in finishing. So I think it worked well because we could offer a high-quality finished product at a reasonable price.

BCD: And did you have folks calling you up and saying thank you, thank you, thank you for sequencing across this region because you got my gene and here's what I've done with it?

LHillier: Oh, yeah, or saying, oh, could you also check this or could you go back and check your traces and see whether there actually could have been an 'A' there? Yeah, we got all those kind of emails.

KM: That's really interesting.

BCD: So tell us a little bit about how that works. So you're actually interacting with the user community that's, I presume some of these people you don't even know.

LHillier: Yeah, and they have no idea what they're doing. This again is why I was saying that the yeast community was kind of nice because it's a small enough community and enough of them had sequenced that everybody understood a draft sequence is not really very meaningful. You have to wait until you get to the finished product.

BCD: So do you have any stories of that sort that you can kind of give us some insight into how the science was proceeding as it made this transition to human?

LHillier: Well I bet you I could find...I have all my emails...I could probably find some really specific examples. I mean I felt in general that we got a lot more of that kind of thing from the worm community than we did from the human community. But we certainly did from both. I could go back and look to get some specific examples.

BCD: Yeah, because there's one story that I'm personally familiar with and that was the story of the inherited form of Alzheimer's disease. There were two genes, presenilin 1 and 2. Presenilin 1 was discovered first on chromosome 14. And my understanding is that presenilin 2 on chromosome 1 was discovered because the sequence from presenilin 1 on chromosome 14 was discovered and all they did then was find a hit in the dbEST to one of your nematode sequences. That then led to fishing out the sequence from [human] chromosome 1. And so within a couple months they had genetic linkage to a full sequence gene, whereas the other hunt had taken 19 years.

LHillier: Yeah, exactly. Yeah, that's a great story.

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KM: And what about folks using the data who weren't really doing genomics, but cell biology? Did you interact with any folks like that? In one of our interviews the person said, yeah, this was huge for the cell biologist community because they were doing other studies further down the ...

LHillier: Downstream.

KM: Yeah.

LHillier: Yes, again if I went back I could find specific examples because, yes, I mean we impacted across the board. It made a big difference for people to have the whole genome.

KM: So we talked a little bit about philosophical stuff. Looking back, what does this feel like? What do the Bermuda meetings feel like? Do you think that they have been part of a norm shift in doing biology or doing science as a whole? What does it feel like?

LHillier: I think it revolutionized the human field. Like I say, the worm was fine; the worm was great. But the human groups were just not like that. I think it was just exactly what was needed at the moment and it was certainly totally effective for the group that it needed to address at the time, the human genomic sequencers. And I think what's great, what's the best thing about it, I mean it continues to be relevant, I think what's the best thing is everyone else that makes agreements now always refers to the Bermuda Principles. Now things change. So Genome Canada, or whatever, they made a slightly different arrangement. But everybody kind of refers back to the Bermuda Principles. Yeah, it's revolutionized all the different projects that have come after it. The ENCODE Project, the HapMap, everyone goes back and looks and says, this is what the Bermuda Principles say, now how can we say ... are we going to adapt it exactly? And then also because now there's been however many, 16 years since then, we know all the ways that it didn't work and all the things that needed to be addressed that weren't addressed. So it gave us all these years of experience of how to know what needed to be changed. Yeah, I think it revolutionized the human community.

BCD: And you're thinking ... is this a rule that is applicable to ... that is the early prepublication release of data ... is that a rule that should be applied to everything or to only when you're doing one of these major public works projects where there are going to be many outside users that are drawing on it?

LHillier: I think it's primarily applicable to these large-scale...what's the word...pre-competitive data. But even projects like the International Cancer Genome Consortium, they're still using something like it even though this is a huge immediate application-rich project. Similarly like the 1000 Genomes Project and the ENCODE project, they're still urging data release. They're not necessarily

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requiring 24-hour release. Obviously people's academic careers rely on them identifying a particular thing and studying it to the hilt. So somebody's little project I don't think necessarily has to be immediately released. But when there is far more benefit than risk associated with releasing quickly, I think it makes sense to release quickly.

KM: How did it feel, talking about scientific careers, how were you guys dealing at Wash U with folks who were involved in generating this data? And how were you sensitive to their careers?

LHillier: We were sensitive because even Bob Waterston and John Sulston, who are just the pinnacle, just absolute most amazing people in the universe, there was some criticism of them because people said "sequencing was not a science." That just totally floors me. It wouldn't have been done without their amazing minds.

BCD: Sorry, [LHillier], are you telling me some people are saying John Sulston is not a scientist?

LHillier: What I'm saying is that people were critical of the sequencing projects being not really science. That it was just this big business thing. And it's true that we were large projects. We weren't a typical academic project. But it required immense scientific advances to be able to make it happen. But there were concerns about where people would go, but if you look across the board at the people that were in our lab at that time they've all gone on, I mean in Cambridge too, a lot of people actually quickly. There were very few bioinformatics people. I had so many offers to consult and to go to companies. And there were lots of people...we lost a lot of finishers. We lost a lot of people to the corporate world because there were so few people that had intimate knowledge of sequencing at that time. And people like Marco Marra who were big in our group, he's with Genome Canada now, the British Columbia Cancer Agency and Michael Smith Genome Sciences Center. David Bentley, he ended up going to a company. Everyone ended up doing very well so it's worked out. Rick Wilson, he's now the head of the Genome Center at Washington University. And there are so many examples of the amazing people that worked on this project. So it's worked out, but there were tense days and we weren't sure. We weren't sure where it was going to end up and we knew that a humongous lab like ours could potentially ... it wasn't going to necessarily work really long term because this was a unique time in history.

BCD: Did it feel to you like you were making a career choice that was risky?

LHillier: That's a good question. Well certainly right at that time, no, because there were so many people that were interested because there were so few bioinformatics people at that time. Since then obviously...at that time there were no degrees in bioinformatics. So it was great at that time but...and I was having so many external offers, it wasn't a question. But yeah, I think it had some risk. But even to

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be a part of those people, to be with those people, to be in a room with Maynard Olson and Francis Collins and Bob Waterston and John Sulston and Michael Morgan, obviously benefits far outweighed any risk.

KM: Were you at any of the later meetings for data sharing? Fort Lauderdale or Toronto?

LHillier: No, actually I didn't go. I moved to Seattle and then I didn't go to nearly as many meetings. I was obviously intimately interested and involved in all the colleagues in St. Louis that were there. So I know about them but no, I didn't go.

KM: Yeah, OK. And so we've talked to maybe two other women. What did it feel like in the Bermuda meetings in terms of gender balance? Did this feel like an old-boys club, or that's just how it was in genomics? Like they invited the scientists who were doing the work and a lot of them happened to be male. What did the gender balance feel like?

LHillier: Well you know at the first Bermuda meeting I actually found an email that I was the only woman to give a talk. Jane Rogers was there and she certainly...I'm pretty sure Jane was there, and she certainly could have given a talk. But for some reason I was the only female. The administrative people too of course were there; they were the other females there. But, yeah, it was pretty unbalanced, but that was just the way it was at the time. And it didn't feel like an old boys club; it was just a fascinating group of people trying to work toward a common goal. I guess you have the list and would know better exactly who was there.

KM: Yeah, and so a question occurs to me that is not so exclusively related but more tangentially related to this project. [BCD] and I last fall taught a course called, "The Genome and the Internet: Growing Up Together."

LHillier: That makes sense.

KM: Yeah, and we started it with World War II and we came all the way up to the present. We did the history of computing and also of molecular biology and up through genomics. And I was just wondering if you could comment a bit on the technology and what it felt like to be a part of biology right when computing and the Internet were becoming entities that could interact with biological science.

LHillier: Yeah, I mean like I mentioned earlier, the timing was just so perfect. Without the Internet the immediate release of data would have been kind of meaningless. The data analysis capabilities, our early ABI machines, the analysis runs right on the PC that's sitting next to the sequencing machine at that time. And so the computing power has grown up at just the right time to be able to deal with the increase in the amount of data. I mean the timing, yeah, I mean maybe it was just

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a necessary, but the buildup of the Internet and of computational power I think was just a necessary accompaniment to the sequence of the genome.

KM: Yeah, well, that's just an interesting point I wanted to double-click on for a second. So I think we've covered ...

BCD: So, [LHillier], were there any ... we've got a standard set of questions about trying to fill any gaps that we might have noticed. Can you think of any constituencies that it would have been useful to have at these formative meetings that were not included, or some groups that were there that didn't really need to be? Or did they hit it about right of who was in the room?

LHillier: I don't remember if Maynard was there. Do you have the list of the ...

BCD: We know that Maynard wasn't because we've interviewed him. He's actually with us out here this semester.

LHillier: Because we obviously could really have used him!

BCD: He didn't want to go.

LHillier: Phil Green was there though, I know at that first meeting, and he's another really important critical individual. I think David Lipman was there, wasn't he? Graham Cameron was another great person to have and of course Eric Lander and on and on and on.

BCD: Yeah.

LHillier: Yeah, so I mean he was obviously critical. I was trying to remember if the ELSI (Ethical Legal and Social Implications) people were there. One of the big things...at Cold Spring Harbor I always enjoy hearing from the ethical/legal people. Were any of those people there?

BCD: Well except for the staff that covered that like Mark Guyer, no.

LHillier: There wasn't, huh?

KM: Not really.

LHillier: So that's kind of an interesting omission because you'd think they would have wanted to be involved in those discussions. But there were cool people there like Ed Southern, who is incredibly insightful. It was great. All of the people across the board, David Cox and Rick Meyers and Eric Green, are amazing people. Michael Ashburner, he's such a colorful person. He was really fun to have there. Yeah, so they did a good job with the database people, with all those sequencing

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people. I wonder about somebody like Shirley Tilghman. She's more in the mouse world, but she's such an insightful person I think she could have been useful. Was David Page there?

BCD: No.

LHillier: Yeah, he would have been...David Page or someone from his lab I think might have been helpful.

KM: He wasn't there at any of the three.

LHillier: I see. Yeah, that's kind of surprising because he was obviously a really key player at the time. That's all that comes to mind.

BCD: Just one other thing. We've already planted one seed in this but just to stimulate your memory, one thing that's, if for no reason other than we're trying to get [KM] into grad school, we're trying to lay down a documentary record of what's happened. And the interviews are great and documents that support the interviews are even better because they allow us to anchor it in kind of an objective fashion. So if there are any documents or anything like that...we've already talked about your notes from this meeting before the first Bermuda meeting...but if you have any materials that you think would be of interest we would love to see them to shore up this history.

LHillier: Okay. Yeah, I mean I have a lot of things. I'm not certain what's of most interest.

BCD: One thing we could do is, I'm sure one of us is going to be out in Seattle at some point in the next two years or something like that. Our grant goes on for the next three years. We might be able to send somebody out and help you think through that.

LHillier: To look at things and say whether they were ...

BCD: Yeah, I've done that a few times with folks, and it's usually a tiny fraction of all the documents that are actually relevant.

LHillier: Like I have my outline of the talk that I gave at the first meeting. There was a two-part informatics session. I think that's totally innocuous. It wouldn't be a problem at all to share. You do have the transcripts of the meeting or is that not...

BCD: So that's kind of in transition. Michael Morgan is trying to work with the...the situation right now is that the Wellcome Trust basically has those transcripts and the library would like to make them public, but because of this ambiguity about what the rules were they want to go back and make sure that it's okay with everybody before they do that.

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LHillier: Yeah, they asked me. That's why I kind of wondered if you might have it because I had been asked. And I said sure, it's fine.

BCD: Yeah, but they're in this position where they have to have all the gates open before they can allow the data to flow out. And I think they're somewhere in that process right now. No, we have not seen the transcript.

LHillier: I see.

KM: We would love to.

LHillier: Yeah, okay. Well, I'll look through what I have.

KM: Yeah, that would be wonderful.

LHillier: And a lot of it was just a scientific meeting. There was a huge session on annotation, and I don't now how interesting...I mean I've got all of that but I don't know how interesting that is.

BCD: Well actually just to let you know a little bit of feedback here, this has been one of the most helpful interviews of all just because you straddle so many interesting areas.

LHillier: Oh, thanks. I'm just a doer. I'm just right in doing the work. I wasn't sure why you'd want to talk to me actually because I'm not the more philosophical driver. I just get to be a part of all of it.

BCD: Yeah, and if you don't mind, even before we hear back from you I'd like to be able to tell Bob that you were wonderful.

LHillier: Oh, thanks, sure. Thank you.

KM: Yeah, but thank you. This has been extremely helpful. We're having a lot of fun talking to all of the scientists because you guys really have an interesting and unique perspective. And you know, historians of science tend to wax kind of poetic and too often stories are not grounded in what actually took place...So this has been really wonderful, thank you.

LHillier: Oh, yeah, no problem. If you come up with other things after you think about what I've said let me know and I'll try to answer.

BCD: Well thank you, and you'll be getting a transcript from us in a couple weeks along with the cover form that gives you the options for what to do with it after you send it back.

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LHillier: All right. Well thanks for your time. I really appreciate you including me.

KM: Yeah, great, thank you.

LHillier: It was fun looking back through everything and just reliving the whole thing because it really has just been an amazing time to live. So I'm really fortunate to have been a part of it.

KM: Well thank you.

LHillier: All right, take care.

BCD: Bye.

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