Protocol 1277 Informed consent statement for Oral History Interviews
(This form can be sent in advance and signed or read into the tape at the beginning of the interview.)

The interview will be recorded, and I will use the audio file to make a transcript. The transcript will be shared with you, with an opportunity to correct it. The attached form indicates options for making the final edited transcript available.

My name is Colleen Mumford and I am a student at Duke University. I am in a course on the history of genomics that includes oral history. One goal is to produce a written transcript of interviews with important figures in genomics. Some of the interviews may be archived or made public through a website. The conditions for making the transcripts public (the audio tapes will not be public) are indicated in the accompanying form, and you can choose any of those options, or write in your own conditions.

I selected you as the person I would like to interview. The interview should last 30-45 minutes. Your participation in this interview is strictly voluntary, and you may withdraw at any time. You do not have to answer every question asked. The information that you choose to share publicly will be “on the record” and may be attributed to you, unless use is restricted the conditions you specify on the form.

This interview is being recorded and I may take notes during the interview. The interviews that are posted publicly will be archived as a history resource. If you prefer that the interview be used only for the course and not made public, please indicate this on the form.

One risk of this study is that you may disclose information that later could be requested for legal proceedings. Or you may say something that embarrasses you or offends someone else when they read it on a public website. The benefit of participating in this study is ensuring that your side of the story is properly portrayed in the history of genomics.

Signed: [Signature] Date: [Date]
Person interviewed: John Sulston Student Interviewer Colleen Mumford
(Print clearly) (Print clearly)
Use of archived final transcript

Members of the Duke University community, students, faculty and staff at other institutions, or members of the general public may access the digital archives. Typical research uses of interview materials include scholarly or other publications, 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.

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.

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

OR

(B) My interview materials may be reviewed, used, and quoted by students and researchers affiliated with 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)

Signature: ___________________________ Date: 28 Oct 2012
CM: So you received the consent form, and I guess the first thing to do is to make sure you understand this interview is being recorded?

JS: Yep.

CM: OK.

JS: Colleen, could you speak up a little? You're pretty faint.

CM: Yes-

JS: Thank you.

CM: Is that better?

JS: Yeah, yeah, that's grand. Thank you. And you presumably received my electronic copy, right, of the consent form?

CM: Yes, I did get that. So thank you for that, that's convenient to not have to do that at the beginning of this call. Are you ready to begin?

JS: Sure, ok.

CM: All right. So in *The Common Thread* you express frustration at times with the wording of Celera's press releases and US statements not mentioning other countries' work. What did you think, overall, about the press coverage on the Human Genome Project?
JS: Well, I was frustrated at times. I mean, these are really in different categories, the sites within the US, but this is true of all major countries and institutions, that they tend to simply forget what other countries are doing. I mean, some of the labs I’ve worked in have been exactly the same, like the Laboratory of Molecular Biology. The point is that these places are so good that it doesn’t really matter whether somebody else did anything because you could do it anyway. Now I mean there is no sort of accusation there, this is purely a sort of style and etiquette, and it was sort of a joke.

On the other hand, the wording of Celera’s press releases were, I think, quite deliberately putting a gloss on it, which was incorrect--statements to the effect that the human genome had been completed or something, which prompted Collins to comment. This is back towards the end, the year 2000. Francis Collins said, “Look, nobody can say they’ve completed the human genome for at least three years.” And he then got told not to make any further statements at all by the powers that be. So I agreed with him that he was referring to a seriously misleading press statement, and obviously it was being picked up and retailed, so that was frustrating.

Now as far as the press as a whole is concerned, here I must say I’ve gradually changed my position a little bit. It was very frustrating at times, and I probably did rant a bit. I can’t remember if I do that in the book, probably not in the book because I’d thought about it by then. But I certainly ranted at the time about journalists being too gullible and not researching properly what they were told. However, the more press I’ve done, and you must remember I was pretty new to the game of serious press at that time, the more I’ve done since then the more I’ve realized how important free press is. And that means having a lot of competing views and people taking their own perspective. This particular thing, it is an anecdote which I always tell, at some point in the whole proceeding after the project a Romanian journalist rang me up for comments and we got onto this topic, and she said, “You may complain about your press, but how would you like it if you only
had one press and it was owned by the state?” So I thought, yeah, ok, you have a point, and I shouldn't be so critical of the press.

The point remains of course, and this continues now, that people are not given the opportunity very often to go into the back-story. Ideally if we really want to inform people as well as entertain them, then anything that happens, any sort of report should always be taking into account what's gone before. There’s a counsel of perfection, and obviously in practice of newsworthy material people haven’t got time to go into all that detail. I think it remains a good aim to cover the back story as far as you possibly can so that you put each thing as it comes along into perspective, and that would obviously make for a much better informed public if people really did that.

CM:  OK, so also what were your thoughts about how the “Security Council”, or some of the heads of the leading labs affected the project? What did you think at the time?

JS:  Well, first of all obviously I should say the “Security Council” was a joke-

CM:  Yeah-

JS:  -that was just because were like “Gosh, we’re acting awfully like the UN the way were behaving.” And it was absolutely necessary at the time because we got into this situation where we were being threatened with outright privatization of the project, which obviously was incumbent on the public labs to get a move on in securing the intellectual property effects of it. So there was enough material in the public domain that nobody could say they have private rights to it. And in order for that to happen, we had to really strip down, much to the chagrin of our collaborators in some of the smaller labs, and much to my shame it was absolutely necessary for the big labs to get together. And that’s all the “Security Council” was, we were saying “Look, we're going to have to drive this project to the point of having this draft
sequence made”, as we’ll come to in a moment. I don’t think it made much difference to the end point....to the timing of the end point. But it certainly meant that we redirected in a way to get this draft data—imperfect data—out, which gave enough coverage of the genome that the public owned it. So that was the positive side... Negative, well I’m not sure there was a negative really, apart from saying that this was a necessary thing. I guess I’ve given you the negative, that it meant that some of the smaller people, the smaller labs felt put upon. And I just went around, Michael Morgan went around, and so on, explaining, “Look, I’m sorry that this is the situation, to try to retain this in the public domain. So I’ve thought about it now, yeah, it’s not changed really. I think it’s exactly what I’ve just said, that it’s a necessary thing to do.

CM: OK. I guess that going along with that, if you could just talk about your view about competition between different factors, say the private and the public, or the large groups versus the small groups... You kind of talked about that, but how did you think that worked?

JS: Yeah, I want to clarify about the competition and the tension. One of my favorite expressions is productive tension. And that’s the sort of thing that we had between Bob Waterston’s lab and my lab. We had competition in the sense of each side wanting to do as well as possible, to make its own advances and implement them. So there was a tension there, but then there was this cooperative tension because we had exactly the same goal. And so it’s a matter of collaboration as a matter of friends as opposed to people who are really competing with each other with rather different goals. So what we were faced with in the human genome obviously, as I’ve already said, is that we were competing to reach different goals. One, wanting to be private and really make very substantial profits and one wanting to be public and make sure that as many people as possible had access to the data freely.

So I had that clarified, and just to completely generalize, this story is common throughout science and I guess all human endeavor throughout all
of time is that you meet somebody, you're on somewhat similar ground, you figure out whether you can collaborate, or do you have to compete because you have different goals? So this is a sort of normal thing to happen, and you have to deal with it when it comes along. Personally I'm very much in favor of collaboration if you can possibly manage it. And what effects did it have on my own work? Well I guess on our work it didn't. I don't think that's probably the question. Did it change the timescale? I think frankly not very much at our end where we had sufficient funding from the Wellcome Trust to do our share of the genome. We had an end date already set in the grant of something like 2003 and we were going to achieve that anyway and it didn't in fact accelerate that. It actually slowed it slightly because we were putting all this effort into what would not have been necessary had it not been for that particular sort of competition. I mean, I personally felt very annoyed, for example, that I had to go on television and justify my position and all that kind of thing. I felt it didn't add anything to the work at all. It was just an encumbrant.

CM: So you talked about it slowing. Was that because you had to, say, prove that what you were working on was helpful or just the press coverage?

JS: I'm sorry, could you say that first bit again? I didn't catch the first part of the sentence.

CM: Yeah, just you talked about it actually slowing it down just a little bit. What was—

JS: Oh, right, right.

CM: --causing that, basically?
JS: Yes. Yeah, it’s a phase, it’s a distraction, really. I mean, possibly—and I know my colleagues in America would say there was some speeding up, I think, in terms of actually getting sufficient funds appropriated to the project in the U.S., to complete the task in a timely way. Maybe the element of competition, maybe that, but I don’t really see why it would be that, because on the whole the discussions, the presentations in Congress were about simply trying to fend off this threat to an already agreed program with a time scale which I consider—well, most certainly—would have been driven by ours. One further argument I would make is that since the independent funding agency the Wellcome Trust had committed funds to us, and we had committed to a time scale, I think there was no way on earth that our colleagues in the U.S. were going to go for another map. Obviously from the question of scientific collaboration, we’d have all gone on the same page, so I just do not think it improved. Now of course, from the simplistic view of regarding the event in 2000 and the publication at the beginning of 2001 as being the key moment, the draft sequence in other words, then of course that was speeded up. There would not have been sequence had it not been for the competition. I don’t personally think the draft sequence added anything to the human genome, I think it was just a confusion. But it was a necessary political tactic at the time in order to avoid losing the public access to the knowledge.

CM: OK. So the next question is what was the biggest surprise you encountered during the project, or afterwards, or at any time, really.

JS: Well, I was thinking about this yesterday, and obviously what one’s supposed to say is something about the science or something. And I’m not sure there were any particular surprises. I mean, some people talk about the number of genes, but personally I think I understood that the number of genes was not well understood anyway, and it just became gradually refined. And we also had quite a head start on that because of finishing chromosome 22 early on,
and getting a clear indication that there weren’t that many genes in the human genome. So all that crept in quite steadily, you know, the refinement.

You know, the biggest surprise I think in inclusion was the political one. I was terribly surprised the way it got pumped up because of this so-called race. And it’s interesting that now, ten years on, a number of us are getting interviewed about didn’t we pump it up too much and make too much of it because look it hasn’t cured cancer yet. And so I have to try to reset the balance and say, look, we’ve got the data, it’s leading to more and more discoveries, indeed there are certain cancer cures in the pipeline, as a direct result of all this and so on and so on. But of course it doesn’t immediately tell you everything. It was never supposed to. And then I thought, “Am I kidding myself?” I went back and looked at the last chapter of *The Common Thread* and let me just read to you what I wrote there.

CM: Sure.

JS: This was just at the end of the Human Genome Project. It says that sequencing of the human genome is not in itself one of the big ideas, but it is a milestone embedded in the big idea of molecular biology. And that’s a theme which I continue throughout that last chapter of the book. So I haven’t changed my view at all. I thought of it as being a job of work which we should do as efficiently as we could because it was really important. That I believed in. I was one of the few people who was very early into genomics in the 80’s, and that led on to the sequencing of organisms in the 90’s, and I always considered that when we got to that point that getting the entire sequence of the genome was important. I think that’s completely vindicated by things that have come out since, the mining of the sequence, the all sorts of things other than the protein coding genes, for example. So it’s very clear it was good to go that way.

But I did not see it as a mean shot, I really did not, and I think those quotes in *The Common Thread* confirm that, that that was my view at the
time. So, OK, I was surprised that we were forced into this position. I mean indeed I fought against it, I fought against appearing on television and having to justify it in these terms. But I had to because otherwise people have said, “Oh, well these guys obviously don't have anything, and we should just go with the company view” and the whole thing would have been privatized. So I felt it absolutely necessary to join in, after all it was sort of hype about it, to defend the patch. It was a surprise I had to do that.

CM: Was there anything you expected to happen that didn't happen, didn't come to fruition?

JS: That didn’t happen... Well, not really, I think things worked out all right. The whole thing is much bigger again than the Human Genome Project, unless we’ve—actually I've do relay this a bit more in my talks now, I'm not sure I did in The Common Thread, but actually, it was rich that we had a lot of public access bio-information attached to all this because we, the Human Genome Project, became a sort of flagship piece of sequence and piece of data for the public databases, the three public databases as they are at the moment, NCBI and EBI here in England, and Inishima in Japan who are the repositories of sequence, but they’re also the repositories of all sorts of other biological information. And so...I'm not giving you any examples of what didn't happen, but I am sort of reinforcing how important it was that things did go the way they did, why we fought as we did to make sure that this information continued to flow into the public domain in a well funded fashion with enough funds also to look after it and to work on it and complete it going on from 2000, 2003. But then on and on and on mining, and it’s lead to the sequencing of multiple human genomes, now multiple organisms, and all of this stuff, all of this stuff apart from a few private bits of work have been put into these public databases so everybody can use them. So I'm afraid I'm giving you something else that did happen, but I'm sort of emphasizing that it might not have done this if we hadn’t pushed it in this particular direction.
CM: Mhmm.

JS: So turning that around, I think what I’m getting at is to say I was surprised that we didn’t get complete, 100% outright support from everybody for what we were doing. I was absolutely amazed that the reaction of society and of some proportion of journalists and all that was nuanced. You know, people were not saying, “Oh, these guys are obviously right and that this obviously must be public.” I just thought it was so self-evident. How could anyone not think that’s right? Anyway, we therefore had to have arguments, and we despite the doubts pushed it through so that’s the way it turned out. It still has to be defended forever and ever, but it’s got to a good point so far. Am I making sense Colleen?

CM: Yes, that does make sense.

JS: Do come in, you know, because I just rant on.

CM: (laughs) You touched a little upon the funding during that last bit. And so I guess, just curious, do you think that the funding...was that part of the reason there wasn’t 100% support for the public database?

JS: Yup.

CM: Do you think that’s the only reason?

JS: Yeah, exactly, I think people are quite rightly critical of the money that scientists spend, and the argument here is simply utility, really. Like I said, this is not a big idea. The mapping that I did and the sequencing of the nematode genome with Bob and the sequencing of the human genome, all of these things are justified as tools. And so what you have to do is say, “Look,
you’re making an investment here, but it will be—you’ll get an enormous return in the empowerment of science in these areas. And I think as we go on and look at what’s going on, I’ll give you one example. For example, mining of the sequence for various sorts of other genes like microRNA. These are things which are opened up, and they’re invaluable, and they’re worth far more than the investment in the genome. There’s a very good return, if you like, on that investment. So I think that’s the sort of argument you have to make in this sort of situation, that you’re doing something that empowers science to tackle the problems. Did that answer the question?

CM: Yeah, it did. So do you think there were any other underlying causes or was it just the money issue?

JS: Oh, you mean about people. Oh, no, no, no, no, no. There’s a lot more to it than that, again it’s covered in *The Common Thread* and quite a lot in my writing since then. I think the whole social structure—we are living in a social situation, a socioeconomic situation that believes very, very strongly in the unfettered free market. And especially in the US, which is the epitome of this, except in Europe to some degree, which has a much more social democratic view as far as possible. And so what happens is that quite a lot of people are rather inclined to back the commercial operator, if you like. And you get phrases like, “Oh, well this saves taxpayers money” and so on. And this has been analyzed a lot since then. That’s fine, and we are part of it obviously, a capitalist structure. We get our pensions and our savings accounts and all the rest, but nevertheless we need to recognize we’re channeling things in a certain way, and if you only invest in new things, this venture capital money, then you will be constrained both only to do things that can make money and also to make money once you’ve done them.

So the human genome is a fine object case of this, that in the case of Celera, which was running on venture capital, it absolutely had to keep it private and to make money from subscriptions and patents and everything
else you could do. And this became clearer and clearer as time went on, that this was obviously going to have to be the business plan of the company. So that's what you get. You certainly save taxpayers money, but then you’re constrained to behave in certain ways. So then it comes back to the argument about whether the human genome and genomic information generally and other biological information, is that the sort that should be done in the other way with public funding?

Now the interesting thing is that although you do get objectors, they’re mostly rather thoughtless objectors. I would say they’re people somewhat infused, the sort you’d see on the very ghastly threads sometimes in wide magazine. But people very often when I’m talking to people in companies, for example, who actually need this data they say it was fantastic it went through the way it did and the data is public because otherwise it would be much more difficult. And we’re reaching this again, but just to embellish the point of it, now with gene patents, we’re getting the same arguments here now. People have been getting, squeezing out patents on individual genes. I've criticized this a good deal about the way the bar is set but I don’t object in principle to people having functional patents. But what we’re seeing is that because there are a lot more and more gene patents, these may be a serious impediment collectively to moving forward into various sorts of epigenetics where you want to test many genes in parallel, for example, in medicine.

So again, the short term is that you get people who react in a certain way and you have to go through the arguments about why some things are pretty competitive and you need to do them collectively. And when we go onto the really big issues then we’re seeing just the same thing. You take a glance at the discussions about climate change, for example, you see all of these same forces and attitudes in play exactly the same. Which is why it’s interesting for me to be thrown into this through the Human Genome Project because I find many, many different examples in our society of how we’ve got to get this balance slightly better than what we have at the moment.
CM: Are you talking about the People and the Planet report you did?

JS: Yes, exactly.

CM: And you're seeing similarities, I guess, to the Human Genome Project in what you did?

JS: Well, exactly. It's short term and long term, it's personal profit balanced against the public good because we all benefit, including those who make personal profit, from the public good. We have to get that balance right. We've swung too far towards the personal short-term profit, I think, for the planet to survive, let alone for individuals to be happy.

CM: So you say we've swung too far... What balance, then, would you think is ideal as far as-?

JS: Well, this is a subjective thing, balance. The only reason for using the word is to simply indicate it's not one side absolutely right, the other absolutely wrong, but we need to have a social structure that allows people to develop their lives, and that includes investing and making profit and all the rest of it, to run their enterprises. But at the same time, to have a view to the big things that affect us all, the long-term changes, for the unfettered use of carbon dioxide or the unfettered use of rare earth metals, or whatever it might be, will simply run us out of resources. To have a view to inhabit the planet in a sustainable way. So why do we need the private side at all? Well partly is for people's rights of self-determination but also because of course, people think of individual ideas that need to be tested out and tried and you want to have exactly that kind of free-wheeling entrepreneurial thing going on. But it shouldn't take over the ship, and nor should a sort of permanent, stable, nothing-changes take over the ship. We need to have a sense of a
status quo, and a sense of long-term goals, but also we need people able to fulfill themselves.

CM: Mhm. So this is shifting topic quite a bit, but I’m curious about how it felt, with your science background, to be writing a popular novel such as *The Common Thread*.

JS: Yes. Yes, it’s interesting. I was thinking a bit about that, how I got in, and I remember clearly actually my first thoughts of writing a book. Getting a book written was the way I thought about it first of all because I had a number of approaches. I mean, it was after we’d had the big bang of talking about the work in the year 2000—that was in the summer of 2000—that it was announced that we had this draft sequence. And I had lots of interviews and going over all this stuff, and I had approaches from different agents who said, “You’ve got a fantastic story here, you really must write it up and I can make you lots of money.”

CM: Mhm.

JS: Literally, you know, people were writing to me and saying this and I thought, “No, no, no, hang on, I don’t want to make money out of this” because I could see very clearly how that would go. It would be hyped up and it would be done badly inevitably. I wanted quite the reverse. However, it brought to my mind that actually there was a story to tell, and I wanted to set the facts down clearly as much, I suppose, for my own sake and my colleague’s sake as anything because I knew I had certain access to certain information, my memories, and so on, about what had gone on. And that side of it is certainly true, because I constantly take *The Common Thread* off the shelf to remind myself about the specifics of certain incidences. So it’s really great it’s all laid down there. And of course this sort of history project you’re doing at Duke
will be the same way exactly. But anyway, I wanted to jump in there and write my own thoughts down before I forgot them all, really.

So I asked around a bit and talked to people and it was absolutely fantastic that Georgina, who I already knew sort of agreed to come in on it. Originally I told her she might write it herself, and she wasn't going to do that. And I never really quite got into her reasons for why she didn't want to do that. But she was very happy to come in as a partner, so we agreed on that basis. So I think that really is pretty much the whole story. I mean, certainly yes, I was aware there was James Shreeves, for example, who was writing something, he was sitting in Celera's office, obviously, writing things. Bob Cook-Deegan had already written his earlier thing on the genome wars. And there were lots of books coming out, so it wasn't any particular target, but it was just sort of thinking, “Well, you know, I’d like to have my own version of this because I think that’s the true version.” I wanted it to be on the record.

CM: So it was just trying to show your perspective—

JS: Oh, the question about writing it as a scientist. It was just a terrific experience. It was really good working alongside Georgina. We both wrote bits separately and then we sat together at her desk and went over editing stuff, and drafts going to and fro. And it was, you know, an entry into a different world altogether for me, or the edge of it. She did a lot of the organizing part of it—I was really part of it.

CM: Yeah. And this is kind of a hindsight question, just looking back on the overall project, how it’s had an effect on science today, especially in regards to collaboration—

JS: Yeah, well my answer to that is that I think that you guys are the ones to answer that. When I was over at Duke, you know Bob and I were there—was
it earlier this year? I think it was. You’ve got that, do you? We came over to be interviewed about the Bermuda agreement.

CM: Yes, I’ve got the transcript of that interview.

JS: Yes, so you’re aware of that.

CM: And I think it was last fall, or this spring.

JS: That makes sense. That was it, that was it, a year ago. Anyway, I was very struck to hear researchers at Duke say the Bermuda agreement—I mean, it was sort of specified to that because that’s what we were there to talk about, but nevertheless—the Bermuda agreement epitomizes the way the whole public side operated on the human genome and indeed set the rules for doing so. And I was quite startled, and delighted in a way, but also wondered what it meant when I was told an awful lot of people are referring to the Bermuda agreement as a model for how to do science and the rest of it. And I think it’s probably in my transcript from then from saying, “Well, that’s fantastic”, but demurring a little to realize that this isn’t the only way of doing science.

It’s important, in fact it parallels very, very much with what I was just saying about the public-private, and the balance, here it’s the same in science. If you have a problem, and you’re solving a problem, and you’re drilling down deep to do that, then that’s one thing. You’re collecting a body of data whose use, number one is useful for everybody and number two, has a lot of unknown uses in the future. In other words, it will go on being mined. Then clearly, you want the Bermuda style operation, where everybody cooperates to generate that data efficiently and without taking advantage of each other.

So there are two extreme ways of how to do science. And of course an awful lot of science is in between, I mean people do share things in science anyways. That’s part of the process, an absolutely critical part of the process, and people are talking a lot about this now in terms of scientific integrity,
have whole meetings about it, talk about it, public access to it, all this business. So it’s important to emphasize that, but equally it’s important not to constrain people’s freedom of maneuver and to acclimate hunches. If they can get the money to try out something and you can drill down to solve a problem that’s great too. And it’s clear from these various comments I’ve heard, and the reason I’m parsing it back to you, is because you are in the position of researching sociologically and historically. And I’m not really, you know, I just pick up anecdotes. Listening to the anecdotes, it’s clear it has had a substantial influence, but I would look for it to have an influence in this slightly balanced sort of way, to say what project have I got here, and how important is it to share the data in this particular area.

**CM:** Would you say it’s actually generated that, or just made people more aware of it?

**JS:** I think it’s always been known in science. After all, the whole idea of scientific publication is very much at the heart of how we’ve done science for the past hundred years now, really. And the whole point about publication is that you share. The thing about—and this is something people have asked me about—the thing about publication, of course, is that you’re sharing all the information but you’re also getting attribution. So the act of publication in a formal sense is really part of the scientific career progress and the cued-off for an individual and for an institution, of course. And, you know, publish or perish—you must do this. This is the way you get the attribution.

So I suppose, with the much larger data sets that are coming out, it’s bound up, it’s not just the human genome. All branches of science are able to collect much more data because of advances in IT. Then the thing is what sort of attribution do you give to people who release these datasets and should they count equivalently in structure to writing specific papers. And when you’re using the data to write the paper who has the right to do that, all of these issues are coming up very much in all sorts of areas and genomics
because it’s quite a data-led area. The sheer collection of data has often been at the forefront of trying to work out the rules, the etiquette as we called it during mapping, of how to behave.

CM: All right, well I think it’s been about half an hour of your time, and I’m sure you’ve got other things to get on to—

JS: Well, if you’re happy with that, that’s fine, but if you have any questions for supplementary or clarification, please do.

CM: Yeah, well, I guess if you have any last comments on... I guess, looking back on the project, if you could have changed anything or-?

JS: Well, obviously it would have been great to be more efficient. Everything I've ever done in science I feel the same way. I think, “How could I have been so stupid, and so slow on the uptake, and taken so long to get this bit or that bit done?”

CM: Do you think that’s part of looking back at it—?

JS: That’s what research is about. You don’t know what is going to happen, you’re exploring. And just like people who explore, you have to set out, and as you set out you make a map of your path and go as far as possible and make mistakes. And you have to backtrack sometimes, you know, and you get new vistas as you move forward, and so on and so on. So all of these things apply to all of human endeavor. And so, no, there’s nothing given my mental capabilities, I would have particularly improved. I mean, we’ve already gone over very considerably my feelings on the hype. I’m not regretting it, what I did, but regretting the necessity of it. And that was a shame. But again, it happens in some areas and I mean, people for example, compare to the people at CERN. I’m sure a lot lot of them have been quite
embarrassed about the hype about the “God particle”. The head himself has repeatedly said he doesn’t want it to be called the God particle--that’s ridiculous. That’s another example of this sort of embarrassing hype. None of these things matter, you know, as long as you pull through and actually learn more about the universe, which is what we’re all about.

CM: And I guess as a conclusion, is there any comments you’d like to make in regard to anything you’ve said to clarify?

JS: Well, I rather liked the way you picked up the People and the Planet, because that’s my sort of front-edge at the moment, the thing I’m having a go at. And all sorts of things could be said about that report, the torturous process of producing the report. Trying to get it together, it’s just the same. One could imagine with hindsight shortcutting it, trying to get it faster, but it was a great, great process because I learned so much along the way from different people. And so I suppose really that’s just to underline what you’ve already said, which is that there seems to be a connection between these various areas. And I suppose it also gives an added answer to your previous question, which is something about where this all fits. I mean, I’ve come to the conclusion that whatever else we do, we ought to survive. And lots of people don’t seem to care too much about that. But this puts the Human Genome Project into a much larger context, really, and it’s more obvious with People and the Planet. I mean, there aren’t any particular risks immediately from the genome. Some people worry about how it might be misused, this sort of information.

CM: Yeah.

JS: But I think those aren’t very direct. I mean, they have to do with synthetic biology, making very virulent organisms or something like that. Certainly we ought to guard ourselves against this sort of thing. But I suppose the general
message is that if we want humanity to survive and to flourish, then we do need to look ahead, and we do need to head off whether it’s the rising temperature of the earth or the pandemic which is caused by a rogue scientist somewhere or indeed a rogue national corporation somewhere. We have to be collectively looking to head off these threats. And indeed I think the human genome is one of the pointers about how to go forward on that and get it right. But we are left with the fact that we are a collection of seven billion people, and we need to have a collective judgment on what I just said is right. Not everybody agrees, and they have other agendas that might conflict with the survival of the species.

And why do I think that’s important? Well, it’s because we don’t have any evidence yet that there’s any other life form in the universe, and we certainly don’t have any evidence yet that there’s any intelligent life form in the universe. There may be, there may not be. But I want humanity to behave as though it was a unique spark and I want therefore generations, our grandchildren, our great-grandchildren and so on to have the opportunity to move on and explore and to flourish in their lives. And we can only do that if we both we take into regard the state of the planet and take regard to human freedom and equality. And so putting all the bits of work together from the last ten, twenty years, that’s where it’s leading me at the moment. This is the most important thing. Much more important than any particular achievement or display of prowess is the survival, but in a flourishing way, of a sort.

CM: So, tying that back to the Human Genome Project, it’s really all about getting down to the core of issues and doing things for the good of as many as possible?

JS: It’s about what really matters. And of course the flourishing always means that we’re going to continue improving people’s health, fixing diseases. That’s all part of the flourishing. We’re not going to just go on content with
people being sick and unhappy, but we need to look at it for everybody. That's the big thing that's missing when we look from our very privileged position and the rich countries and the sort of science we can do and the sort of things we can do in our personal lives. It's just so vastly unequal with the people in the least of our countries, and we need to be-

CM: -aware of that?

JS: -making room for people to move into a position of greater equality. That's going way off your brief, I know, but you asked me where I was.

CM: No, I think it’s important and interesting to see, you know, how your work has shifted from the work of the C.elegans, the worm, to now working on improving the planet.

JS: Yes, I think probably this is the fuller answer to your question 3—what effects did it have. I mean, clearly one of the effects has been that I’ve sort of injected myself into a different area of work altogether, which is social policy, science ethics, that sort of thing, because it made me realize if one can do good work in the lab one also has to find ways of applying that work well. And then that reacts back onto the work you’re doing, perhaps. But certainly the way you apply it is important. And this can be part of the future, or it can actually make the future more difficult if one tries to exploit it in a way which makes one group of people on the earth even richer relative to the others, which is obviously a bit of a tendency in medicine. It just doesn’t help the people who have less advantage.

I must say, it’s just a very big challenge facing humanity, is this issue of equality. And we’re not solving it at the moment. We’re getting more and more unequal. Of course it’s not just global, although that’s the most extreme version, but it also happens within countries. I mean the UK and the US have both gotten much more unequal during the past 50 years. And this has been
tolerated. You know, the level of salary at the top compared with that at the bottom has hugely increased in both countries. And this is dreadful. I think it’s understood now that doesn’t make for a happy society.

CM: No.

JS: So people are not flourishing, and this sort of thing is going on. So yes, indeed I have shifted. But, you know, in a logical way. It’s not a frustration with science, it’s rather a feeling that we need to take science more seriously about its potential to good, as well as my primary purpose of science, which is to discover and explore. After all, what is the purpose of humanity other than to discover and explore? I can’t think of a better one.

CM: No. Well, I think that’s a good ending point.

JS: Yeah, I think I’ve given you way more than you wanted. I apologize for bending your ear so long.

CM: No, I appreciate all of it. Thank you again for agreeing to this interview and for giving up some of your time.

JS: Yes, I’m delighted. Thank you so much for listening to me. So I hope the project goes well. You’re going to write this up now as a specific thesis, is that the idea? Are there other interviews you’re doing?

CM: Yeah, well all the students in this class are collecting interviews from different people, different angles, and then if they agree to it we’re using them to contribute to the institute’s overall research project, and we’re also all writing individual final papers for the class.
JS: Well, good luck with your course, enjoy. Hope it all goes very well. All the best, Colleen.

CM: Again, I really appreciate it. Thank you very much.

JS: OK. Bye, then.

CM: Goodbye.