

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: Eric Green, M.D., Ph.D. Date of interview: Dec. 8, 2011
Current institutional affiliation: National Human Genome Research Institute
Street Address: 31 Center Drive, Building 31, Room 4B09, Bethesda, Maryland 20892
Phone: (301) 496-0844 Email address: egreen@nhgri.nih.gov

Interviewer Information.

Full name(s): Robert Cook-Deegan, M.D.; Kathryn Maxson, B.S.
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: _____

Date: FEB 27 2012

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  _____

Printed Name Eric Green, M.D., Ph.D. _____

Date 12/8/11 _____

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)

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+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.*



THE WELLCOME TRUST

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FACSIMILE TRANSMISSION

REF: JS/SO'D/FAX198.DOC

TO: Dr Eric Green

FAX NO: 001 301 402 4735

FROM: Jilly Steward

DATE: 17th January 1996

No. of pages including this: 8

Dear Dr Green

Re: International Strategy Meeting to Progress Large-Scale Human Genome Sequencing, 25th - 28th February 1996

Please find attached formal letter of invitation to the International Strategy Meeting in Bermuda from the 25th - 28th February 1996.

A hard copy will follow in the post.

Yours sincerely

Mrs Jilly Steward
Meetings and Travel Manager



THE WELLCOME TRUST

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JS/SO'D/INVLET\USA\Bermuda

17th January 1996

Dr Eric Green
National Institutes of Health
NCHGR
Bldg 9 Room 1E 124A
Bethesda Maryland 20892
USA

Dear Dr Green

Re: International Strategy Meeting to Progress Large-Scale Human Genome Sequencing, 25th - 28th February 1996

I am writing further to Dr Morgan's E.mail of 21st December 1995 inviting you to attend a closed International Strategy Meeting on Human Genome Sequencing to be held at the Hamilton Princess Hotel, Bermuda from Sunday 25th February - Wednesday 28th February 1996.

As you know, the aim of the meeting is to facilitate the co-ordination of research groups involved in large-scale human genome mapping and sequencing. The meeting will include discussion about different strategies, potential mechanisms for co-ordination, new technologies, informatics and data release policies.

A skeleton programme and provisional participants list is attached and delegates will be contacted again in the near future as to their exact role. However, it is anticipated that most delegates will play an active part in the proceedings.

The Wellcome Trust will meet the cost of your accommodation and subsistence for the duration of the meeting.

It is envisaged that participants will be able to meet their own travel expenses, but please contact me if this causes any great difficulty. The Trust has negotiated special rates with American Airlines and if you wish to avail yourself of these discounted fares please contact American Airlines on their 0800-433-1790 number or ask your travel agent to book it quoting star field number S7826MK.

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Professor Roy Anderson, FRS, Professor Christopher Edwards, MD, FRCP, FRCPed, FRSEd, Professor Sir John Gurdon, DPhil, FRS, Sir David Cooksey, Bridget M Ogilvie, ScD, FIBiol, FRCPath (Secretary)

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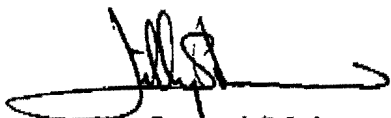
The programme is scheduled to commence at 1800 on Sunday evening and the Trust would be willing to meet the cost of accommodation on the previous night if flights preclude arrival on Sunday. The meeting will conclude on Tuesday evening and delegates should plan to depart on Wednesday 28th.

To facilitate the administration of the meeting, I should be most grateful if you could complete the attached registration form and return it to me as soon as possible.

Should you have any enquiries relating to the scientific content of the meeting, please contact Dr Barbara Skene or Dr Michael Morgan on 0171-611-8232 or 0171-611-8432. Any other administrative queries should be addressed to me.

We look forward to your participation in this meeting.

Yours sincerely



Jilly Steward (Mrs)
Meetings and Travel Manager

***International Strategy Meeting on Human Genome Sequencing
The Hamilton Princess Hotel, Bermuda***

25th - 28th February 1996

Title _____

Surname _____

Forename _____

Academic Address

Tel No: _____

Fax No: _____

E. Mail _____

I confirm I will/will not be able to attend the *International Strategy Meeting on Human Genome Sequencing* from 25th - 28th February 1996.

I shall undertake my own travel arrangements and my itinerary is as follows:

Departure Date _____ **Time** _____ **From** _____

Return Date _____ **Time** _____ **From** _____

Accommodation dates required _____

Any special dietary requirements _____

Any AV requirements _____

Other comments

Please return this form immediately to: Mrs Jilly Steward
Meetings and Travel Manager
The Wellcome Trust
183 Euston Road
LONDON NW1 2BE
Fax +44(0)171 611 8237

INTERNATIONAL STRATEGY MEETING ON HUMAN GENOME SEQUENCING
25TH FEBRUARY 1996-28TH FEBRUARY 1996

PROVISIONAL PARTICIPANTS LIST

Dr Mark Adams
Dr Wilhelm Ansorge
Dr David Bentley
Dr Anthony Carrano
Dr Tom Caskey
Dr Ellson Chen
Dr Daniel Cohen
Dr David Cox
Dr Richard Durbin
Dr Glen Evans
Dr Liz Evans
Dr Chris Fields
Dr Richard Gibbs
Professor Peter Goodfellow
Dr Eric Green
Dr Mark Guyer
Dr Manuel Hallen
Dr LaDeana Hillier
Dr Leroy Hood
Dr Eric Lander
Dr Frank Laplace
Dr Hans Lehrach
Dr David Lipman
Dr Yusuke Nakamura
Dr Diane McLaren
Dr Robert Moyzis
Prof Naotake Ogasawara
Dr Michael Palazzolo
Dr Ari Patrinos
Dr Jane Peterson
Dr Bruce Roe
Dr André Rosenthal
Professor Ed Southern
Dr John Sulston
Dr J Craig Venter
Dr Susan Wallace
Dr Robert Waterston
Dr James Watson
Dr Jean Weissenbach
Dr Richard Wilson

THE WELLCOME TRUST

Dr Michael Morgan
Dr Barbara Skene
Mrs Jilly Steward

INTERNATIONAL STRATEGY MEETING
TO PROGRESS LARGE-SCALE HUMAN GENOME
SEQUENCING

Provisional Programme

AIMS:

1. To discuss mechanisms to co-ordinate, compare and evaluate different strategies for human genome mapping and sequencing.
2. To consider the potential role of new technologies in sequencing and informatics and to discuss different scenarios for data release.

Sunday 25th February 1996

Arrival of Delegates

1800 DRINKS RECEPTION

1845 DINNER

2000-2200 **SESSION I - INTRODUCTION**

CHAIR: TBA

Statement of existing plans

2200 CLOSE

Monday 26th February 1996

0800 Breakfast

0900-1300 SESSION II - SEQUENCE-READY MAPS

CHAIR: Dr David Cox

Issues:

1. What sort of maps are required for different strategies; alternative starting points?
2. What is available in terms of maps? reagents?
3. Potential mechanisms/policies for distribution of maps and reagents

1100 COFFEE

1130 Discussion of key issues and action plan

1230 LUNCH

1330-1500 FREE TIME OR "BREAKOUT" SESSIONS

1500 TEA

1530-1830 SESSION III - INFORMATICS

CHAIR: TBA

Issues:

1. Tools for sequence handling (data collection/assembly, tracking)
2. Tools for analysis
3. Distribution of software etc.
4. Update/long-term maintenance
5. Data release

1700 REFRESHMENTS

1730 Discussion of key issues and action plan.

1830 CLOSE

1900 DRINKS

1930 CONFERENCE DINNER

Tuesday 27th February 1996

0800 Breakfast

0900-1230 SESSION IV - LARGE-SCALE SEQUENCING

CHAIR: TBA

Issues:

1. Is the technology there?
2. What are the further improvements?
3. What is currently feasible/should be followed?
4. New technologies
5. Should we wait for new technologies to be developed?
6. What is the product? Cost/finish?
7. What is/should be the policy on data release?

1100 COFFEE

1130 Discussion of key issues and action plan

1230 LUNCH

1400-1600 SESSION V - PANEL/OPEN DISCUSSION

CHAIR: JOHN SULSTON

Issues:

1. Co-ordination; what and how?
2. Criteria for comparing cost/accuracy/value of sequence data
3. Funding agency viewpoints

1600 TEA

1630-1800 Available for continued discussion or freetime

1900 DINNER

Delegates depart Wednesday 28th February 1996