

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)
rachel.ankeny@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.*



THE WELLCOME TRUST

JS/SO'D/LET560

12th February 1996

Dr Eric Green
NCHGR
National Institutes of Health
9 Memorial Drive MSC0945
9/1E124
Bethesda, MD 20892
USA

Dear Dr Green

***International Strategy Meeting on Human Genome Sequencing
25th-28th February 1996***

I am writing to you with final instructions and arrangements in respect of your attendance at the meeting on Human Genome Sequencing to be held at The Hamilton Princess Hotel, Bermuda from the 25th to 28th February 1996. Please find enclosed a copy of the final programme. Included at the end of the programme is a page entitled "Resources Available". **This should be completed prior to the meeting and be handed to me on arrival at the hotel and will be discussed in Session 2.**

A brochure of the hotel is attached, and contact details at the hotel are as follows:

The Hamilton Princess Hotel
P.O.Box HM 837
Hamilton HM CX
Bermuda

Tel: 809 295 3000
Fax: 809 295 1914

Ground transportation to and from the airport has been arranged with Bee-Line Transportation who have been sent details of all flight arrivals and departures. Please let me know **immediately** if your flight schedules have changed from those stated on your registration form.

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183 Euston Road

London NW1 2BE

Telephone: 0171 611 8888/Direct: 8899

Fax: 0171 611 8545/Direct: 8237

E.mail j.steward@wellcome.ac.uk

Accommodation has been arranged for you at The Hamilton Princess Hotel for the nights of 25th, 26th and 27th. During the meeting the Trust will meet the cost of your accommodation and subsistence, plus the drinks receptions and wine at the conference dinner on Monday evening as detailed in the programme. All other drinks, telephone calls, newspapers and other incidentals should be met by individuals prior to departure from the hotel. The Trust does not therefore expect to meet the cost of any additional expenses. Could we also ask that, for ease of handling at the hotel, **all your luggage is clearly marked with your name.**

Please note that it is a requirements of The Hamilton Princess that for all evening functions dress for delegates should be smart casual with gentlemen wearing a jacket. This dress code also applies to the restaurant for the conference dinner. The dinners, including the conference dinner, are an essential part of the programme and delegates are therefore expected to attend all of these events unless previously agreed with the Trust.

It is the policy of the Trust that all delegates are expected to stay for the entirety of the meeting unless personally agreed with the Trust prior to the start of the meeting. Unfortunately, due to recent experiences, it is necessary to add that no unexpected delegates will be accepted to take part in the meeting.

In the event of severe delays on your way to the meeting or any last minute changes to itinerary please contact me as soon as possible. I may be contacted at The Hamilton Princess from Thursday evening, 22nd February 1996 on telephone number 441-295-3000 or facsimile 441-295-1914.

I look forward to meeting you at The Hamilton Princess later in the month, and to an interesting and successful conference. In the meantime, should you require any further assistance, please do not hesitate to contact me.

Yours sincerely



Jilly Steward

Meetings and Travel Manager