

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.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.*



THE WELLCOME TRUST

JS/ME/LET/Ber1208

22nd January 1998

Dr Eric Green
National Institutes of Health
National Human Genome Research Institute
49 Convent Drive
Building 49, Room 2A08
Bethesda MD 20892-4431
USA

210 Euston Road

London NW1 2BE

Telephone: 0171 611 8888 / Direct: 8899

Fax: 0171 611 8545 / Direct: 8237

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

Dear Eric

We are delighted you are able to join us at the Third International Strategy Meeting on Human Genome Sequencing in Bermuda from 26th February to 1st March 1998, and on behalf of the organising Committee I am writing to confirm your agreement to chair Session V on Saturday 28th February which is being convened by Pieter de Jong.

Please find enclosed a copy of the draft programme and the participant list. I have also enclosed a copy of the letter that has been sent to all delegates.

You will note in the programme that most sessions have both a convenor and a chair. It is suggested that chairmen should liaise with their convenor to determine the significant issues to be discussed in their session. The chairman will have responsibility at the meeting itself, for the content of the session to ensure that sufficient time is allowed for discussion within the time constraints. It is expected that convenors will have approached key individuals to speak or contribute to the discussion, although we are not suggesting a set structured series of presentations. Where appropriate we would appreciate convenors collating information from, and consulting with, all sequencing groups.

In view of the problems we have experienced in the past copying acetates whilst at the meeting, it would be helpful if a paper copy of any acetates to be used could be brought to the meeting. If you or your convenor require any other audio-visual than OHP or slide projector please contact me immediately so I can arrange this for you.

The Wellcome Trust is a registered charity, no. 218183

Trustee: The Wellcome Trust Limited - Registered in England, No. 2711980 - Registered Office, 121 Euston Road, London NW1 2BE

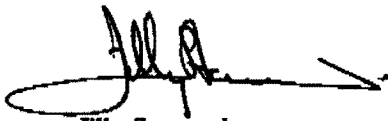
Board of Governors: Sir Roger Gibbs (Chairman), Professor Julian Jack, BM, PhD (Deputy Chairman), Professor Sir David Weatherall, MD, FRCP, FRS, Professor Roy Anderson, PhD, FRS, Professor Christopher Edwards, MD, FRCP, FRCPed, FRSEd, Professor Sir John Gordon, DPhil, FRS, Sir David Cooksey, Professor Sir Michael Rutter, CBE, MD, FRCP, FRCPsych, FRS, Professor Martin Babron, CBE, FRCP, FRCPath, Bridget M Ogilvie, ScD, FRCPath, FRCPath (Secretary)

A final bound programme and instructions for the meeting will be sent to you at the beginning of February.

Please do not hesitate to contact me if I can be of any further help in the meantime.

With kind regards.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Jilly Steward', with a long horizontal flourish extending to the right.

Jilly Steward
Meetings and Travel Manager

Enc