

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:

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Kathryn Maxson, B.S. (Duke University)

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Robert Cook-Deegan, MD (Duke University)

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(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.*

Evaluation and ranking of GSC home pages according to several criteria (Nos 1 to 5)

Group 1: good

Sequencing center	Web address	1 Sequence access. Hierarchical organization?	2 Information content. Physical map. Marker information? Status report.	3 Sequence annotation?	4 Blast search options?	5 Output information. Layout	General comments
Baylor College, Houston	Kiwi.imgen.tmc.edu:8088/home.html	link to human seq on first page downloadable seqs	very good color coded clone map. Physical dist., markers genes etc.	no annotation on web site	not found	not found, but table with clone sizes and joint projects	Clear presentation Blast option desirable
Sanger Center, Hinxton,	www.sanger.ac.uk	Seq. acc. via map. Hierarchical org: yes.	Clear homepage. Mark. info: Good Stat. rep.: Tables, color coded	Only released data	Yes. Via mask.	Progress statistics available for each organism. No distinction between unique seq and overlaps	very good, but annotation missing
University of Texas, Dallas	http://gestec.swmed.edu/sequence.htm	hierarchical organization, direct sequence access	maps with sufficient marker information, status report colour coded	yes, map and table	yes, via mask, no batch mode	no information about sequencing progress	good homepage

Evaluation and ranking of GSC home pages according to several criteria (Nos 1 to 5)

Group 2: average

Sequencing center	Web address	1 Sequence access. Hierarchical organization?	2 Information content. Physical map. Marker information? Status report.	3 Sequence annotation?	4 Blast search options?	5 Output information. Layout	General comments
LBL, Berkeley	www-hgc.lbl.gov	Seq. acc. on site (FastA) and GenBank-link. Starlike organization.	Frontpage and website structure very clear. But: physical map w/o links. With some browsers not readable. Map not to scale. Status report unclear	No	No	Only finished seq. No distinction overlaps/unique	good, but some features improvable (new version currently under construction)
JSTC. Keio Univ.	http://www-alis.tokyo.jst.go.jp/gdv/kitasato.html	good hierarchy, sequence available, for single clones and regions in state "finished"	detailed map, scale, much markers, genes etc.,	not found	not found	not found	good presentation, easy to handle but few sequences available (last update May 97) good: sequencing schedule, marker-info, help function
Whitehead Inst. Cambridge	http://www-genome.wi.mit.edu	hierarch. organized by chromosome and organism sequence access. by links from tables to ftp-files	no maps related to sequencing project found	not found	not found	Human & Mouse Data together; Total Finished, Total In Finishing, Total In Assembly	comprehensive, not very informative,
Univ of Oklahoma	http://dna1.chem.uoknor.edu	hierarch.organized by organisms and chromosome, sequence access only via GenBank	marker information insufficient, status report colour coded	only via GenBank	only via GenBank	progress statistics available, all species together	improvement desirable

Washington	www.genome.washington.edu/UWGC	Well organized but seq only thru GDB	could not read maps due to format problems	no annotation on web site	not found	sequencing and mapping summary available	Clear presentation Blast option desirable
Univ. of Tokyo	http://www.hgc.ims.u-tokyo.ac.jp	good hierarchy, sequence available, but only for regions and in state "finished"	detailed map, much markers, genes etc., but no scale	exons, repeats and other features, good presentation in asn format	yes, for single sequences	not found	good presentation, easy to handle but few sequences available, good: keywordsearch
TIGR	www.tigr.org	Seq.acc. via GDB incomp.seq only with password	no graphical map tabular map very informative	genes, repeats, STS for released data	via GDB	Progress statistics available for each organism. No distinction between unique seq and overlaps	Easy to work with But all info thru GDB

Evaluation and ranking of GSC home pages according to several criteria (Nos 1 to 5)

Group 3: below average

Sequencing center	Web address	1 Sequence access. Hierarchical organization?	2 Information content. Physical map. Marker information? Status report.	3 Sequence annotation?	4 Blast search options?	5 Output information. Layout	General comments
Wash U	genome.wustl.edu/gsc/gschmpg.html	Only via ftp server. Map and sequence separated	Homepage not well organized. Mark. info: insuff. Stat. rep: Only color coded	No	Yes. Via mask.	Only finished seq. No distinction between unique seq and overlaps	improvement desirable, e.g. link map-sequence
MPI Berlin	www.mpimg-berlin-dahlem.de/~xteam/sequencing.html	Hierarchy: yes. organized by projects. Map yes. Sequence link invalid	one finished project: scale, marker, gene visible	Exonfinder	No Blast search	No sequencing information. No time stamp	Site difficult to find. No data.
Stanford Univ.	http://shgc-www.stanford.edu/	hierarchy: partial, organized by status, subdivided into projects sequence access: yes, links from tables to ftp-files	not found	not found	not found	only text (Last Updated: 3/10/97)	not very comprehensive since organized by status, not informative
LANL	www-ls.lanl.gov/LSwelcome.html	Seq. not generally accessible. No link map-seq. Clone info. hidden	Not user friendly. Many links password protected or not active. Marker information: unreadable (too small) map. No status report.	No	No	Unclear	pretty bad