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.*

Bermuda Meeting 2/1996

Bob W. -

Regional STSs → 10x Bact clones → Local Maps
Submit ← Annotate ← Sequence

Product → High Quality (>99.99% for most)
Continuity

Goals: 50 Mb for Consortium / 1st Yr.
(22, X, 7, 6)

Lander -

Anchored BACs
Distinctive Focus — Front-End Automation
Hands off Assembly
5 Mb / 1st Yr.

Venter -

Chrom. 16
Est. cost ~100 mill for mapping bact clones
BAC End Sequencing Proposal -
15x BACs
End Sequenced x 300,000
Sequence @ 5 Kb

Hood -

MCO Mapping & Informatics

Hattori

Japanese Genome Project

1-2 Mb by end of year

Carrano

Chrom. 19, 60 Mb

Alu Rich

Automation

Gibbs

X, 12

6 Machines, 25 People

Map Gapping

5 Mb in Next year

To 2¢ per base

Moyzis

Chrom. 16

SASE

Hood

The usual

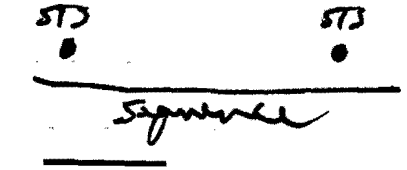
Ansorge

Alternate Fluorescent Labeling

Wafer

Whole genome sequencing (10X)

0.5¢/bp



Cox Session

1st 100 Kb Map

2nd Minimal Clone

3rd High-Resolution / Validate Clones

Sulston

7 Gaps in current Map

39 Mb Finished

1 gene per 5 Kb

Predict 14,000 genes

45% of Predicted genes = database hits

Lessons - Communal

Multilevel Map

Fingerprint bait clones

High Resolution → Seq. Efficiency

Quality & worthwhile (± Feedback)

Use of YACs (20% ± in Cosmids)

Gap Filling — (slow + Asymmetric)

1) Long PCR

2) Alternate bait clones

3) Shotgun YACs

Venter

Human 1 gene per 50 Kb (EST 1 per 4Kb)

TIGR: 350,000 ESTs

51,000 TACs

130,000 singletons

TIGR Assembler

→ clones to link sequence contigs

30¢ / bp [Direct]

50¢ / bp [Total]

Myers

RH Maps → BAC Contigs

Low Redundancy

Chr. 4: 20 Mb [50 ¢/b, 1-3 yrs. → 20 ¢/b

RH Panels—

G3: 400 Kb, TNG: 100 Kb

7300 STSs on G3 (1200 on WEB)

Sequence chips for Checking

To 30,000 STSs

G3: Stop at 10,000; TNG: All 30,000

Bentley

X, 22, 6

YAC → Cosmids → Fingerprint → Walk

10 Mb X done

Flow Sorted Libraries → Fingerprint

Lander

16,500 STSs < 8000 RH / 11,500 YACs

60% of CHLC + Genethon Loci

To 20,000

Mouse: 6500 STSs (Genetic Markers)

14X YACs, 6X BACs

de Jong

400,000 clones (PAC)

Planning 10-20X BACs

* Novel End Recovery Scheme

- Random Primers

Simon

Another 3x 6y April

Save Old Stuff

3 Sources in BAC Libraries

Glen Evans

Cosmid Pilot Project

End Sequence Sampling

#1 primer — New Automated Method

Bob + John Proposal

- Immediate Data Release
- No Protection Before Release

Hood

BAC sequencing
Phred + Phrap Assembly

Wilson

0-2 gaps per clone
Orient Contigs + Est. Gap Sizes
99.9% Accurate
Reduce to 10¢/base
"Gatlaner" ⟶ "TPP"
64-96 lanes/gel

Gibbs

Bodipy Dyes (no Mobility Δ's)
4 Colors → Primers
should only do selective reverses

Trevor

Solid-Phase Reversible Immobilization
Sequatron - 8000 samples/24 hr
5 Mb / 20 Mb / 80 Mb

Rosenthal

36 People, 13 Machines
↑ Terminators → ↓ Compressions
Several 1-2 Mb projects on Chrom 7, 11, 17

Drosophila

Adams

Tracks
Sequence Assembly (TIGR Assembler)
Sequence Annotation → Major effort even after complete

Hillier

Immediate release of finished sequence
Assessing Error Rate -
  Perform Locally
Public Availability of Raw Trace Data

Weber

Polymorphism Detection
Sequence Assembly / Gene Myers
Simulations
Need Long-Insert Clones
  ① Goal = detect common Polymorphisms
  ② 2× More Centers for Assembly
  ③ Whole-Genome Shotgun

Lander: 1-Pass sequence after set
  Some genomic sequence → Polymorphisms!

Durbin

Illustrated steps in sequencing
pipeline where informatics tools
replace human intervention.

Summary Issues

$ —

NCHGR: (Millions)

	Current	RFA	Total
Technology	16	5	21
Production	14.5	15	29.5
			50.5

Total: $128

(To '80 in 23 yrs)

$75 Million @10¢/bp → 750 Mb/yr.

20 proposals → Awards in Mid-April
Site visits in Dec., '97

Welcome:

Sanger Center Built by End of '96
10-25 Mill Pounds → Genome Research
Sanger: $91 Million/16 over 7 yrs.
$9 Million/16/yr. for Sequencing

DOE:

$70 Million → $10 Mill for Sequencing
To $150 Million o/n 3-4 yrs.

2003