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Extraordinary Biotechnologies for Everyday Life: Domestication of Genomic Technologies & Emergence of Biomedical Citizen Science

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PREFACE: background & salient biases
YES I really do have X-RAY VISION
trickle down innovation
(huge investments have made genomic data cheap)
cost of 1 human genome

$3,000,000,000  2002
$2,000,000     2007
$2,000         2012
trickle up innovation
DNA sequencing is accessible: new teen hobby
low cost bio tools

(forget DTC genomes, go DIY!)
Open qPCR: DNA Diagnostics for Everyone
by Chai Biotechnologies • You're a backer

374
Backers

$132,380
pledged of $50,000 goal

17
days to go

This project will be funded on Thu, Dec 4 2014 9:00 PM EST.
grassroots communities

(who wants to start a revolution?)
Ask a Biosafety Expert
ask.diybio.org

“biohacker hotline” for free biosafety advice

Produced by 501c3 DIYbio.org and fulfilled by volunteer biosafety professionals.
Global Network of Personal Genome Projects

1. UNITED STATES
Harvard Medical School
founded 2005

2. CANADA
Univ Toronto / Hosp Sick Kids
founded 2012

3. UNITED KINGDOM
Univ College London
founded 2013

4. AUSTRIA
Center for Molecular Medicine
Founded 2014

**UNDER DEVELOPMENT
Sites in 12+ countries
Unique Set of Features

1. **DATA ACCESS**
   Equal, integrated, open

2. **PARTICIPATORY**
   People are co-investigators

3. **INFRASTRUCTURE**
   Shared tools, protocols

4. **GOVERNANCE**
   Open consent framework

5. **INFORMED COHORT**
   Life-long learning community

6. **HUMAN VARIATION**
   Not 1 disease, wellness
Equal Access

begin counting 3 slides now
Equal Access Defined

Equal access is a model of governance where research participants and research scientists share individual-level research data with each other. Researchers do not have unilateral control over data generated during the course of research. Raw data flows in both directions. In short, “sharing by default”.
Open Humans

Two primary goals:

• Assist and reward researchers for practicing “equal access” in their studies.

• Advance health and participatory research by enabling people to access and share their personal data that would otherwise be left to languish in private data silos.

Knight Foundation
6 Hypotheses About Equal Access

1. More reproducibility of biomedical science because errors in the research record can be corrected.

2. Improve research literacy and informed consent.

3. Increase recruitment, participation, & retention. Reciprocity is powerful.

4. Participant mediated data sharing means, overall, more data will be shared.

5. Cognitive surplus is real, engaging participants as co-investigators will lead to important discoveries.

6. Research will go the way of medical records, ability to request and access personal research data will be a federally protected right.
Thank You!
Extra Slides
Before/After

The first rule of Fight Club

is you do not talk about it.

vs.

and Helena Bonham Carter in a David Fincher film.
Citizen Science: Sushigate was just the beginning
(citizens can create real value)
State moves to take action against mislabeling of fish

Panel weighs DNA testing, bar coding

By Jenn Abelson | GLOBE STAFF | JANUARY 12, 2012

State officials are considering the use of DNA testing to combat fish mislabeling, weighing a ban on the sale of escolar, and launching a pilot program in partnership with Legal Sea Foods to trace fish through the supply chain. Leaders of various Massachusetts agencies disclosed these new efforts during a three-hour hearing on fish mislabeling held yesterday by the state Legislature’s Joint Committee on Consumer Protection and Professional Licensure.
never underestimate a motivated person with access to the right tools

Hugh Rienhoff set up a home laboratory to expedite research on his daughter's syndrome, leading to genetic discovery.
Participatory Research
The time has come for Homo sapiens to become our key model organism

Personal Genome Project, founded 2005 by George Church at Harvard Medical School

https://my.pgp-hms.org/profile/hu43860C