

Jan 13, 2015

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



Personal
Genome
Project

GET
GENOMES • ENVIRONMENTS • TRAITS
CONFERENCE



Open
Humans



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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)

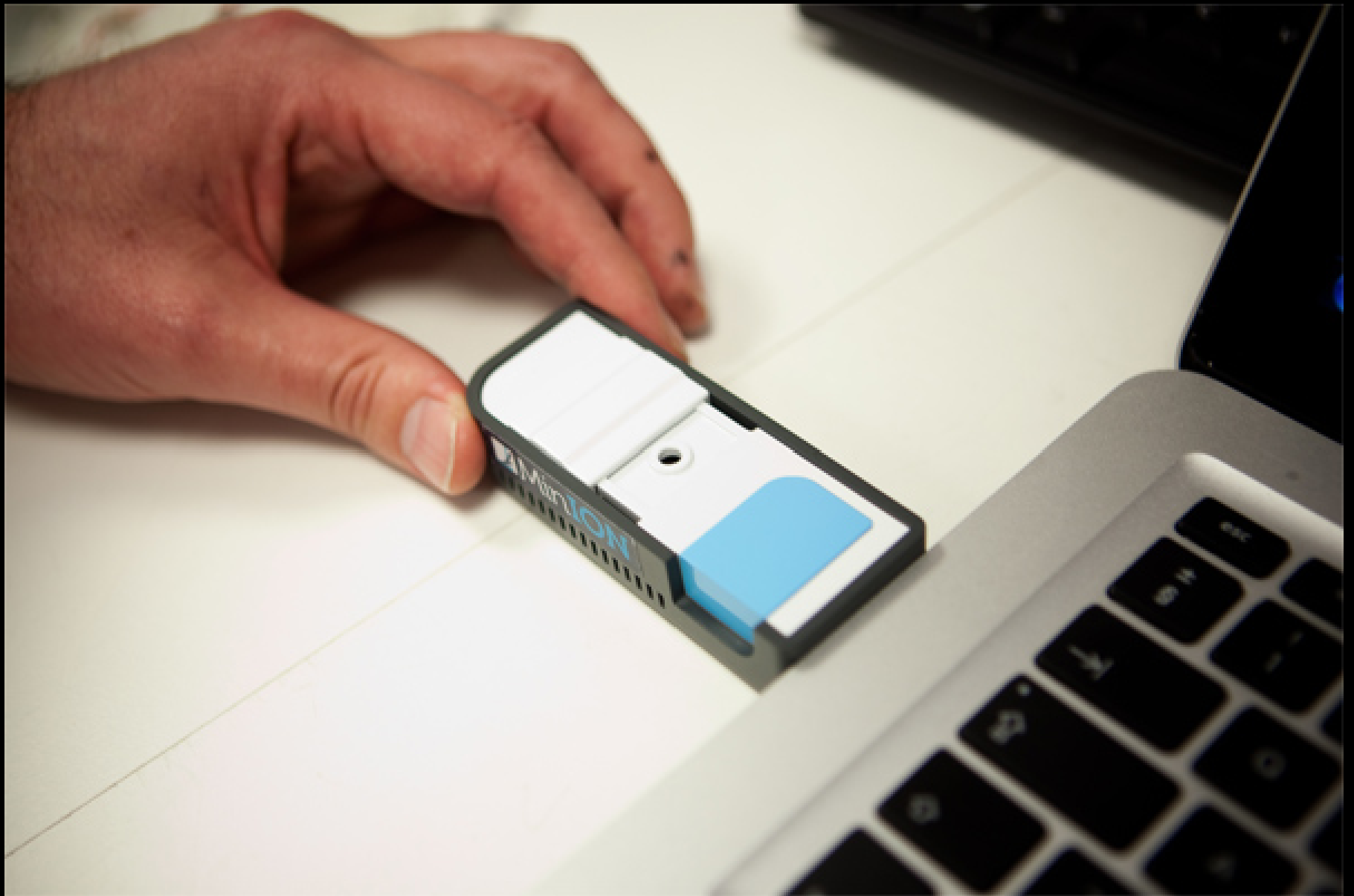
cost of 1 human genome



\$3,000,000,000	2002
\$2,000,000	2007
\$2,000	2012



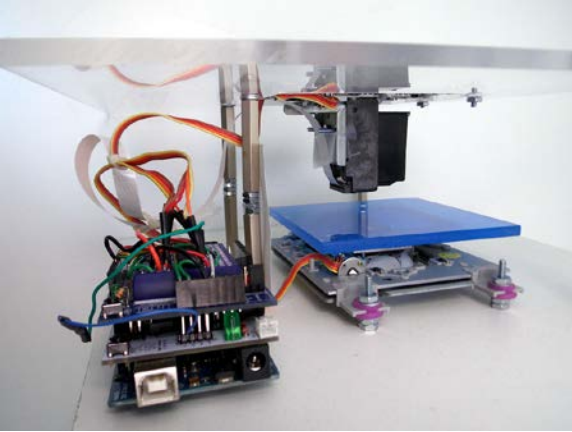




trickle up innovation

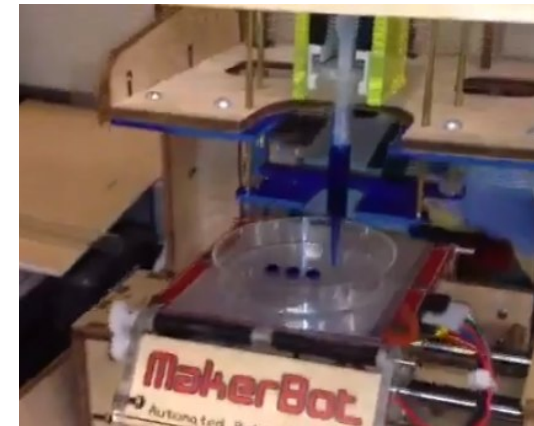
DNA sequencing is **accessible**: new teen hobby





low cost bio tools

(forget DTC genomes, go DIY!)



Open qPCR: DNA Diagnostics for Everyone

by Chai Biotechnologies · You're a backer

Home

Updates 3

Backers 374

Comments 42

Santa Clara, CA

Hardware



374

Backers

\$132,380

pledged of \$50,000 goal

17

days to go

Manage Your Pledge



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

grassroots communities

(who wants to start a revolution?)

hack/ reduce

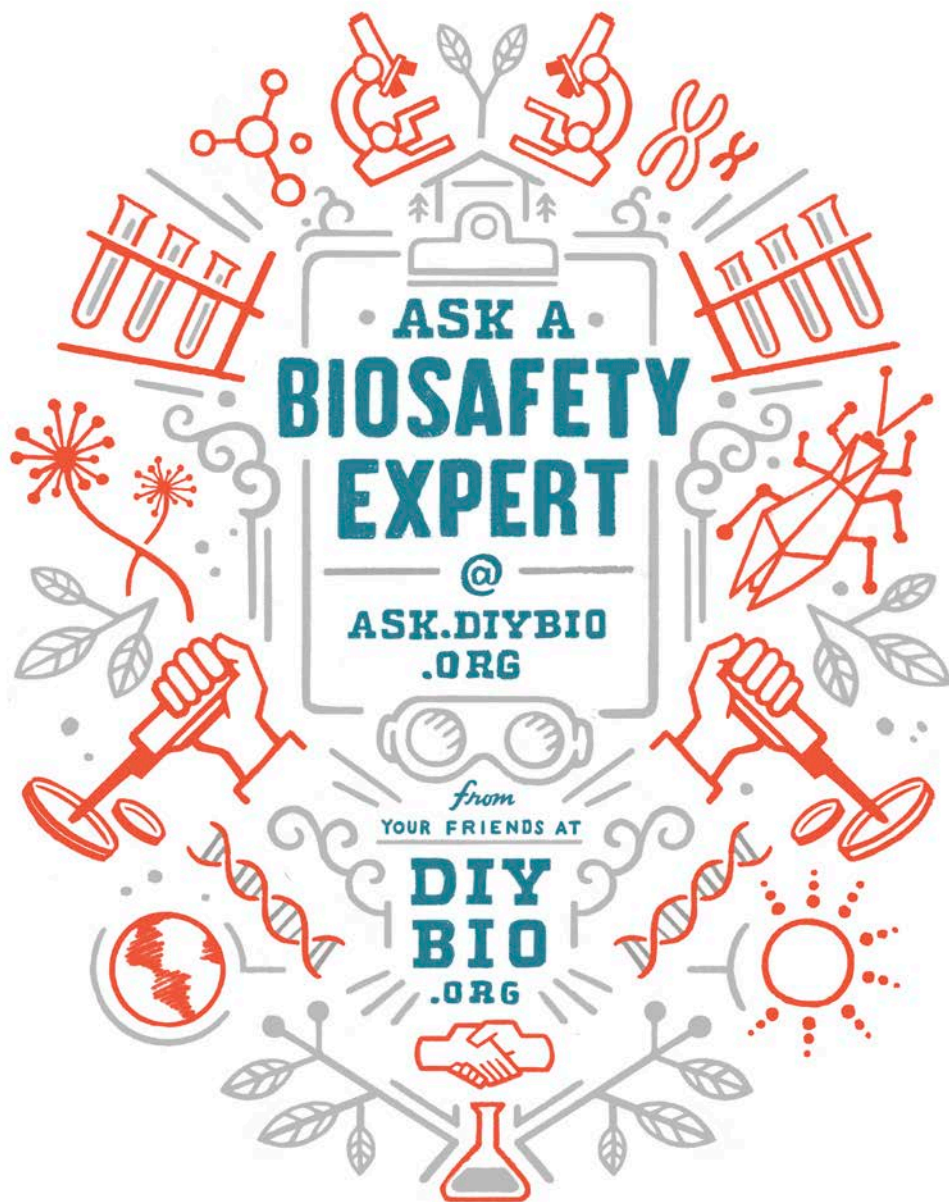
CODE BIG OR GO HOME



GENSPACE







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.



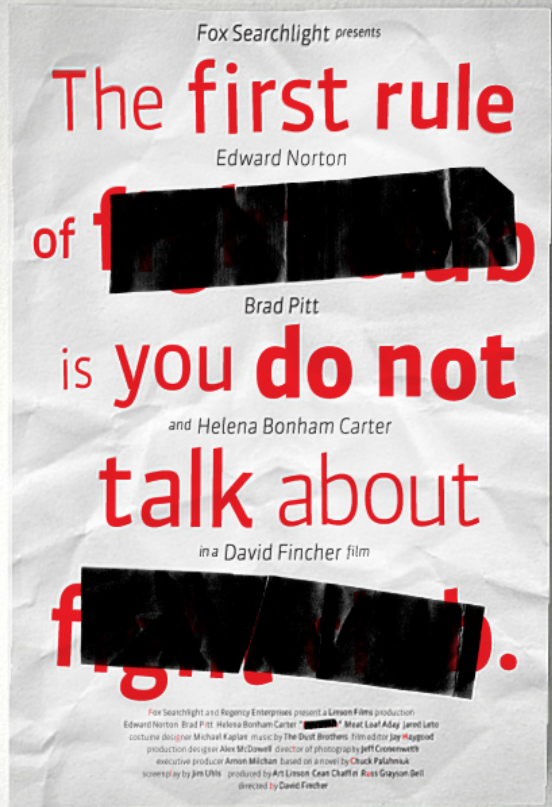
6 Hypotheses About Equal Access

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



VS.



Citizen Science: Sushigate was just the beginning

(citizens can create real value)



CAPTAIN WHITE'S CREDIT CARD POLICY
 All credit card sales require picture I.D.

WHITING FILLET
 13.95 LB.

RED HAPPER FILLET
 16.95 LB.

ORANGE POLLOCK FILLET
 8.95 LB.

YELLOWFIN TUNA
 18.95 LB.

WILD BLUE CRAB
 18.95 LB.

CHESAPEAKE PEA SALT

SALMON FILLET
 16.45 LB.

SALMON PEAKE
 15.50 LB.

NO SHRIMP
 1/2 95¢ LB
 65¢ 50¢
 1.55 \$2.25
 1.55 \$2.25

3 1/2 TIGER SHRIMP
 \$17.95 LB
 2 LB \$22.95
 3 LB \$32.95
 5 LB \$49.95

EX-LARGE SHRIMP
 \$11.95 LB
 2 LB \$22.95
 3 LB \$32.95
 5 LB \$49.95

LARGE SHRIMP
 \$11.45 LB
 1 LB \$22.95
 3 LB \$33.95
 5 LB \$49.95

LARGE TIGER SHRIMP
 \$10.45 LB
 2 LB \$20.95
 3 LB \$30.95
 5 LB \$42.95

CAPTAIN'S SPECIAL SHRIMP
 \$10.45 LB
 2 LB \$20.95
 3 LB \$30.95
 5 LB \$42.95

HEAD ON SHRIMP
 \$7.95 LB
 2 LB \$15.95
 3 LB \$22.95
 5 LB \$33.95

MED TIGER SHRIMP
 \$9.45 LB
 2 LB \$18.95
 3 LB \$27.95
 5 LB \$43.95

LG CAROLINA
 \$9.45 LB
 2 LB \$18.95
 3 LB \$27.95
 5 LB \$43.95

MED TIGER
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 2 LB \$16.95
 3 LB \$24.95
 5 LB \$38.95

SUPER SIZED SHRIMP
 \$24.95 LB
 2 LB \$49.95
 3 LB \$74.95
 5 LB \$109.95

DAY & SEA CALLOPP
 1000

WILD BLUE CRAB
 18.95



Kate Stoeckle



Louisa Strauss

State moves to take action against mislabeling of fish

Panel weighs DNA testing, bar coding

By **Jenn Abelson** | GLOBE STAFF JANUARY 12, 2012

 ARTICLE PREVIEW	 VIDEO	 COMMENTS	SUBSCRIBE
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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

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



“The time has come
for *Homo sapiens*
to become our key
model organism”

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