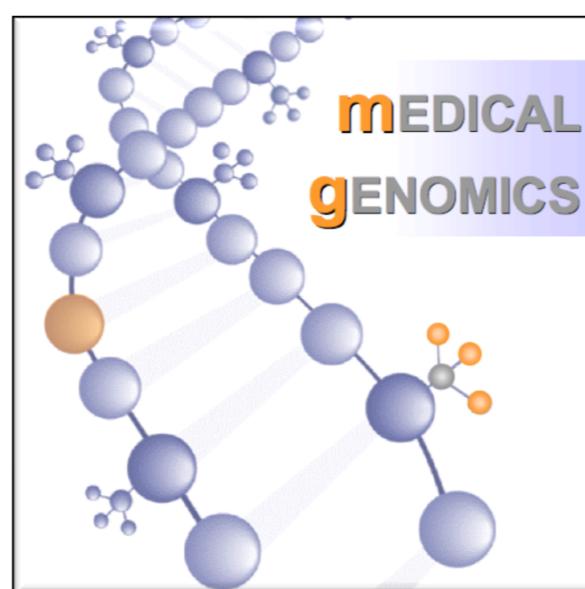




# Personal Genome Project



Stephan Beck  
Medical Genomics  
UCL Cancer Institute  
University College London  
[s.beck@ucl.ac.uk](mailto:s.beck@ucl.ac.uk)



# opportunity



Consensus among researchers, clinicians, politicians and the public that ‘omics’ will transform healthcare and lifestyle choices



# motivation

BBC [Sign in](#) News Sport Weather iPlayer TV R

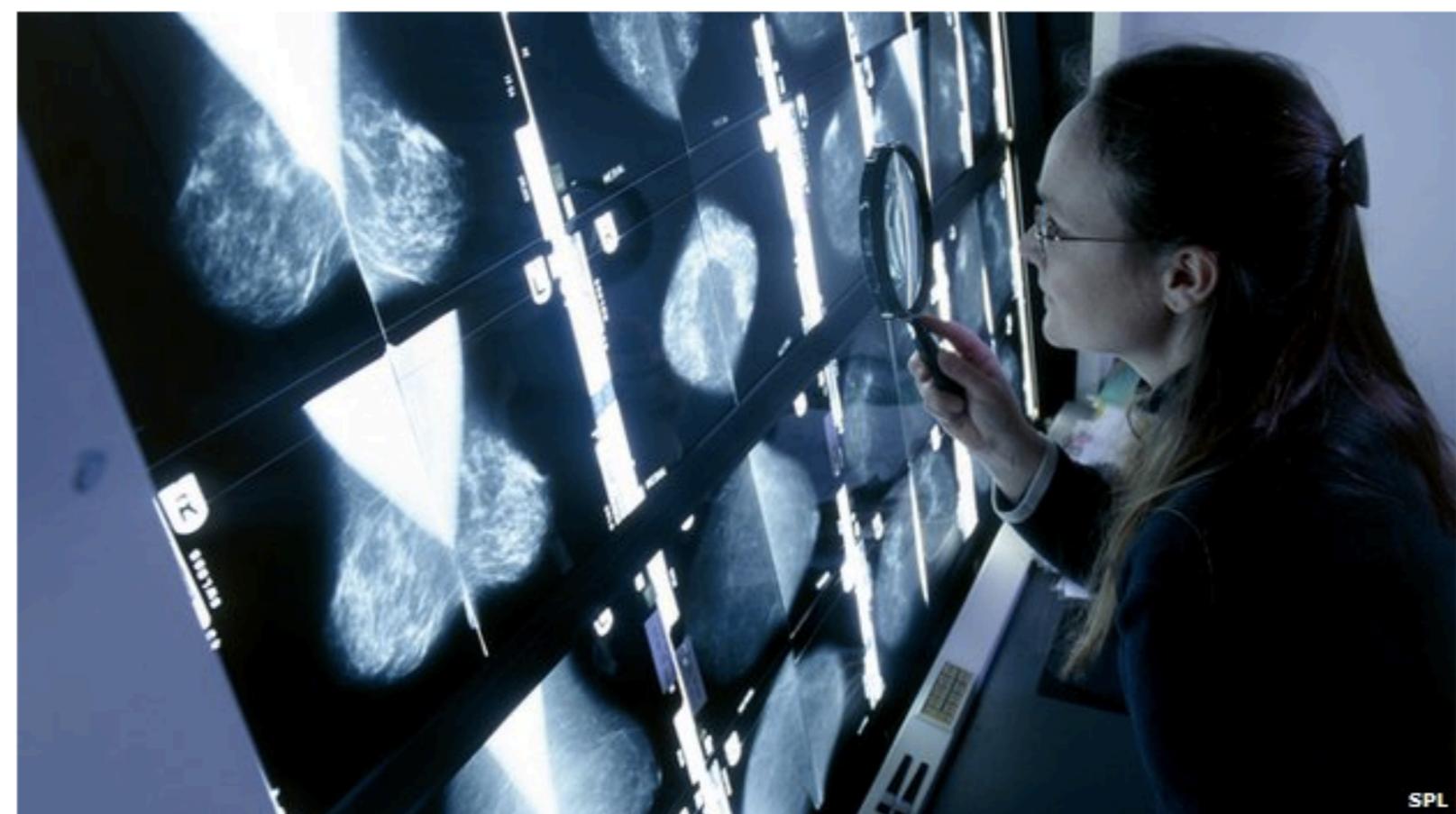
## NEWS HEALTH

[Home](#) | [World](#) | [UK](#) | [England](#) | [N. Ireland](#) | [Scotland](#) | [Wales](#) | [Business](#) | [Politics](#) | [Health](#) | [Education](#) | [Sci/E](#)

4 February 2014 Last updated at 06:33

Share

## Cancer 'tidal wave' on horizon, warns WHO



Large numbers of people do not know there is a lot they can do to reduce their exposure to risk

The globe is facing a "tidal wave" of cancer, and restrictions on alcohol and sugar need to be considered, say World Health Organization scientists.

### Related Stories



# how do we get there?

- 2001: First Human Genome Sequence



- 2005: Personal Genome Project (PGP-US)



- 2007: UK Biobank ([www.ukbiobank.ac.uk](http://www.ukbiobank.ac.uk))



- 2008: 1000 Genomes Project (<http://www.1000genomes.org>)



- 2010: UK10K Project ([www.uk10k.org](http://www.uk10k.org))



- 2013: UK100K Project ([www.genomicsengland.co.uk](http://www.genomicsengland.co.uk))



- 2013: PGP-UK ([www.personalgenomes.org.uk](http://www.personalgenomes.org.uk))



- Many other national and international projects



# Personal Genome Project UK

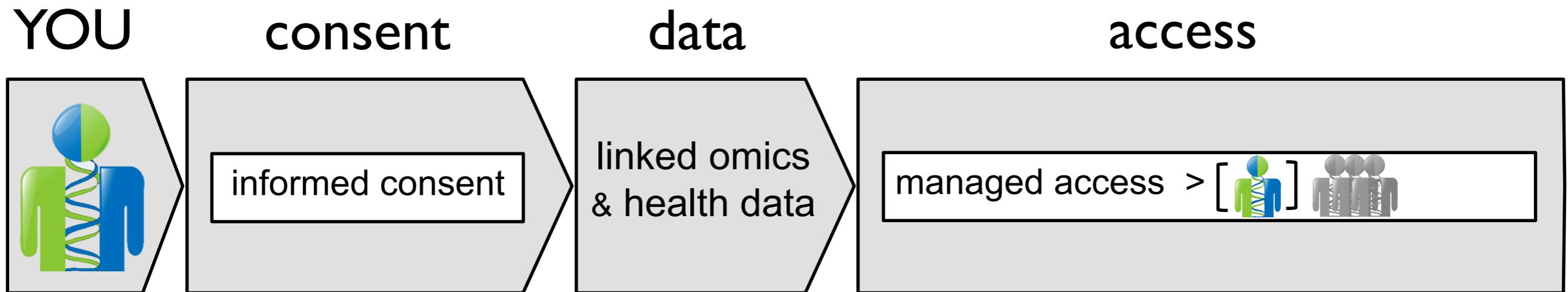
The Personal Genome Project UK is dedicated to creating public UK genome, health, and trait data. Sharing data is critical to scientific progress, but has been hampered by traditional research practices—our approach is to invite willing participants to publicly share their personal data for the greater good.



- Launched on Nov 6, 2013
- Open to all UK citizens and permanent residents over 21 years
- Uses Open Consent and Open Access policies
- Classified as research project
- Over 10,000 UK volunteers already registered



## Most Projects

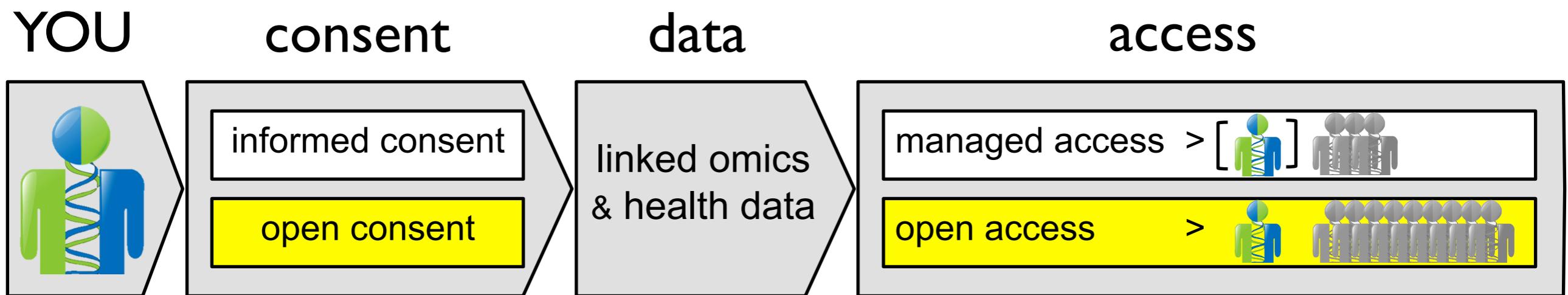


- Promise of anonymity
- No or limited (e.g. CSFs, Kaye et al EJHG 2014) feedback to YOU
- No or restricted public access to data

# consent / access options



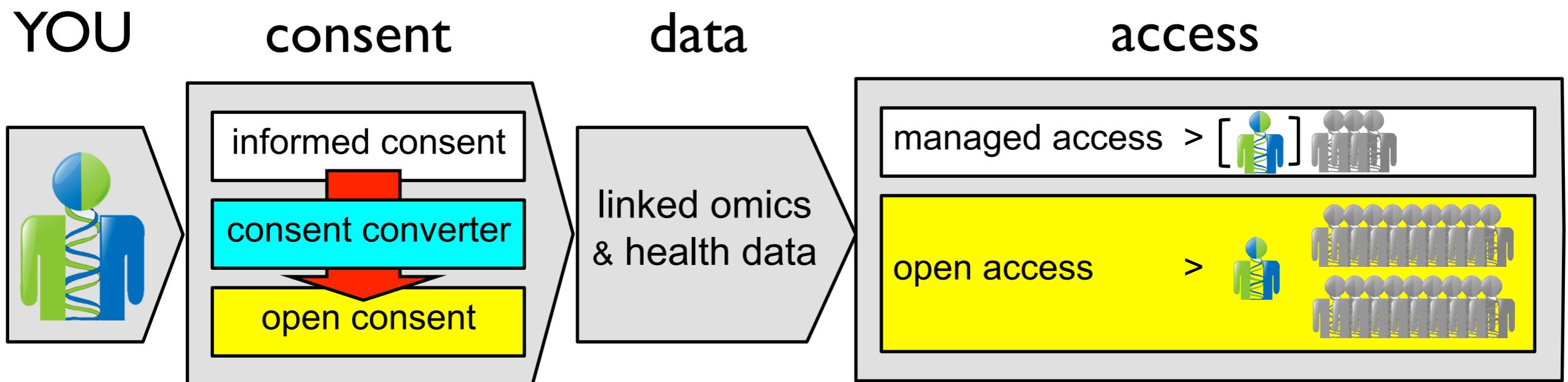
## PGP-UK



- No promise of anonymity
- All data returned to YOU
- Free and unrestricted public access to data



## PGP-UK (planned)



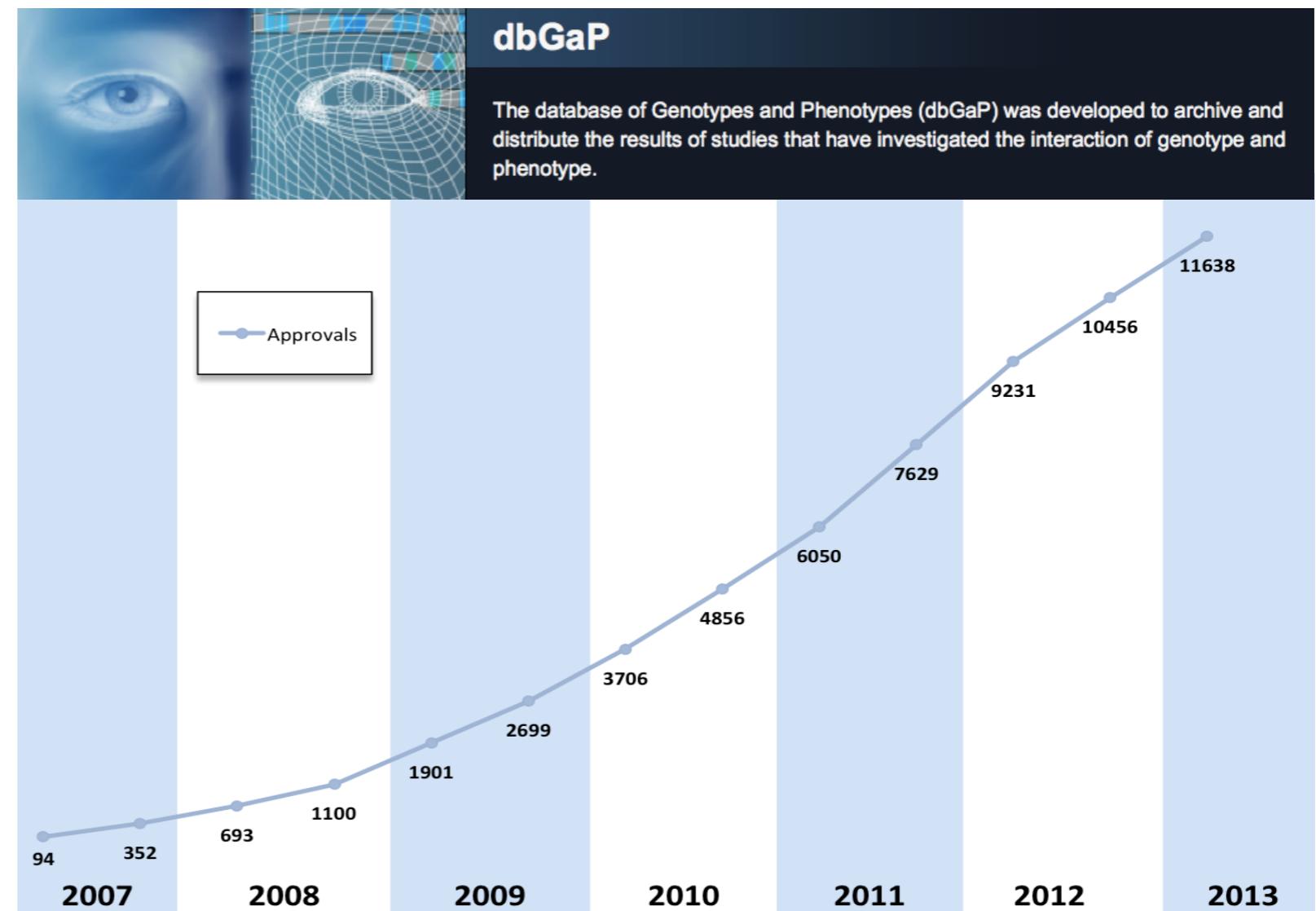
- Converts informed to open consent
- Facilitates genome donations e.g. to PGP-UK
- Converts managed to open data access

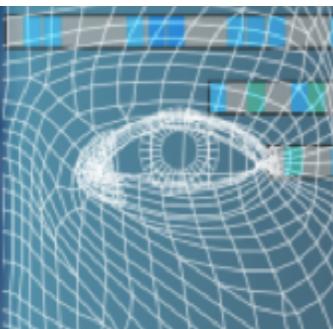


# openness matters



11638      in total  
1662      per year  
138      per month





dbGaP

The database of Genotypes and Phenotypes (dbGaP) was developed to archive and distribute the results of studies that have investigated the interaction of genotype and phenotype.



# 500,000 fold difference

# majority of funding

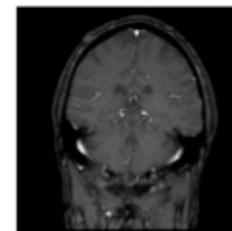
# accelerated research



# PGP enables *citizen science*



Genome In a Bottle Consortium  
National Institute of Standards & Technology (NIST)



Longitudinal Body Microbiome  
University of Colorado



Mapping Flu Incidence  
Childrens Hospital Boston



Critical Assessment of  
Genome Interpretation  
Univ California Berkeley



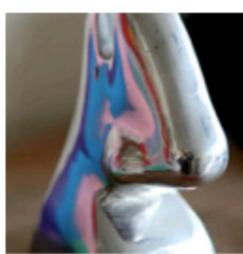
Environmental Exposures  
Silent Spring Institute



Home Microbiome  
NC State University



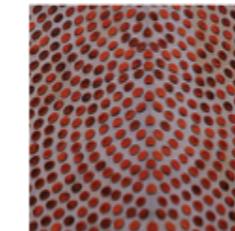
active NOT passive  
collaborators



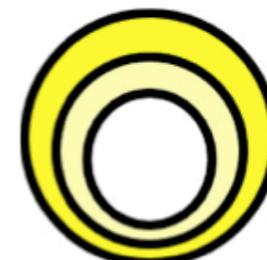
Olfactory Response  
Rockefeller University



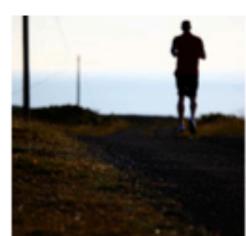
Absolute Pitch  
Feinstein Institute



TestMyBrain.org  
Harvard



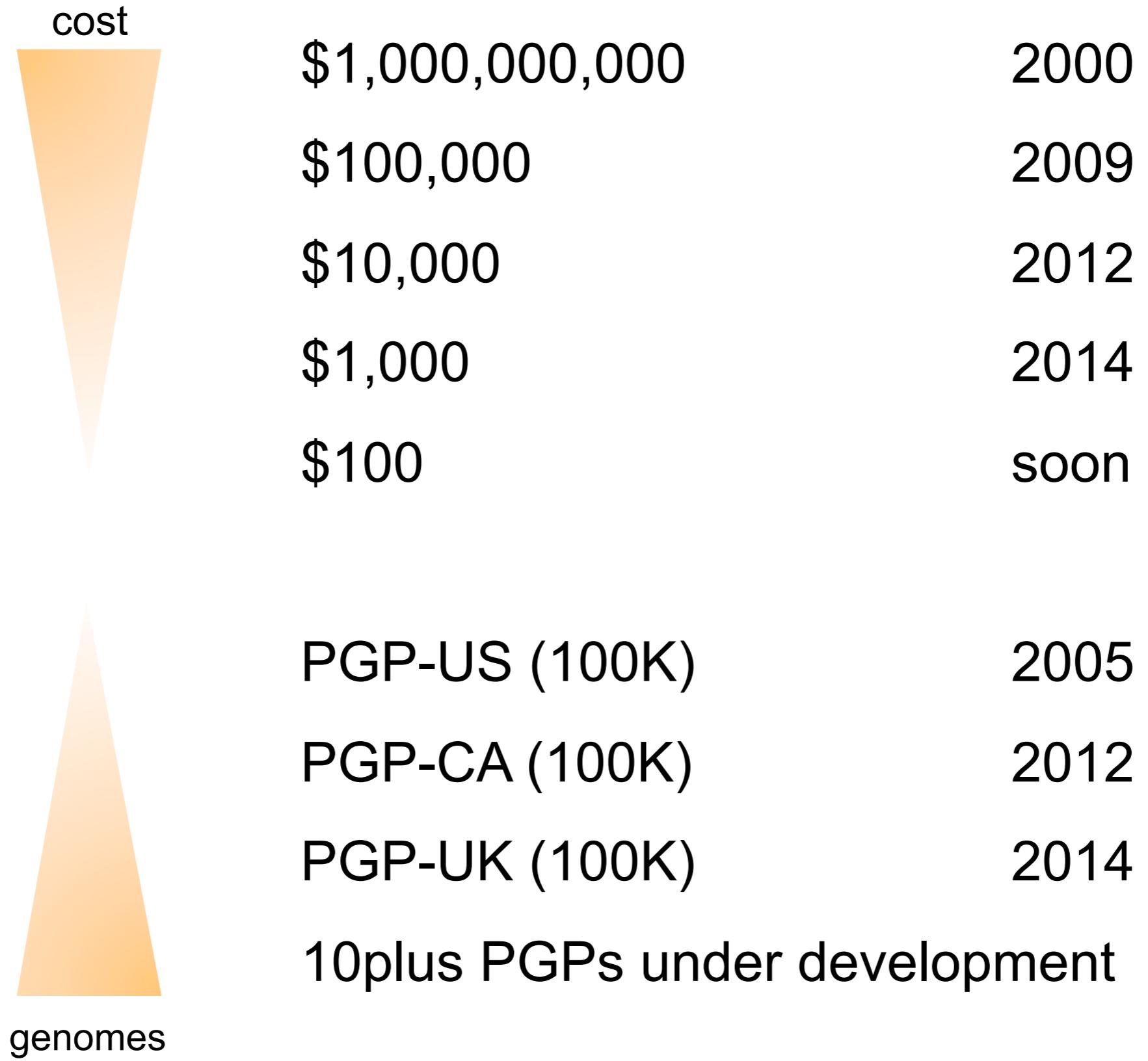
Circles in Evolution:Areola  
Tabin Lab at Harvard



Activity Levels and Obesity  
Center for Connected Health



# genomes for all



# how does it work?



- Register at [www.personalgenome.org.uk](http://www.personalgenome.org.uk)
- Complete eligibility screening
- Download study material
- Create PGP-UK account and upload personal/trait information
- Take entry exam
- Sign open consent form
- Sign MTA
- Provide sample
- 4-week decision window for exit or progression to open access
- Complete mandatory quarterly surveys
- Option to withdraw at any time and without reason

# PGP-UK summary



## ➤ Open Consent

- No promise of privacy or confidentiality
- First in UK and Europe

## ➤ Open Access

- CC0 public domain license
- Integrated genome, environmental, medical and personal data

## ➤ Participants

- Highly informed > study guide, entrance exam, regular feedback
- Receive all information, incl. CSFs
- Active (not passive) collaborator > *Citizen Science*
- Most analysed humans (<http://bit.ly/pgplinks>)



# acknowledgments



PGP-UK Team  
[pgp-uk@ucl.ac.uk](mailto:pgp-uk@ucl.ac.uk)



Stephan Beck, Director



Jane Kaye, ELSI



Rifat Hamoudi, Informatics

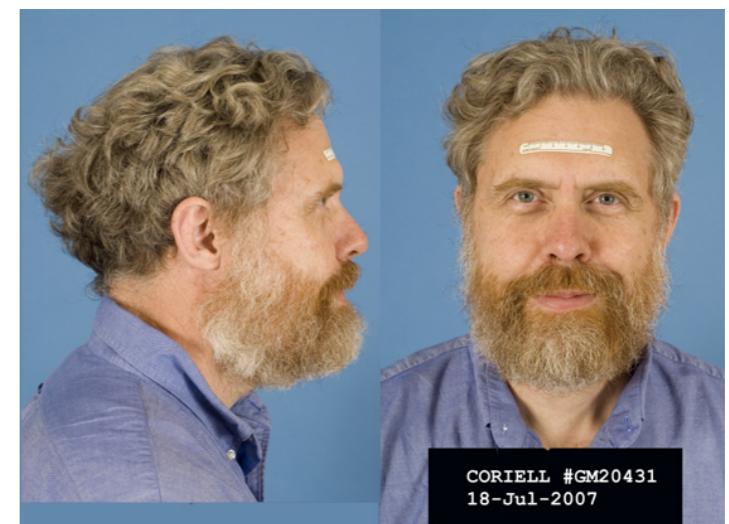


Emanuele Libertini, Analysis



Paul Harrison, Outreach

special thanks to



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



Jason Bobe  
Director, PersonalGenomes.org