

# Health Literacy and Personalised Medicine: Dragging Down the Tower(s) of Babel



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Global Alliance  
for Genomics & Health




European Alliance for  
Personalised Medicine

# Personality Medicine

- 14<sup>th</sup> May 2013 <sup>1</sup>
- The day personalised cancer medicine and genomic technologies came of age for our society



<sup>1</sup> Jolie A. New York Times (2013)

A close-up photograph of Angelina Jolie smiling warmly. She has long, wavy brown hair and is wearing a light-colored, possibly white, top. Her right hand is raised near her head, and she is wearing a green bracelet. The background is a blurred crowd of people, suggesting a red carpet event.

## The New York Times

"I can tell my children that they don't need to fear they will lose me to breast cancer."

Angelina Jolie in "My Medical Choice"  
Published on May 14, 2013



# The Value of Hereditary Cancer Testing

PERSONAL or FAMILY HISTORY  
of BREAST and/or OVARIAN CANCER



Red Flags  
for HBOC

## BRACAnalysis®

KNOWLEDGE IS POWER

Mutation Positive



### HEREDITARY RISK

Mutation Negative

FAMILIAL RISK

INCREASED CANCER RISKS

PERSONALIZED MEDICAL  
MANAGEMENT PLAN

GENERAL POPULATION RISK

**8%**  
Breast

**>1%**  
Ovarian



- Annual clinical breast exam
- Annual mammogram



up to  
**40%**  
Breast

up to  
**11%**  
Ovarian

- Clinical breast exam every 6-12 months
- Annual mammogram
- MRI as adjunct to mammogram



up to  
**87%**  
Breast



**44%**  
Ovarian



- Clinical breast exam every 6-12 months
- Annual mammogram and MRI
- Risk reducing drug therapy
- Risk reducing surgery



# Testing the “Angelina Jolie” Effect<sup>1</sup>

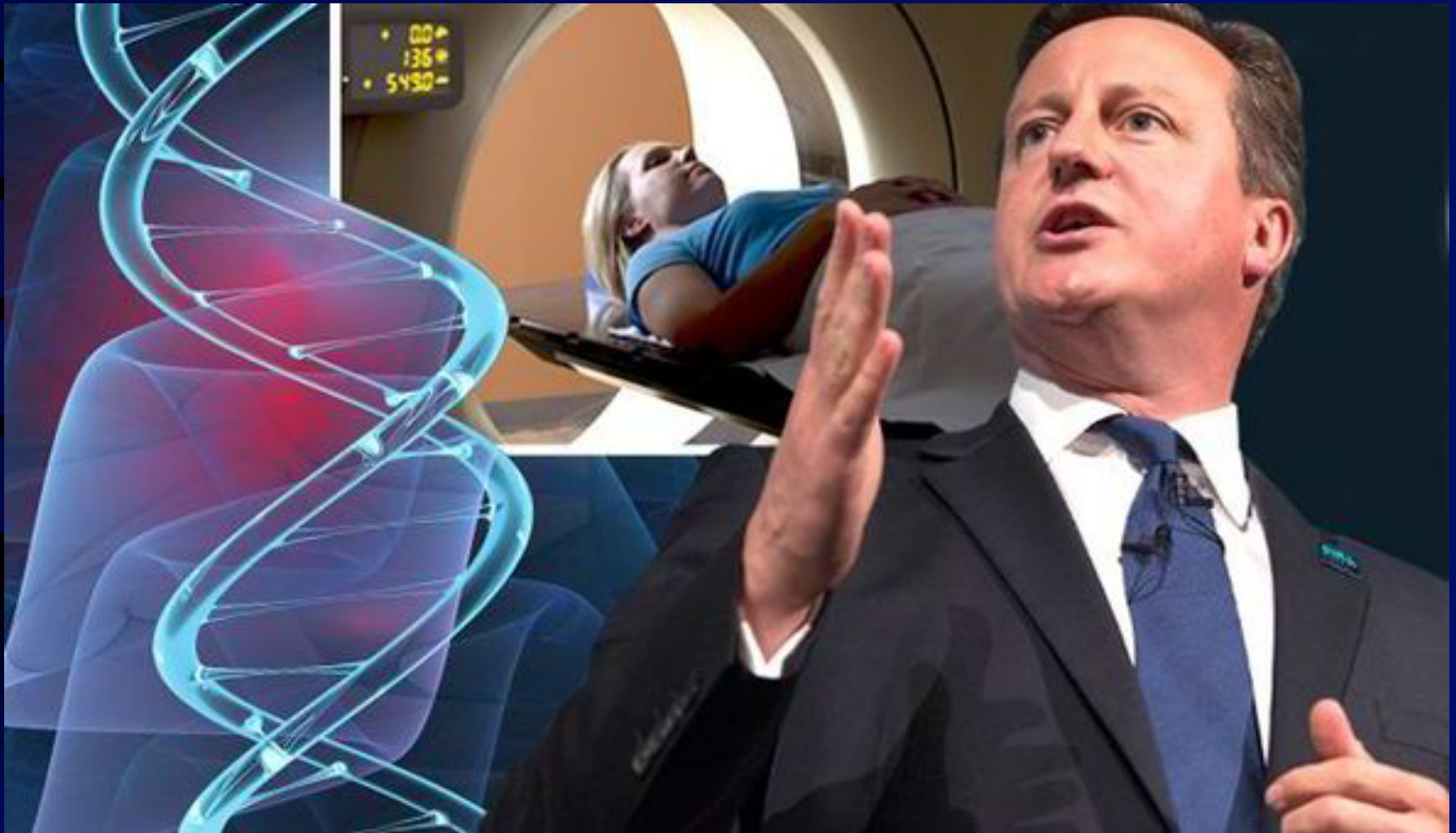
- Referral data specific to breast cancer family history 2012 *versus* 2013.
- **Rise in referrals** from May 2013 onwards.
- **2.5 fold increase**: 1,981 (2012) to 4,847 (2013)
- Remained at **two-fold** to October 2013.
- **Demand** for *BRCA1/2* testing almost **doubled**
- **Increased enquiries** for risk-reducing mastectomy.
- **No increase** in **inappropriate** referrals.

# The Positive Effect of Personality Medicine

- “The Angelina Jolie effect has been long **lasting and global**, and appears to have **increased referrals** to centres **appropriately**.”

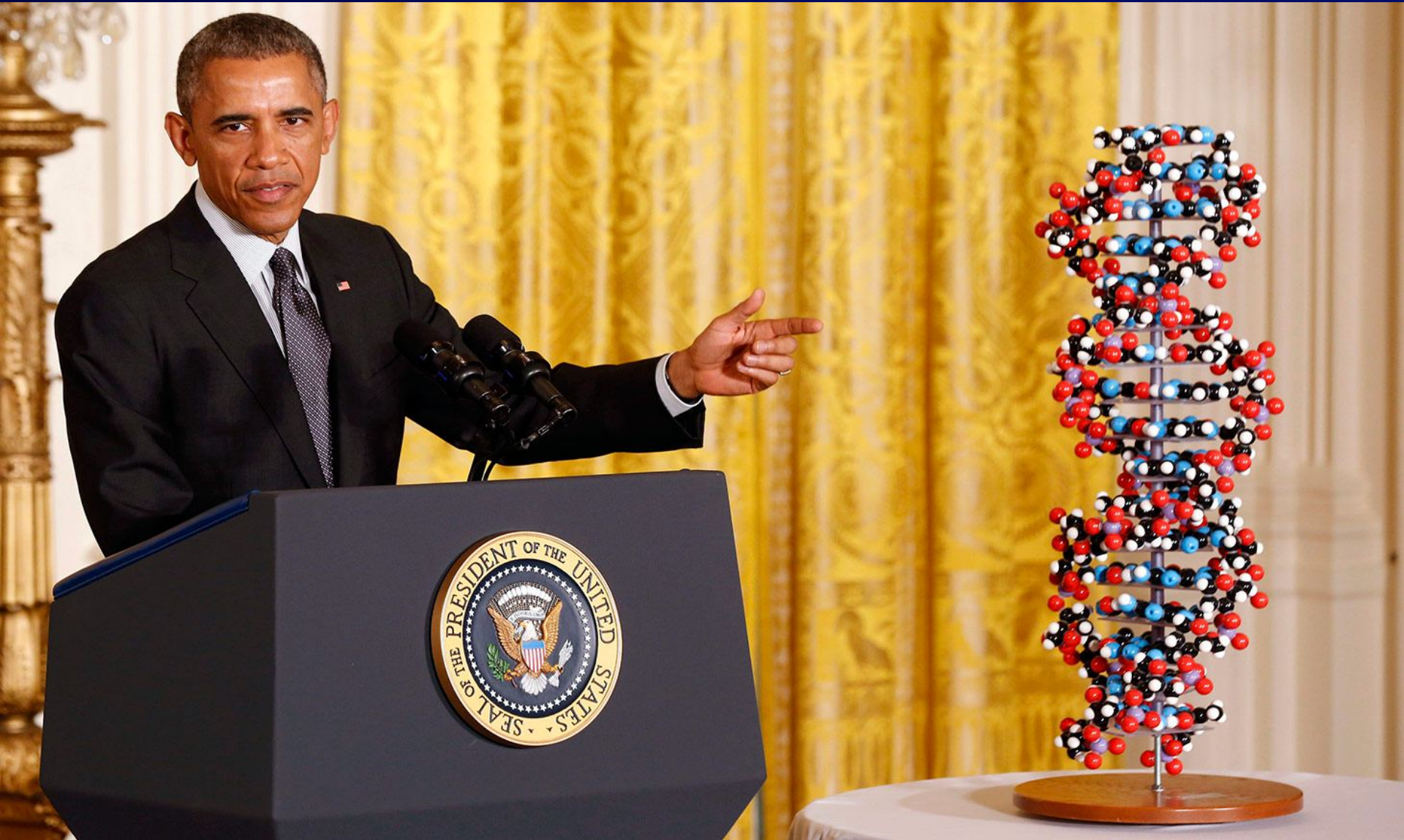


# 100,000 Genomes Project





# State of the Union Address 2015





# The New Language of Medicine is Genomics

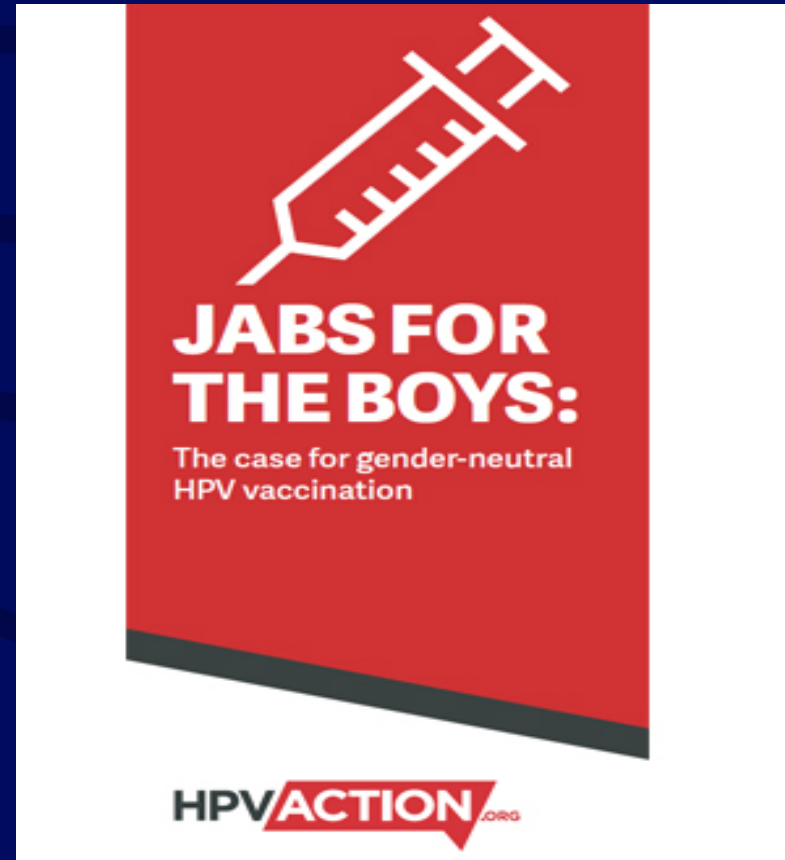


# Awareness of Personalised Medicine

- Interviews with 895 physicians and 811 patients
- Patients (78%) **understood biomarker for treatment decision making** and would be willing to participate in a **personalised medicine (PM) treatment plan.**
- **85% of patients** understood their PM treatment when it was explained to them, but **only 23% of doctors** felt that their patients were fully informed.
- **90% of physicians reported using biomarkers**; the most cited obstacles were **local availability, speed of obtaining results, and cost.**
- Significant **regional variation**

# Precision Prevention

- HPV not just linked to cervical cancer
  - Head and Neck
  - Penile
  - Anal
  - Others
- Need to **consider vaccination for boys** too



# Universal HPV Vaccination

- The **case** has become **irrefutable**
- We can **invest** in the **future** of our **young people AND reduce** health **costs**
- **Particularly relevant in Northern Ireland** given recent **drop in vaccination rates for cervical cancer in Republic of Ireland**
- **Finally** recommendation for universal vaccination in the UK accepted in **August 2018**





**OPINION**  
Pepper...and Salt




**WORLD NEWS**  
Science-Fiction  
Writer Ursula K. Le Guin  
Dies at 88



**WORLD NEWS**  
The Internet Is Filling  
Up Because Indians Are  
Sending Millions of ...



Leadership can be learned.  
See you in class.



MUHTAR KENT  
CHAIRMAN OF THE BOARD,  
THE COCA-COLA COMPANY



LESSONS IN LEADERSHIP

LEARN MORE

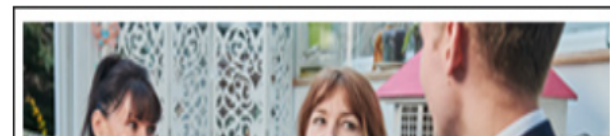
LIFE

## The New Einsteins Will Be Scientists Who Share

From cancer to cosmology, researchers could race ahead by working together—online and in the open

By Michael Nielsen

October 29, 2011





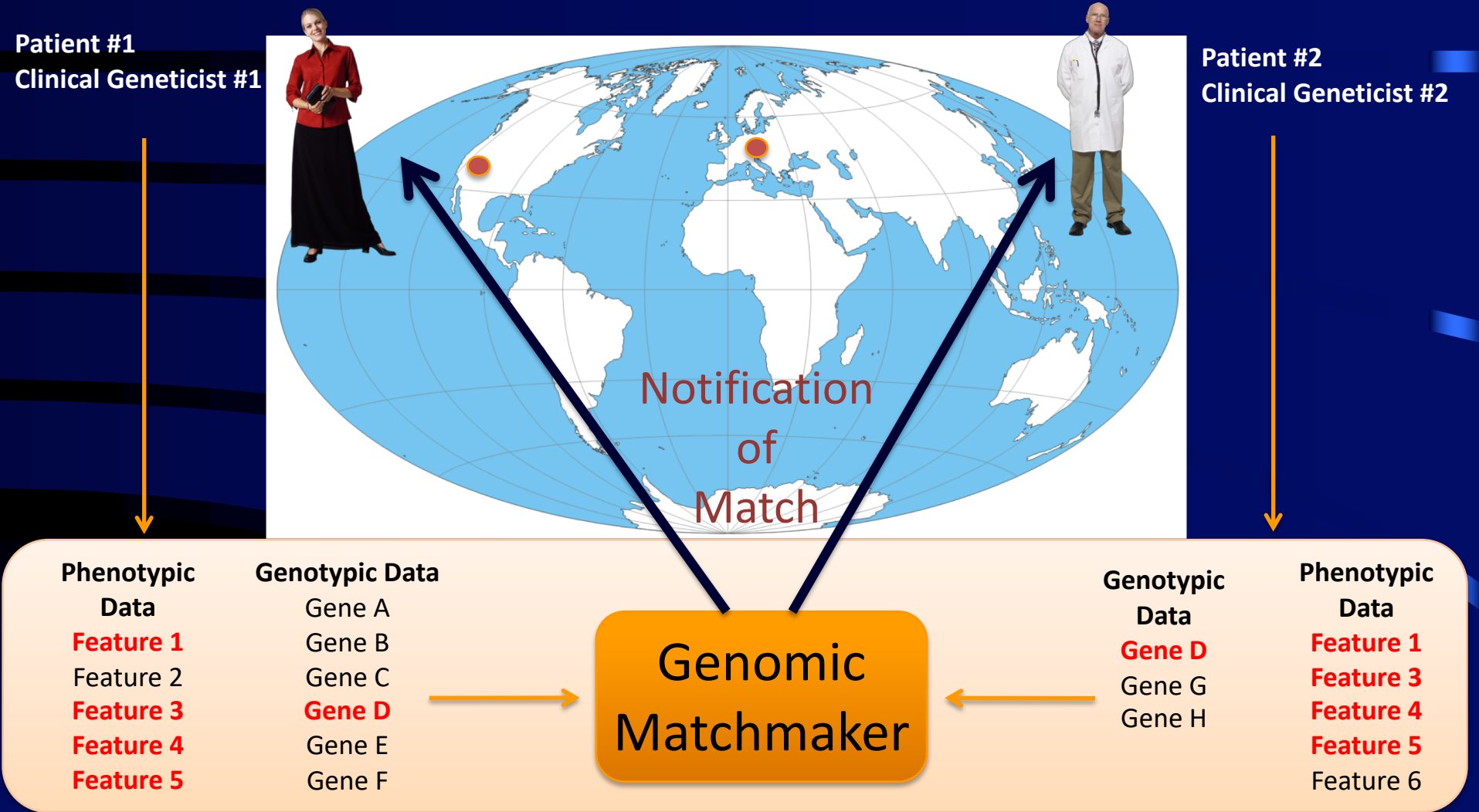
# Global Alliance for Genomics & Health

**Collaborate Innovate Accelerate**

An international coalition to promote  
**responsible and effective sharing of genomic,  
epidemiological and clinical data**

<https://genomicsandhealth.org>

# Genomic Matchmaker



*Courtesy of Joel Krier*

# A Call to Action from the “Coalition of the Willing”

- **Championing a Data Sharing Culture**
- Establishing a **Cancer Knowledge network**
- Moving from a Closed **“Selfish Silo”** Mentality
- To an Open Source **“Collaborative Culture”**

The NEW ENGLAND  
JOURNAL of MEDICINE



## Sharing Clinical and Genomic Data on Cancer — The Need for Global Solutions

The Clinical Cancer Genome Task Team of the Global Alliance for Genomics and Health

Mark Lawler, PhD; David Haussler, PhD; Lillian L. Siu, MD; Melissa A. Haendel, PhD., Julie A. McMurry, PhD; Bartha M. Knoppers, PhD; Stephen J. Chanock, MD; Fabien Calvo, MD., PhD; Bin T. The, MD; Guneet Walia, PhD; Ian Banks, MD; Peter P. Yu, MD; Louis M. Staudt, MD, PhD; and Charles L. Sawyers, MD.



# Your DNA, Your SAY

reset answers and start again



- Welcome
  - Online footprint
  - Data access by others
  - Access by medical doctors
  - Access by non-profit researchers
  - Access by for-profit researchers
  - Perceived harms
  - Expectations of information
  - Trust
  - Last few questions about you
  - Submit your response

films can be skipped, paused or watched again

## Welcome

YourDNAYourSay.org (Anna Middleton, Wellcome Trust Sanger Institute)

<https://surveys.genomethics.org/action/Survey/r2vGcSU9Q7uqUQK0x6t6hQ>

This is a survey about your online health data and how it might be used by others.

# A Question of Trust

- Citizen-focused **Data Sharing Cooperative**
- Articulate a clear **Social Contract**, where citizens (as data donors) are at the heart of decision making.
- Embed **ethical rigour** in all our data-driven processes
- **Democratise data analysis** for maximum scientific and clinical value
- *“Safe people, working on safe data, in safe places, with safe outputs”*
- **Data safe havens** with a **“shop-window”** to the public



# Million European Genomes Alliance (MEGA)

- Declaration of Cooperation
- *“Towards access to at least 1 million genomes sequenced in the European Union by 2022”*
- Joint Declaration indicating **political support** for **linking existing and future genomic databanks** (on a voluntary basis) in order to reach a cohort of **1 million sequenced genomes** accessible in the EU by 2022



# Million European Genomes Alliance (MEGA)

- Signed by **17 European nations**
- Austria, Bulgaria, Cyprus, Croatia, Czech Republic, Estonia, Finland, Greece, Italy, Lithuania, Luxembourg, Malta, Portugal, Spain, Slovenia, Sweden, UK,



# Personalised Medicine Awareness Month

- 🧬 In November, ECPC will launch **the first Awareness Month on Personalised Medicine**,<sup>1</sup> focusing on molecular /biomarker testing **Awareness, Education and Advocacy** aimed at patients and patient organisations, healthcare professionals and policymakers.



<sup>1</sup>Developed in close cooperation with **Cancer Drug Development Forum (CDDF)**, **European Alliance for Personalised Medicine (EAPM)** and **International Quality Network for Pathology (IQNPath)**







**2nd European Alliance of Personalised Medicine Congress  
Personalising Your Health: A Global Imperative!**

26 - 28 NOVEMBER 2018 | MILAN ITALY