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

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• The day personalised cancer medicine and genomic technologies came of age for our society

1 Jolie A. New York Times (2013)
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

BRACAnalysis®

KNOWLEDGE IS POWER

Mutation Positive

Mutation Negative

General Population Risk

Familial Risk

Increased Cancer Risks

Personalized Medical Management Plan

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

General Population Risk:
- Breast: 8%
- Ovarian: >1%

Familial Risk:
- Breast: up to 40%
- Ovarian: up to 11%
Testing the “Angelina Jolie” Effect

• 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.

1 Evans et al Breast Cancer Research 2014
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.”

Evans et al Breast Cancer Research 2014
100,000 Genomes Project
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

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
Collaborate   Innovate   Accelerate

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

https://genomicsandhealth.org
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”

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.
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

YourDNAYourSay.org (Anna Middleton, Welcome 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,
In November, ECPC will launch the first Awareness Month on Personalised Medicine, focusing on molecular /biomarker testing Awareness, Education and Advocacy aimed at patients and patient organisations, healthcare professionals and policymakers.

1 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