



Public and Patient Involvement in Genomics in Ireland

Presented by:

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A personal Case study: Genomics to accelerate Diagnosis

- Early Diagnosis
 - 12 year journey
- Avoid
 - Emotional upset/uncertainty for future
 - Delay in interventions
 - Unnecessary testing
 - Multiple appointments across multiple specialties
 - Difficulty in justifying additional supports
 - Delay connecting with support network



A personal Case study: Genomics to ensure precision therapy

- Tumour genetic analysis
 - Personalised treatment plan
 - 'Sniper shooting' vs carpet bombing' **(Prof Owen Smith)*
- Genetic testing for mutations causing cancer (BRCA)
 - Preventative treatments
 - Family discussions/implications



Increasing Discussions re Genomics in Ireland

(Noted in IPPOSI Jury on Genomics Report)

- Reviews show large/increasing disparity between genomic medicine services in Ireland and internationally
- Medical Genetics in Ireland is under-resourced for both clinical and laboratory services
 - Lack of timely access to genetic opinions/testing,
 - Delays in diagnosis, treatments, and interventions.
- Prof Owen Smith submitted a paper in 2016 to the HSE with recommendations, 2018 commitment to action
- **May 2022 HSE took the first step toward developing a National Genetic and Genomic Strategy for Ireland, with the inaugural meeting of the HSE National Genetic and Genomic Steering Group**

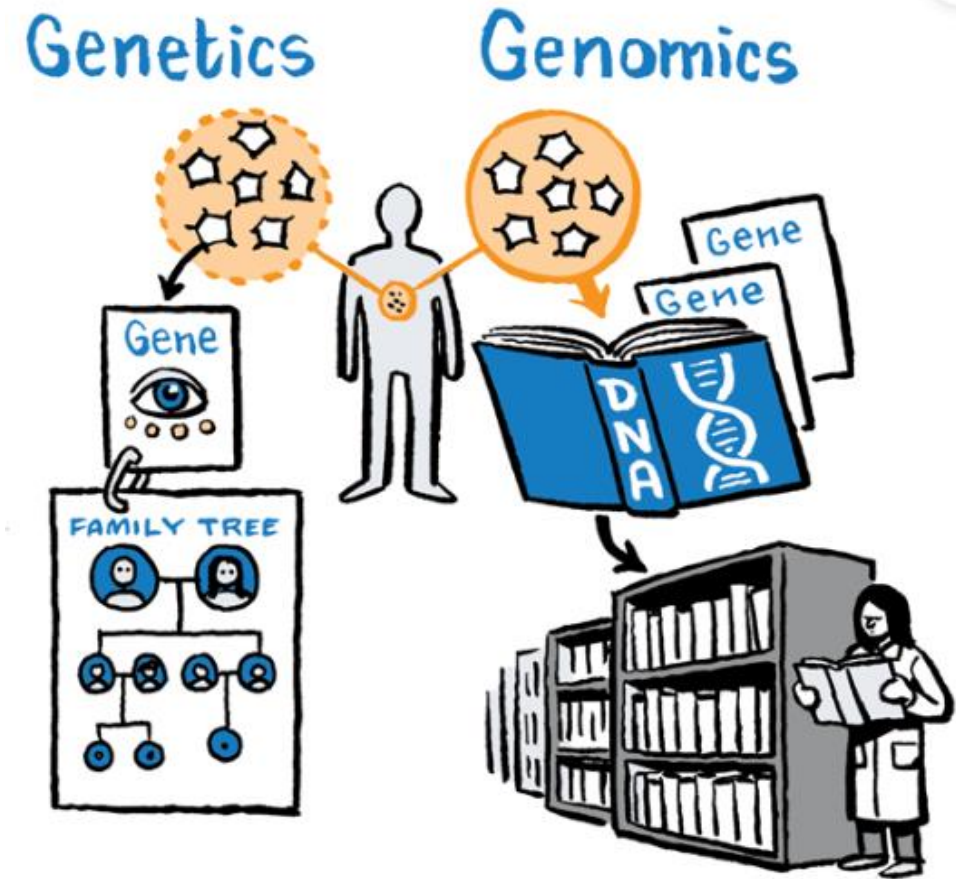


Strategy to address:

- Shortage of trained genetic specialists
- Knowledge gaps in clinical workforce
- Lack of genetic/genomic literacy across healthcare professionals and the public
- Look at appropriate governance structures, policies, procedure, and protocols needed for National body

The role of Patients/Public in Genomics

- With breakthroughs in science, as humans, we have learnt about the **human genome**
 - **Cause, targeted treatment, treatment toxicities**
- **Use of this data**
 - to improve our health as individuals
 - or at the population level
- **Our data, Our say!!**
 - Public/Patients should have a say in how genomic information should be used in Ireland for health care and health research
- **Initiative: Rare Advisory Panel Ireland**
- **Key initiative: IPPOSI Jury on Genomics**
 - **Jury explored**
 - to what extent we should increase the use of genomics in our health care and health research,
 - the challenges and opportunities that may arise as individuals and as a society, and
 - the safeguards that need to be put in place to balance the benefits and the risks.



THE JURY VERDICT IS IN!



**WE NEED A NATIONAL
PROGRAMME FOR
GENOMICS IN IRELAND**



**WE NEED A NEW AGENCY
TO MONITOR
IMPLEMENTATION**



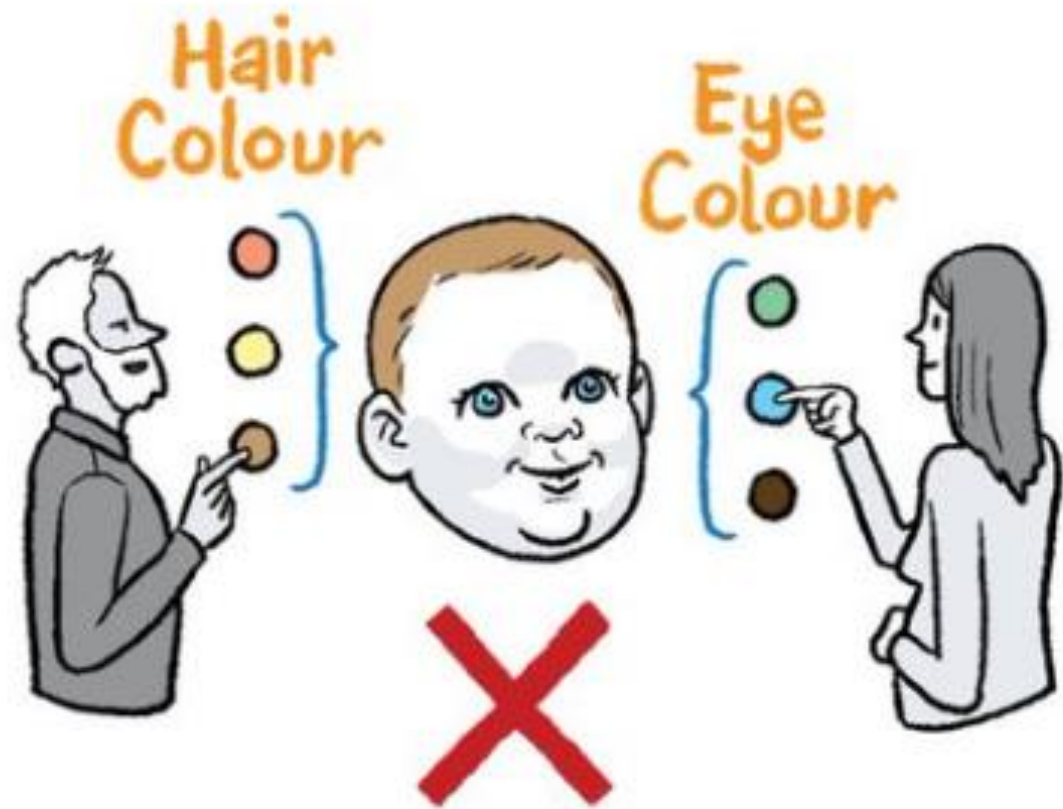
**WE NEED A SECURE
INFRASTRUCTURE TO
MANAGE GENOMIC DATA**



**WE NEED A CITIZEN-
CENTERED MODEL OF
CONSENT TO INFORM CHOICE**



**WE NEED AN INCLUSIVE
PUBLIC ENGAGEMENT PLAN
TO INCREASE LITERACY**

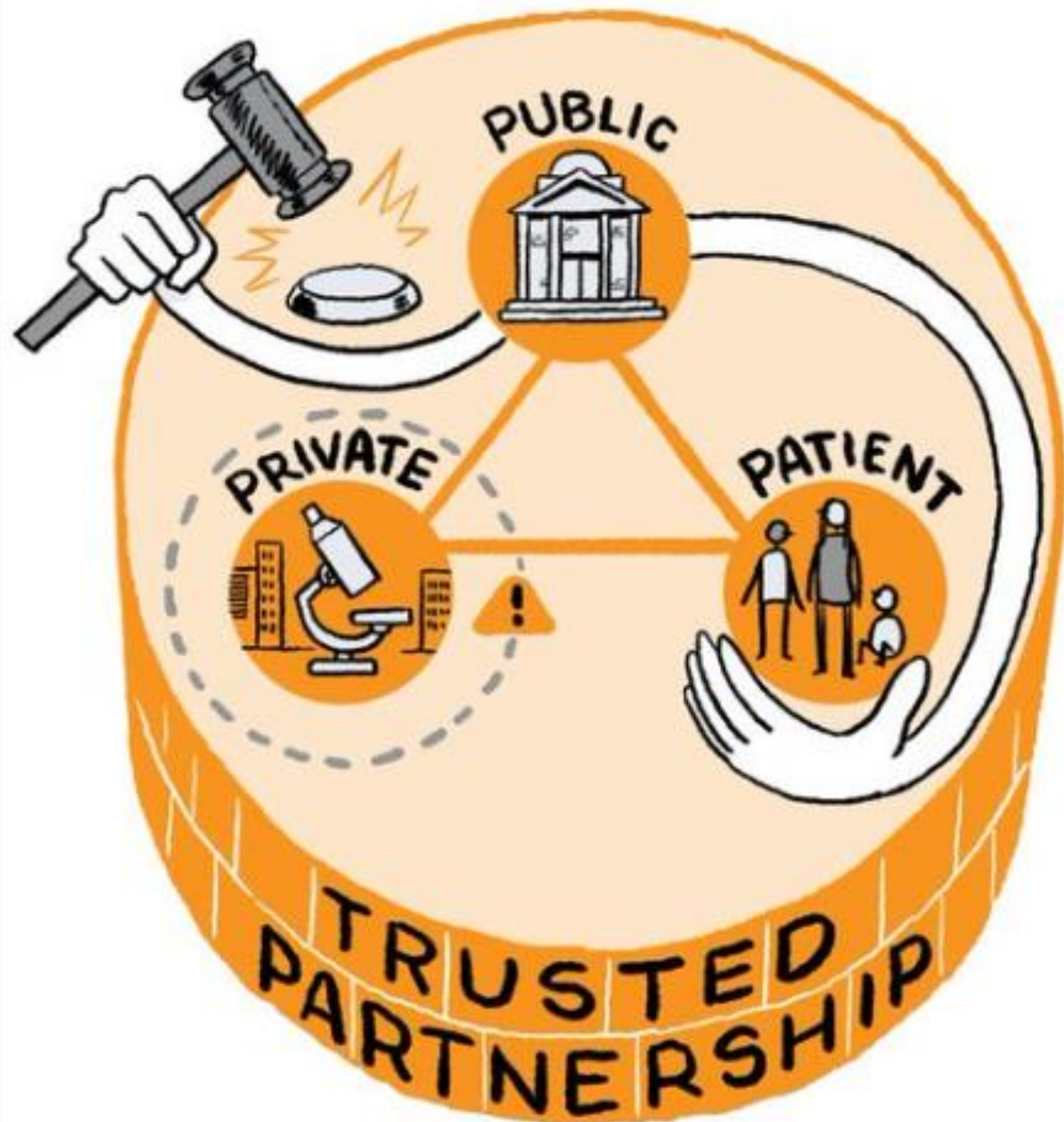


THEME #1: APPROPRIATE USE

Jurors decided that genomics should be used in health care in a targeted way for the purpose of diagnosing and treating disease, but not for aesthetic purposes. The option to share genomic data with health research should be decided on an individual basis and follow a clear consent process.

THEME #2: NATIONAL PARTNERSHIPS

Jurors agreed that Ireland should develop a national genomics programme based on a trusted partnership between the public and private sector. The implementation of the programme should be directed by a new state-appointed national genomics agency.



Protecting
PRIVACY



We
propose
...

We
recommend
...

DATA

Protecting
SOCIETY
as a
whole

INDEPENDENT STATE AGENCY

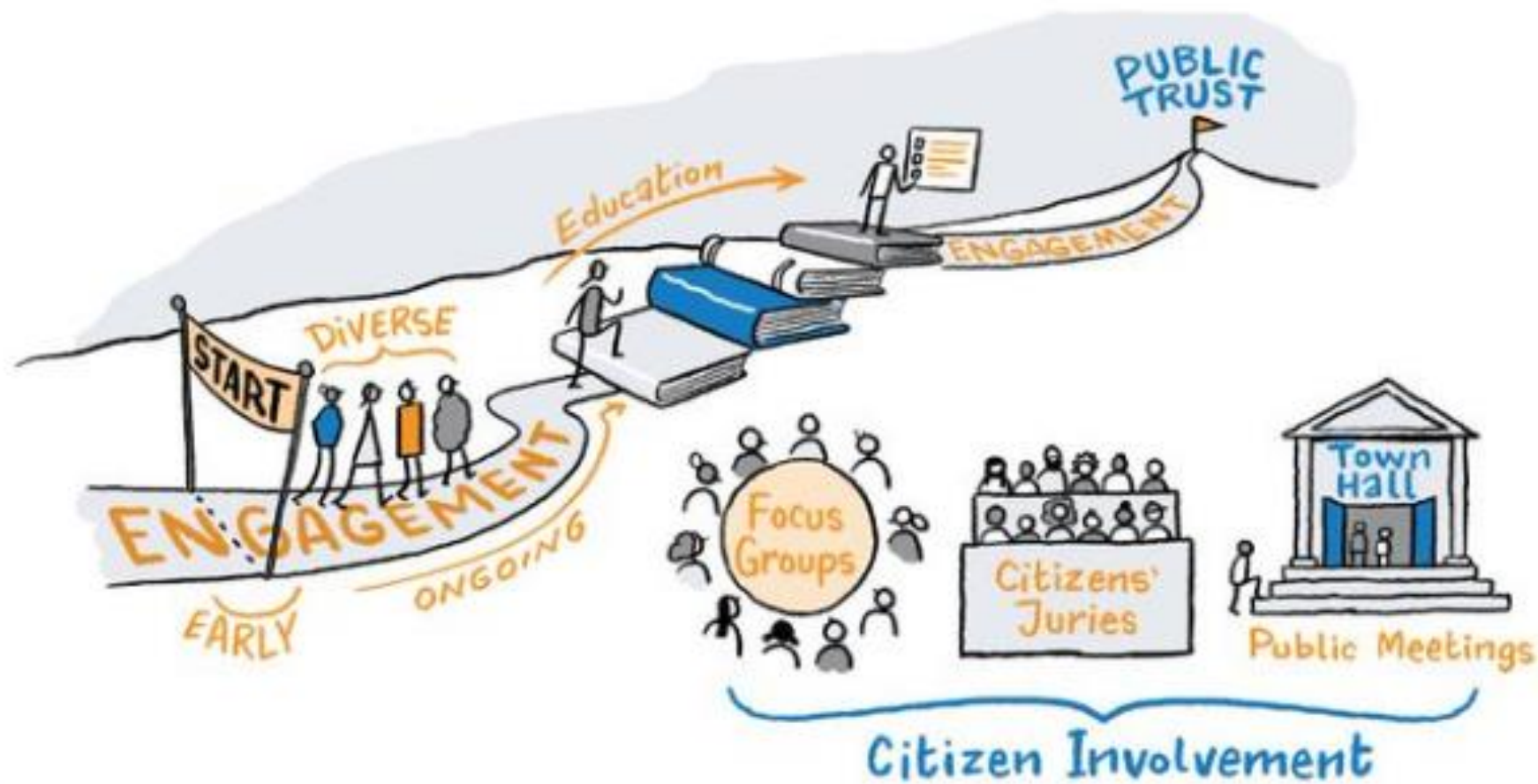
THEME #3: DATA SECURITY

Jurors proposed that Ireland establish a national genomics database to securely store and manage genomic data. Any breaches or misuse of data should be met with serious consequences. An Ombudsperson should be created to receive and respond to complaints from individuals.

THEME #4: CONSENT

Jurors maintained that individuals should be able to view and manage their own genomic data. People should be asked to 'opt-in' to share their data, and a consent process should provide individuals with the time and information needed to make an informed decision.





THEME #5: PUBLIC ENGAGEMENT

Jurors underlined the importance of engaging the public in decisions about our collective health future. Public information and education should accompany engagement to allow for meaningful, sustained and inclusive engagement.

Next Steps

- Deliberative Dialogue meetings
- Continued public engagement and awareness

Any Questions?



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