
Public Health Genomics Programmes and Policies in the UK

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Structure of Talk

- 1. Public health genomics**
- 2. Public health and policy in the UK**
- 3. Challenges faced by public health genomics**
- 4. Translation**
- 5. Consequences of genetic exceptionalism**

The Bellagio Statement

**The responsible and effective translation of
genome-based knowledge and technologies
for the benefit of population health**

Genetics

1. **Genetics as inheritance (genetics)**

single gene disorders inherited in a mendelian fashion

genetic services

familial association

medical genetics

2. **Genetics as cell and molecular biology (genomics)**

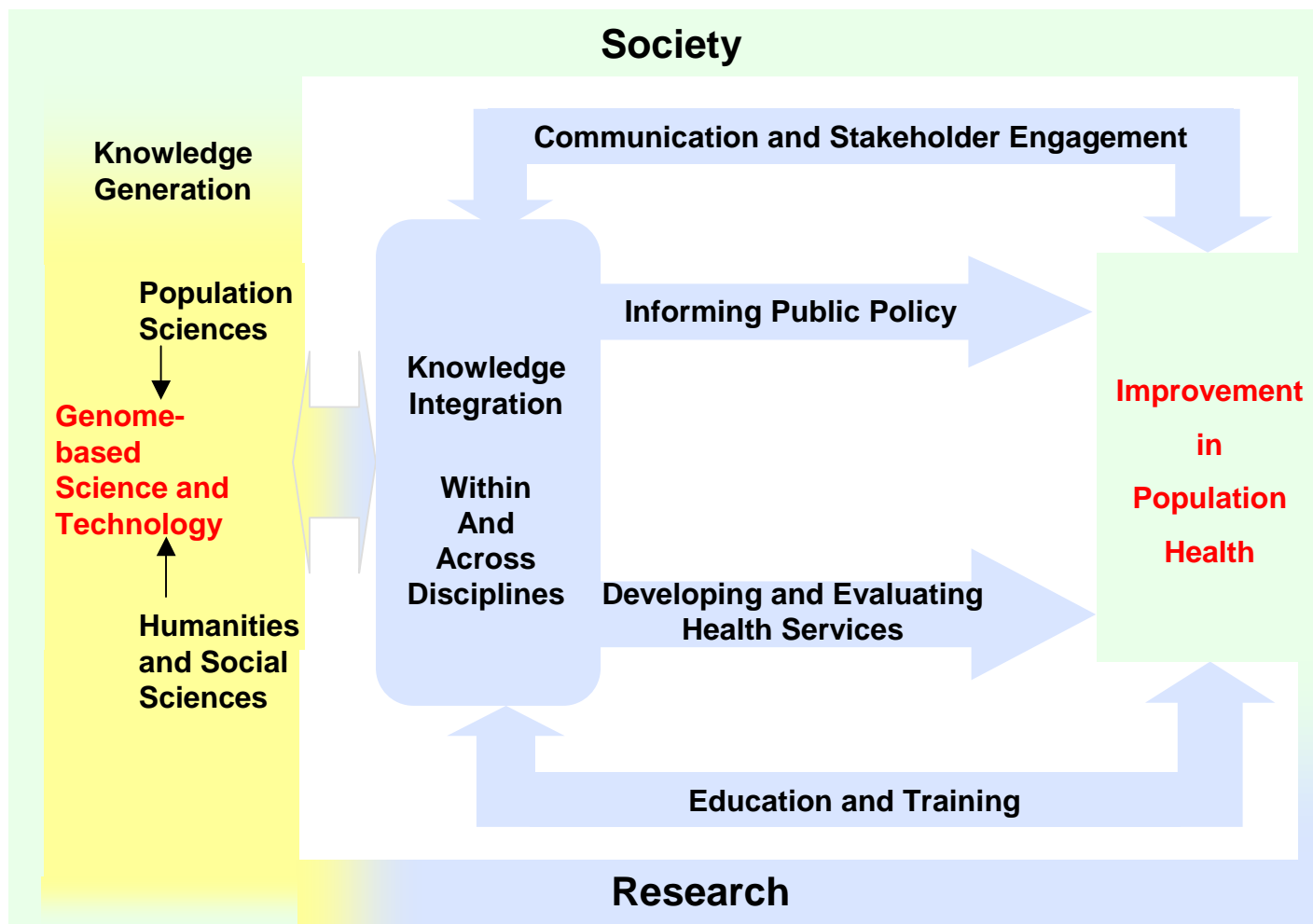
the genetic component of all human traits and diseases

the basis of development

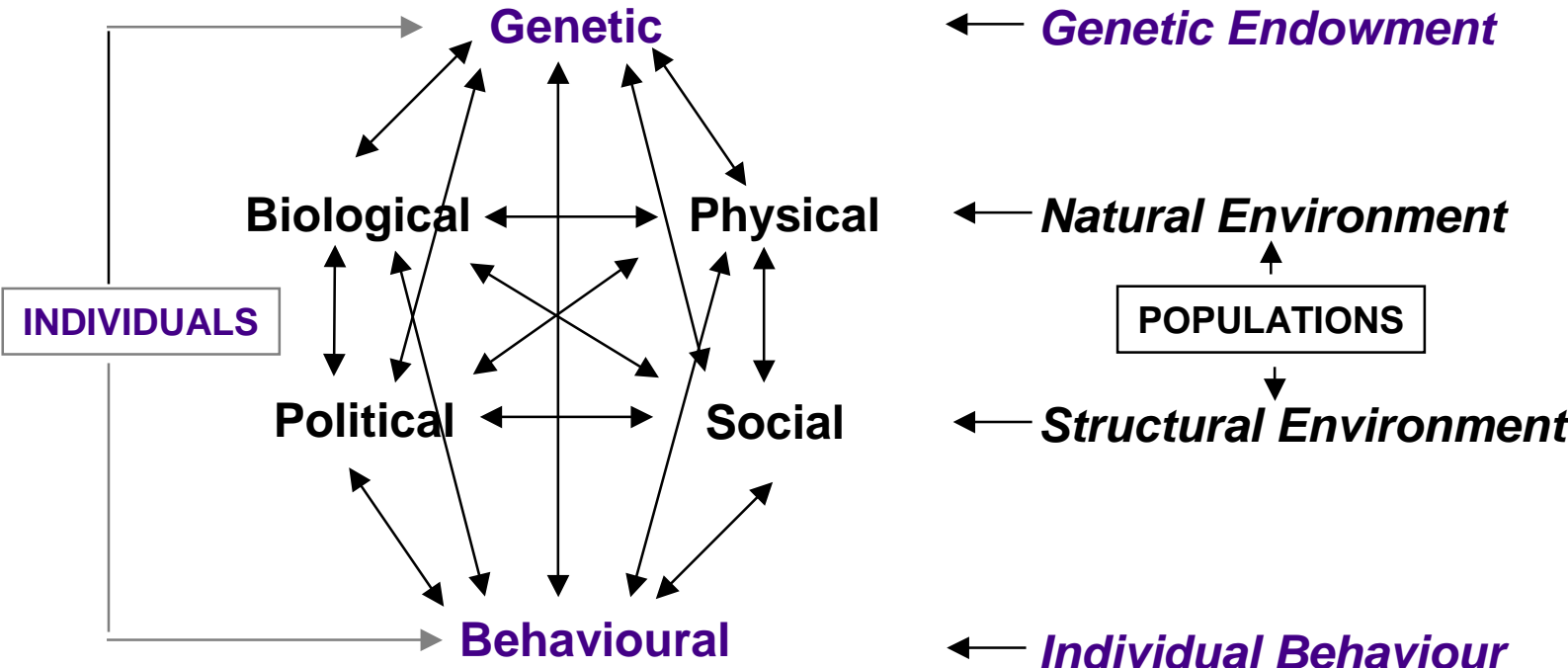
modern biology

genomic medicine

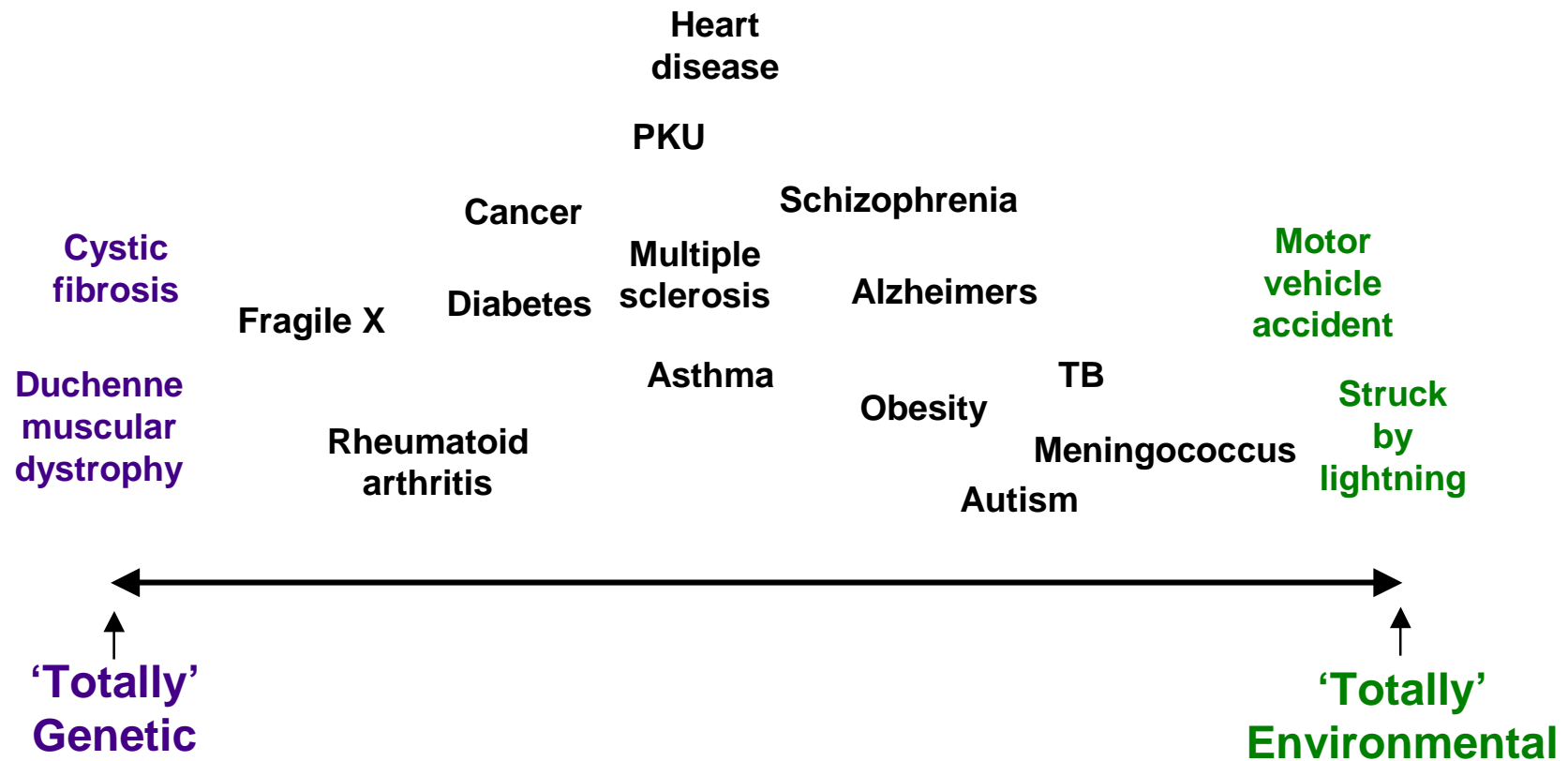
The Enterprise of Public Health Genomics



Determinants of Health



Gene-environment Interaction



Disciplines within the CGKP

1. **Geneticists and molecular biologists**
2. **Public health physicians**
3. **Epidemiologists**
4. **Biostatisticians**
5. **Lawyers**
6. **Philosophers**
7. **Social scientists and social anthropologists**
8. **Information and IT specialists**
9. **Educationalists**
10. **Public involvement specialists**
11. **Industrial liaison**

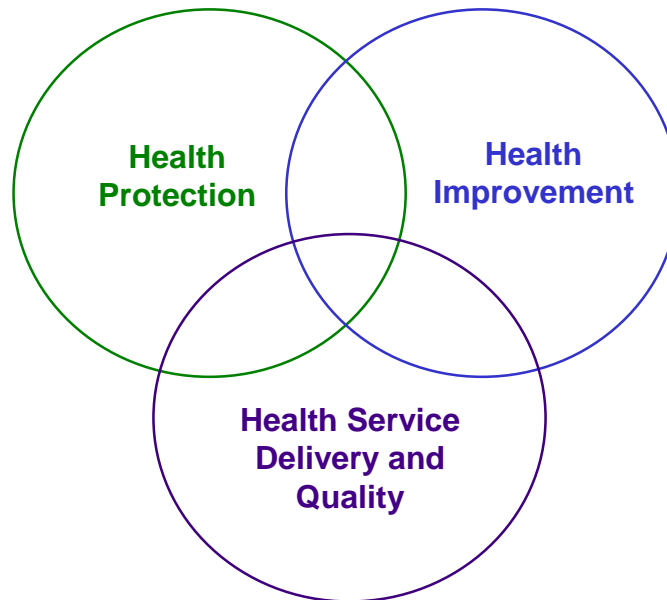


Strangeways Research Laboratory

“Working under one roof”

Public Health in the UK

Infectious diseases
Chemicals
Radiation
Environmental hazards
Emergency response
Clean air, food and water
Preventing wars



Inequalities
Education
Housing
Employment
Communities
Lifestyles

Service planning
Audit & evaluation
Clinical effectiveness
Efficiency
Clinical governance
Research

UK Policy Context

1. [Our Inheritance, Our Future – Realising the potential of genetics in the NHS \(Jun 03\)](#)
2. [Strengthening Clinical Research \(Oct 03\)](#)
3. [Lambert Review of Business University Collaborations \(Dec 03\)](#)
4. [Bioscience 2015: Improving National Wealth, Improving National Health \(Nov 03\)](#)
5. [Securing Good Health for the Whole Population: Wanless Report \(Feb 04\)](#)
6. [Science and Innovation: A Ten Year Investment Framework \(Mar 04\)](#)
7. [Research for Patient Benefit Working Party \(Mar 04\)](#)
8. [Public Health Sciences: Challenges and Opportunities \(Mar 04\)](#)
9. [Choosing Health: Making Healthier Choices Easier \(Nov 04\)](#)
10. [NHS Improvement Plan: Putting People at the Heart of Public Services \(Nov 04\)](#)
11. [Better Health Through Partnership. HITF \(Nov 04\)](#)
12. [Creating a Patient Led NHS \(Mar 05\)](#)
13. [Best Research for Best Health: A New NHS Research Strategy \(Jul 05\)](#)
14. [Modernising Pathology: Building a Service Responsive to Patients \(Sep 05\)](#)
15. [Cooksey Review of UK Health Research Funding \(Dec 06\)](#)

Impact of UK Policy Context

- 1. Importance of genetics and molecular science research**
- 2. Need for a vibrant research base and research capacity**
- 3. Imperative of strong and well developed links between academia, the NHS and the commercial sector**
- 4. Importance of the NHS as a unique resource for clinical trials and all forms of clinical research including epidemiological studies and health services research**
- 5. Growing importance of public health and preventive medicine**
- 6. Need for appropriate and balanced regulatory regimes**
- 7. Increasing emphasis on translation**

The Basic Thesis

- 1. Public health practice in the twenty first century can no longer ignore the knowledge derived from genetic and molecular science. An understanding of the cellular mechanisms of disease will be as important to the public health community as an understanding of the social determinants of health.**
- 2. The separation of disciplines - of the humanitites from the sciences, of clinical from public health medicine, of genetic from environmental factors and of the basic sciences from the clinical sciences - are all false antitheses that must be discouraged and broken down.**

Intellectual Challenges

1. **Understanding basic genetics, cell and molecular biology and their complexity**
2. **Understanding that genetic factors are important health determinants and the implications of gene-gene and gene-environment interaction**
3. **Understanding that genetic influences do not entail determinism**
4. **Understanding the basic principles of genetic epidemiology and their implications for population health**
5. **Understanding the complementary nature of high risk and population approaches to disease prevention**
6. **Understanding the ethical, legal, social and policy implications of genetics and molecular science**

Practical Challenges

- 1. Leadership in public health genetics**
- 2. Knowledge integration and evidence synthesis**
- 3. Service development and evaluation**
- 4. Education and training**
- 5. Informing public policy**
- 6. Genomics and global health**

Leadership in Public Health Genetics

1. Developing awareness

genetic literacy

2. Building capacity

specialist public health geneticists

a small cohort of public health professionals with detailed understanding of issues

other professional groups

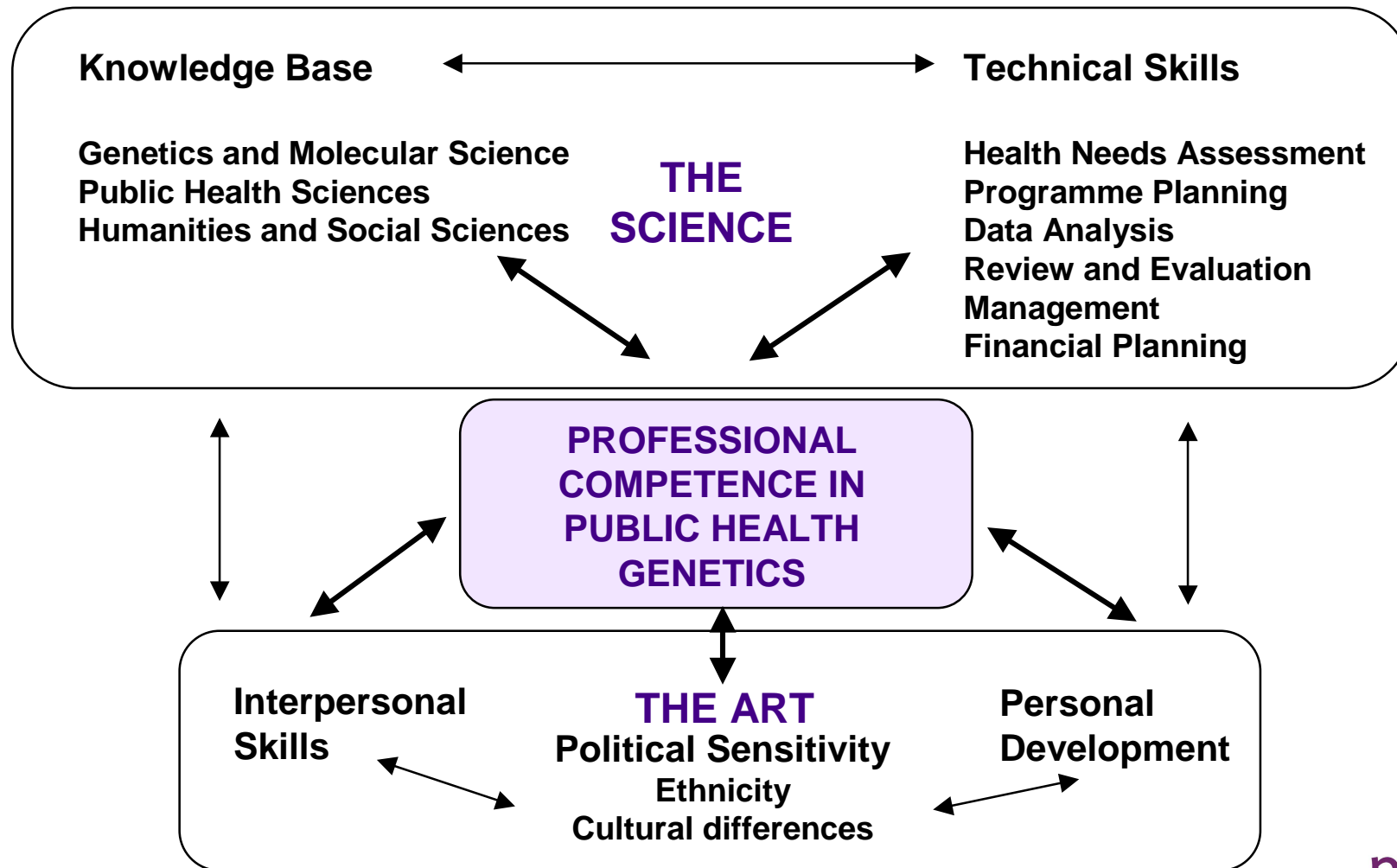
informing intelligent commissioning [reimbursement]

3. Establishing networks

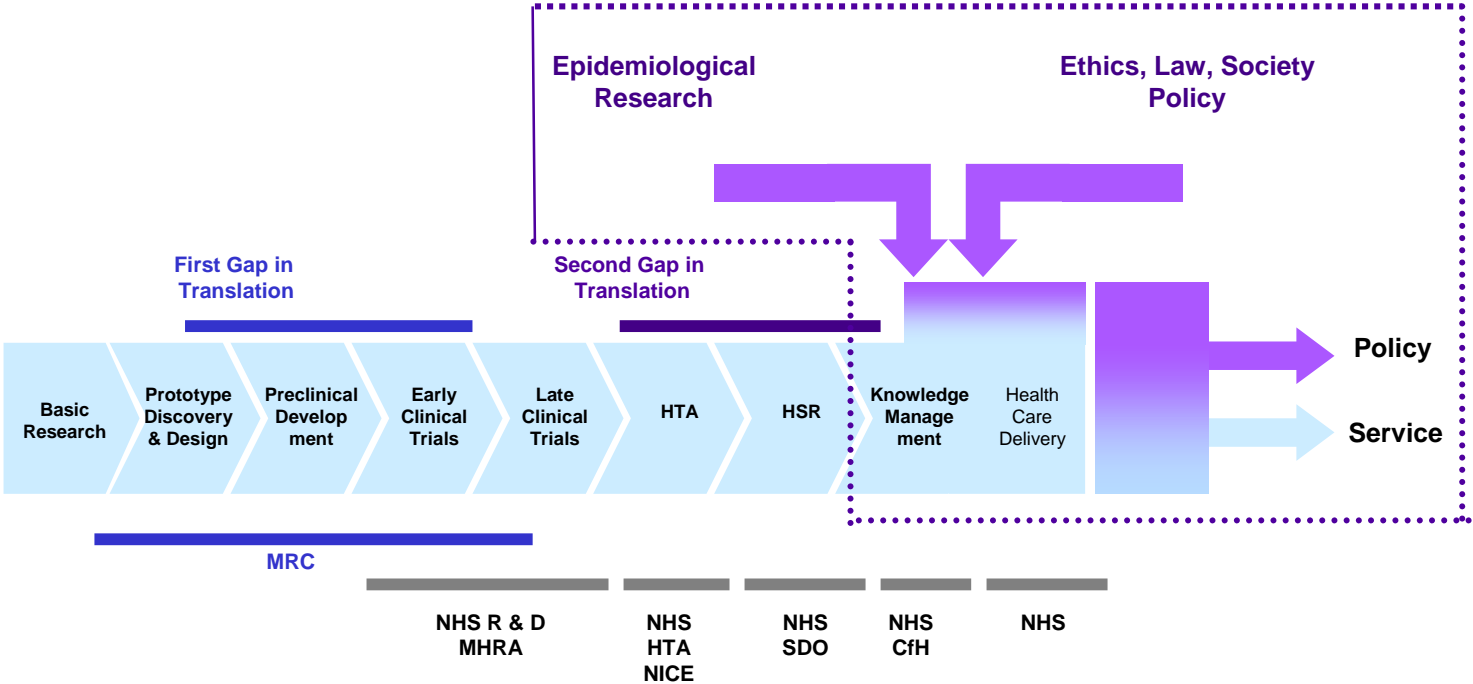
national and international

PHGEN, GRAPHInt, [Eurogentest]

Professional Competence



Translation (1)



After Cooksey (2006)

Translation (2)

First gap in translation

- Type I translation
- Translational research
- Bench to bedside

Second gap in translation

- Type II translation
- Research into practice
- Products and interventions into service and policy

PHG Foundation (1)

Vision

A world in which people gain maximum health benefit through the responsible and evidence based application of biomedical science

Purpose

To be an independent world leader working with partners to promote the responsible and evidence based application of biomedical science for health



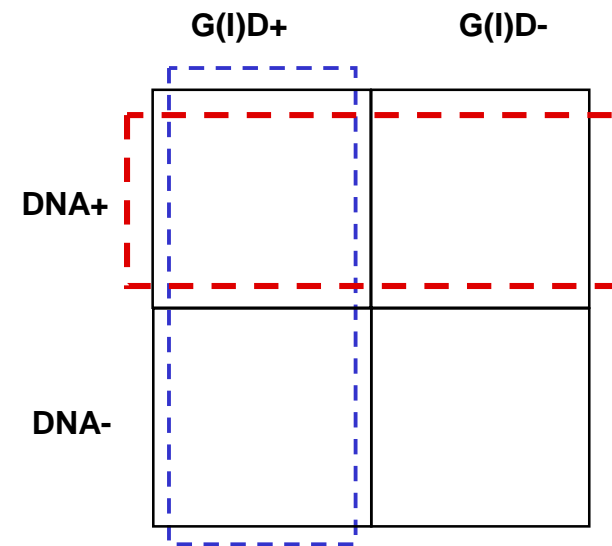
PHG Foundation (2)

Strategic Objectives

- 1. To identify the potential of biomedical science to benefit health and to disseminate that knowledge for public benefit**
- 2. To contribute to the integration of biomedical science into mainstream clinical and public health services**
- 3. To foster a social and regulatory environment receptive to the application of biomedical science for health**
- 4. To promote the development of systems and policies for the evaluation of technologies that derive from biomedical science**
- 5. To work with partners to provide education and training to support the responsible application of biomedical science for health**

Genetic Exceptionalism

Genetic exceptionalism is the claim that genetic information is sufficiently different from other types of health information that it deserves special protection or other exceptional measures



Information about **people with inherited disorders**

Information derived from the use of **DNA technology**

Consequences (1)

European Parliament Resolution on the Commission communication on Life Sciences and Biotechnology [21 Nov 2002]

51. Calls on the Commission to draft a regulation for the introduction of a standard for genetic tests

52. States that genetic testing and analysis must be conducted under clear rules within the frame of competent, independent and personal counselling

54. Notes that genetic testing analysis and diagnosis data.....should be used only for the benefit of the person requiring that test...

55. Calls on the Commission to take the necessary steps for an EU-wide regulation on DNA-testing, choosing, if possible a legal basis (Art 152 (health) or Art 153 (consumer protection)and asks its competent Committee....to consider drafting an own-initiative report on the legal aspects of genetic testing

Consequences (2)

Hansard 15 Mar 2006 Debate on Genetic Discrimination

I said that the government would at some time in the future have to consider passing legislation making it illegal to discriminate on the grounds of genetics

Subject of genetic discrimination came to my attention when I realised that those with diagnosed genetic conditions were receiving unfair treatment when applying for insurance

I want to make sure that people with genetic conditions feel safe in having a test

All people with a genetic condition will be protected by the Disability Discrimination Act 2005 once their condition results in their becoming a disabled person within the meaning of that Act

We...intend to extend discrimination law into new areas, including genetic predisposition. Genetic tests are becoming available to show that a person has an increased risk or likelihood...of developing a particular medical condition later in life.

The discrimination law will look to calls for specific legal protections to be introduced in the area of genetic predisposition

GRAPH *Int*

GRAPH *Int* is an international collaboration that facilitates the responsible and effective translation of genome-based knowledge and technologies into public policies, programmes and services for the benefit of population health

Aims

- To provide an international forum for dialogue and collaboration**
- To promote relevant research**
- To support the development of an integrated knowledge base**
- To promote education and training**
- To encourage communication and engagement with the public and other stakeholders**
- To inform public policy**

**PERTH
Western Australia**

23 to 26 Nov 2008

**Population Health
Genomics:
Translating
Research into
Public Benefit**



www.graphing.org

Official Launch
Genomics and Public Health
Montreal, Canada
4-7 June 2006

PHGEN

Public Health Genomics European Network

1 Jan 2006 – 31 Dec 2008 (36 months)

EU Project: 2005313



<http://www.phgen.nrw.de/>

Funded by DG Sanco

Institute of Public Health NRW (Iögd)

German Center for Public Health Genomics (DZPHG)

Public Health Genetics Unit (PHGU)

**Collaborating Partners from all EU
Member States, Applicant Countries,
EFTA-EEA Countries:**
public health, human genetics, competent
authorities

Representatives of EU Networks:
e.g. EuroGentest, EUnetHTA, Orphanet,
NuGo

Representatives of Organizations:
e.g. WHO, WTO, OECD, UNESCO, STOA

Experts on European Law

Experts from outside EU:
e.g. CDC, AETMIS, P³G

Ten Work Packages

- Project Coordination
- Evaluation
- Dissemination
- Network Meetings
- Steering Group Meetings
- Assessment
- Policy Development
- Assurance
- Final Conference
- Final Report