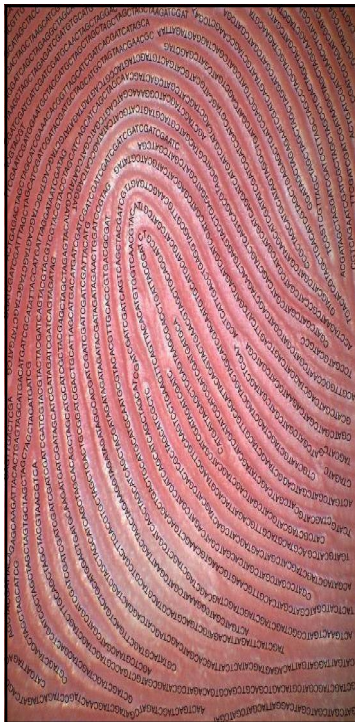


## From data to health

Mark Walport  
30 March 2011



## Data Sharing

- personal information is individual & precious to each one of us – it's vital that we treat it properly
- there is a long-standing and healthy debate about the balance between the right to privacy and the necessity to hold and share data


### Hunt for lorry killer stepped up



Surrey Police are to set up a mobile police station in a bid to catch the killer of a lorry driver who died after being hit by a brick.

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### INNOCECE PROJECT



**Brandon Moon**  
Served 17 years in Texas partly due to crime lab misconduct.

---

### Family's shock at council spying



A couple have spoken of their shock after their local council spied on them to see if they had been cheating the school catchment system.

Data sharing

## Public & private benefit

- law enforcement/  
public protection
  - national security
  - crime
  - protecting the vulnerable
  
- key issue:
  - proportionality




Data sharing

## Public & private benefit

- provision of services
  - targeted services
  - easier transactions
  - improved efficiency
  
- key issue:
  - choice of terms of service



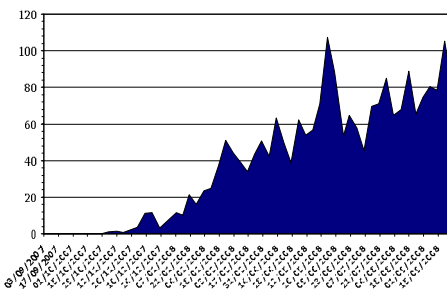
BMJ 2001; 323: p363  
 Br J Cancer 2002; 86: p1732  
 Prenat Diagn. 2007; 27 p1191

Data sharing

## Public & private benefit

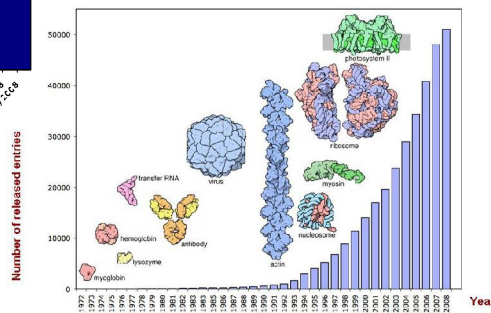
- research and statistics
  - enabling robust and evidence led policy
  
- key issue:
  - confidentiality vs consent

## Health research is generating rapidly increasing volumes of data...



**DNA sequencing: total gigabases by week**  
*(80 gigabases per week is 130,000 bases per second)*  
 Courtesy of Julian Parkhill

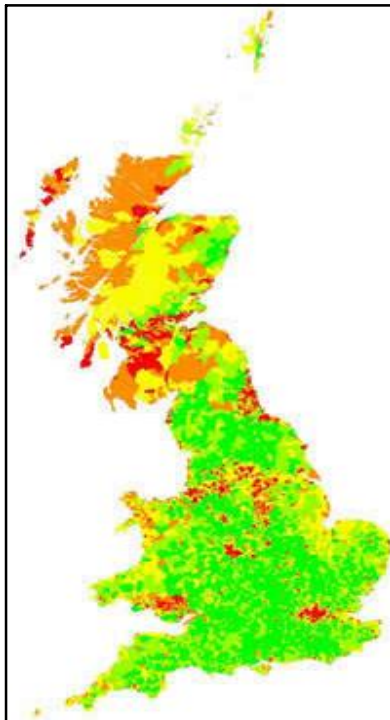
### Structural Biology: Structures deposited in the Protein Data Bank\*



wellcome trust

\*graph extracted from the Interim Report of the Blue Ribbon Task Force on Sustainable Digital Preservation and Access (Dec 2008)





Case study:

## Small Area Health Statistics Unit

- deaths (from 1981)
- cancers (from 1974)
- hospital admissions (from 1991)
- congenital anomalies (from 1983)
- births, stillbirths (from 1981)

Professor Paul Elliott  
Imperial College



Case study:

## Landfill sites and health

- 80% of population live within 2km of a landfill site
- risks:
  - small (1-7%) excess risk of low birth weight babies in populations living near landfill sites
  - small (1-19%) excess risk of birth defects near landfills
  - no excess risk of Down syndrome
  - no excess risk of cancer
- further understanding needed of causal mechanisms and possible exposure pathways to humans

BMJ 2001; 323: p363  
Br J Cancer 2002; 86: p1732  
Prenat Diagn. 2007; 27 p1191

wellcome trust



# biobank<sup>uk</sup>

Improving the health of future generations

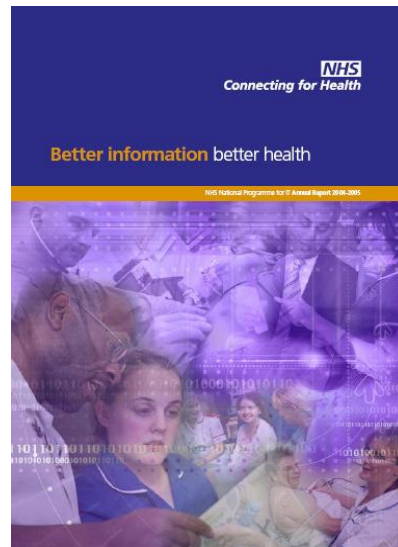


- a long-term project, >20-30 years.
- demographics, health (diet, diseases, drugs etc), environment
- enable the study of diseases of later life such as cancer, heart disease, diabetes, Parkinson's disease, Alzheimer's disease
- 500,000 volunteers aged 40-69
- blood and urine samples, confidential lifestyle questionnaire
- full recruitment commenced in 2006

wellcome<sup>trust</sup>

## Possible futures in health

- ability to link large datasets
  - demographic
  - health: diet, disease, drugs
  - housing
  - environment
- example of benefits
  - better public health
  - policy based on evidence!
  - personalised medicine



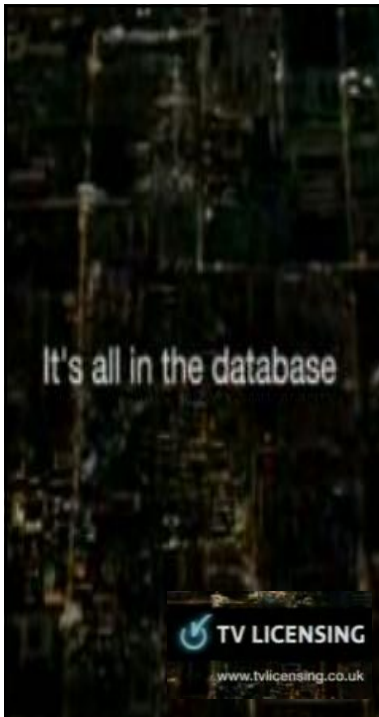
wellcome<sup>trust</sup>



## Data Sharing Review

Richard Thomas and Mark Walport

- **develop mechanisms for safe and secure research and statistical analysis:**
  - develop 'safe havens' as environment for population-based research and statistical analysis
  - create system for accrediting approved researchers
  - government departments wishing to develop, share and hold should work with academic and other partners to create safe havens
  - call on HMG and NHS to maximise potential benefits made possible through safe havens
  - NHS should develop a system to allow approved researchers to work with healthcare providers to identify potential patients



## Conclusions

- data is empowering
- it can be sensitive
- good governance crucial