

Framing common goods: From Genomics to Forensic 'big data'

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Framing common goods: From Genomics to Forensic ‘big data’

This presentation will:

- Outline the basic premises of ethical governance – ‘Framing Common Goods’
- Briefly outline two Genomic ‘Big Data’ projects: FP7 RD: Connect and the Genomics England 100,000 Genomes project.
- ‘Open’, ‘Slippery’ and ‘Secret’ contexts of ‘Big Data’
 - ‘New and pervasive architecture of biosurveillance’ (Parry 2012)
- Moving forward: possible solutions and unresolved questions

- About RD-Connect
- An introduction from the coordinator
- Objectives
- Partners
- Governance
- About IRDiRC
- About -omics
- Events
- Publications and outreach

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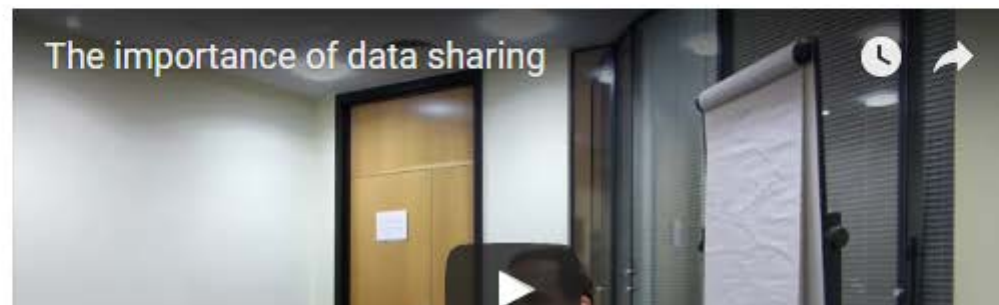
About RD-Connect

RD-Connect is a unique global infrastructure project that links up databases, registries, biobanks and clinical bioinformatics data used in rare disease research into a central resource for researchers worldwide.

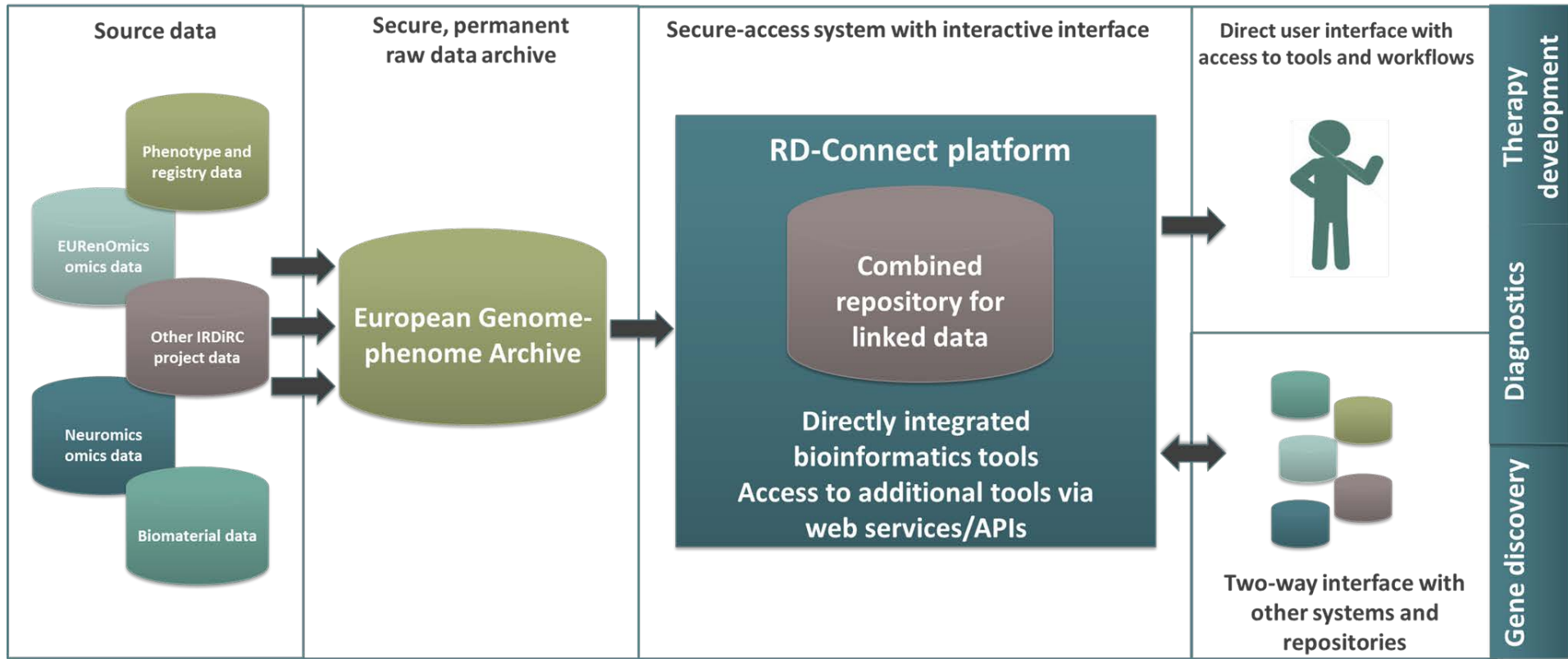
In a six-year project funded by the European Union but uniting researchers across the world, it will develop an integrated research platform in which complete clinical profiles are combined with -omics data and sample availability for rare disease research, in particular research funded under the [International Rare Diseases Research Consortium \(IRDiRC\)](#).

 [RD-Connect overview page](#)

RD-Connect Associated partner, [Mike Brudno \(PhenoTips\)](#), talks about the potential impact of RD-Connect on the rare disease community:



RD-Connect: overview



About Genomics England

Genomics England, with the consent of participants and the support of the public, is creating a lasting legacy for patients, the NHS and the UK economy, through the sequencing of 100,000 genomes.

Genomics England is a wholly owned company of the Department of Health and this programme was made possible by the [National Institute for Health Research](#), [NHS England](#), [Public Health England](#) and [Health Education England](#). Genomics England was set up to deliver the 100,000 Genomes Project. This flagship project will sequence 100,000 whole genomes from NHS patients and their families.

The project is focusing on patients with rare diseases, and their families, as well as patients with common cancers.

Our aims

- To bring benefit to patients
- To create an ethical and transparent programme based on consent
- To enable new scientific discovery and medical insights
- To kickstart the development of a UK genomics industry

Useful links

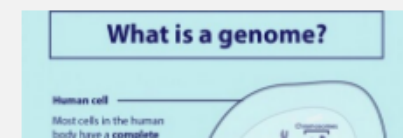
Events

Upcoming talks, debates and seminars, plus videos of past events,



About genomics

See our infographics, films and resources on genomics.



Framing common goods: From Genomics to Forensic 'big data'

This is not a paper of solutions but one of unanswered questions and exploratory framing of the interface between medical genomics and forensic genomics.

1. Technological advances in the post genome era: NGS
2. Affordability and availability of the technology \$1,000 -100 genome
3. Reference set expanding – BIG Data initiatives driving medical research
4. Data mining capacity – 'Google-ization' of data - DeepMind

Threats

1. Known privacy issues – v the virtues of open data approaches (c.f. Watson and dementia genes)
2. Information beyond 'fingerprint'
3. Citizenship – bio-citizen > 'forensic 'bio-citizen'
4. Routinization – screening, medicine, Government data.

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- State Obligations
- Primary Goods (“Natural and social”)
- Common Goods
 - Individual
 - Collective/s
- Rawls: "certain general conditions that are...equally to everyone's advantage."
- Conditions for flourishing (Sen, Nussbaum)

Possible Primary Goods



Liberty

Health
(care)

Wealth

Justice

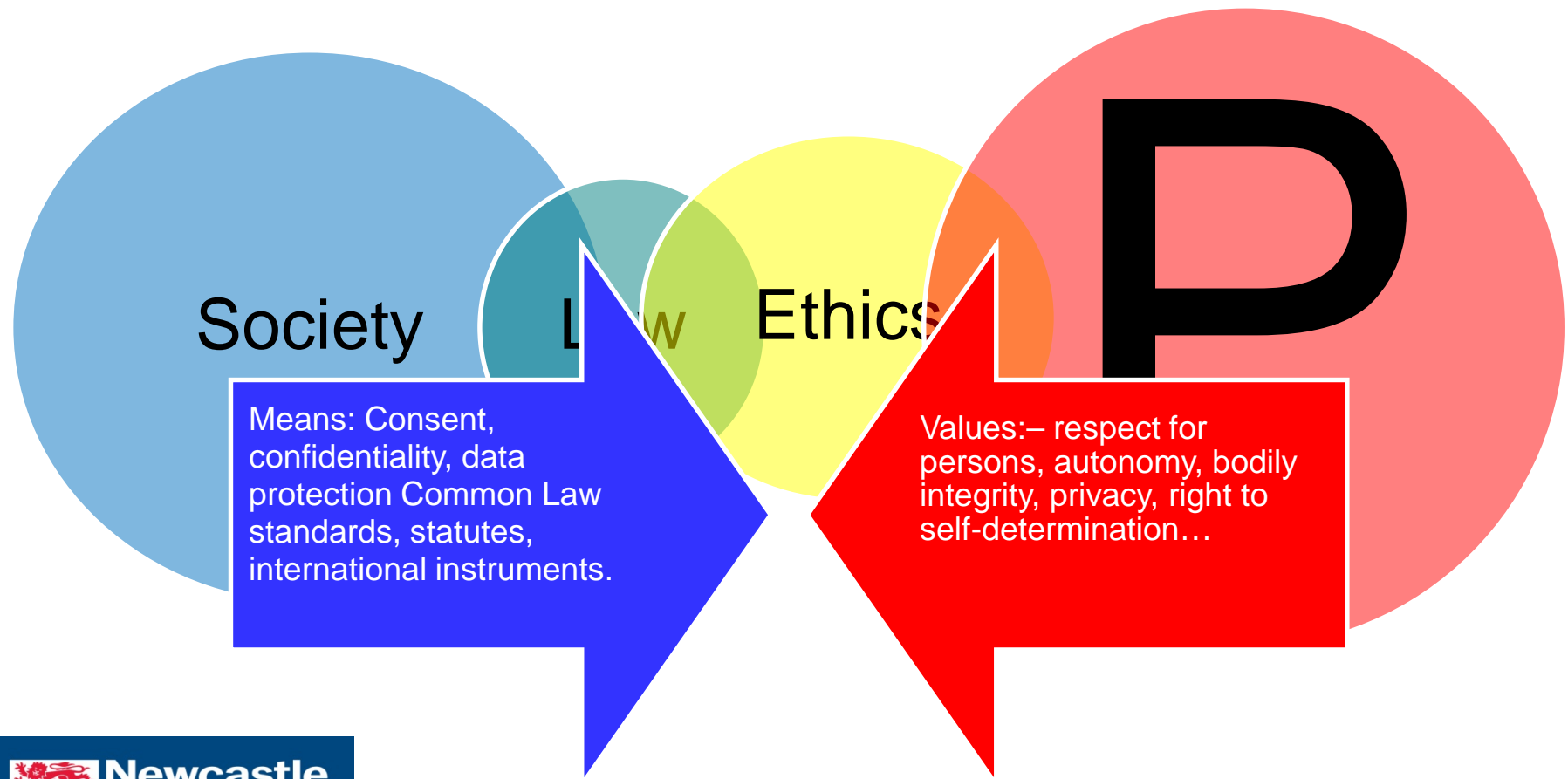
In all its
species

Rawls: Conditions.

- The publicity condition says that the parties are to assume that the principles of justice they choose will be publicly known and recognized as the basis for social cooperation among the people whose relations they organize and regulate. This implies that people will not be uninformed or have false beliefs about the bases of their social and political relations. There are to be no “noble lies” or false ideologies obscuring a society's principles of justice. (Freeman 2014)

Let's consider how justice might
play out in the contexts of
particular common goods e.g.
health

Framing common goods: 1. Clinical care of individual patient.



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Rv Kelly (Scotland) resulted in the criminal prosecution of an HIV infected drug-user for the transmission of HIV to his partner.

“The prosecution of Mr Kelly has also underlined the need for research scientists to anticipate that potentially incriminating results, even in unlabelled studies, may be followed up by forensic requests from individual study participants or by police warrant” (Bird and Brown 2001)

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Public Interests v Private Rights

Police and Criminal Evidence Act 1984 – a **Judge** must weigh the public interest before granting rights of access to confidential data

Statutory Powers

Human Rights Article 8(2)

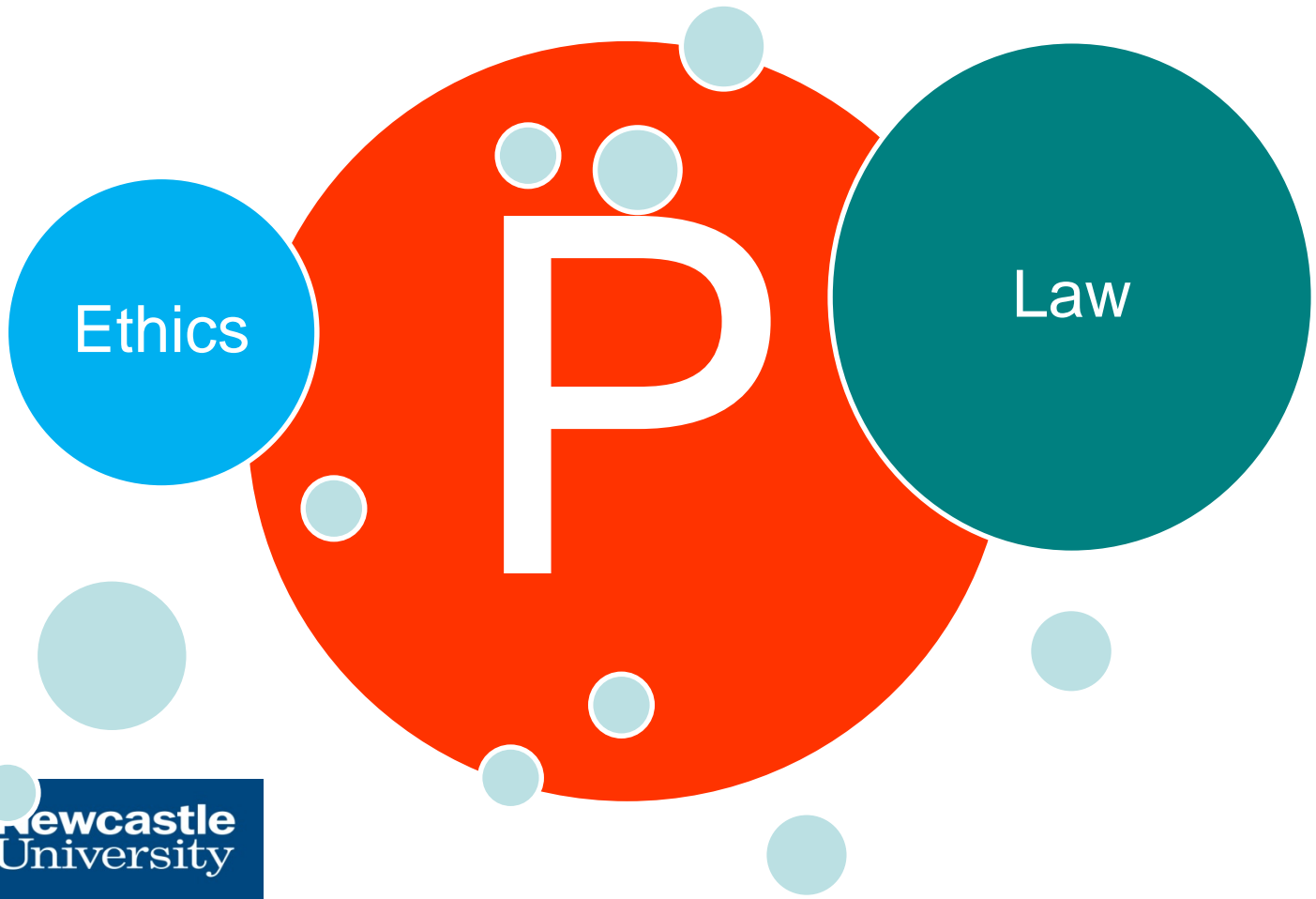
Terrorism Act 2000

The Counter Terrorism and Security Act 2015

The Serious Crimes Act 2015

Disclosure – can only rely on a public interest justification in all but the most extreme cases.

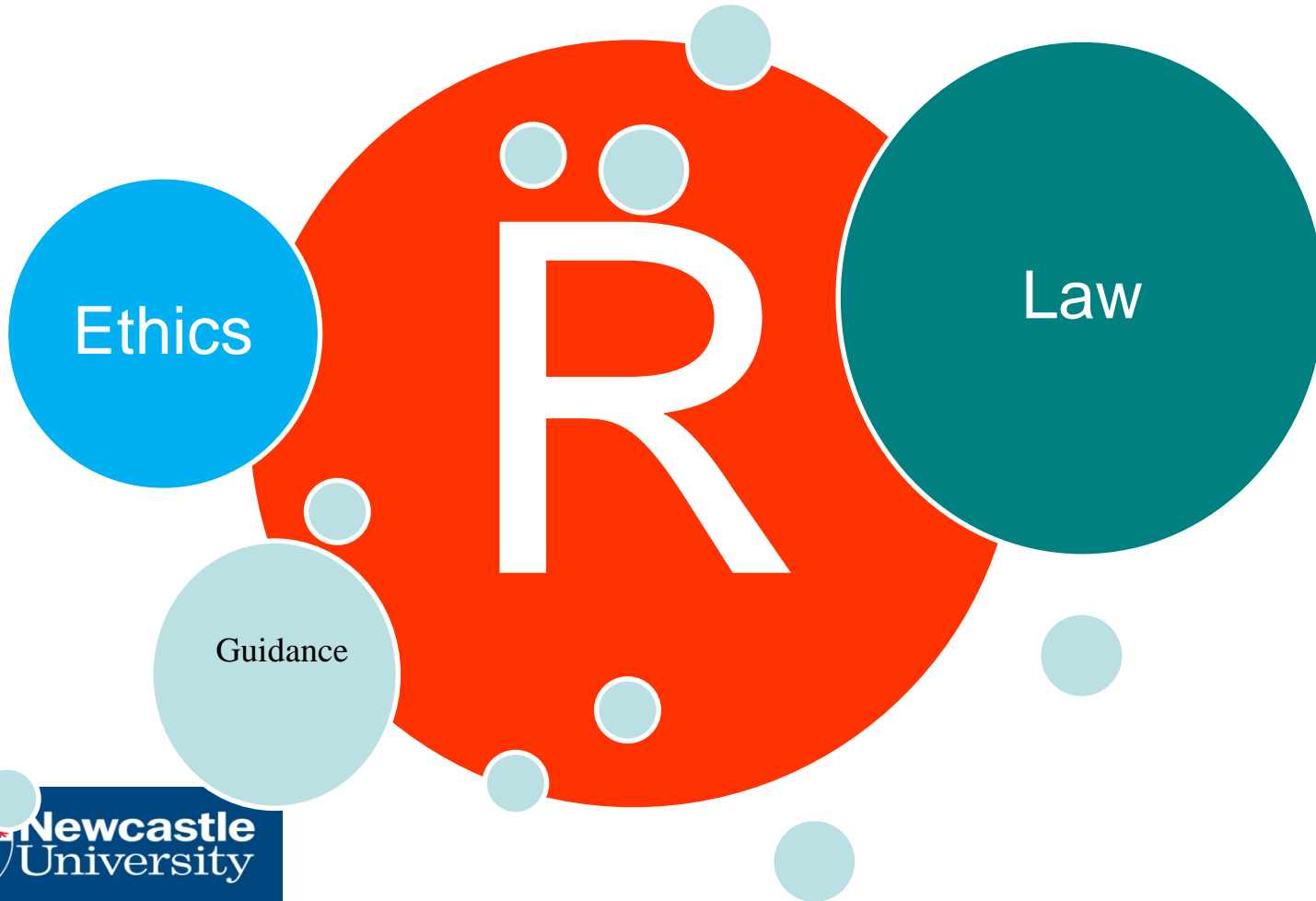
Framing common goods 2: Public Health



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- Public Health (Control of Disease) Act 1984 together with the Public Health (Infectious Disease) Regulations 1988 (England and Wales)
- Health Protection (Notification) Regulations 2010
- a local authority may apply to a justice of the peace for an order compulsorily to remove a person suffering from such a disease to hospital and to detain that person in hospital.
- The Infectious Diseases Act 1988 (Sweden) *Enhorn v Sweden*
- Article 8 – Right to respect for private and family life
 - Everyone has the right to respect for his private and family life, his home and his correspondence.
 - There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

Framing common goods 3: Research



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Interests of science and society (Declaration of Helsinki)

Solidarity: research 'with' not 'on' patients

Respect for persons:

- Autonomy (Individual and collective)
- Consent
- Future interests
- Beneficence (doing good)

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- Broad consent: consent to a range of different kind of conditions:
 - Consent to a particular kind of governance arrangement
 - Undetermined future research
 - A general research programme
 - A broad set of values
 - Some restrictions on the expectations of participants (e.g. general feedback not individual)

Sheehan M. Can Broad Consent be Informed Consent? *Public Health Ethics* (2011) 4 (3): 226-235

Mascalzoni D, Dove E, Rubinstein Y, Dawkins H, Kole A, McCormack P, Woods S, Riess O, Schaefer F, Lochmüller H, Knoppers B, Hansson M. *International Charter of principles for sharing bio-specimens and data. European Journal of Human Genetics* 2014, 1-8.

100K GP Broad consent

- You are agreeing that past medical records (from birth), as well as current and future information about your condition (health data) can be collected by the 100,000 Genomes Project.
- You are agreeing that this information can be studied now and after your death.



Options

P3G Biobank consent form template:

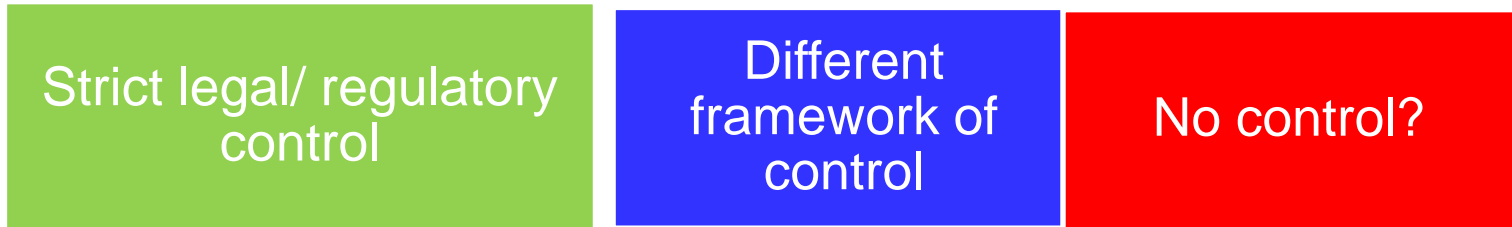
- Unless required by law or a court order, access to this information will not be offered to third parties such as employers, insurance companies or other family members. Only authorized staff members will have access to your information. For requests for access by researchers, they will not be given any information that would allow them to identify you. The utmost care will be taken to ensure the confidentiality of all data.
- Certificates of Confidentiality are issued by the National Institutes of Health (NIH) Under section 301(d) of the Public Health Service Act (42 U.S.C. 241(d)) the Secretary of Health and Human Services may authorize persons engaged in biomedical, behavioral, clinical, or other research to protect the privacy of individuals who are the subjects of that research. This authority has been delegated to the National Institutes of Health (NIH).



‘Open’, ‘Slippery’ and ‘Secret’ contexts of ‘Big Data’

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- Biosurveillance (Wagner et al 2006)
- Post terror state legitimised dramatic expansion of powers (Fearnley 2008)
- Hyper-vigilance (Katz 2008)
- ...'we feel it is inappropriate and unfair for an honest citizen to have their genome forensically inspected even when there is no evidence whatsoever of them having committed a crime' (Stajano et al 2008)





Our vision

Healthcare faces a growing number of challenges worldwide as demand increases on systems already struggling to scale. The NHS

Testimony of Philip R. Zimmermann to the Subcommittee on Science, Technology, and Space of the US Senate Committee on

Lord Justice Sedley (2004) "Going forwards has very serious but manageable implications," he insisted. It means that everybody, guilty or innocent, should expect their DNA to be on file for the absolutely rigorously restricted purpose of crime detection and prevention."

from power. But the wrong technology infrastructure could allow such a future government to watch every move anyone makes to oppose it. It could very well be the last government we ever elect.

DeepMind Health, the building links to heal algorithms for prevent NHS Royal Free Hosp

It's the second agree agreement inked last year, wh request by *New Scientist* reveal flowing from the Royal Free to

and scale technologies that help them provide the best possible care to their patients.



Snowden

Ethically, he frequently, and wisely, asks what kind of society we want to live in. Is it one marked by fear and mutual suspicion, where data are collected promiscuously and kept forever, in systems that never forget, making forgiveness obsolete and creating much to fear even though you have nothing to hide? Is it one where vulnerability is amplified, democracy diminished and where ordinary people are more exposed to organizations that are themselves more opaque? These are questions that Big Data surveillance obliges us to confront. (Lyon 2008)

Concluding thoughts

- Wither ‘solidarity’?
- Use of deliberative methods in governance of forensics?
- Statutory methods to privilege certain data?
- Other?

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Thanks for listening

Quiz

Nothing
to hide

Goebbels?

nothing
to fear?

Orwell ?

Balancing individual

Snowden?

governance and use
of the National DNA
Database

NSA?

A report by the Human
Genetics Commission
November 2009

Harry Potter



Human
Genetics
Commission



I knew perfectly well who those spies were, and allowed one of them to think he was my friend. From first to last I had nothing to hide, and for that reason I had nothing to fear,” (*The Brass Check*. Upton Sinclair 1919, 171)

And in 1918 in *The Profits of Religion: An Essay in Economic Interpretation*:

Not merely was my own mail opened, but the mail of all my relatives and friends—people residing in places as far apart as California and Florida. I recall the bland smile of a government official to whom I complained about this matter: ‘If you have nothing to hide you have nothing to fear.’