

Keeping it real (getting the best out of post-award monitoring & evaluation)

starting premise: post-
award monitoring &
evaluation are important
and valuable

Wellcome Trust

established 1936

funded from private
endowment valued at £13 billion
(July 2010)

independent research-funding
charity - largest charity in UK

annual spend £600 million

interests range from science to
history of medicine



the rationale for monitoring & evaluation

accountability & validation

funding & process monitoring

learning

strategy & planning

policy & advocacy

starting premise: post-award monitoring & evaluation are important and valuable

in practice: post-award monitoring & evaluation of research is challenging

the elusive 'impact'

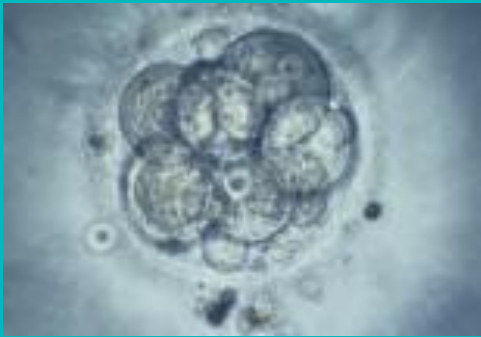
time frame involved

serendipity of science



the long road to discovery

early 1960s



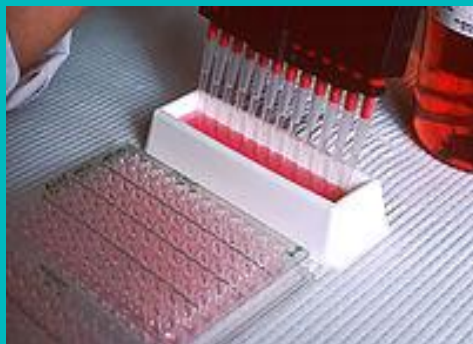
In vitro fertilisation (IVF)

18 years between Robert Edwards first cultivating & maturing human eggs in the lab & first test tube baby being born

1978



early 1970s



Monoclonal antibodies

30 years between Milstein & Kohler manufacturing first monoclonal antibodies & widespread adoption in therapies

early 2000s



"Our discovery of DNA fingerprinting was of course totally accidental ... but at least we had the sense to realise what we had stumbled upon."

**Sir Alec Jeffreys (1950 -)
geneticist**

**inventor of DNA
fingerprinting which has
revolutionised forensic
science & the criminal
justice system**



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attribution & contribution

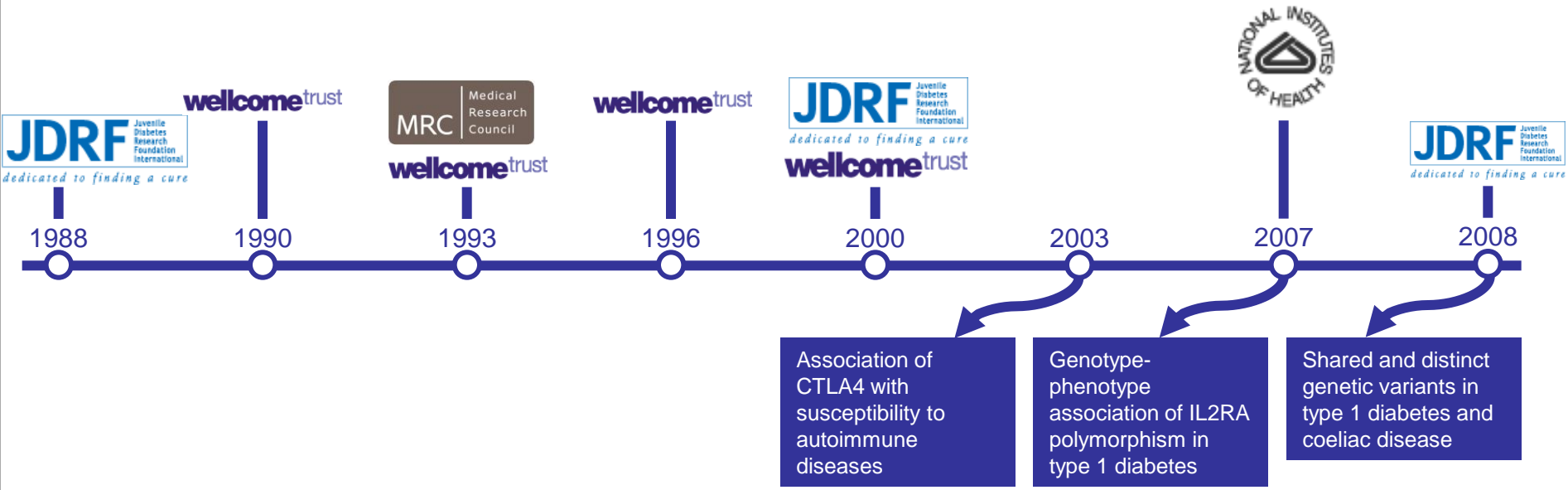
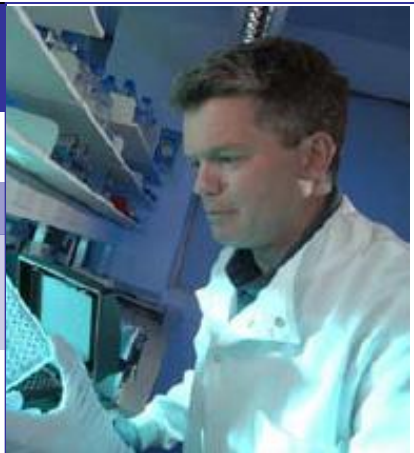


Discovery: a collaborative enterprise

Professor John Todd: the genetics of type 1 diabetes and complex genetic diseases

Understanding type 1 diabetes

Type 1 diabetes is caused by the interaction of multiple genetic and environmental factors that result in the immune system destroying the insulin-producing beta cells in the pancreas. To study how type 1 diabetes develops, Professor Todd maps susceptible regions of the human genome and then attempts to identify specific genes in these regions.



Salaried by various

the elusive 'impact'

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'ripple effects'

counter-factual

value of negative findings



" If you're sufficiently far ahead of the field, you don't get any support. I remember what Professor Borst in Amsterdam said when he heard that I was going to work on a heart/lung machine. He said,

***'But Mr. Kolff, this is impossible! If something is impossible, these guys in the NIH are not going to give you high grades for your grant proposals, and no money'.*"**

**Willem Kolff, quoted in 2008
(1911-2009)**

pioneer in field of artificial organs



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**do we measure what counts
or count what we can
measure?**

counter-factual

value of negative findings



Keeping it real

understand stakeholder questions & interest

different players: different drivers

government

promote research

efficiencies

national perspective

improve health & quality of life

contribute to wealth of nation

industry

develop new profitable drugs & treatments

dividends for shareholders

not-for-profit/charity
sector

promote research

improve health & quality of life

tackle disease X

Monitoring progress: key indicators

Outcomes	Key indicators of progress
Discoveries	<ol style="list-style-type: none">1. significant advances in the generation of new knowledge2. contribute to discoveries with tangible impacts on health
Applications	<ol style="list-style-type: none">3. contribute to the development of enabling technologies, products and devices4. uptake of research into policy and practice
Engagement	<ol style="list-style-type: none">5. enhanced level of informed debate in biomedicine6. significant engagement of key audiences & increased reach
Research leaders	<ol style="list-style-type: none">7. develop a cadre of research leaders8. evidence of significant career progression among those we support
Research environment	<ol style="list-style-type: none">9. key contributions to the creation, development and maintenance of major research resources10. contributions to the growth of centres of excellence
Influence	<ol style="list-style-type: none">11. significant impact on science funding & policy developments12. significant impact on global research priorities and processes

Keeping it real

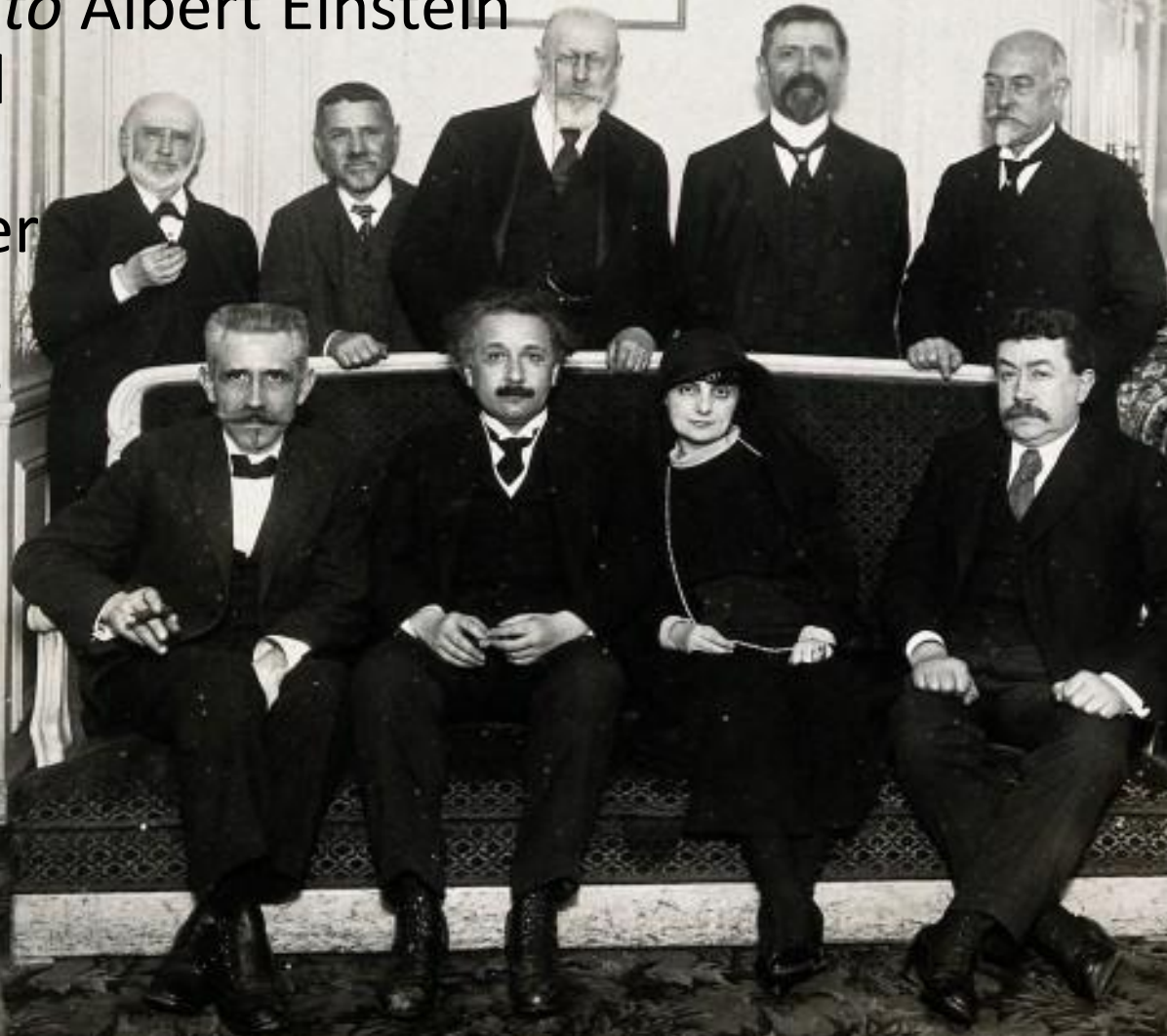
understand stakeholder questions & interest

ensure access to key information

- **integrated into funding from start**
- **prospective**
- **options for core/common data sets**
- **consistency**
- **value of qualitative data**

“Not everything that counts can be counted, and not everything that can be counted counts.”

attributed to Albert Einstein
theoretical
physicist,
philosopher
& author
1879-1955



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role of subject-experts in post-award evaluation

1868 Mendel publishes his work on inheritance

1900 Human blood groups described

1915 Hunt Morgan describes linkage and recombination

1952 Development of protein sequencing

1955 First autosomal disease gene linkage

1956 Genetic mutation underlying sickle-cell anaemia is identified

1959 Down's syndrome characterised

1968 First gene mapped to an autosome

1973 First Human Gene Mapping workshop

1974 Identification of the first human gene deletion as a cause of disease in α -thalassaemia

1977 'Dideoxy' DNA sequencing first DNA genome is decoded

1981 Human mitochondrial DNA sequence completed

1983 Huntington's disease: first disease gene mapped

1986 First positional cloning of disease gene (DMG)

1988 Office of Human Genome Research created in NIH (later becomes NHGRI)

1989 DNA is discovered

1990 Avon Longitudinal Study of Parents and Children (ALSPAC) inception

1991 Sanger Centre established

1992 First genome of a free-living organism sequenced (*Haemophilus influenzae*)

1993 Microsatellite map of human genome

1995 Patrick Brown demonstrates DNA chips

1998 Nematode worm sequence published

2000 Working draft of human genome announced by HGP and Celera

2002 Draft sequence of the mouse genome published

2004 Chicken and rat genomes published

2006 Copy number variation of human genome described

2008 1000 Genomes Project launched

2010 'UK10K' - new project to identify the links between both rare and common variation related to human disease

1911 ABO blood group inheritance discovered

1924 Blood group inheritance characterised

1963 The structure of DNA is described

1966 Human chromosome number is determined

1966 First edition of Mendelian Inheritance in Man

1972 First recombinant DNA molecules produced

1975 Southern blotting developed

1978 The first DNA prenatal diagnosis of genetic disease (sickle-cell anaemia)

1982 GenBank database formed

1984 DNA fingerprinting developed

1985 Physical map of nematode developed

1985 Genomic imprinting described

1988 NIH and Department of Energy coordinating memorandum

1989 US National Center for Biotechnology Information established

1989 Cystic fibrosis gene identified

1990 Human Genome Organisation formed

Landmarks in human genetics

1990 Human Genome Project begins with initial five-year plan

1993 MicroRNAs (miRNA) first described

1993 Discovery of *SFY* gene for sex determination

1993 Discovery of *BRCA1* mutation (*BRCA2* mutation discovered 1995)

1996 First sequence of large complex organism, *Saccharomyces cerevisiae* (brewer's yeast)

1996 Bermuda Meeting of human genome scientists agree data-sharing principles

1996 European Bioinformatics Institute opens (at the Wellcome Trust Genome Campus)

1999 First complete human chromosome sequence (no. 22)

2001 Draft sequences of human genome published

2001 SNP Consortium maps genome variation

2003 'Gold standard' human genome sequence is completed

2005 Publication of first draft of human haplotype map - genotyping of 1.1 million SNPs across four populations

2005 Chimp genome published

2005 Wellcome Trust Case Control Consortium established (WTCCC)

2007 Publication of largest genome-wide association study of common diseases (WTCCC)

2007 ENCODE publication: new insights into genome function

2007 Human Induced pluripotent stem cells produced

2009 23andMe launches collaborative Parkinson's disease research initiative

2009 Identification of two complete cancer genomes - malignant melanoma and small cell lung cancer

2001 Structural Genomics Consortium launched

2001 ENCODE project launched by NHGRI

2005 Launch of DeCODEme and 23andMe

2009 Launch of DeCODEme and 23andMe

KEY
 Scientific advance
 Funding development
 Policy development

Portraits
 1868: Gregor Johann Mendel
 1869: Johann Friedrich Miescher
 1952: Fred Sanger
 1972: Sir Walter Bodmer
 1985: Sir John Sulston

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role of subject-experts in post-award evaluation

be proportionate & practical

- **beware over-evaluation !**
- **manage the burden of reporting**
- **avoid perverse incentives**

starting premise: post-award monitoring & evaluation are important and valuable

in practice: post-award monitoring & evaluation of research is challenging

conclusion: post-award monitoring & evaluation needs to reflect the realities of what's being evaluated and who is asking the questions

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