

Accessing patient data

A personal view, Paul Affleck

My background

- Trained as an adult nurse in Kent
- Worked as a research nurse in London and Leeds
- Currently manage the UK Colorectal Cancer Intelligence Hub
- Member of the Ministry of Defence Research Ethics Committee
- Member of the Independent Group Advising on the Release of Data
- Ethics 'Expert' for Horizon 2020

Data mountains and types of use

- Transition from paper to electronic records
 - New opportunities/dangers
- How might it be used?
 - Direct care
 - Service provision
 - Commissioning
 - Audit
 - Service evaluation
 - Research

Research journey

- Idea
- Funding application
- Other applications
 - Research Ethics Committee, Confidentiality Advisory Group, Data provider application (NHS Digital, Public Health England, Office for National Statistics, Information Services Division of National Services Scotland, Business Services Organisation in Northern Ireland, etc.)
- Analyse and interpret
- Amendments
- Dissemination, final reports

SPOILER ALERT: **Patients can make a difference at every step.**

Why can the process take many months/years?

Law and policy is complicated:

- Common law duty of confidentiality
- UK General Data Protection Regulation
- The Mental Capacity Act 2005
- Statistics and Registration Service Act 2007
- UK Clinical Trials Regulations
- The Health Service (Control of Patient Information) Regulations 2002
- The Care Act 2014
- Health and Social Care Act 2012
- The National Data Opt-out policy

Why can the process take months/years?

Data providers have competing demands in terms of maintaining public confidence, safeguarding confidentiality and enabling research.

There are multiple application steps and not all bodies may agree on interpretation of the law/policy/guidance.

Some data applicants have more institutional support than others.

Final points

Patients can make a difference at every step of the research journey.

Funding bodies and Research Ethics Committees need patient/public members.

The Independent Group Advising on the Release of Data is planning to recruit later this year.