Using health data for research

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Aims

Outline a researcher's journey when using data

Provide an overview of how health research is governed

Highlight some of the bottlenecks

Public involvement

What approvals are needed?

1. Research Approvals

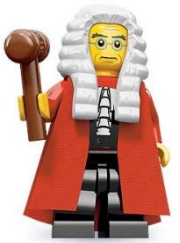
- Local approval
- Research Ethics Committee
- *Others*

2. Data approvals

- Data providers

Local approval: Sponsorship

- The sponsor is the organisation that takes on responsibility for confirming there are proper arrangements to **initiate**, **manage** and **monitor**, and **finance** a study
- A UK Policy requirement for research organisations
- Varying levels of researcher support available



Research Ethics Committee approval

- Looking after the safety, rights, dignity, well-being of research participants, their data, tissue
- **NHS:** single application system (IRAS)
- **Non-NHS:** various processes

Legal Avenues

- Use of confidential patient information requires a legal avenue
- Can be consent to share / provide access
- When consent isn't possible?

Confidentiality Advisory Group and Section 251

- Applications (England and Wales) reviewed by The Confidentiality Advisory Group
- Independent group of people acting under legislation
- Review about 60 applications a year; via a single system: IRAS
- Difficult approval to obtain

Scotland: Caldicott Guardian or Health and Social Care Public Benefit and Privacy Panel

- Data from a Single Board: Caldicott
- Data from multiple Boards: HSC PBPP
- Can approve if in the '*Substantial Public Interest*'
- Standalone application system
- HSC PBPP also give governance approvals, irrespective of legal avenues

Northern Ireland

- Currently, common law i.e. can approve if in the ‘Substantial Public Interest’

- Moving towards using The Health and Social (Control of Data Processing) Act i.e. legislation akin to Section 251

- Standalone application system

What approvals are needed?

Data approvals

- GP Practice (Caldicott)
- NHS Trust / Board (Caldicott)
- NHS Digital (IGARD)
- Clinical Practice Research Datalink (ISAC)
- Public Health England (ODR)
- Secure Anonymised Information Linkage Databank (IGRP)
- Public Health Scotland (HSC PBPP)
- Honest Broker Service (HBGB)

Approvals summary

- Work out what approvals are needed?
- What order to apply?
- Align all the approvals

Data access

- Time
- Money
- Data Sharing Agreement

Research

- Analyse the data
- Changes?
- Publish
- Delete / anonymise / store / deposit / share

Summary

- Heavily regulated environment
- Coordination of approvals
- Awareness of the environment

Questions?