An independent taskforce to improve conversations about patient data

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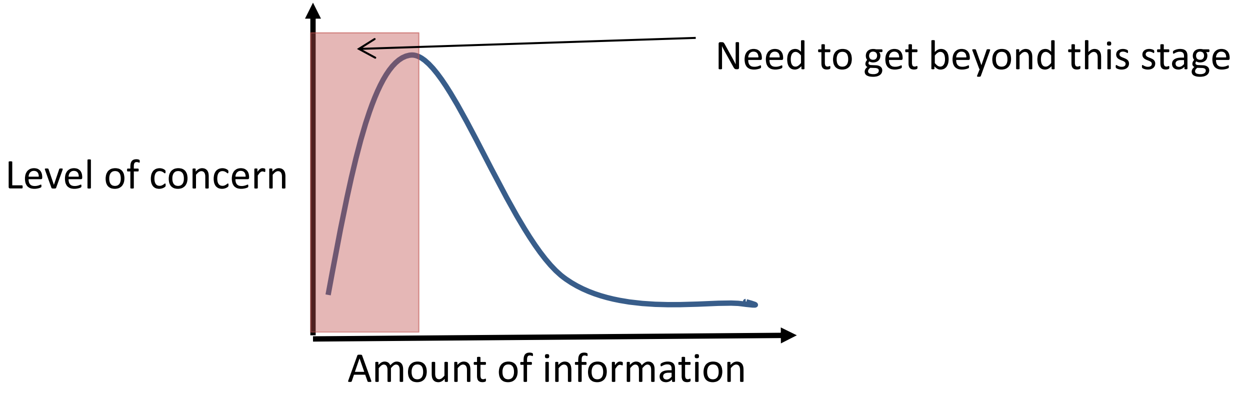
Context

- NDG Review: Call for a full conversation about how data is used in the NHS.
- Currently low awareness (Wellcome commercial access report):
  - 33% feel they have good awareness of how data is used in the NHS
  - 18% aware of academic uses; 16% for commercial use
- Broadly, more information leads to greater acceptance of wider uses of data
  - But, a little information can lead to greater wariness



Aims

- Taskforce will aim to improve the conversations about data use at a national level:
    - Consistent, clear, accurate, accessible language
    - Toolkits to improve quality of information
    - How to talk about public benefit
    - Co-ordinating range of existing initiatives
- Ways of working:
    - Practical, ongoing outputs
    - Not a fixed panel of experts
    - Series of champions to represent different work streams
    - Broad ownership and engagement

Stakeholder engagement

Funding from:

wellcome

MRC Medical Research Council

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

Department of Health

Supported by:

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UK CLINICAL RESEARCH COLLABORATION

Involve, National Voices, Genetic Alliance, Rare Diseases UK,
Arthritis Research UK, Macmillan, BHF, MQ, Richmond Group,
Genomics England, CPRD, Science Media Centre, Public Health England
Information Governance Alliance, NHS Digital, NHS England, NDG Office, NIHR

Planned work streams

Social attitudes/ public engagement

Policy and governance to build public confidence

Resources & tools for conversations

- Vocabulary
- Bank of case studies
- Analysis of ‘public benefit’

Stakeholder engagement

- Clinicians/HCPs
- Media
- Patients
- Researchers
- Policy makers
- Parliamentarians
- Industry

Forward look

- Emerging digital tech (apps, wearables, new data uses)
- Data linkage