Using Administrative Data In Research: Learning from the Public Dialogues

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My personal experience

• Coming down from the ivory tower
• Generalised anxiety
• Reassurances: what resonates, what doesn’t
• Unlocking the truth or opening a can of worms?
Key Takeaway Lessons

• Transparency, transparency, transparency
• Independence from government is good
• De-identification and linkage procedures are very important
• Virulent opposition to commercial usage
• Public benefit must be clear
• Understandable but accurate messages are hard
Changing Landscape

• Care.data
  • Talk to other services before acting
• HSCIC
  • Have your back office in order
• HMRC
  • Consult your potential opponents as well as your friends
• The can will be opened
Implementation of Lessons Learned

• Publication of all business:
  • access requests, plain English research summaries, disciplinary actions, code/syntax, Board meeting minutes, etc

• Governing Board convened by UK Stats Authority

• Standardisation of split-site linkage, data handling, security

• Absolutely no commercial projects
Implementation of Lessons Learned

- Independent Approvals Panel criteria:
  - **Necessity** (question can’t be answered by less sensitive data, or use another service)
  - **Feasibility** (question can be answered by data/methods proposed)
  - **Scientific Merit** (question worth spending resources to answer)
  - **Privacy** issues assessed and mitigated
  - Formal **Ethics** Review has been passed
  - **Demonstrable Potential Public Benefit**
Implementation of Lessons Learned

- Involve public in decision-making
  - Lay members on Governing Board
- Consultation, not fait accompli
  - Beta-test period
- Talk to potential opponents
  - Engaging with activists
- Be prepared for intense scrutiny & spin
Questions?

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