



Using Administrative Data In Research: Learning from the Public Dialogues

Melanie Wright, ADRN
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Administrative Data
Research Network

An ESRC Data
Investment

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?

Melanie Wright
melanie@essex.ac.uk

