

Using Administrative Data In Research: Learning from the Public Dialogues

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14 July 2014



Administrative Data
Research Network

An ESRC Data
Investment

Public Dialogue

“Public Dialogue brings together members of the public, policy makers, scientists and other expert stakeholders to deliberate and come to conclusions on national public policy issues involving science and technology”



Public Dialogues on Data

- Commissioned Ipsos Mori
- Events in Manchester, London, Stirling, Cardiff, Wrexham, King's Lynn and Belfast
- Cross-section of public recruited
- Two day-long sessions Oct/Nov 2013 exploring range of issues around admin data sharing
- Report available at <http://www.esrc.ac.uk/public-engagement/public-dialogues.aspx>





- Wide geographic spread, covering all of the UK
 - Wales (Cardiff and Wrexham)
 - Northern Ireland (Belfast)
 - Scotland (Stirling)
 - England (Manchester, London, King's Lynn)
- 18-20 participants per workshop, reflecting a range of criteria
 - Age
 - Gender
 - Ethnicity
 - Social grade
 - Attitudes (trust in researchers, views on uses of data)
- Included age specific workshops in:
 - Cardiff (all over 55)
 - King's Lynn (all under 35)



Aims of the Dialogues

- to better understand people's views on the linking of administrative data
- to begin the process of creating a terminology describing the re-use of admin data and data linking that is understandable to the general public
- to help inform the development of the governance and operational procedures that the ADRN will adopt and provide data on public attitudes for the ADRN to inform our future strategies and priorities for public engagement



Findings

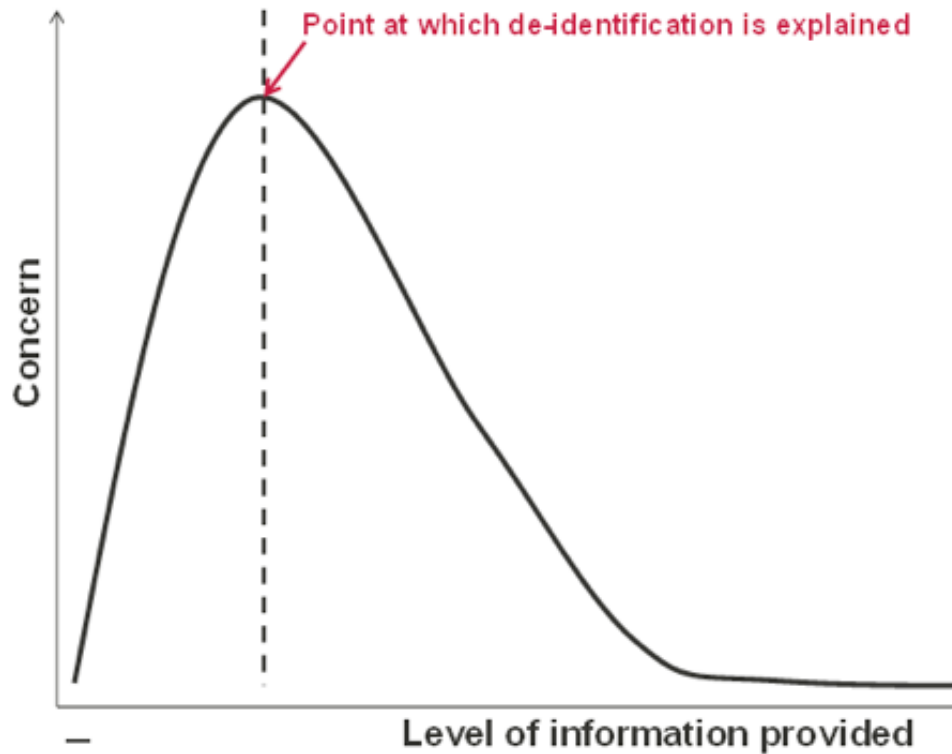
- Value of social research
- Assumptions about current data linkage
- Difficulty in explaining de-identification
- Difficulty in explaining linkage



Concerns	Reassurance points	Remaining questions
<ul style="list-style-type: none"> ❖ De-identification – will it be possible to identify people even without their ‘personal details’ ❖ De-identification process – is this secure? Where does the personal data ‘go’? ❖ Security – is it possible to hack? Does that even matter? ❖ Cost – is this £34 million well spent? 	<ul style="list-style-type: none"> ✓ ADRCs’ independence ✓ Data could improve public services or allocate funding better ✓ Efficiency – Save money, or reduce data collection burden ✓ Better regulation than current system ✓ No ‘super-database’ ✓ Limitations on researchers 	<ul style="list-style-type: none"> ? Can this improve operational use of administrative data? ? How much have government departments ‘bought in’ to this idea? ? Who works for the ADS and how are they governed? ? What will be the punishment for any misuse of data by researchers?



Participants recognised a pattern in their own reactions to ADRN plans...



But split on comms implications...

Tell people nothing

- It's just too complicated
- Might panic people unnecessarily
- Telling everyone would be costly

BUT

- This could lead to suspicion
- Some will be interested, and understand

Therefore

- Be as transparent as possible
- Keep active comms minimal, but stress the messages of de-identification, security, benefits



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
- Strong opposition to commercial usage
- Public benefit must be clear
- Understandable but accurate messages are hard



Changing Landscape

- Care.data
 - Talk to other services
- 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:
 - Policies, procedures, 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

- 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 answering)
 - **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 ADRN Board, Approvals Panel
- Consultation, not fait accompli
 - Beta-test period
- Talk to those with concerns
 - Engaging with activists
- Be prepared for intense scrutiny & spin

