Three questions…

1. Why does it take so long to get access to data?

2. Will all my problems be solved if I get consent or anonymise data?

3. What else can I do to streamline access to data?
Three answers…

1. **Reality:** Culture of caution surrounding the use and sharing of administrative data (not just for research).

2. **Myth:** Key barriers are legal (no, they are multiple and largely cultural).

3. **Reality:** Focus on your research impact but broadly (including the data controller, specific publics and society).

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Reality: Pressure to share and protect data

- Increased calls to share/link data across sectors in health, education, benefits, housing, criminal justice, social care (for research, health and social care integration)
- Legal obligations to retain/share data e.g. Freedom of Information obligations, open data initiatives, official evidence gathering/inquiries…
- Regulatory pressure and uncertainty, forthcoming General Data Protection Regulation (c. 2018) and Brexit…
Reality: A mixed (and complex) legal landscape

- Administrative Law
- Data Protection Law
- Human Rights Law
- Common Law Duties of Confidentiality
- Freedom of information law
- Data sharing gateways
- Data Protection Act 1998
- General Data Protection Regulation (2018)
- But Brexit…

Reality: A culture of caution

Pressures + legal complexities fuels the current culture of caution.

The culture of caution is further perpetuated by:

- **Resources** lacking
- (Mis)perceived **controversies** and **risk**
- **Incentives** & **disincentives** to use/share data unclear
- Data ‘**ownership**’ complex
Reality: The impact on researchers

- ‘Get consent or you can’t access this data!’
- Months (sometimes years) of approvals…(oh the forms!)
- Opaque decision-making on the ‘how’, ‘when’ and ‘why’ of data access
- Delays, altering research…or even worse, abandonment

Myth: Law is the key barrier

- ‘We cannot disclose the requested data for data protection reasons.’
- Fundamental misperceptions of:
  - Legal requirements to share & use data
    - REALITY: Legal complexity ≠ impermissibility
    - REALITY: Consent or anonymise = ‘safe option’
  - The purpose of data protection legislation
    - REALITY: Facilitate use of data AND protect data
Myth: To use personal data for research you must…

- Get consent or anonymise data BUT…

- Consent is neither necessary nor sufficient…
  - But communication and engagement are essential

- Anonymisation is a technical and not an ethical solution…

Recap…

1. Why does it take so long to get access to data?
   IT’S COMPLICATED!
   Resources, potential for controversy, unclear incentives to share (how does this research benefit my organisation/service users?)

2. Will all my problems be solved if I get consent or anonymise?
   SHORT ANSWER – NO!

So what else can I do?
See the differences…

Data controller
Resources
Operational priorities
Perceived risk of sharing
What’s in this for us?!

Understand incentives/disincentives

Funding
Delays
How many more forms?!

Researcher

Account for differing perspectives

<table>
<thead>
<tr>
<th>Data controller concern</th>
<th>Researcher concern</th>
<th>Consider…</th>
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| < Resources             | Funding deadlines, timing, delays | • Start the access process early!  
                          |                    | • How does my research align with (or run counter to) the policy objectives of the data controller?  
                          |                    | • Narrow down research questions: no fishing expeditions! |
| Concerns over liability | Academic objectivity | • What risks are posed by my research to the data controller? To their service users? To the wider public? |
| Reputational damage and public backlash | Impact | • What are the potential benefits from my research? To the data controller? Their service users? Society?  
                          |                    | • What are the potential harms from not being able to do my research? |
Research impact

Who will benefit?
What are the risks to particular publics or the data controller?
What is the harm from not doing the research?

THANK YOU

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