



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

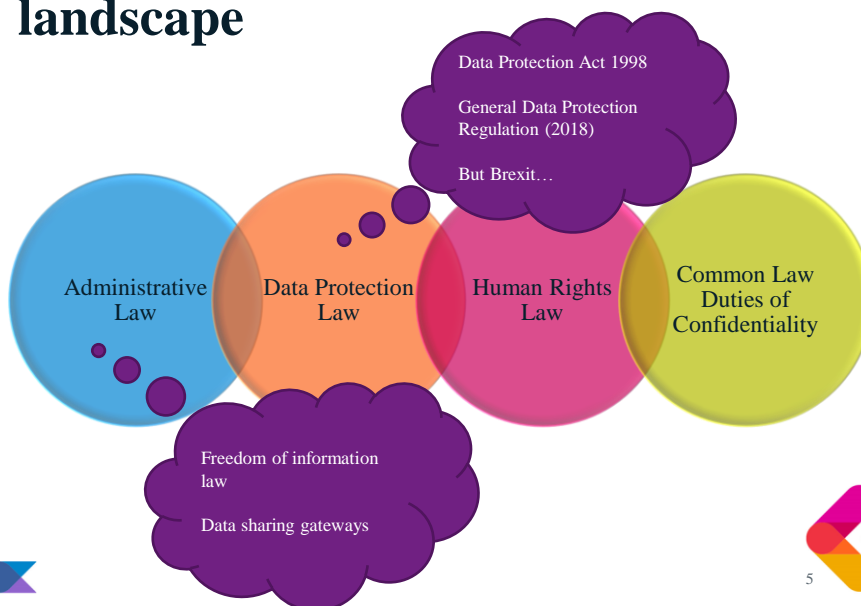
- ▶ Increased calls to share/link data across sectors in health, education, benefits, housing, criminal justice, social care (for research, health and social care integration)
- ▶ Legal obligations to retain/share data e.g. Freedom of Information obligations, open data initiatives, official evidence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



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Reality: A mixed (and complex) legal landscape



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



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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**



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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 \neq impermissibility
 - ▼ REALITY: Consent or anonymise = ‘safe option’
 - ▷ The purpose of data protection legislation
 - ▼ REALITY: Facilitate use of data AND protect data



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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...



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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!

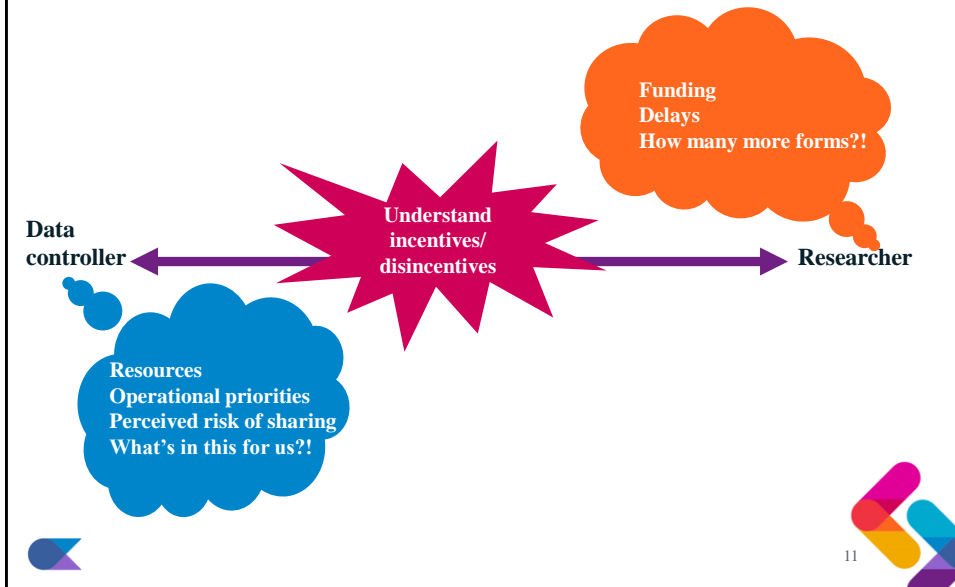
So what else can I do?



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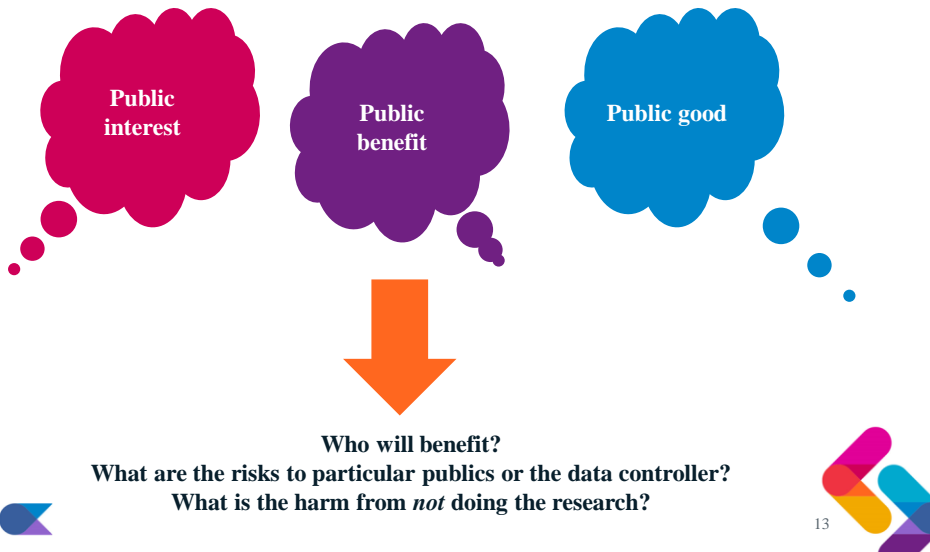
See the differences...



Account for differing perspectives

Data controller concern	Researcher concern	Consider...
< Resources	Funding deadlines, timing, delays	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> What are the potential benefits from my research? To the data controller? Their service users? Society? What are the potential harms from <i>not</i> being able to do my research?

Research impact



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THANK YOU