Better Knowledge
Better Society

Myths and Realities of Public Sector Information Governance – Moving Beyond a Culture of Caution to a Culture of Confidence

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Three things…

1. **Reality: <u>Culture of caution</u>** surrounding public records/data

2. **Myth:** Key barriers are **<u>not</u>** legal but **<u>cultural</u>**

3. **Reality:** Public sector data are **<u>public resources</u>** - need practical tools to support good information governance

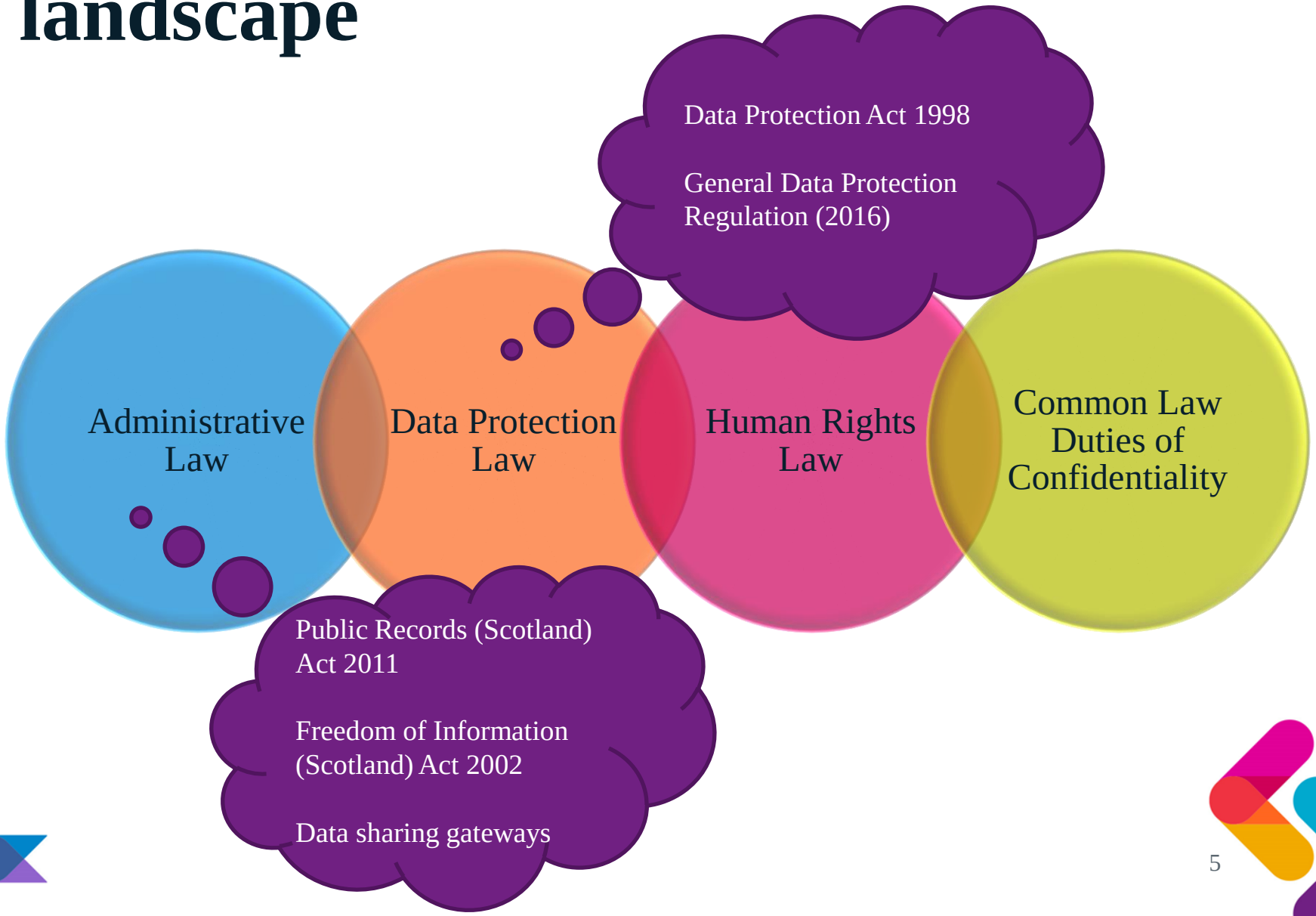
Reality – increasing demands for public sector data

- Increased calls to share/link data across sectors – health, education, benefits, housing, criminal justice, social care (for research, health and social care integration)
- Legal obligations to retain/share data e.g. The Scottish Child Abuse Inquiry; FOI obligations; open data initiatives…
- Regulatory pressure for good records management and information governance e.g. Public Records (Scotland) Act 2011, forthcoming General Data Protection Regulation (c. 2018)

Myth: law is the key barrier

- "We cannot disclose the requested data for data protection reasons."
- Fundamental misperceptions of
  - Legal requirements
    - REALITY: Legal complexity ≠ impermissibility
    - REALITY: Ownership and (individual) liability over decisions
    - REALITY: Questions over data quality
  - The purpose of data protection legislation
    - REALITY: Facilitate AND protect the use of personal data

Reality: a mixed (and complex) legal landscape



Examples of legal myths – the Data Protection Act 1998

- **CONSENT or ANONYMISATION ARE THE ONLY WAY** however…

- Consent is neither *necessary* nor *sufficient*…

- Anonymisation is a technical and *not* an ethical solution…

Reality: the culture of caution

Legal complexities fuel legal myths and thus the current **culture of caution**

- (Mis)perceived **controversies** and **risk**
- **Resources** lacking
- **Incentives** & **disincentives** to use/share data unclear
- Data '**Ownership**' complex

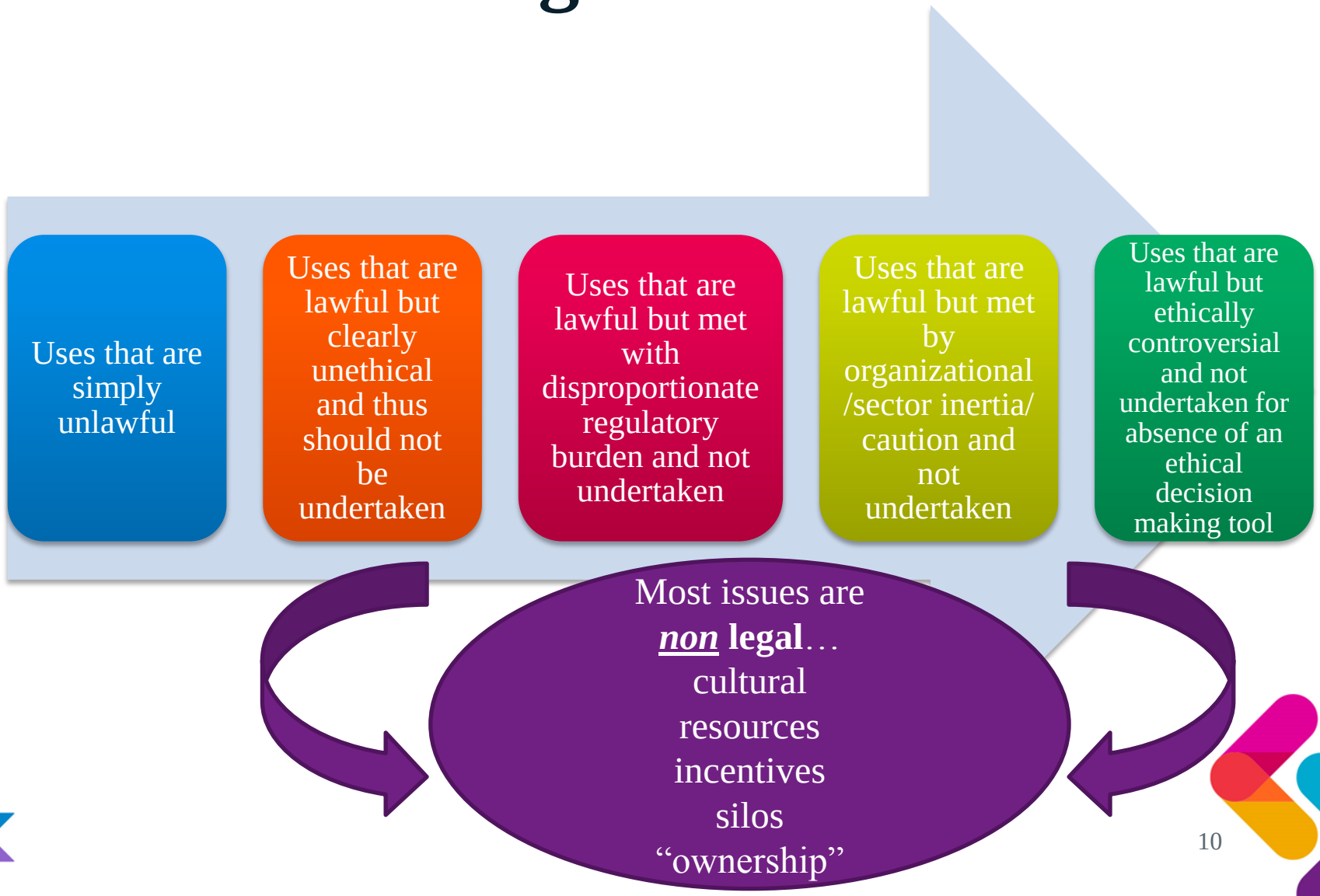
Solutions?

- Where are solution(s) to be found?
  - More law/less law?
  - More rules/fewer rules?
  - Clearer direction from above/more action on the ground?

Identify and distinguish between real versus perceived barriers

- Legal uncertainty has resulted in cautious, risk-averse decision-making
- First critical step is to identify and distinguish between real versus *perceived* barriers
  - Legal – complexity and uncertainty versus legal prohibition
  - Ethical – unclear public interest benefits, novel use of data
  - Regulatory – excess red tape, disproportionate effort versus actual/potential risks posed
  - Institutional/organisational – resources, incentives lacking, silo-working (*culture of caution*)

Administrative Data Decision-making Matrix



Solution? Developing a public interest mandate for public sector data

Identify level of data readiness

Deploy decision making matrix

Commit to the public interest

Consider and justify what is the public interest in context

Meaningful public engagement

Reflect on whether there is social licence for sharing

Proportionality

Assess and manage risks and benefits as they relate to each other

Uncertainty

Keep arrangements and public interest under regular review

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THANK YOU

Whither consent?

- **Consent?** informed, broad, open, blanket, generic, specific, explicit, appropriate, valid and written…

- **Clinical Trials Directive 2001/20/EC (Art 2(j))**: written and informed consent

- **Clinical Trials Regulation 536/2014 (Art 29)**: written, free and voluntary expression of their will to participate, informed of all aspects of the trial relevant to their decision to participate
  - Comprehensive
  - Concise
  - Understandable to a layperson

Re-use of Clinical Trials Data for Research

Principles

- **Re-identification possible:** Mechanisms for permitting re-identification by the principal data source - important for pharmacovigilance
- **Transparent contact arrangements:** The specific circumstances and conditions governing whether or not patients involved in clinical trials can be contacted and by whom, should be clearly set in place in transparent policies.
- **Prior and specific consent to re-contact**: Researchers should only re-contact participants as to information arising from a clinical trial in which they took part where prior consent to be re-contacted for specific purposes has been obtained

Best practice

- **Re-use only with consent:** It may be desirable and permissible to link with clinical trials data for research; however this should only occur where patients have given explicit consent for extra information about them to be gathered by the researcher
- **Re-contact through an intermediary** i.e. the original data source, and request that they contact or arrange for contact with participants