

Bottom-up **data Trusts**

doi: [10.1093/idpl/ipz014](https://doi.org/10.1093/idpl/ipz014)

S. Delacroix and N. Lawrence

Data ownership is unlikely to provide
the level of control wished for.

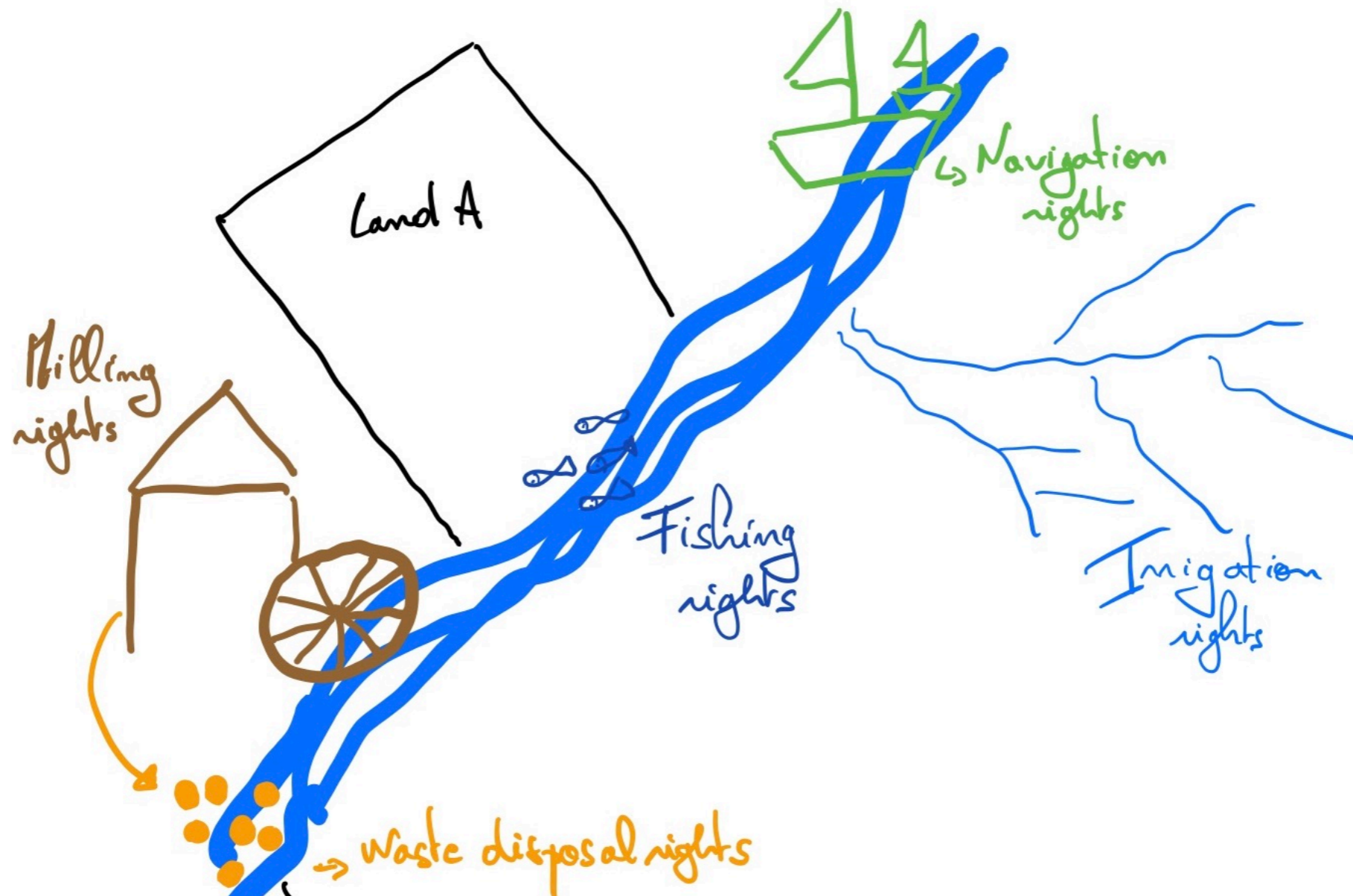
It is also a poor answer to the type of
problems (and vulnerabilities) at stake.

Because of the discovery of:



Framing in terms of ownership

Is Data like a river?



To 'own' a river is to have non-exclusive rights (and obligations)

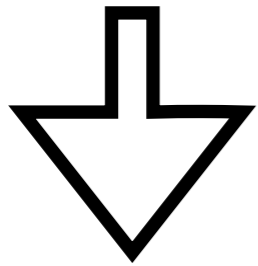
Letter: Legal instruments exist to empower us, the data subjects

From Sylvie Delacroix and Neil Lawrence, The Alan Turing Institute



19th Century Land Societies

Pooling resources



Right to vote

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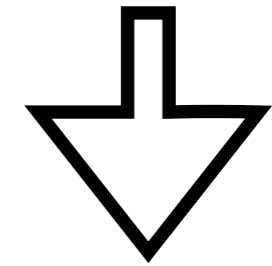
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21st Century Data Trusts

Pooling data



Political
&
Economic
Empowerment

Data Trusts = Remedy to:

- Lack of tool enabling long-term **collective** action
- Data **consent** rarely more than ‘make believe’
- Lack of governance that **removes obstacles** to the research potential underlying datasets

Data Trustees

- *Fiduciary* obligation of undivided loyalty
- *Intermediary layer* between data subjects and data controllers

21st-century profession?

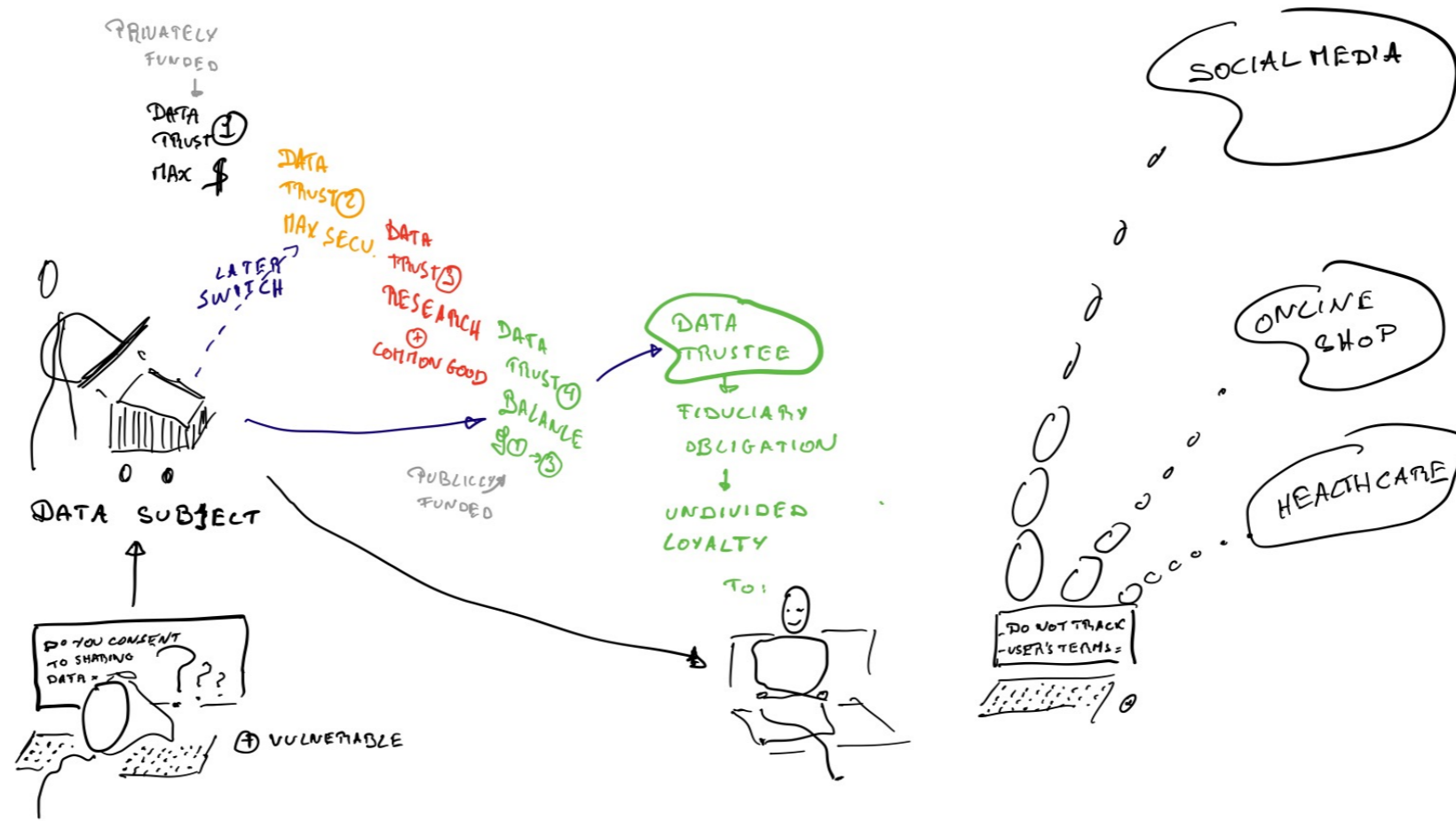
- 19th Century: advances in medic.Sc. called for birth of medical profession.
- Today: advances in data science call for Data Trustees

Holding data rights under a Legal Trust

Implementation Models

- Participatory governance v. Hands-off delegation
- Centralised v. Decentralised

Challenging the one size-fits-all approach



Reversing direction of consent

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Two challenges

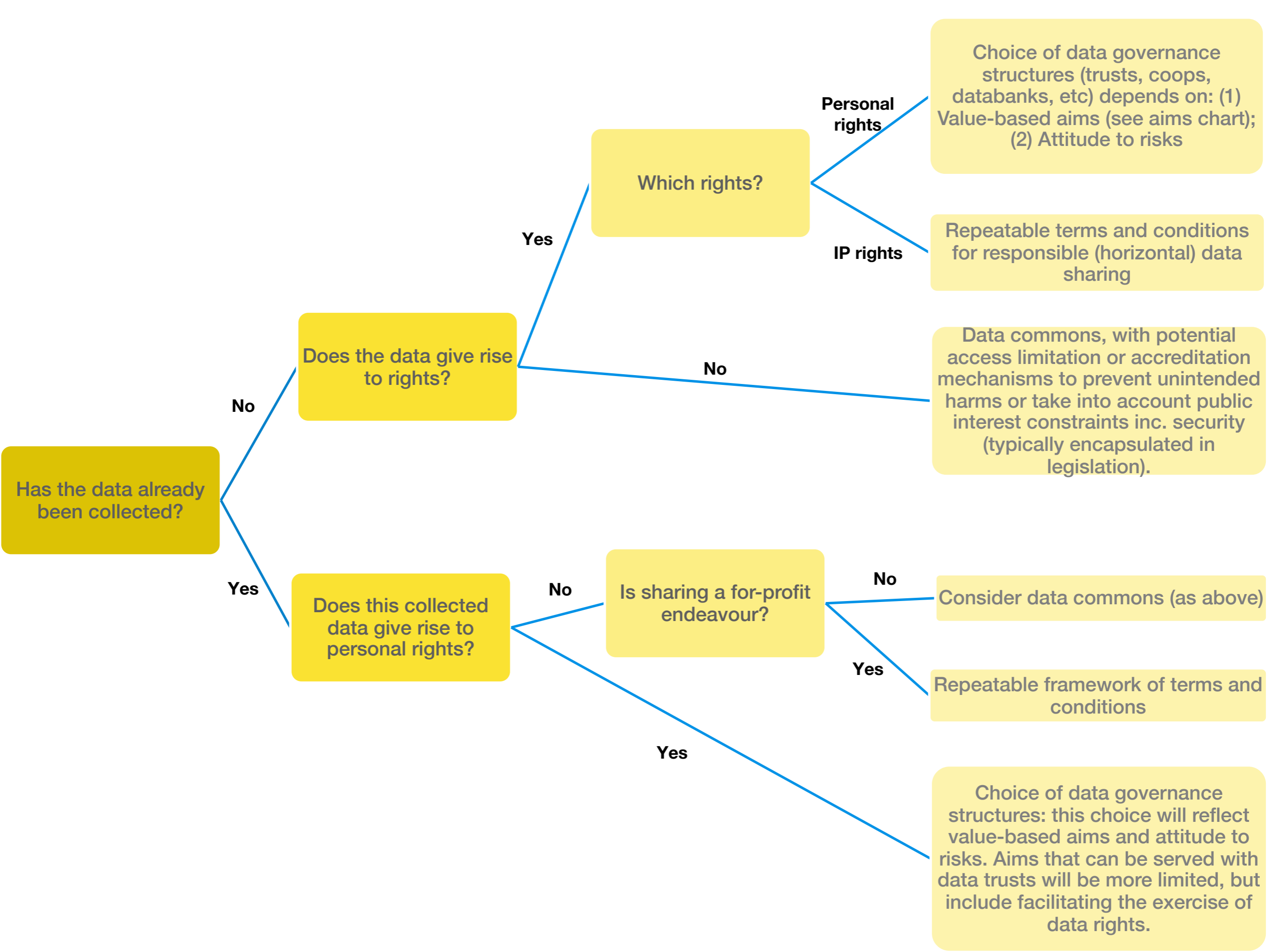
- 1. Conflicts of Trusts?**
- 2. Uptake:** publicly funded 'default' Trust in the absence of choice? Local data sharing needs?

Worth it?

Given the vulnerabilities at stake:

Yes

Unlike contractual or corporate frameworks, [e]quity employs ex post moral standards, emphasizes good faith and notice, couches its reasoning in terms of morals, and is sometimes vague rather than bright line'



Datatrusts.uk