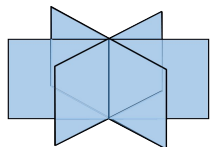


Data Trusts

A solution to our mass data collection
discontent?



Orthogonal Research and
Education Laboratory



Angela Risius

Why Data Trusts?

A structure whereby data is placed under the control of a board of trustees with a fiduciary responsibility to look after the interests of the beneficiaries.



Many working definitions:

- a set of relationships underpinned by a repeatable framework, compliant with parties' obligations, to share data in a fair, safe and equitable way."
- "a data trust provides independent, fiduciary stewardship of data."

Mass Data Collection Problems

- “Companies decide what to collect and for what purpose
- Harms are collective, benefits private
- Consequences that are hard to understand.

Data Privacy

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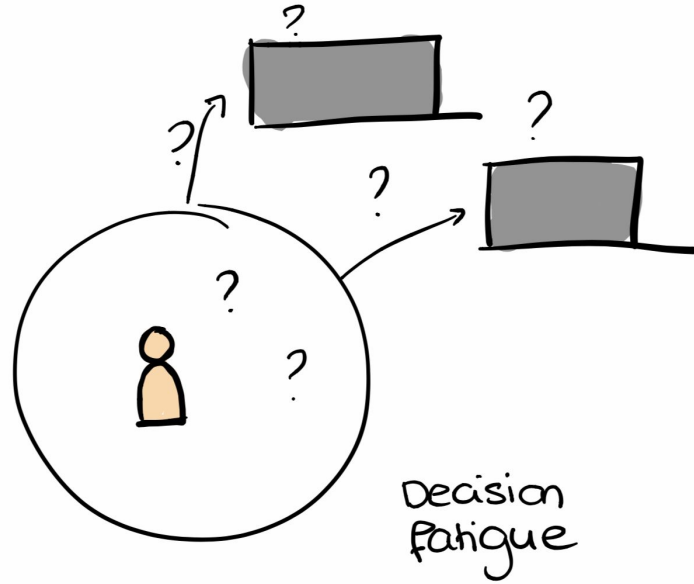
Their job is **not** to ensure your privacy or to make data available for the public good.

Solution?

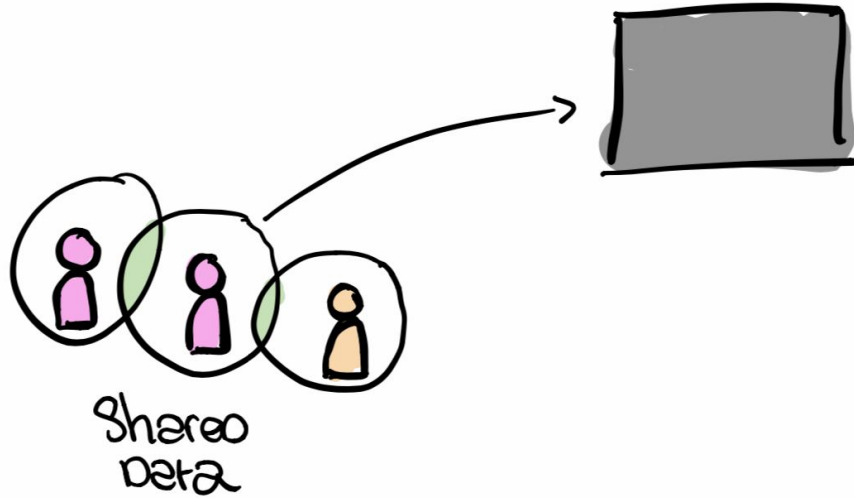
We could decide to divorce those who wish to use data from those who control its use. Personal Data Stores, by placing the data with the internet user rather than the service provider, hope to put the user back in control.

This approach fails to account for our limited ability to decide how we would want to share data.

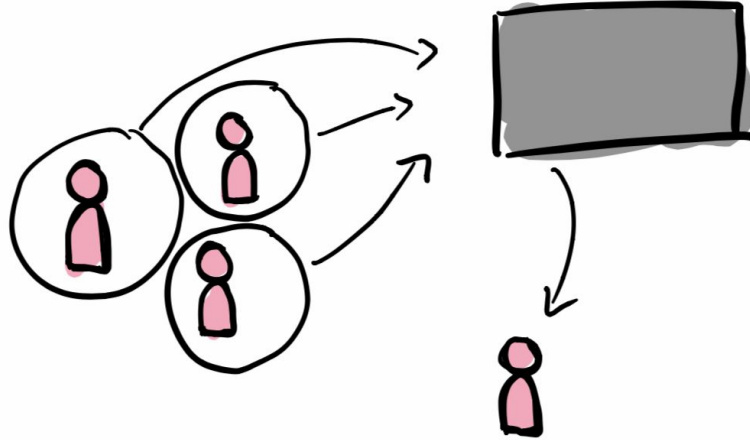
Decision Fatigue



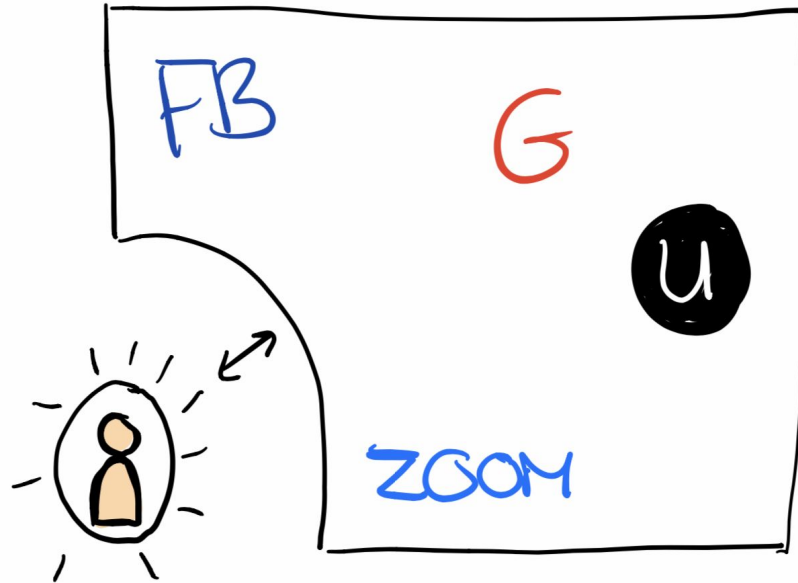
Data is shared

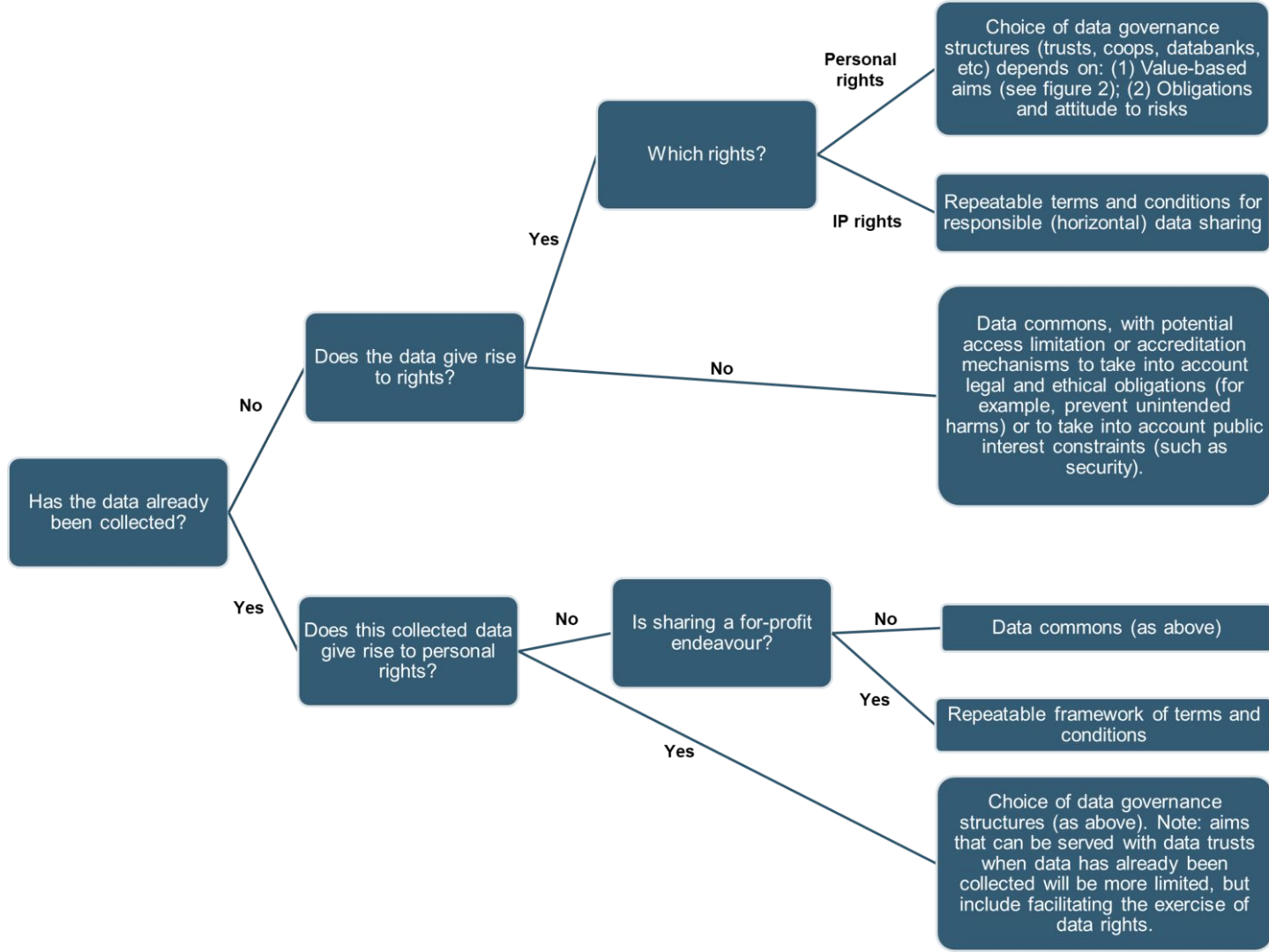


You sharing data affects me

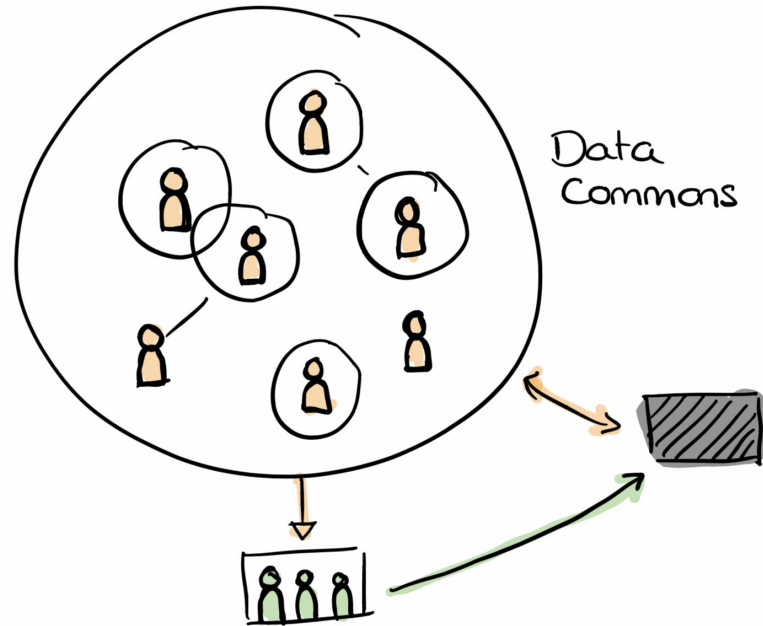


Power Imbalance





Data Commons



Data Commons

“Data Commons is an open knowledge repository that combines data from public datasets using mapped common entities.”

Data Commons → Data Trusts

“Data trusts allow individuals or groups to hand over their data or data rights to a board of trustees, who will govern it on their behalf, and on the behalf of the beneficiaries of the data trust.”

How do Data Trusts Solve Mass Data Collection problems?

Data Privacy Concerns:

“When you share your DNA with services like 23andMe, that data reveals a lot about your family’s genetic make-up.”

“What you share on social media could influence your friends’ insurance premiums.”

“Your income statements could affect your neighbor’s ability to obtain a loan.”

Should sharing this information be solely up to you?”

Social & Mobile Applications

“In a recent study that looked at permissions usage among VPN apps on the Android Play Store, it was observed that more than 60% of these apps require “dangerous” permissions that are not needed for them to function. These “dangerous” permissions pose a risk to users’ privacy by allowing access to sensitive information such as users’ location, mobile phone data, phone status, and a lot more.”

- 90% of free apps on the Google Play store share data with organizations.

Key Elements of Data Trusts

Data trusts must meet all legal requirements, including legal authority to collect, hold or share data.

They also need:

- (i) an accountable governing body to ensure that the data trust achieves its stated purpose and is transparent,
- (ii) comprehensive data management including clear processes and qualified individuals responsible for the collection, storage, access, disclosure and use of data,
- (iii) training and accountability requirements for all data users and
- (iv) ongoing public and stakeholder engagement (Paprica et al., 2020)



1. Legal: The data trust must fulfill all legal requirements, including the authority to collect, share and hold data

12 min specs



Governance

2. The data trust must have a stated purpose
3. The data trust must be transparent in its activities
4. The data trust must have an accountable governing body
5. Governance must be adaptive

Management

- 6. There must be well-defined policies and processes for the collection, storage, use and disclosure of data
- 7. Policies and processes must include data protection safeguards which are reviewed and updated regularly
- 8. There must be an ongoing process to identify, assess and manage risks



Data user requirements

9. All data users must complete training before they access data
10. All data users must agree to a data user agreement that acknowledges that data use will be monitored and includes consequences for non-compliance

Public and stakeholder engagement

The background of the slide features a large, stylized graphic of interlocking gears in red, blue, and grey. At the bottom, there is a silhouette of a diverse group of people standing and sitting, representing a community or stakeholder group. The overall theme is public and stakeholder engagement.

11. There must be early and ongoing engagement with stakeholders including members of the public

12. Where there is a reasonable expectation that specific subpopulations or groups would have a particular interest in, or would be affected by, an activity of the data trust, there must be direct engagement tailored for that subpopulation/group

A light blue world map with white outlines of continents and countries, serving as a background for the slide.

Points of Consideration:

- Cross-border data trusts will need to identify multiple legal requirements and ensure that governance addresses all of them.
- There are typically binding terms and conditions in data sharing agreements established between legal entities when data are shared.
- There will often be project specific requirements detailed in the documentation used to obtain consent from data subjects, and in the data management plan in submissions to Research Ethics Boards.

Characteristic	Option 1	Option 2	Option 3
Funding: how to finance the trust's activities	Commission on data licenses	Public funding	Data-specific taxes
Executing organization: what type of organization can be a data trust	Any kind of organization, including for-profit companies	Non-profit organizations	State-run organizations
Decision-making mechanism: how the trustee makes decisions about data sharing	Majority voting by beneficiaries on individual sharing agreements	Voting of representatives	Aggregation of individual preferences
Default setting: the default regarding data sharing	Opt-in throughout	Consent champions or average of actively chosen settings	Opt-out throughout
Negotiation objectives: what the trustee should maximize in its negotiations with data-using organizations	Income only	Combined utility of income and consumer-friendly data usage	Consumer-friendly data usage only
Data monetization: if the trustee should monetize data	No a allowed	Exemption of sensitive data types from monetization	All data can be monetized
Benefit distribution: how a trustee distributes its benefits among beneficiaries	Dependent on their data contribution	As decided by its beneficiaries	Fully equal
Evaluation: how performance is assessed	Majority voting by members	Optional certification	Mandatory external certification

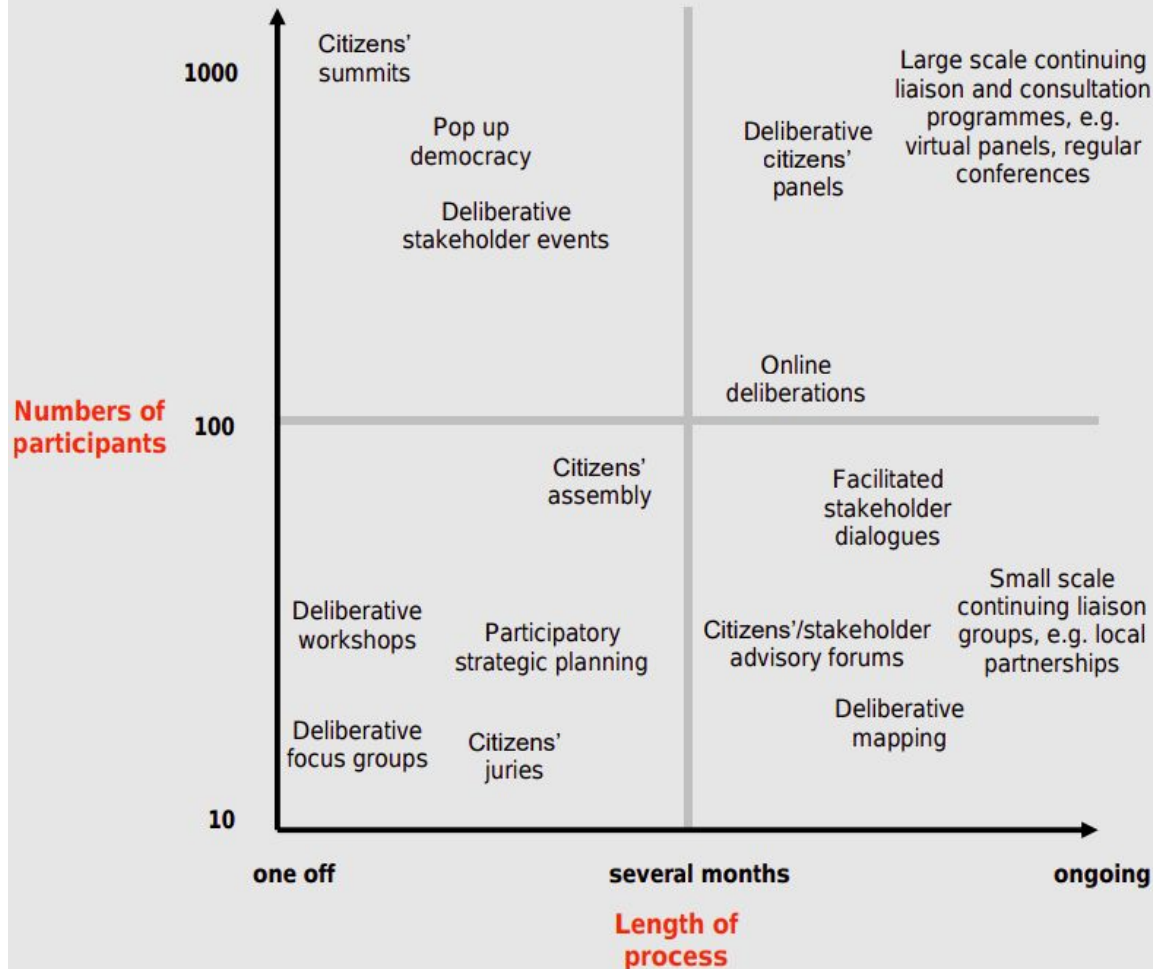
How are decisions made within the trust?

- What decisions does the trust need to make?
- What objectives and values should govern those decisions?
- Who are the stakeholders in the trust and what are their incentives?
- What policies, processes and activities will the trust use to make and enforce its decisions?
- What accountability mechanisms will the trust use to demonstrate trustworthiness, protect stakeholders' interests and manage risks?

Deliberative:

- Discussion between participants
- Involvement of a range of people
- A clear task or purpose

Figure 5 Map of deliberative methods⁵²



Real Life Implementation

- UK Biobank was set up in 2006 to steward genetic data and samples from 0.5m people and takes the form of a charitable company with trustees.



Enabling scientific discoveries that improve human health

Facebook's Oversight Board Trust

Purpose:

“to facilitate the creation, funding, management, and oversight of a structure that will permit and protect the operation of an Oversight Board for Content Decisions (the “Oversight Board” or “Board”), whose purpose is to protect free expression by making principled, independent decisions about important pieces of content and by issuing policy advisory opinions on Facebook’s content policies.”

- **Delaware's Purpose Trust Statute**



Data trust experimentation

“We are piloting a brand new way of dealing with data - the abolition of private ownership of data, replaced by collective decision making over the use of collectively produced data.

All collected data and any intelligence that springs from it should be collectively owned by the community it is about and put to use for this community.

A loss of privacy should never result in a loss of (social) power. In this way, we go beyond traditional models of informed consent for data.”

~ Zarinah Agnew

Future Possibilities

- Dynamic consent for data subjects (in cases where data require consent for collection)
- Data traceability so that data trusts can fully execute on patient consent withdrawal, bias monitoring, audits, and regulatory agency review
- Standard and computable data use conditions
- Secure and auditable computing environments
- Public engagement that goes beyond informational transparency and into activities like co-design and deep involvement of data subjects in governance

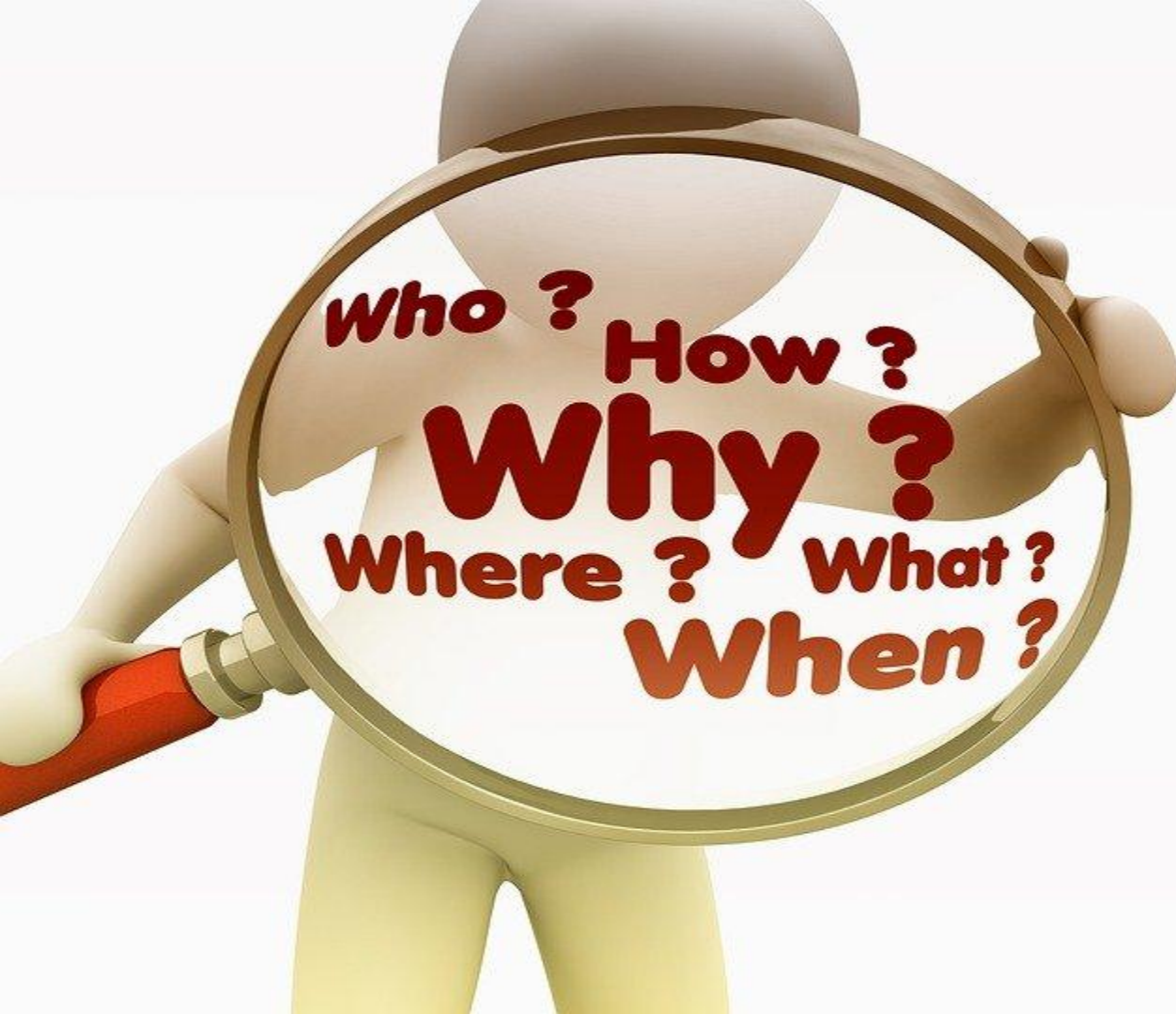
Funding to Make Your Own Data Trust

- Go to: <https://datatrusts.uk/pilot-projects>
- Enable collective action, empowering individuals or groups to influence how data about them is used.
- Provide independent stewardship of data rights by a data trustee on behalf of the beneficiaries of the Trust; and
- Create strong institutional safeguards to steward data use, based on trustee fiduciary duties together with oversight mechanisms.

The background of the image is a dense grid of vertical bars. Each bar is a different color, creating a vibrant, multi-colored pattern. The colors include shades of red, orange, yellow, green, blue, purple, and pink. The bars are arranged in a regular grid pattern across the entire image.

thank you

al warren



Questions?

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