

Open Data Institute 2019 / Data Trusts summary report

A data trust is a legal structure that provides independent stewardship of data.

'Data stewards' decide who has access to data, under what conditions and who can benefit from it. Organisations that collect and hold data usually have this role.

With data trusts, the organisations that collect and hold data permit an independent institution to make decisions about how that data is used and shared for an agreed purpose.

The data trust becomes a steward of the data.

Trustees of the data trust take on responsibility to make decisions about the data how it is used and shared. They have freedom to share data in ways that unlock its value. They also take on some liabilities - they must ensure these decisions support the purpose of the data trust and the benefits it is intended to bring.

# Why set up a data trust?

There are different potential benefits that setting up a data trust could help to bring.

A data trust is an independent institution, so it could help balance conflicting views and incentives about how data should be shared and who can access it.

A data trust could help organisations deliver some of the many benefits that better data access can bring - from enabling collaboration on common challenges to creating new products, service or insights.

A data trust could be used to reduce costs and skills needed to steward and share data, or be designed to generate revenue.

A data trust could **create new opportunities** for startups and other businesses to access and innovate with data, and enable new technologies, such as AI, that help people make more informed decisions, create jobs and stimulate growth.

A data trust could make control more representative over how data is used and shared, so people have a say who otherwise wouldn't have, especially when the data is about them or its use affects them.

A data trust could ensure data's benefits are distributed more widely, ethically and equitably.

# Data trusts could be used in lots of different ways...







**NGOs or charities** could use data trusts to make sure that data created by academics or businesses can be used to solve a problem, like illegal wildlife trade or food waste



**Businesses** could use data trusts to meet consumer demand for more participatory decisions on how data is shared and used. or to collaborate on a shared goal



Al developers could use data that's made available via a data trust to develop new technologies, which people can use to make better and more informed decisions, create jobs and stimulate economic growth

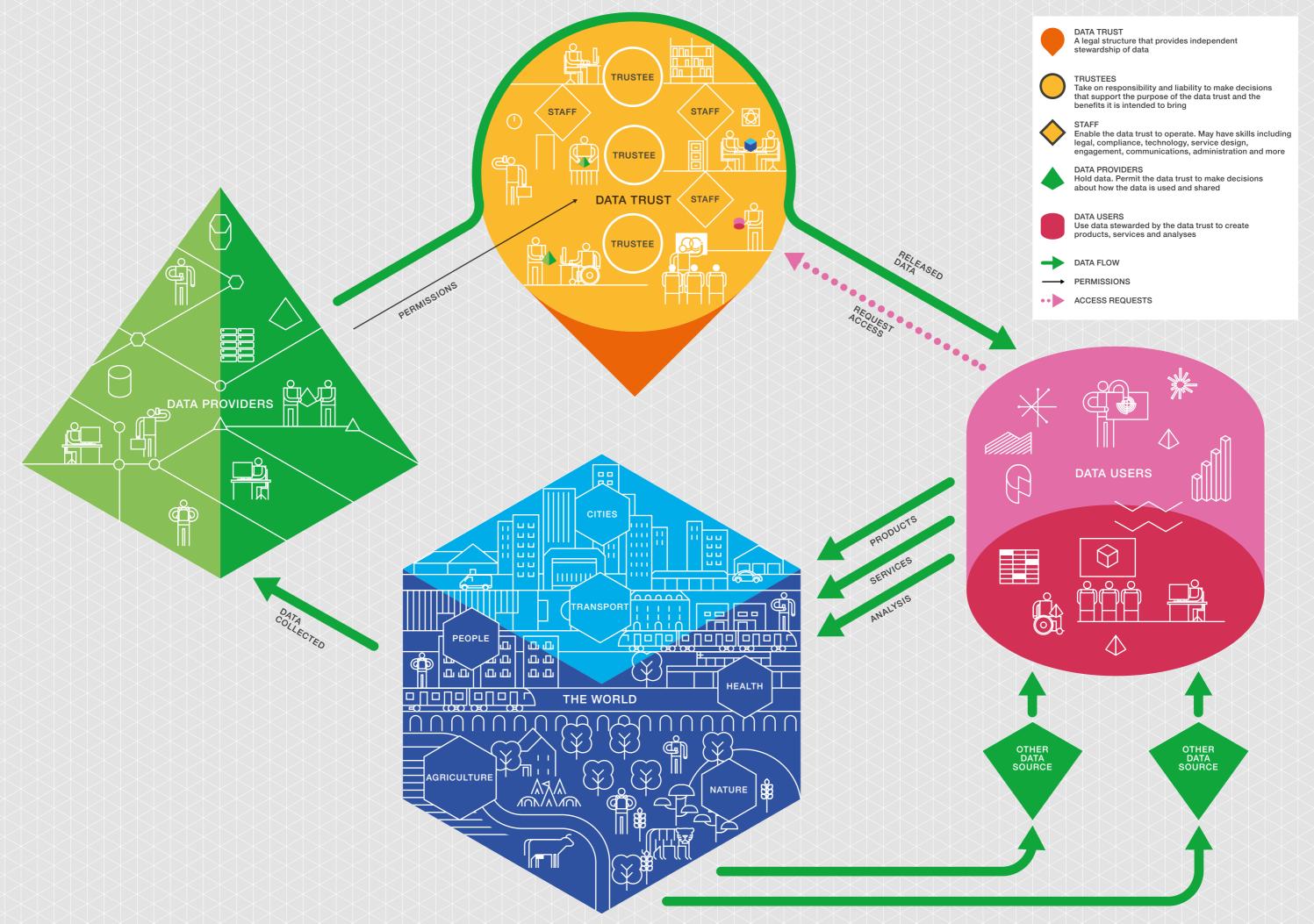


Illustration: Ian Dutnall

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# What makes a data trust different?

There are many approaches to stewarding data.

Data holders should consider and choose between different approaches to ensure that people, communities and organisations have access to the data they need. All of these approaches to data stewardship form part of our data infrastructure.1

A data trust is one approach to deciding who should have access to data. Other approaches include data cooperatives - mutual organisations that are owned and controlled by their members – and data commons – which draw on lessons from managing common resources, and apply them to data.

Data trusts are not legal trusts but they take what we have learnt from them. Trustees take on responsibility to make decisions about the data, along with some liabilities, to support the data trust to achieve its purpose.

> How can organisations that need data get hold of it?

# Who can be involved?

Many different types of people or groups might be involved in creating, using or advocating for a data trust.

Data holders from the private, public and third sectors could increase access to the data they hold, while reducing the costs and skills they need to do so. Delegating data stewardship to a data trust, which might be better equipped to make decisions about it, can help bring about better impacts with the data, and respond to calls from citizens or consumers for more participatory decisions about data sharing and use.

Groups working with data holders could help them scope, design and operate a data trust, or independently assess it so that other people know whether to trust it.

Citizens and consumers might advocate for a data trust to be created because they want the decisions about how data about them, or whose use affects them, is shared or used to be more open, participatory and deliberative. They might want that data to be used to benefit more people.

Data users such as startups and researchers might engage in data trusts because they want access to data held by organisations, which might be granted to them if a data trust has control over how the data is used and shared.

Governments might mandate a data trust, for example because data holders are unfairly restricting access. In other cases they might support people to create data trusts themselves through funding and sharing research on how to do it.

1 For more on data infrastructure, see theodi.org/data-infrastructure.



# Building adata trust

The concept of a data trust is still fairly new, and building and operating a data trust is not an easy or well-understood task.

However, ODI research and data trust pilots have begun to show what a life-cycle of a data trust might look like.

This life-cycle is still in development. We know more about the early stages – **scoping** and **co-designing** – than we do about the later stages – **launching**, **operating**, **evaluating** and **retiring** – because our work on data trusts has not reached those stages yet.

This life-cycle can give a framework for those researching or trying to build data trusts, for groups that might want to help, or for governments that want to create a policy landscape that will support them.<sup>2</sup>

The life-cycle will be adapted over time as more people start to implement data trusts.

2 You can read about these stages in more detail in the ODI's report 'Data trusts: lessons from three pilots' available at theodi.org/data-trusts.

### **Data trusts life-cycle**

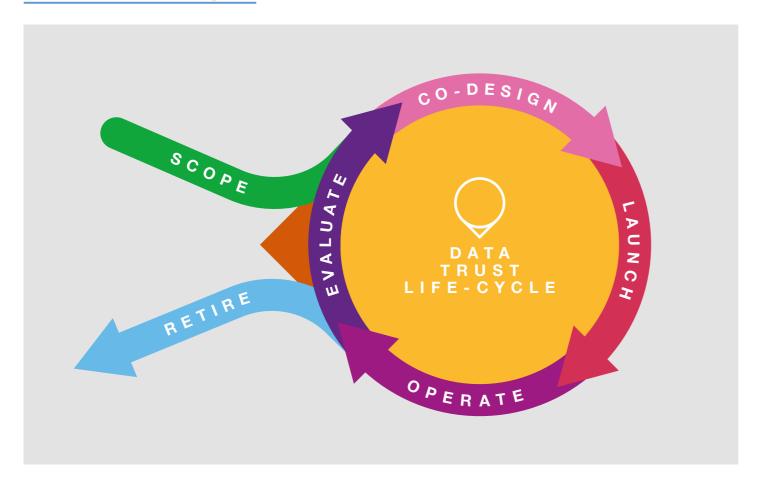


Illustration: Ian Dutnall

#### Scope

Scoping a data trust should begin by aligning around an issue or challenge, researching existing efforts that already address it – such as independent or intermediary bodies – which could be adapted, and looking at different types of data stewardship that would be most fitting for the need at hand. This will help to clarify whether a data trust is needed.

You should also: engage the relevant data holders, users and beneficiaries; develop use cases to help confirm the incentives and explain what the data trust would be trying to solve; make an effort to understand the ecosystem and surrounding risks; and secure funding for the Co-design stage.

#### Co-design

In designing a data trust, it's important to agree its purpose, how it will be funded or its business model, its legal and organisational structure, how it will be staffed, and the roles that stakeholders will have.

At this stage, it is important to agree how benefits will be created and shared by the data trust, who are the data holders that can provide data to the trust and any rules around new data holders joining, along with how decisions will be made around who can access data that is stewarded by the trust. It is also important to agree the 'change mechanism' – how often the data trust will re-evaluate its operation and how changes to the trust will be approved.

It is important to agree the technical architecture and standards around it – how data will be shared, for example – and the technical and support services this will need.

At this stage it is also useful to draft template agreements that will be used to underpin the design decisions that have been made.

#### Launch

When launching a data trust, it is necessary to set up and register the new, or updated, organisation in line with its agreed purpose; transparently publish information about its processes, as agreed during the co-design stage; develop the technology to support data sharing, services and operations of the data trust; make agreements with data holders for how the data will be provided; and communicate with stakeholders, so they know the data trust exists.

#### **Operate**

For a data trust to operate, its stakeholders will need to ensure the data is maintained and will continue to be available. Data contributions, and data requests, will need to be accepted, processed and responded to, and there may be technical services and reporting systems that are needed to support those.

The data trust may need to fundraise or carry out marketing and business development activities. Its benefits may need to be administered to data holders or beneficiaries, as agreed, and audits or checks may be needed to ensure that stakeholders conform to the data trust rules. Breaches of rules about how the data is used will need to be detected and dealt with.

Stakeholders may benefit from training or guidance, and the data trust could be promoted or supported with communications or targeted engagement using case studies of how the data is used to maintain interest and momentum.

#### **Evaluate**

In evaluating a data trust, it will be important to: consider positive and negative impacts on people, survey stakeholders to understand where they would like to see improvements or refinements; examine service use to evaluate how data and services are being used in practice and whether the decisions being made are consistent with the trust's purpose. Some of this evaluation may need to be done by external third-parties to build trust in the operations of the data trust. Regulators will also evaluate data trusts.

The data trust's finances or business model will need to be examined to clarify whether it is sustainable for the data trust, and ultimately a decision will need to be made around whether it will need to be redesigned or retired.

#### Retire

If a data trust has been evaluated and a decision has been made to retire it, the timeline for its close-down period will need to be determined and communicated to stakeholders. Services will need to be wound down and information archived. Agreements with data providers and other relevant people will need to be terminated – this may mean deleting data or transferring intellectual property. In closing down the related organisation, notices may need to be issued and registers updated.

You can read more about the stages in data trust life-cycle, and a discussion around their context and implications, in the ODI's report 'Data trusts: lessons from three pilots' available at theodi.org/data-trusts..



# What we have learned from our research and data trust pilots

We have learned about how data trusts could work and what is needed to enable them.

We need to consider whether the term 'data trust' is appropriate. The word 'trust' has many meanings and connotations. Our definition uses features of legal trusts and it distinguishes data trusts from other approaches to stewarding data. We hope there will eventually be convergence on a single definition with accessible language.

A data trust's main purpose is to provide independent stewardship of data through strong responsibilities and duties. We found that UK trust law is not appropriate, and that not-for-profit corporations are more suitable.

We found that organisations that hold data but aren't able to use and share it would benefit from data trusts. Trustees of a data trust could be better placed to make decisions about who should have access to the data and why, and can centralise and simplify processes like handling data requests.

There is a huge appetite for trialling data trusts. Many want independent data stewardship, however some are simply frustrated with how data is currently used and shared, and want something to unblock it. To ensure that people, communities and organisations have access to the data they need, we need to make it easier for data holders to find effective approaches to stewarding data.

To pilot data trusts, our team included people and organisations with skills in management, policy, organisational governance, data governance, compliance, ethics, decision-making processes, technology, law, user-research, economics, product design, and finance. Not all of these skills are needed at once but if you are building a new data trust you will need a multidisciplinary team.

Finally, we found many people interested in data trusts being drawn to technology solutions. Our definition of data trusts is deliberately independent of technology architectures, solutions or vendors – independent stewardship could work with centralised data sharing platforms, decentralised data publishing, cloud hosting, or blockchains. What is important is that data trusts – and those seeking to build them – retain technical flexibility and are able to respond to changing needs.

How can we balance different people's interests when sharing data?

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# Recommendations



Data trusts could be a useful way of increasing access to data while retaining trust. We have developed a data trust life-cycle to help people build them. We need action from a range of people to realise the benefits that data trusts, and similar approaches, can bring.

# People who want to create an enabling environment for data trusts:

#### These might be governments, policymakers or funders

- · Recognise data stewardship as an appropriate company purpose
- Consider where data trusts should be mandated
- Develop guidance to help organisations create data trusts
- Develop tools to enable people and organisations to assess the trustworthiness of data trusts
- Monitor the use and impact of data trusts
- Conduct or fund further research into data trusts and other approaches to data stewardship and data access

## **Data holders exploring** data trusts:

#### These might be companies, academics or governments

- Ensure data trusts are an appropriate data stewardship approach to meet your goals
- Be clear about what you mean by the term 'data trust' and use a different term if necessary
- Use and improve the data trust life-cycle the ODI has developed
- Engage a multi-disciplinary team
- Be trustworthy in how you collect, use and share data
- Adopt principles that strengthen data infrastructure
- · Work in the open and make use of existing networks

# People who want access to data held by organisations, or are concerned about how it is held:

#### These might be citizens, communities or organisations

- · Join forces with others to request access to data
- · Advocate for data trusts, and other models, over point-topoint data sharing agreements

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The views are those of the authors.

We will continue to explore data trusts and other data stewardship models at the ODI.

> You can find out more about our work, and explore the findings set out in this summary report in more detail at theodi.org/data-trusts.

> > If you would like to contribute to our research, or discuss data trusts with us, contact info@theodi.org.



The Open Data Institute works with companies and governments to build an open, trustworthy data ecosystem.