

# Developing a data trusts research agenda

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**WORKING PAPER 3**

29 June 2021



Data  
Trusts  
Initiative

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# Developing a data trusts research agenda

## Working Paper 3

### Summary

Despite much progress in establishing the case for data trusts as a necessary innovation in data stewardship, important questions remain about the function and form that such trusts should take when responding to real-world challenges. Addressing these questions requires further work to clarify how data trusts fit in the current data governance landscape, and to identify the operational strategies that can ensure their success.

To better understand how data trusts can be taken from theory to practice, the Data Trusts Initiative is funding seven research projects that each address a gap in current understandings.

These projects ask:

- What do recent use cases tell us about operational strategies for data trusts?
- How can legal mechanisms associated with data trusts enhance participation in healthcare research?
- How might data trusts operate in the urban context?
- How can data trusts support civic engagement and environmental stewardship in local communities?
- How can data trusts be created in civil law jurisdictions?
- Does the General Data Protection Regulation (GDPR) allow individuals to mandate their data rights to a trust (or other data intermediary)?
- What combination of technical and legal infrastructure can give individuals more control over data about them?

A workshop convened by the Data Trusts Initiative on 29 June 2021 brought together the leaders of these research projects, to explore current issues in their work. While each considers a different aspect of data trust theory or practice, across the projects the following areas of shared interest emerge:

- Understanding the nature of the legal landscape – the rights that exist in different jurisdictions and the legal environment in which data trusts might operate – and the implications of this for how data trusts manage data and data rights.
- Exploring the points of interaction between individuals and data trusts, identifying the interventions necessary to ensure data trusts are accessible to all and effective at representing their beneficiaries.
- Characterising the tensions that will arise in data trust design and identifying pathways to negotiate these tensions.

**The Data Trusts Initiative would like to thank all those that participated in the 29 June workshop. This note summarises discussions at the workshop. It is not intended as a verbatim record and does not reflect an agreed position by workshop participants.**

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## 1. Moving from theory to practice: the knowledge gap

The central mission of the Data Trusts Initiative is to shift the dial on data trusts research and implementation, moving the field from theory to practice. Achieving this goal will require action to clarify the nature of the rights and responsibilities of those involved in a trust, identify the tools that can manage those rights and responsibilities, and set in place the mechanisms that can ensure data trusts achieve their intended purpose. These areas for action form the basis of a varied interdisciplinary research agenda that spans:<sup>1</sup>

- *Conceptual clarity*: How do data trusts fit in the wider data governance landscape, and which core capabilities must sit at the heart of any real-world data trust?
- *Accountability*: What institutional safeguards would help ensure a data trust represents and operates for the benefit of those it purports to serve?
- *Participation, inclusion, and digital equity*: Which interventions can help make data trusts accessible to all in society, and ensure that all those in a trust can meaningfully contribute to decision-making?
- *Finance and sustainability*: Which business models can help ensure the continued sustainability of a data trust?
- *Implementation issues*: Which use cases can help clarify how data trusts would work in practice?

Tackling these research challenges will require a community – of lawyers, technologists, policy experts, design specialists, social entrepreneurs, and more – that can bring different perspectives to bear on the challenge of operationalising data trusts. To help start this community, the Data Trusts Initiative is funding research projects seeking to bridge the knowledge gap between theoretical discussions about data trusts and real-world practice.

## 2. Bridging the knowledge gap: current research activities

Reflecting the diverse challenges that data trusts might encounter in real-world contexts, research projects funded through the Data Trusts Initiative are exploring different aspects of data trust design and deployment. They seek to understand:

- What do recent use cases tell us about operational strategies for data trusts?
- How can legal mechanisms associated with data trusts enhance participation in healthcare research?
- How might data trusts operate in the urban context?
- How can data trusts support civic engagement and environmental stewardship in local communities?
- How can data trusts be created in civil law jurisdictions?
- Does the GDPR allow individuals to mandate their data rights to a trust (or other data intermediary)?
- What combination of technical and legal infrastructure can give individuals more control over data about them?

The sections that follow briefly introduce their work.

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<sup>1</sup> Explored in more detail in Data Trusts Initiative (2021) Data Trusts: from theory to practice, Working Paper 1, available at [www.datatrusts.uk](http://www.datatrusts.uk)

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**Data trusts: Bridging theory and practice with use cases, Aline Blankertz, Stiftung Neue Verantwortung**

***What do recent use cases tell us about operational strategies for data trusts?***

By reviewing recent attempts to establish new data institutions, this project will consider the technical, economic and legal issues that influence the operation of data trusts. Through four use cases, it will identify different strategies for operationalising data trusts and generate ideas to promote further development and practical implementations of the data trusts model. With data trusts remaining an active area of policy development in Germany, this work will feed into current policy debates about what frameworks can support the development of data trusts.

**Exploring the concept of a data trust in the health research context: suitability, desirability and considerations for translation of theory into practice. Dr Jessica Bell, University of Warwick, in collaboration with Professor Melissa Wake.**

***How can legal mechanisms associated with data trusts enhance participation in healthcare research?***

Bringing together insights from law, healthcare and research governance, this project is exploring how data trusts could be operationalised as a governance model for longitudinal health studies. The project analyses legal concepts associated with data trusts in this context, such as the scope and implications of fiduciary duties, and mechanisms for increased engagement and participation in healthcare research. In collaboration with a birth cohort study, one area of focus will be the role and engagement of children enrolled in longitudinal research studies, and how data trusts might be used to give these research participants a voice in decisions about data use.

**Urban Data Trusts in Theory and in Practice, Professor Bilyana Petkova, University of Graz**

***How might data trusts operate in the urban context?***

Using cities as a lens through which to consider questions about the collectivisation of data rights, this project is investigating how a civil data trust might be created in Graz, Austria. By combining insights from urban law and data protection law, it hopes to identify how Urban Data Trusts can be made compatible with both the provisions of the General Data Protection Regulation and other regulatory interventions that influence the design and operation of urban environments. It will also explore the opportunities for sharing data between different city trusts.

**Data Trusts: Local data and placemaking in coastal communities, Natasha Nicholson and Pamela Charlick, charlick + nicholson architects**

***How can data trusts support civic engagement and environmental stewardship in local communities?***

Bringing an architectural perspective to bear on the design of data institutions, this project is exploring the practical application of data trusts in a small-town coastal community, and the value that this type of governance can create for local communities. Topics of interest for this project include placemaking, civic engagement and governance, and the role of data in environmental stewardship and conservation. By engaging local communities, this project will identify the touchpoints that can bring citizen voices into decisions about data use.

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## **Exploring the Core Concepts of a Civil Law Data Trust through the Design of a Constituting Act, Jessica Leblanc, TIESS**

### ***How can data trusts be created in civil law jurisdictions?***

While Quebec is a Civil Law jurisdiction, its Civil Code makes provision for the creation of purpose-led trusts to address general interests or social concerns. The Quebec Trust offers an innovative legal solution to promote collective action, and this project aims to create a model constituting act for such a trust. This constituting act would identify the purpose for which the trust is established, the rights that might be transferred to the trust, and the accountability mechanisms required to oversee its operations.

## **Mandating Data Rights: Exploring issues and opportunities, Jef Ausloos, University of Amsterdam and KU Leuven, Sylvie Delacroix, University of Birmingham, Alexandra Giannopoulou, University of Amsterdam, Heleen Janssen, University of Amsterdam and University of Cambridge**

### ***Does the GDPR allow individuals to mandate their data rights to a trust (or other data intermediary)?***

Core to the operation of data trusts is their ability to exercise individual data rights on behalf of their members. Data subject rights in the EU are complex and diverse. The General Data Protection Regulation neither rejects nor explicitly condones the idea that data rights can be exercised by a third party, but in some areas does make explicit provision for individuals to mandate non-profits to take remedial action on their behalf. This project will seek to unravel some of this complexity surrounding legal requirements for the mandatability of data rights.

## **Personal Data Accounts James Kingston, Dataswift**

### ***What combination of technical and legal infrastructure can give individuals more control over data about them?***

Moving data trusts from theory to practice will require better understandings of what can be settled in trust, how it is settled, and who will then govern it. This project proposes to create a proof-of-concept data trust, based on personal data accounts that provide an infrastructure for individuals to control their personal data. By creating this infrastructure, the project will explore the interaction between data trusts and data rights, using a hypothesised use case of social media data as a lens through which to explore these issues.

### **3. Shared themes or challenges**

These research projects are applied by nature; they combine insights from both theory and practice to generate new understandings of how to operationalise data trust methods, given the complex challenges that emerge in any real-world use case. In negotiating these challenges, common areas of interest emerge across research projects. These relate to:

- Understanding the nature of the legal landscape – the rights that exist in different jurisdictions and the legal environment in which data trusts might operate – and the implications of this for how data trusts manage data and data rights.
- Exploring the points of interaction between individuals and data trusts, identifying the interventions necessary to ensure data trusts are accessible to all and effective at representing their beneficiaries.

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- Characterising the tensions that will arise in data trust design and identifying pathways to negotiate these tensions.

***What different rights or legislative frameworks arise in different domains, and what does this mean for the legal and technical infrastructure of data trusts?***

The foundational questions that must be addressed in establishing a trust relate to what is being placed in trust and which interventions then govern it. These questions play out differently in different jurisdictions and domains, depending on the nature of the rights citizens have over their data and the ways in which that data may be used.

In the EU, the General Data Protection Regulation sets a framework for individual data rights, but questions remain about the extent to which individuals can mandate their rights to a trust – or other data intermediary – to act on their behalf. In other jurisdictions, there exist different types of rights that influence what rights citizens have over data about them, how data can be aggregated and what value it creates, with implications for what may be settled in a data trust.<sup>2</sup>

Similarly, the legal traditions of different countries contribute to differences between jurisdictions in relation to the legal tools that are available to create data trusts. In common law jurisdictions, trust law can provide the combination of independent stewardship, collective action and strong institutional safeguards that characterise data trusts. Alternative legal interventions are available in some civil law jurisdictions. In Quebec, for example, the Quebec Trust offers a framework for creating data trusts oriented around a specific purpose within a civil law environment. This framework offers flexibility for settlors to define a purpose for the trust that suits their needs, but in turn raises questions about how the work of the trust might adapt when new opportunities or conditions arise. In other civil law jurisdictions, absence of legal concepts equivalent to the duty of undivided loyalty – central to fiduciary duties under UK trust law – may require further innovations in data intermediary design to overcome. Further work will help identify the ‘proxies’ for data trusts that could be developed in civil jurisdictions and what interfaces may be needed between data trusts operating across countries with different legal traditions.

Legislation relating to data governance also interacts with other regulations or laws, specific to the context at hand. In the context of cities, for example, the use of data relating to mobility patterns may be influenced by both data protection laws and regulations relating to the operation of local transport networks. Such requirements shape the form and function of data trusts operating in this environment and may generate opportunities to create different forms of data intermediary.

In areas where there are few or no legal protections around data, or where there is little capacity for the courts to intervene and adjudicate data issues, technology can play an important role in setting limits on what data can be accessed for what purpose. Personal data accounts, or similar technological interventions, can provide an alternative framework to allow citizens to set limits on data use.

Current debates and practices focus on the development of data intermediaries built around a specific purpose, with the aim of creating value for their community and relevant stakeholders. In the longer-term, it may be possible to build data trusts around a general service, acting as an intermediary layer between individuals and data users across a wide range of domains.

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<sup>2</sup> Explored in more detail in Data Trusts Initiative (2021) International perspectives on the development of data institutions, Working Paper 2, available at [www.datatrusts.uk](http://www.datatrusts.uk)

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The combinations of legal, technical, and other governance interventions that can steward the rights available to citizens in different areas – with the aim of empowering those citizens to influence the terms of data use – require further exploration.

### ***How will individuals or communities relate to data trusts?***

If data trusts are to effectively represent the diverse interests of citizens and communities, it is imperative that they are available and accessible to all in society. With understandings of patterns of data use and workings of digital systems generally low, and knowledge of data trusts even lower, the data trusts community must consider why individuals would want to join a trust and how they might wish to interact with their data trust.

As a starting point, those establishing data trusts need to consider what types of value a trust can create by enabling data use and why different groups might engage with data trusts. They will need to identify what types of data a community has access to or generates, what types of data the community and the different stakeholders it interacts with consider valuable, and what value can be created through data exchange.

One of the goals of data trusts is to create institutions that represent data subjects, and support these individuals to challenge existing power asymmetries in the digital environment. Such representation requires careful design of the interfaces between citizens and data trusts – the touchpoints that make the complexity of the digital world, and the choices therein, tangible to individuals and amenable to decision-making. Creating these touchpoints requires better understandings of the points of common connection between people and data, through studies that work with and within communities to understand the issues and data sets that are important, relevant, and useful to that community. From these understandings, natural points of interact between communities, data and data trusts may emerge.

Lessons can also be drawn from fields that have embedded citizen dialogue in their ways of working. In some regards, healthcare research has been a pioneer in the design of mechanisms for participatory governance. Large-scale projects to sequence the human genome, and govern the resulting data, have invested in systems to engage citizens and consult with research participants. Today, institutions such as UK Biobank – a charitable company that governs data from over half a million healthcare research participants – provides an example of how citizen engagement and institutional safeguards can be combined in data governance. There are opportunities today to both learn from the successes of participatory governance in healthcare research and to explore what data trusts can add to this legacy. Data trusts could, for example, play a role in helping to link different health datasets or in providing a stronger voice for research participants in complex longitudinal studies, where perspectives may change over time.

In practice, each data trust will likely need to deploy a variety of institutional and procedural innovations to ensure it engages effectively with citizens and its membership. One point of interaction may be the physical space occupied by the data trust itself – and the cues this gives about its trustworthiness. Other important considerations relate to how trusts engage and attract individuals to their work, the user experience of interacting with a trust, and how trusts communicate how data is being used.

### ***How will stakeholders negotiate the tensions associated with data trust design?***

In determining how best to serve its members, data trusts will need to navigate a variety of trade-offs. These might relate to tensions between:

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- the desire for bottom-up engagement with citizens – and the need for structures that enable widespread engagement – and the creation of top-down boundaries on what a trust does to determine its actions;
  - the competing requirements of flexibility and consistency in trust ways of working, the former being necessary in responding to new areas of opportunity or need and the latter playing an important role in institutional stability and trustworthiness;
  - the need for ease of access for individuals wishing to join or create a data trust, and ease of transfer between trusts and individual ambitions change, without destabilising the operations of a trust.
  - different demands or interests being promoted by different individuals or groups engaging with the trust, requiring mechanisms that help resolve conflicts of interest;<sup>3</sup>
  - the relative advantages of centralised and decentralised approaches to managing data and user interactions with a trust;
  - delegating decision-making to a professional trustee, and the role data trusts should play in empowering citizens in decisions about data use.

At the same time, data trusts will be operating in a changing environment. Patterns of data use, technological capabilities, and citizen interests and concerns will all vary over the lifetime of a trust. Trusts will need strategies for future-proofing and adaptability, while maintaining their institutional stability.

#### **4. Next steps**

Research projects funded from the Data Trusts Initiative will continue through 2021-22, producing outputs that generate new insights into the operationalisation of data trust methods. These will lay the foundation for future work that supports Data Trust Pioneers to establish and run pilot projects to serve their communities.

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<sup>3</sup> Some of the tensions that arise in community decision-making processes are explored in: Data Trusts Initiative (2021) Where next for proposals from India's Committee of Experts on Non-Personal Data? In conversation with Astha Kapoor and Sylvie Delacroix, available at: <https://datatrusts.uk/blogs/where-next-for-proposals-from-indias-committee-of-experts-on-non-personal-data-in-conversation-with-astha-kapoor-and-sylvie-delacroix>



## About the Data Trusts Initiative

The Data Trusts Initiative is an interdisciplinary programme that pursues research at the interface of technology, policy and the law to better understand the role data trusts can play in addressing the challenges of data governance in the 21st century.

Supported by a donation from the Patrick J McGovern Foundation, the Data Trusts Initiative will fund research and engagement activities to clarify the conceptual foundations of data trusts and explore potential models of operation. By building a community of researchers and social entrepreneurs, the Initiative will shift discussions about data trusts from principle to practice.

For further information about the Initiative, and opportunities for funding in some of the areas discussed in this note, please visit [www.datatrusts.uk](http://www.datatrusts.uk)