# Agency and Guardianship

What does a human rights based approach to personal data look like?

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A Human Rights Approach to Personal Data

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#### Introduction

This paper examines how to implement a human rights approach to personal data and, in doing so, how to implement a human rights approach to all services that deal with identified individuals.

It shows how it is possible to build a personal data ecosystem that is interoperable, flexible, certifiable, scalable and that is also safe, secure and consensual, where taking a human rights based approach also results in genuine personal, social and economic benefits.

The biggest challenge with attempts to embed human rights approaches into service provision is that very often it is hard to translate good intentions into practical, operational day-to-day actions. Here, we show how this can be done by digging deeper into how control, human agency and guardianship can work in relation to the collection and use of personal data, and how these three concepts of control, human agency and guardianship interrelate.

Control without agency risks becoming an empty platitude. More lip service than operational reality. Guardianship is crucial because, perhaps counter-intuitively, the psychological, human benefits and need for agency often grow as and when individuals find themselves 'losing control' within their lives - when they become sick or frail for example. Finding practical ways to help people assert agency - and to help those seeking to help these people - is a critically important part of control and agency not only as it relates to personal data itself but what people do with this data: manage their lives.





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This Paper is best read in conjunction with its sister Paper on the <u>Surprising</u> <u>Economics of Personal Data</u>, which explains the hard-nosed instrumental reasons why empowering individuals with their data makes good economic sense. The other side of the coin is the personal, psychological and emotional benefits. The two are inextricably linked because the different types of benefit that they bring are both needed for human wellbeing, and because they are both powerful motivators. Also they are intimately connected because they both revolve around practical operational realities - *how to actually get stuff done*.

#### Setting the scene

Below, we flush out some of these practical operational realities. But first, some scene-setting is necessary.

Three themes thread their way through all current discussions about human rights and about the best ways for our society to collect, use and treat personal data. First, **semantics matter**. The words we use to describe things and how we interpret these words can have huge - and often unnoticed - consequences for the things we subsequently end up doing. **'Simple', 'innocent' words can define complete agendas** as we show in this Paper particularly in relation to the words 'user' and 'control'.

Drawing on our decades-worth of on-the-ground, practical, front-line experience we explore nuances and wrinkles in the interpretation and application of the key words of 'user', 'control', 'agency' and 'guardianship'. These nuances and wrinkles may not be obvious at first sight, but they can determine whether good intentions are realised or lost along the journey of implementation ... perhaps even undermined or subverted.

Second, the reason why words are sometimes so powerful is because they act as vehicles for the mental models by which we understand and act in the world. These **mental models frame the pictures we create** of the world we live in: what's included and what's not included; what's placed in the foreground and treated as centrally important versus what is placed in the background.

In the case of human rights and personal data, the key mental model in question is whether we see it from an organisation- or person-centric perspective. Many people simply assume an organisation-centric perspective because that is how the system currently works, with organisations collecting data about individuals, holding this data in their proprietary systems, and using this data to provide their services. It's therefore simply assumed that this will always be the case.





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Organisation-centric data collection and use will indeed remain an important part of the picture. But what it leaves out of the frame - to be subsequently overlooked and ignored - is the possibility of equipping individuals with their own tools and means to collect, hold, store and share their own data, independently, in their own databases: where they can assert control and agency *directly*, in their own lives. **This person-centric perspective on personal data gives the implementation of human rights approaches a new and different complexion**.

This leads us to the third common thread. Time and time again, we find that in discussions around issues such as human rights a big gap soon opens up between what people say (especially those with some degree of organisational power) and what they actually end up doing. We don't think this is because they don't care or are dishonest. Often they care deeply and are as honest as the day is long. **But the systems they are relying upon to deliver what they want to do are not up to the job, and end up delivering something else entirely**.

Good outcomes do not automatically follow good intentions. It takes careful thinking and diligent implementation for that to happen, and that means getting systems, processes, and enabling infrastructure right. It's a practical, operational challenge, not just a policy one.

## A Human Rights Approach

As a concept, human rights has some drawbacks. One of these drawbacks is that different people use the same words to mean different things. This generates confusion. For example, the European Convention on Human Rights focuses on how states treat citizens (e.g rights to free speech and fair trials and freedom from arbitrary arrest). The Scottish Government's proposed Human Rights Bill extends the notion of human rights to standards of living, including access to adequate food, housing and clothing, rights to "the highest possible standard of physical and mental health", participation in cultural life, and the ability to enjoy the benefits of scientific progress and the right to a healthy environment. These are quite different interpretations.

Other definitions focus on the processes by which people are treated by organisations. The United Nations talks about Participation, Accountability, Non-Discrimination, Empowerment and Legality (PANEL) but healthcare professionals tend to talk about FREDA: Fairness, Respect, Equality, Dignity, Autonomy.





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Some people's interpretations of human rights are legalistic. They focus on what the law says. Others' interpretations are more ethical, focusing on how people should be treated, regardless of what a particular law says or fails to say.

Finally, there is often a big difference between human rights as ideals that people talk about - talk which can easily turn into empty hot air - versus the practical, operational matter of how to put these ideals into day-to-day practice.

#### Mydex's take on human rights is ethical, practical and focused.

- *Ethical* because we are concerned about how people are treated in their day-to-day lives. Here, basically, human rights boils down to an attempt to codify the Golden Rule of 'do unto others' into how processes work.
- *Practical* because our platforms are designed to operationalise this ethical focus into how stuff gets done, day in and day out, to the finest level of detail.
- *Focused* because we are applying notions of human rights specifically to the collection and use of personal data.

There is an important point about this focus. Being focused is not the same as being narrow. How personal data is collected and used relates to *every* citizen's life, from birth to death. And because personal data is key to the provision of services that deal with every aspect of peoples' lives including their health and care, money, shelter, education and work, travel and leisure etc, the practical import of how our society handles personal data reaches into every nook and cranny of every person's life.

Mydex personal data platforms do two things. First, they provide individuals with the practical tools and means to assert their rights in everyday life. Second, they help organisations make human rights happen.

Mydex platforms empower individuals with their data, their own digital identity and a set of tools that builds considerations of fairness, agency and respect (and utility) into the details of the collection, storage, sharing and use of their personal data throughout their life, in all aspects of their life. And by using Mydex platforms for these purposes we help organisations build practical implementation of human rights approaches into their day-to-day operations. We enable them to move from talking to doing. This 'doing' extends to all services that use personal data and related identity and information services to improve human lives.

The rest of this Paper delves into the practical challenges of 'doing' personal data and service provision well.





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#### What do we mean by 'User'?

The world of service provision is currently awash with **"user"** talk. We should always, we are told, "start with user needs". Services should be designed to be "user-centric", as should the process of designing such services.

It all sounds wonderful and no doubt the intentions are benign. But **all this talk of user need and user centricity - and all resulting actions - has a fatal flaw at its heart. In focusing on the 'user' it loses sight of the** *person;* **the human being.** 

The clue lies in the word itself: 'user'. For someone to be a 'user' they have to be using something in particular i.e. a particular service provided by a particular organisation. Focusing on 'user need' and designing services so that they are 'user-centric' means focusing *only* on a user's interactions with that particular service and organisation and *forgets the context of the rest of that human being's life, and their life needs.* 

There is an old joke about a narcissist in conversation with a friend. Having talked about themselves for hours on end the narcissist stops and says to their friend "Hey, but that's enough about me! What about you? What do you think of me?" **The stronger the focus on the 'user's need' in relation to a particular service or organisation the stronger the focus turns to the organisation**, including what it needs in relation to that user.

The person and the context of their lives get pushed to the background, acknowledged only to the degree that they connect with the organisation's much narrower service delivery priorities.

Take a very simple example: filling in a form. A 'user need' approach to form filling is to look as closely as possible at each step of the form to make filling it in as easy, clear and simple as possible - the benefit to the organisation being that drop-out rates are reduced.

That's great. But what this forgets is the fact that this *person* is probably going to have to fill in many different forms in their lives, and that as each different organisation designs its forms in a different way to fit its particular circumstances, the person ends up having to navigate many different forms, thereby *adding* to the time, effort (and stress) of form filling.





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Focusing on 'user need' to make one particular form easier, clearer and simpler does very little if anything to address the real problem in the person's life - the hassle of having to fill in many different forms. And it ignores entirely different solutions that focus on the person as a whole in the context of their lives. **What about a service that enables people to automatically supply all the information required by** *all* **the forms they come across, so that they never have to fill in a form again?** 

That's the vision we are working towards - a vision that embraces benefit to the individual too, that organisation-centric 'user need' and 'user centricity' renders invisible.

#### Therefore, every time we come across 'user' terminology in projects we know, *right from the start,* that this project is highly unlikely to recognise the real needs of the people it is dealing with in all their richness and complexity.

In real life, people operate in any number of contexts and roles: as citizens, as students, as employees, as patients, perhaps as a refugee or a vulnerable person or a person with protected characteristics. There are care experienced young people, people in specific regulated professions, people who have been arrested, peop; le who are victims of crime or asylum seekers. There are people acting for another who hold a lasting power of attorney, people who support others informally and formally. In each role they have different practical and emotional needs.

For a service to be designed really well it needs to look beyond 'users' to the human being: to people operating in different contexts and roles. It needs to understand the context they are operating and to gain clarity about this context. Because (amongst other things) only by gaining this clarity can we understand what words like control, agency and guardianship mean *for them*.

For this reason, in an ideal world, every time the word 'user' is used, we would recommend it be replaced by 'person' with all that follows about the needs and context of that person.

#### Control

Just as the term 'user' can become an easy way for an organisation to forget that it is dealing with real people, so the word 'control' (as it relates to personal data) can be interpreted to mean two opposite things.





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We explain this in detail in this <u>recent blog post "Beware what you wish for</u>!" but it boils down to this: there is a chalk-and- cheese qualitative difference between individuals being able to exert some control over data that organisations collect about them and individuals being able to receive, collect and use their own data about themselves independently of these organisations and being able to use this data directly to manage their lives better.

Many projects, initiatives and policies aiming to 'empower' individuals with 'more control' over their data focus only on the first narrow meaning of control. The net effect is that organisations maintain a monopoly stranglehold on the collection and use of personal data with individuals *never* being genuinely empowered with their data.

What's more, this first, narrow, organisation-centric interpretation of the word 'control' *adds* burdens to individuals in their lives because they are now having to exert control dozens of times over, once for each separate organisation collecting data about them. This sort of control turns people into 'consent monkeys', forever having to tick boxes to provide consent for this or that use of their data - without ever leaving the person with anything of reusable value - e.g. the data they have provided.

As with 'user need', looking at the person in the context of their whole life, including the fact that they are having to deal with many different organisations, transforms what is meant by the word 'control' and how it is best enabled.

Amongst the particular issues that arise on this front (time and time again) are:

- The frustration of having to learn how to navigate each different service provider's or app's systems - a frustration that generates threat vectors for individuals as they get impatient and speed up the process of jumping through so many different hoops. What if, instead, there was a **personalised experience layer** for all services and apps, so that the person seeking to use the service or app experiences the same look, feel and navigation across all such services and apps? How much simpler would their lives be then?
- **Relationship Portability** If a person is to have genuine control and agency, the details of the process of moving their data from one relationship to another need to be worked through. This challenge of interoperability goes deeper than many people realise into the creation of an 'ontology' of personal data a full comprehensive list of the names, definitions and attributes of different data points as they relate to an individual. It also involves the ability to map all the individual's different data relationships. This work has hardly begun, but it is sorely needed.





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• **Nuanced rights and data 'ownership'** - There are many discussions about people 'owning' their data but all of them are flawed because current notions of 'ownership', which are based on exclusive notions of private property (e.g. it's 'mine' and therefore cannot be 'yours') just don't work with data. The non-rivalrous nature of data plays havoc with such notions of ownership.

The Romans had a much subtler understanding of the nuances of 'ownership,' when they created separate legal rights and processes for 'usus', 'fructus' and 'abusus'.

**Usus** (use) was the right to use or enjoy a thing directly, without altering it. For example, to walk on a piece of land or eat a fig off a fig tree. **Fructus** (fruit, in a figurative sense) was the right to derive profit from a thing possessed: for instance, by selling crops (but not the land on which they were produced), taxing for entry, etc. And **abusus**: (literally abuse) was the right to alienate the thing possessed, either by consuming or destroying it or by transferring it to someone else (e.g. sale, exchange, gift). These nuances apply just as much to personal data as they do physical items.

Such notions of *usus, fructus* and *abusus* can be helpful thinking through the details of what 'control' actually means in different contexts: what rights they imply both inside and outside what boundaries.

Trust Frameworks and their operating schemes are a good example of this in practice. People need to be able to exercise their rights within these schemes. They also need to have a proper sense of control and coherence about their involvement across multiple schemes and rules and the use cases within them. Certification has to accept variances in the resulting definition of rights.

# Agency

Agency happens when individuals feel able to act deliberately and effectively in the world: they can do things to achieve desired outcomes. 'Control' without agency is ultimately meaningless. But that is what current agendas to give individuals 'more control' over their data amount to.

Also, agency isn't always just individual agency. Collective agency occurs when people act together, such as a social movement, a network of friends and family in a circle of support around another, or a network of community members working together in local activities.





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A sense of agency is crucial to a sense of personal psychological wellbeing for obvious reasons. If a person does not have agency - if they cannot act effectively in the world around them - then they are powerless. At the mercy of others. This is a source of anxiety, because when you are powerless you are at risk of harm.

Agency means having real choices - the ability to choose between alternative courses of action. When it comes to people interacting with services this raises fundamental service design questions. Is the service designed to enhance or undermine individuals' agency? If so, what is the best way of going about it?

On the dark side, **some organisations have become expert at denying individuals agency as it relates to their personal data via 'dark patterns'**. Dark patterns are deliberately designed to frustrate peoples' attempts to achieve what they want to achieve, or to trick them into doing things they don't want to do. One simple example is making it so difficult to understand a privacy policy or make changes to privacy settings that most people give up trying, or end up agreeing to just give their data away.

More often in the third and public sector, services undermine citizen agency not because they are deliberately designed to do so, but because they are designed with other priorities in mind - such as organisational convenience. Many onboarding systems and apps remove a little bit more agency with each step through the journey, building peoples' frustration as they do so.

Sometimes, services that genuinely intend to empower people still end up doing the opposite. For example, many well-meaning services have many types of message, controls, double checks and complex information provision that are meant to empower them, but where the main effect on the person is fatigue, exasperation, irritation and doubt. This is one reason why drop-off rates in so many digital journeys are so high.

The brighter, more positive side is that there are services, such as Mydex's, that genuinely do empower. They are carefully designed, based on real world experience, to give people real agency.

This is often harder than it seems. For example, there are many different ways to signal options and choices to people as they navigate their way through a service, including visual iconography, sounds and a wide range of other alerts and warnings. But very often these techniques fail the real person test. Sound varies by culture, so it needs to be personalisable. Icons and symbols are more consistent but colours and warnings need to be configurable for different cultures and accessibility issues.





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Crucially, if every service or app we encounter is designed differently, with different journeys, signposting, messaging and so on, the very fact that we are having to find our way through many different mazes undermines our agency from the very get go. As noted above, this is something that is universally ignored by 'user-centric' approaches which focus only on one organisation's service at a time, in isolation.

Many people seeking support e.g for health or financial issues end up having to make applications to many different services and agencies. Even with current 'user-centric' approach **they end up having to repeat themselves time and time again, dishing their data out to all and sundry while never gaining any real control over it, in ways that feel demeaning and disempowering and that are riddled with microstress**. These negative experiences are multiplied even further if you are trying to support another person either as a formal guardian or informal supporter or carer (See Guardianship below.)

What is really needed to enhance and enable citizen agency is a **personalised experience layer that enables individuals to interoperate with many different schemes and ecosystems via a familiar, consistent interface** that becomes second nature to them. Like driving a car. 'Personalised' because it fits that particular person.

This experience layer needs to be designed in a truly person centred way. We all lay out our homes, desks, shelves and filing cabinets the way we want to, to fit our needs, our areas of focus and our frequency of use. Why not the same with digital and online services?

Practically speaking, this means **each individual should have their own personalised cockpits or dashboards** that display the data about their life, their transactions, their accumulated proof points and so on, in the ways that they find intuitive and easy to use.

Within this, **agency means being able to use your data where and when you want, and to be able to share it easily with whomever you want safely and securely.** Here, safety and security don't only mean things like secure systems. They include data sharing agreements that are consistently laid out to a specific level in terms of scope of data, frequency of use, specific use case, GDPR declarations - and which are auditable via an audit trail that logs activity across all transactions.

Mydex has worked very hard to make agency a practical reality. But much more needs to be done. We and others are still at the early stages of developing all that is needed to really enhance online agency and agency as it relates to personal data. But the potential is huge, even if data monetisers in the private sector stay clear.





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Service commissioners for services for employers, health care providers, energy saving advisers, debt advice, money and pensions advisors and so on have big opportunities to improve service journeys and outcomes by adopting this approach.

# Guardianship

While control and agency are key to a fair, human rights approach to data, not everybody is always able to assert such control or achieve such agency - for example, those with certain illnesses and disabilities.

There are many millions of such people even in a small country like the UK, along with many more millions tending to their needs. For example, there are 16m people with disabilities <sup>1</sup>, 15m chronic health conditions <sup>2</sup>, and 4.9 million informal carers (around 60% of them women) <sup>3</sup>. That's on top of all the people working in health and social care working in the NHS, local authorities and in their service providers in the third sector. In financial services, telecommunications, utilities and third sector charitable services, those needing debt and poverty advice the numbers get larger and larger. (Government figures say there are now 14.4m people in the UK living in poverty <sup>4</sup>.)

If people are not able to act on their own behalf, then they need a proxy agency by which one individual (or individuals) acts on behalf of them. This raises many complex questions including how their personal data is collected and used.

How to help and protect those who may be vulnerable or inexperienced with exercising their own agency or delegating agency to others should be treated as an important design challenge. Mydex has been working on this for many years.

There are many problems with current standard processes.

One of the biggest problems is the gulf between informal processes where a person needing help asks other people to do things for them, versus highly legalistic processes such as Lasting Powers of Attorney that require both the individual and the helper to jump through many time-consuming legal hoops.

On the informal side, there are few if any services specifically designed to help people share information and make arrangements. They have to rely on existing tools such as phone and SMS messaging, and their very informality creates risks.



<sup>&</sup>lt;sup>1</sup> House of Commons Library: <u>UK Disability Statistics</u>

<sup>&</sup>lt;sup>2</sup> Kings Fund: Long Term Conditions and Multi-Morbidity

<sup>&</sup>lt;sup>3</sup> House of Commons Library: Informal Carers

<sup>&</sup>lt;sup>4</sup> Gov.UK <u>Households Below Average Income Statistics</u>



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Many people who are ill or frail (for example) start relying on others to undertake financial transactions (pay bills, buy things on their behalf etc). This may mean handing over passwords and other details that could be misused.

In addition, many digital terms of service (e.g. for payment cards) invalidate protections if a person acts for someone else. People do this everyday, logging into digital services using the supported person's digital identity because there is no other way they can do so without jumping through multiple bureaucratic hoops needed for setting up a formal arrangement (e.g. lasting power of attorney). These are costly and complex both to set up and to implement.

On the formal side, because public and other services are so concerned with avoiding such risks that they make the process of recognising one individual as acting on behalf of another extremely complex and difficult to set up and use.

#### **Circles of support**

To address these issues, and to enable a smooth transition from small informal pieces of support ('could you do some shopping for me? Here's my card.') through to highly formal processes like Lasting Powers of Attorney, over the last six years we have developed **an approach to guardianship based on 'circles of support'**. Some people call them 'circles of care'.

**These circles of support are modelled on what people do today, every day** e.g. have face-to-face conversations, use the phone, WhatsApp, texts and emails and share documents by carrying around piles of paper, photocopying documents and sharing access to cloud documents.

The jobs they undertake may vary widely e.g. driving the individual to appointments, paying their bills, doing shopping for them, helping them read letters, discussing things with them and others including their service providers, listening to their story. Separately and together they all build up a rich picture of the individual and a sense of what they need - far beyond what most service providers ever get to see.

Over time, managing all these tasks so that they fit together well in the person's life can become difficult, complex and even chaotic. 'Circles' are designed to eliminate this chaos and effort while building in safety and security. With them, an individual needing support can create one or more circles of support, depending on what their purpose is. They can give each Circle a name (for example, 'managing appointments' or 'domestic arrangements'), choosing who exactly to invite and deciding which tools and features they want to members of the circle to be able to use (such as shared timelines, calendars, member profiles, preferences).





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Some circles may be just with friends and family. Others may be with both formal and informal carers. Others may be small service providers who cannot afford commercial software, or staff working in front line teams serving and supporting people with their issues. Often called link workers, because of the way they use their knowledge of individuals to join dots and filter information, they often have to invest much time and effort in unproductive data entry tasks (often across more than one system) as well as administration of manual processes. This saps resources away from the front line teams serving people. Solving their own FERC (Friction, Effort, Risk and Cost) issues in service / transaction journeys unlocks capacity within existing budgets.

Individuals invited to join a Circle can be provided with an array of specific powers e.g. to manage invites, resend and forward messages, archive information etc. All those accepting the Circle invitation are automatically provisioned with their own App and personal data store.

To make the system safe and secure, each invitee/supporter agreeing to join the Circle is presented with a Basic Data Sharing Agreement (BDSA) that sets out the understanding of expectations (effectively a contract) between the delegatee and the individual doing the delegating. This starts to formalise arrangements that were previously completely informal - with implied understandings that are rarely written down.

All the data used to drive the Circle, including all the data generated via its use, is automatically lodged in the individual's and their supporters' personal data stores and is added to an immutable log with a time and date stamp and a record of any before and after changes made or actions taken. This immutable activity log provides transparency, accountability and auditability because it holds the metadata about each transaction and activity.

With some informal arrangements, this might seem unnecessary, but it's there anyway, just in case. And as the guardianship process gets more formal, for example with organisations wanting to name and verify specific guardians, it becomes essential for purposes of audit and security.

It can be useful in other ways too. For example, Mydex is currently working to co-design how members could use the activity log, in the context of delegated access to the individual's data, to append labels, tags and notes to say how they want to be notified of changes and to share elements of their activity log with others such as a professional adviser.





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In this way, control and agency are protected and promoted as an individual realises the need for, and seeks help from others in managing important aspects of their lives. Parents could start this journey for their own children as they explore their own networks as they grow and develop. The ability to record your own story of your life and reflect on it overtime will be a powerful tool for gaining a sense of coherence about their own life journey.

#### **Corporate Social Responsibility and ESG**

It's true. Some organisations have adopted corporate social responsibility and environmental, social and governance programmes as forms of greenwashing and social-washing - as PR stunts. But many CSR and ESG practitioners genuinely want their organisations to have a positive social impact and to be governed in ethical, responsible ways.

For these practitioners, Mydex platforms offer an important way to help meet one of the biggest challenges facing the CSR and ESG movements: a way to practically implement best intentions via day-to-day operations.

By ensuring that their organisations adopt the approaches to consent, agency and guardianship outlined in this Paper they can build respect, fairness, agency and participation into everything they do every day.

Issues of control, agency and guardianship are critical to service design and delivery wherever personal data is used to provide services to people as customers, citizens, members, employees, volunteers etc. It applies across nearly all roles, all age groups (including the very young and the very old) and across every sector where an organisation deals with named individuals.

The infrastructure needed to achieve control, agency and guardianship as described in this Paper is simultaneously transformational at multiple levels.

At one level, it transforms cost structures because it is based on enabling individuals to act as points for the aggregation of all data that relates to them as individuals and to act as hubs for the safe sharing of this information. By allowing data to be minted once but used many times - by enabling safe, efficient data sharing - it eliminates multiple layers of duplicated effort, delay and risk from service provision, thereby helping to reduce costs *and* improve quality and outcomes.





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At the same time, because this approach is based on empowering citizens with their data, with built-in privacy protection and GDPR compliance, it helps to counter the multiple imbalances of power and reward that currently exist in the digital economy and to rebuild trust in the collection and use of personal data.

Because it is designed to deal with the real life issues that people face when tackling complex problems in areas such as health, care and personal finance, it supports people and services currently struggling to help people where human needs are most pressing.

And, along the way, it makes life easier for those who are currently finding it most difficult: individuals needing support from others, and those providing this support whether informal (e.g. friends, family and local communities) or formal (especially front line teams working in organisations of many different types).

In achieving all the above it speaks to corporate and government policy priorities relating to corporate social responsibility and human rights. In particular **it provides organisations with a simple means to operationally implement a human rights approach to personal data and service provision,** including all the key attributes of common human rights approaches such as FREDA (Fairness, Respect, Equality, Dignity, Autonomy) or PANEL (Participation, Accountability, Non-Discrimination, Empowerment and Legality).

One of the occupational hazards of attempts to implement human rights approaches is the trap of identifying all the good things that 'should' be done without also identifying how to actually do them. This approach avoids that trap in a key area of corporate activity.

# Conclusion

We write this Paper in a context of rapid change. Right now, there is a huge amount of work and activity focused on new trust-building ways to enable better uses and sharing of personal data. These include:

- EU Data Governance Act which attempts to build "a framework to enhance trust in voluntary data sharing for the benefit of businesses and citizens."
- The European Data Spaces movement which is focused on "ensuring that more data becomes available for use in the economy and society, while keeping the companies and individuals who generate the data in control."





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- The UK's Digital Identity and Attributes Trust Framework (UKDIATF), part of a wider plan by the UK Government to make it quicker and easier for people to verify themselves and access services effortlessly using modern technology. An important development on this front is its recognition of a category of service providers called 'Holder Services' which enable individuals to hold, use and share data independently of the organisations that collect and hold data about them.
- The work of the UK Government Digital Service (GDS) to enable easier access to and use of public services, including the creation of a 'single log-in' for citizens to access Government services.
- A plethora of initiatives focused on the development of digital and data wallets, including the work of the Open Wallets Foundation "a consortium of companies and non-profit organisations collaborating to drive global adoption of open, secure and interoperable digital wallet solutions based on open source software and open specifications"
- Experiments with 'Super MyAccount' services that aim to provide citizens with more control over their data, including the ability to authorise the sharing of their data with other organisations. Open Banking is an example of this approach but there are others emerging under the heading of Smart Data.

Change is in the air. The challenge - and opportunity - is to make sure the right sorts of change happen. Our day-to-day work is showing that **it is possible to build a personal data ecosystem that is interoperable, flexible, certifiable, scalable and that is also safe, secure and consensual, taking a human rights based approach that results in genuine personal, social and economic benefits.** 

