MY DATA
my rules

From data extractivism to digital empowerment

2019
Why?
The web has evolved into an engine of inequity and division, swayed by powerful forces that use it for their own agendas. **People want apps that help them do what they want and need to do—without spying on them**, Apps that don't have an ulterior motive of distracting them with propositions to buy this or that”

Tim Berners-Lee, 2018
“The web has evolved into an engine of inequity and division, swayed by powerful forces that use it for their own agendas. People want apps that help them do what they want and need to do—without spying on them, Apps that don’t have an ulterior motive of distracting them with propositions to buy this or that”

Tim Berners-Lee,
2018¹
What?
How can digital platforms empower digital users with their own data?
How can digital platforms empower digital users with their own data?

What other data uses can be unlocked? (monetary and non monetary)
How can digital platforms empower digital users with their own data?

What other data uses can be unlocked? (monetary and non monetary)

What if we turned data into a common good?
How?
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Context: empowerment and disempowerment in the digital era

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Three inspiring examples of digital empowerment through personal data

1. Estonia

2. Cozy Cloud

3. MIDATA

### Part 3

Ten examples of social innovation and digital empowerment

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- CitizenMe
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- Meeco
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- Solid
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## Part 4-5
- Discussion & Takeaways
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Empowerment?
The act of sharing personal data such as DNA with researchers to promote societal good is seen as a desirable, empowering act.

Empowerment through Self-Expression and Data Sharing

Not only does Digital Literacy boost online users' effectiveness, it also lets them exploit their creative potential and use platforms in critical, alternative ways.

Empowerment through Digital Literacy

Empowerment through control of data

Exercising greater control and ownership over their data boosts users' online empowerment.

The role of transparency and accountability

Digital citizens can use information to decide whether they want to share their data and how they can minimise the risks of doing so.
The four principles
Breaking down data silos
Breaking down data silos

Differentiate data collector & service editor
All that is needed is an integration point that relates all the data. In the case of a map, the aggregation is of GPS coordinates, whereas in the case of Health Data, it is the individual (and his/her blood pressure, fitness data, personal genomics, MRI, prescriptions and medical history).
Breaking down data silos

Differentiate data collector & service editor

Involving citizens in the data life cycle
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<td>Once-only principle followed;</td>
<td>Proactive data collection; no consent needed for official purposes</td>
<td>Consent, through the APIs and connectors</td>
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<tr>
<td>On information systems of X-tee members;</td>
<td>No centralised database; each service has its own information system</td>
<td>Not proactive data collection</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>Held in private information system, connected to X-tee</td>
<td>Only under consent</td>
<td></td>
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<tr>
<td>Visible to citizen through State Portal</td>
<td>Transparent but consent not needed for mandated activities</td>
<td>On Cozy servers (in France) or self-hosted</td>
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<td>Among governmental agencies and service providers</td>
<td>Permission of government needed for specific uses</td>
<td>Offers OVH hosting (larger in Europe)</td>
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<td>No option for legal users; citizen’s right for non-necessary purposes</td>
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<tr>
<td>No possible in most cases</td>
<td>User’s decision</td>
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<td>Citizens can demand it</td>
<td>None</td>
<td>Only under consent</td>
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*Third parties*
Breaking down data silos

Differentiate data collector & service editor

Involving citizens in the data life cycle

Money is not the only reward
How to use the report
### List of icons used

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- The role of transparency and accountability
Mydex CIC

**Foundation**
- 2007 - Scotland

**Legal Form**
- Community Interest Company (CIC)

**Prizes & Awards**
- ISO27001 and FairData Certified

**Website and Social Media**
- https://mydex.org/
- Documentation: https://dev.mydex.org/
- Community: https://community.mydex.org/
- Publications: https://medium.com/mydex
- https://twitter.com/mydex
- https://www.linkedin.com/company/mydex-cic
- https://www.youtube.com/user/MydexCIC

**Social Impact**
Mydex CIC is present throughout Scotland, serving over 750,000 citizens and 220 collaborating organisations. They have identified over 430 use cases creating re-usable solutions to problems involving personal data, typically covering public services, health and social care, employability, financial services, utilities.
Glasgow included is a good example: a single integrated service where individuals can access many services catering to their specific circumstances via a single App powered by a personal data store. Proven impacts include reduction in friction, effort, risk and cost leading to improved outcomes, efficiency, effectiveness and satisfaction. Users report a greater sense of coherence in their lives, and greater choice and access.

**Financial Sustainability**
Individuals have free access to and use of Mydex CIC tools and a platform for the management of their identity, and the collection, storage, distribution and control of their personal data. Organisations pay a low one-off fee for every system they connect to and per citizen they connect to over the platform. Thereafter they pay an annual support fee based on the volume of services and citizens connected.

**Innovation Type**
- Enable a safe, secure and easy-to-use personal data ecosystem (including MydexD and a Personal Data Store) with the citizen as the integration point. They can view their contents and manage their connections.
- The majority come via the services they are working with, who are accessing and storing data in the personal data store.
- This allows clusters of organisations to work together serving a common cohort of citizens seamlessly, safely and securely under a trust framework and data sharing agreements that are GDPR-compliant.

**Cross-Sector Collaboration**
The Mydex CIC platform is sector neutral and work across public, private and third sector and all sub sectors.
They have been working with the Digital Health and Care Institute across the public, private and third sectors for 5 years now to help develop truly person-centric health services where data from many specialists is incorporated in the individual’s health record.

**Replicability and Scalability**
The platform has been designed to be global in application and is already being used across regions and cities internationally. As a secure certified cloud-based distributed platform, it should scale easily and safely.
What the foregoing reveals is that citizen empowerment is now a burning issue. There are reasons for thinking that it is set to arouse great social and business interest. It may well be that digital awareness beyond data extractivism, is, from now on, an unavoidable discussion.
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Liliana Arroyo - Obaid Amjad - David Murillo