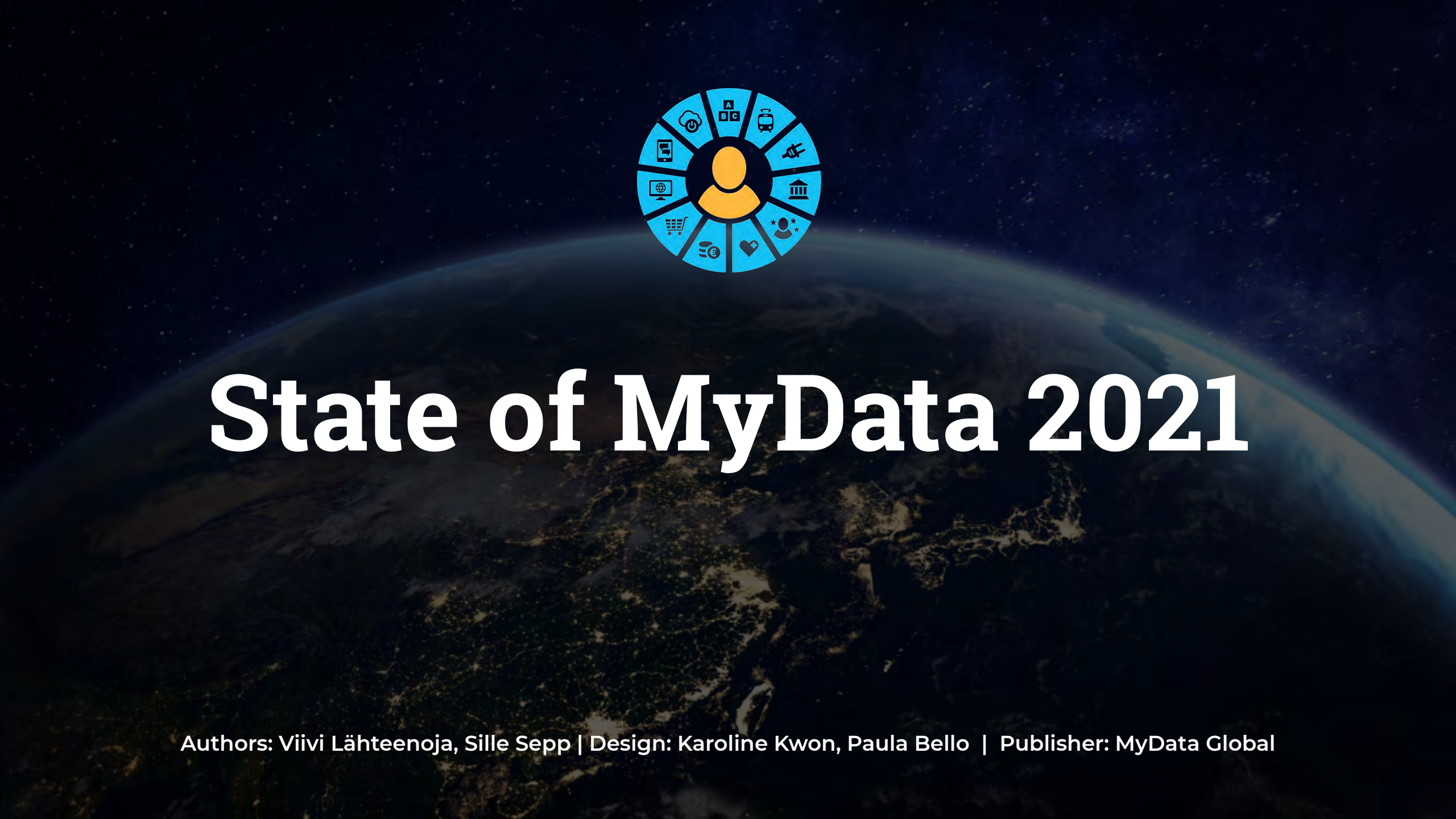

State of MyData 2021

Authors: Viivi Lähteenoja, Sille Sepp | Design: Karoline Kwon, Paula Bello | Publisher: MyData Global

Foreword

We at MyData Global have a dream and a mission to bring about a more fair, sustainable, and prosperous digital society for all. Thousands of individuals and organisations around the world are collaborating to make that dream and mission a reality. I'm grateful to the authors of this publication and all contributors for providing a snapshot on how we are moving forward on this journey together.

While people across the globe have experienced and continue to experience great hardship in the past year, we've also seen significant advances in the way communities around the world think about, use, and share personal data. Looking into the near future, we're confident that we will see acceleration of the shifts towards a more human-centric approach to personal data across sectors, domains, and perspectives. Hopefully this publication helps to understand the landscape of MyData and serves as a useful guide for leveraging MyData in various contexts, encouraging further work in governance and standardisation, and highlighting the important pillars crucial for implementing MyData in practice. As we continue forward on our path, let's "make it happen, make it right!"

Helsinki, 22 April 2021

Teemu Ropponen, *General manager, MyData Global*

Acknowledgements

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- **Lieve Vereycken (Co-Inpetto)**

1. Executive summary

MyData is alive. It has roots all over the world and history that spans sectors and domains. It's also not a finished product. Always evolving and proactively seeking to understand more and better, MyData also has an as-yet unwritten future path.

This publication is intended to give the reader a snapshot of some of the most interesting and relevant developments in the MyData movement as it is in 2021 in chapters 5-7.

Chapter 5 discusses the ongoing journey of interoperability, a metaphor developed in the context of the highly active MyData operators work, and describes an emerging dialogue between approaches to interoperability through efforts in **governance** on the one hand and **standards** on the other.

Chapter 6 highlights two strengthening trends in MyData applications: the importance of **design** as cross-cutting the business, legal, tech, and societal perspectives; and the role of **cities** as pioneers in MyData implementations.

Chapter 7 takes a bird's eye view of the MyData discourse space and highlights some key topics a) that are reaching **maturity**, b) where we're seeing **convergence** of opinion, c) which are subject to **tensions** and disagreement, and d) that seem to be **missing** or underrepresented currently.

This snapshot is framed on one side by chapters 3-4, which aim to leave the reader with a sense of some relevant strands of MyData history (ch. 3), and how MyData concepts relate to the wider context and conversations that humanity is engaged in right now (ch. 4).

On the other side, framing is provided in parts of chapter 7 and chapters 8-9 which point towards potential future lines of MyData development (ch. 7), as well as calls to action for how we, you and I, can work to further develop and promote MyData in our lives and work (ch. 8), and offer resources for doing do in (ch. 9).

2. Introduction

Who this publication is for

This publication is intended for you, who are interested in MyData. You have an interest or expertise in personal data and you are enthusiastic about its responsible and ethical use. You have a basic understanding of MyData as a human-centric approach to personal data and its management. You have probably heard talks about or referencing MyData, you might have read the MyData declaration and maybe some of the white papers. You may have attended one or more editions of the MyData conference (2016, 2017, 2018, 2019, 2020), joined the MyData Global slack space, and/or become a member of MyData Global.

In short, whether or not you consider yourself an advocate, you'd like to understand what's going on with MyData a little better and figure out how it's relevant for you, your and your organisation's work, and society at large.

How this publication came to life

This publication is inspired by the MyData Online 2020 conference programme with its wealth of content from all regions of the globe and from various perspectives across the business, legal, tech, and society (BLTS) perspectives and beyond. This is not, however, a conference report. The authors have collected here strands of MyData thinking and doing also from the activities of the MyData Global local hubs and thematic groups, MyData Global's individual and organisation members' work, other organisations whose work complements MyData Global's, and individual thinkers and doers in the wider movement for a human-centric approach to personal data. You can get a snapshot of the size of the community, and explore the list of MyData Global's organisation members in Annex B and Annex C.

The authors' goal is to help readers *connect the dots* between the various threads of thinking and doing in the vibrant MyData community and also to highlight their relevance to some of the global narratives that affect us all.

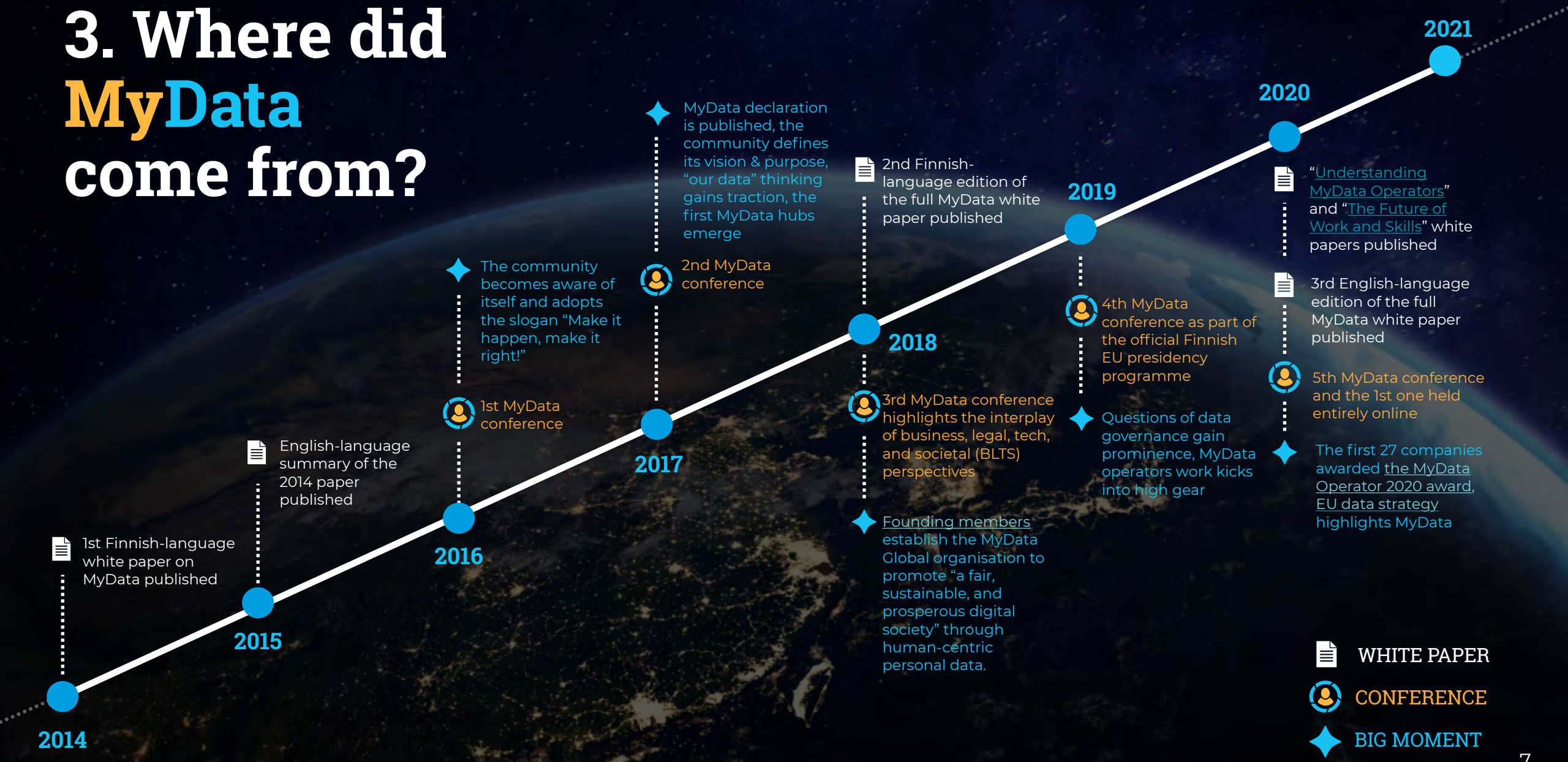
This publication aims to ...

- Increase understanding of the current state of MyData thinking within and beyond the MyData community.
- Help readers situate themselves and their thinking and doing in the wider context of MyData.
- Catalyse new thinking and doing spurred through the insights presented in this publication (through, e.g., new or invigorated MyData Global thematic groups).
- Increase collaboration between MyData Global and other organisations through a shared understanding of how their work complements each other.
- Provide an outreach tool for people and organisations who want to spread MyData thinking and doing in their networks.

It does not intend to ...

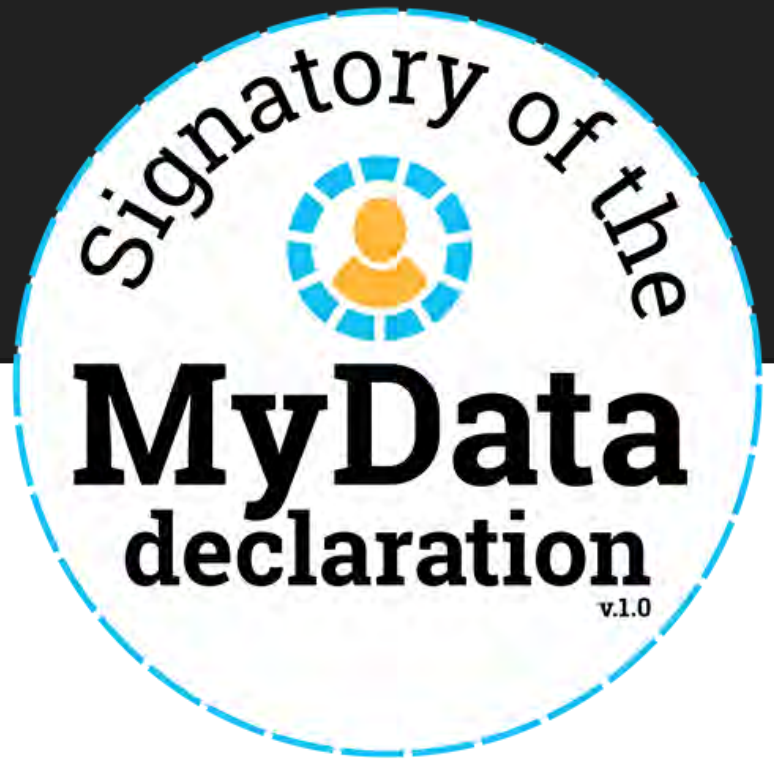
- Provide an introduction to MyData thinking for entirely new audiences.
- Commit MyData Global to specific positions on controversial issues within the community. In these cases, this publication aims to describe, not to prescribe.

3. Where did MyData come from?



Declaration

As a result of international collaboration, in 2017, the MyData community produces the MyData declaration, including the major shifts the community works towards, the roles of a personal data ecosystem as envisioned by MyData, and the six principles underlying MyData thinking and doing. This declaration is explicitly framed as a first version and a living document, to be revised as the need arises.

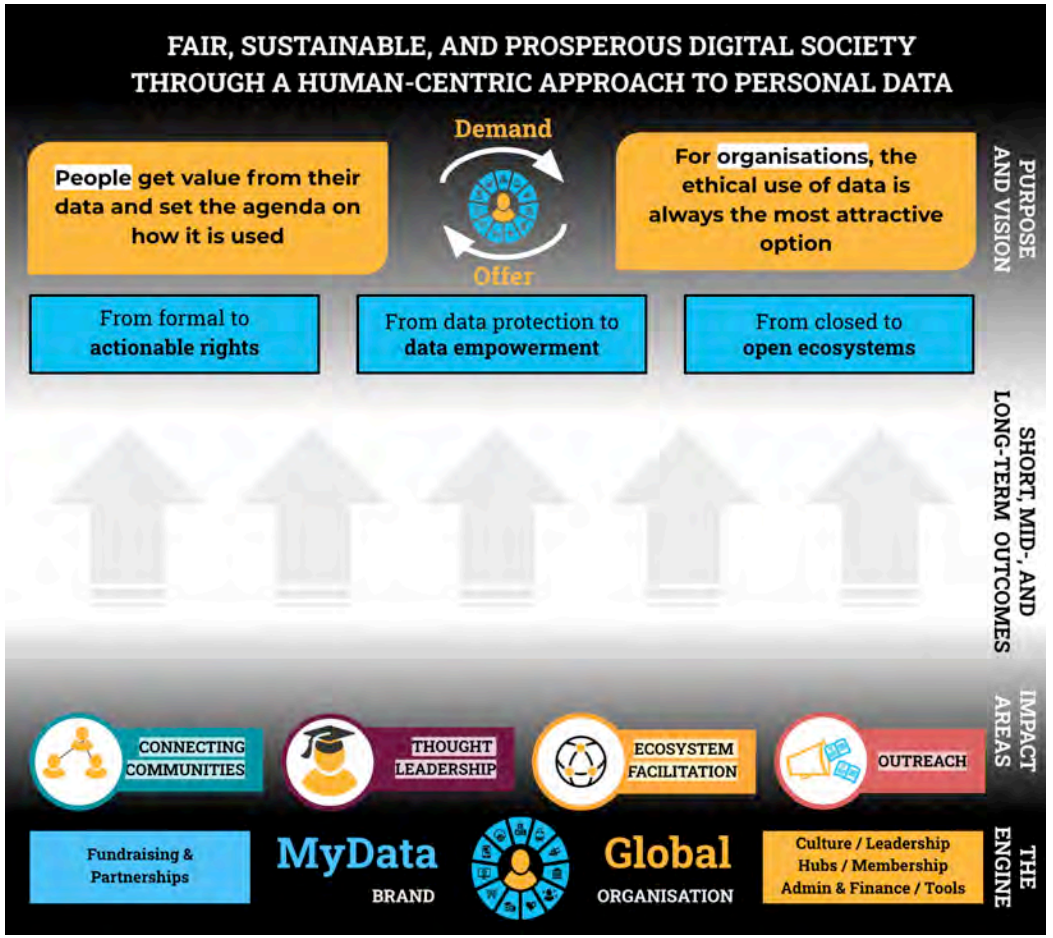


774 signatories

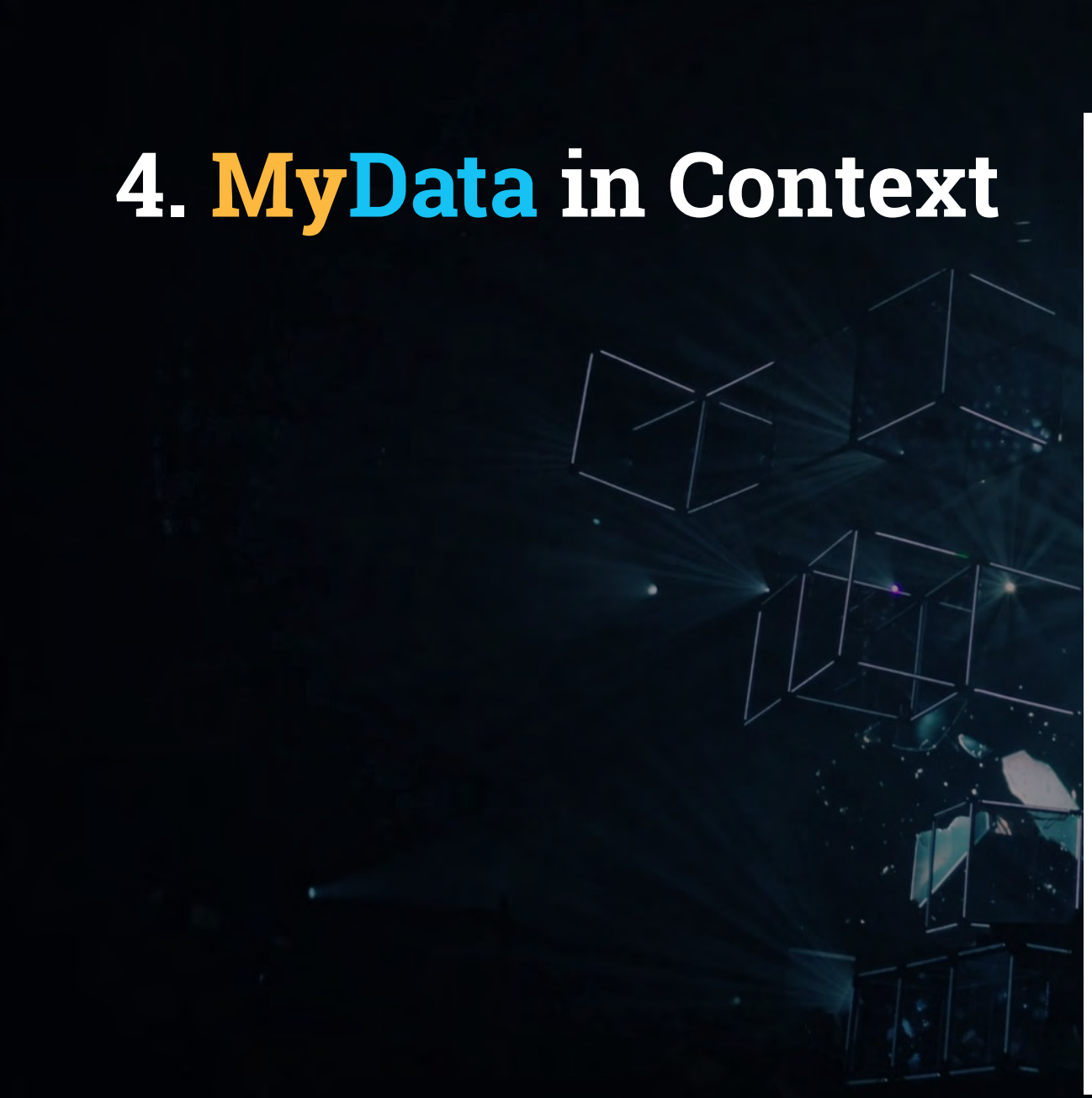
As of April 2021

Theory of Change

After the founding of MyData Global association in late 2018, the new organisation defined its vision for success and set off to establish its strategy. The strategy is summarised in the MyData Global Theory of Change, included in Annex A, which outlines the organisation's strategic path towards the three shifts outlined in the declaration in the short, medium, and long term.



4. MyData in Context



This chapter illustrates the connections between core MyData concepts themselves as well as their relevance for the “big conversations” that humanity is currently engaged in.

Everything MyData does is anchored around the idea that a **human-centric** approach to personal data will bring real **benefits and value** for individuals and groups as well as organisations of all kinds. These concepts are not further explicated in what follows, but taken as foundational to all.

MyData concepts
are concepts and values that are central to MyData thinking in various contexts. These are things you’ll find coming up in MyData-related discussions.

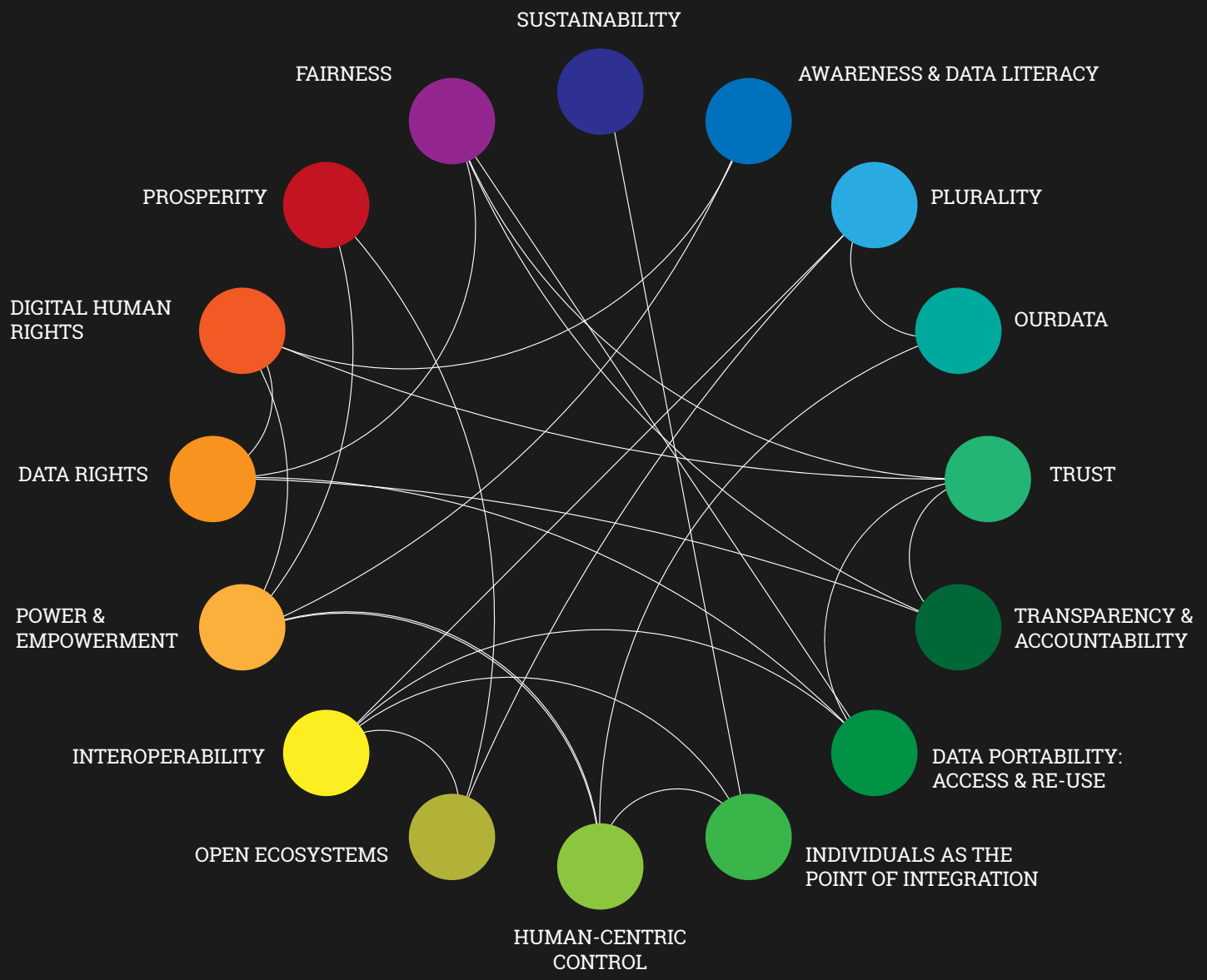
Big conversations
are ongoing societal discussions. These are things you’ll read about in the news and find yourself discussing with those around you.

MyData Concepts & Connections

Click the topics to read more...

BIG CONVERSATIONS

- Climate change
- Economic inequality
- Artificial intelligence
- COVID-19 & future pandemics
- Global geopolitics
- Big Tech & the future of democracy
- Social justice



Sustainability

Critical to getting MyData right, questions of sustainability are raised in different contexts around personal data. It is understood widely to encompass ecological as well as societal and ethical sustainability (consider e.g., United Nations' Sustainable Development Goals). Furthermore, it includes areas such as the environmental effects of technologies (e.g., certain blockchain technologies) and the discriminatory effects of certain business practices. Sustainability is however often overlooked as a key component of the MyData approach.

MyData concepts also enable innovative services like, e.g., carbon footprint calculators, which can empower individuals to make better-informed consumption decisions and align their actions with values like sustainability.

CONNECTIONS

Individual as the point of integration
Climate crisis

Fairness

Fairness is one of the essential qualities that characterise the digital society that MyData works toward. Data can be a force in the quest for fairness and fight against inequality and discrimination of all kinds. People and groups controlling the data about themselves can harness that force for their benefit: to help make their case in front of decision-makers and build innovative solutions to address issues affecting themselves.

Fairness is a broad concept that includes values like *proportionality* (e.g., of responsibilities and rights), embracing *plurality* of cultural and social approaches to issues like trust, encouraging a *diversity* of voices and representations, *equity* (e.g., between parties in data relationships), and *inclusion* of all relevant and affected parties in data ecosystems.

CONNECTIONS

Data portability & access
Trust
Social justice
Artificial intelligence

Prosperity

One of the core ideas of MyData is that human-centric personal data can create prosperity for entire societies through innovative and ethically sound business models. One of the most crucial challenges for MyData in 2021 is to demonstrate the feasibility of these kinds of business models as challengers of the status quo.

Prosperity can also come in the forms measured by metrics other than economic growth and GDP. Striving for prosperity through MyData approaches takes a holistic view of prosperity and includes features like health, happiness, and other important sources of prosperity.

CONNECTIONS

Power & empowerment
Economic inequality
Global geopolitics
Social justice

Digital human rights

Digital human rights are the application of human rights-based thinking to the digital era. Some established rights, like the right to privacy, are easily translated into and understood within a digital context, while others, like the principle of equal dignity, are harder to pinpoint. Further, it seems inevitable that new rights are needed, such as the right to uncompromised internet access. MyData is part of the larger movement in support of digital human rights addressing issues such as the digital divide and digital colonialism, the rights of indigenous peoples and marginalised populations, and children online.

Digital human rights are also one of three broad approaches currently dominating the global data economy.

Emphasised most heavily in the EU, the rights-based approach to data can be contrasted with an emphasis on free markets and corporate interests (most heavily present in the US) on the one hand and an emphasis on state control (most heavily present in China) on the other hand. MyData has roots in the European, rights-based tradition, although it recognises that a plurality of these cultural traditions and approaches is essential for any successful human-centric project.

CONNECTIONS

Data rights
Awareness and data literacy
COVID-19 & future pandemics
Big Tech & the future of democracy
Global geopolitics
Power and empowerment
Economic inequality

Data rights

Data rights are specified legal rights with regard to personal data. The most common ones are the rights to information, access, rectification, erasure, restriction of processing, data portability, objection, and not being subject to automated decision-making. One of the key shifts that MyData is working towards is making these rights more and more actionable, easy and convenient for people to use.

CONNECTIONS

Digital human rights
Data portability and access
Transparency & accountability

Power and empowerment

One of the key insights of MyData is that the current systems of personal data are asymmetrical and disproportionately favour companies and other organisations at the expense of individuals and groups of people. MyData is an effort to make these power relationships between people and organisations more equitable.

MyData also recognises that power asymmetries exist between individuals and groups of people whereby skills, knowledge, and opportunities to exercise power are not equitably distributed. It's also clear that market and political power, as well as data, is asymmetrically and at times unfairly distributed or concentrated in the context of organisations.

As a fundamentally constructive force, MyData Global's strategic efforts to correct for undesirable asymmetries in power focus on empowering the currently disempowered (rather than focusing on tearing down the currently powerful). This empowerment has several layers. Perception of one's capacity to influence, skills and knowledge needed to exert influence, and acts of influencing are all needed for empowerment - these are what MyData seeks to enable and promote.

CONNECTIONS

Human-centric control
COVID-19 & future pandemics
Big Tech & the future of democracy
Global geopolitics
Social justice
Digital human rights
Awareness and data literacy
Prosperity

Interoperability

Interoperability – widely understood to include semantic, technological, organisational, and regulatory layers – is one of the most critical aspects of making MyData happen *and* making it right. Interoperability across the BLTS perspectives is necessary for data to be useful across various (re-)uses; for multiple systems, organisations, and ecosystems; across different business models; and between jurisdictions.

Interoperability is the antidote to current trends of data hoarding, gatekeeping, and lock-in effects, which unfairly advantage already very large and powerful organisational actors.

Two major strands of MyData thinking and doing that rely on and call for increased interoperability are in the fields of ***standardisation*** (mainly but not exclusively addressing semantic and technological issues) and ***governance*** (mainly but not exclusively addressing organisational and regulatory issues). See more in chapter 5.

CONNECTIONS

Individual as the point of integration
Open ecosystems
Data portability and access
Plurality

Open ecosystems

MyData advocates for open ecosystems, which enable people to have freedom of choice between different service providers and engage with those who serve them the best and according to their preferences. In these ecosystems, also smaller businesses and other actors have more opportunities to participate. Further, open ecosystems enable alternative operating models to vendor lock-in and walled garden models, they require interoperability, and they enable positive network effects to benefit whole ecosystems and all their participants.

CONNECTIONS

Interoperability
Prosperity
Plurality

Human-centric control

In contrast to organisation-centric control, human-centric approaches are designed to enable and facilitate humans to exercise control over what happens with personal data about themselves. In order to enable individuals and communities to have more agency in pursuing their goals on their terms, they should have practical means to negotiate how data about them is collected, used, and shared. Human-centric control is about being able to design one's experience in the digitised context meaningfully and to participate (or not!) in the data handling processes where needed and wished. And: it's never desirable to require people to be experts on all things related to data in order to benefit from, and not be harmed by, personal data and its use. Companies and governments have responsibilities to ensure the person's interests are considered when control over personal data is exercised.

CONNECTIONS

Power & empowerment
Individual as the point of integration
OurData

Individual as the point of integration

The principle of the individual person as the point of integration in terms of all the data that exists of them is a keystone in enabling human-centric control of personal data. It's also a strong connection point between MyData and various initiatives in digital identity, such as self-sovereign identity. Without functional, ethically sound, and easy-to-use identity solutions that connect data and its flows to the individual concerned, human-centric control over those data flows is impossible.

Questions of (digital) identities, in turn, are deeply connected with important questions of social justice and digital human rights affecting especially marginalised populations and indigenous peoples. "Who gets counted, counts."

CONNECTIONS

Interoperability
Human-centric control
Sustainability

Data portability: access & re-use

Data rights like portability and access enable the re-use of personal data to benefit people and societies. This re-use can take the form of enabling new innovative services by novel combinations of data or by brand new technological applications. Through enabling legislation that grants individuals these data rights, and practical ways to exercise them, personal data re-use for improved services and quality of life can empower individuals, groups, and whole societies with data.

CONNECTIONS

Data rights
Interoperability

Transparency & accountability

Transparency and accountability are principles whose implementation is essential for trust in data, ecosystems and other actors. Individuals and communities need to have the confidence that the organisations to which they've entrusted their data use it according to the people's wishes and interests and, if needed, to have the practical means to call them out on breaches of this responsibility. While regulatory mechanisms and moral standards for corporate responsibility are the key enablers for ensuring transparency & accountability, they need also to be incorporated in the design of all the technology involved as well.

CONNECTIONS

Fairness
Data rights
Trust

Trust

Trust is integral to what is needed to make MyData happen, while it is also something that MyData-based solutions generate by making things right. MyData also recognises that trust is always a two-way relationship. It's not enough to make people trust more, it's also imperative to promote the factual trustworthiness of data-handling organisations. As trustworthiness becomes increasingly considered an advantage in the market, crucial for organisations to keep working towards incorporating the principles of transparency and accountability in practice in order to demonstrate their trustworthiness.

CONNECTIONS

Fairness
Transparency & accountability

OurData

OurData thinking has been evolving in the MyData community for some years in recognition that not only are we social creatures but that also much of the data about us is relational and created in interactions with each other. OurData thinking emphasises collective benefits and potential harms that can result from personal data use. Concepts like group privacy and collective bargaining are also central to OurData thinking.

CONNECTIONS

Plurality
Human-centric control
Social justice

Plurality

The human-centric approach that MyData is an example of must account for the plurality of humans and their values. Plurality means recognising cultural and individual differences in preferences and values regarding questions like whom to trust with what and how much transparency is necessary and enough when it comes to data handling. Plurality means allowing for and encouraging the development of diverse approaches to shared challenges.

CONNECTIONS

OurData
Open ecosystems
Interoperability

Awareness and data literacy

Navigating within a digitalised and data-based world requires a certain level of awareness about how data ecosystems and economy function, and understanding of and skills for how to make better use of data for personal use as well as professional life. Promoting this kind of awareness and data literacy is a form of empowering people and groups.

CONNECTIONS

Power & empowerment
Digital human rights

BIG CONVERSATIONS

Climate crisis

Climate change is one of the key challenges of our time and it requires joint efforts to prevent further strain to the environmental ecosystems and mitigate the already unavoidable consequences incurred. There are numerous initiatives empowering individuals and organisations to reduce their carbon footprint by providing precise data-based recommendations, aiming to help people and organisations to change their behavior and practices to more sustainable ones. Data, digital infrastructures, machine learning, AI etc. have a vital role in helping us succeed.

While investing in these digital solutions, it's important to also stay attentive to the environmental footprint of tech itself to avoid contributing to the problem we're trying to solve.

CONNECTIONS

Sustainability
Fairness
Artificial intelligence
Power & empowerment

Economic inequality

MyData aims to counter the global processes that are increasing economic inequality by promoting a more level playing field for companies of different sizes in the personal data economy and more balanced and fair relationships between people and organisations. Further, personal data is crucial to understanding better the implications of digitalisation to global trade, and addressing the effects it may have on exacerbating economic inequality between the Global North and South.

CONNECTIONS

Fairness
Prosperity
Digital human rights
Power & empowerment
OurData

Artificial intelligence

As its promises and perils are being debated worldwide and in different contexts, MyData recognises that ever-increasing amounts of personal data will be used as fuel for developing and training machine learning and AI applications. It's important to ask ourselves what role will we, as individuals whose data is being used, have in the symbiotic existence of AI and data about ourselves, and how do we empower individuals and communities and avoid depriving them of agency.

CONNECTIONS

Fairness
Social justice
Awareness and data literacy
Plurality
Trust
Transparency & accountability
Human-centric control
Power & empowerment

COVID-19 & future pandemics

The global COVID-19 pandemic highlighted the state of our national, regional, and global systems' resiliency in dealing with such crises. Further, it put on the forefront heated conversations about the potential use of personal data in, e.g., contact tracing apps and immunity and vaccination passes. These debates have been surrounded by heightened concerns around the loss of privacy, lack of individual agency, and social justice. Balancing public health justifications for surveillance and individual and collective rights to self-determination is also affecting how the "new normal" will look for different societies. MyData emphasises the fact that we do not have to choose one over the other – we can leverage personal data and protect individuals' rights and interests at the same time.

CONNECTIONS

Sustainability
Fairness
Digital human rights
Data rights
OurData
Human-centric control
Transparency & accountability

Global geopolitics

Global geopolitics is increasingly moving to the digital realm. The European data strategy stresses digital sovereignty and seeks to increase Europe's share of the global data economy, currently dominated by the US and China. Ethical considerations like privacy rights and economic interests get easily conflated with geopolitical ambitions, and cyber- and hybrid warfare are the new faces of global conflict. Personal data is at the centre of much of these developments: who gets to access data about whom and where, and do what with it.

CONNECTIONS

Digital human rights
Prosperity
Power & empowerment
Open ecosystems
Transparency & accountability
Big Tech & the future of democracy

Big Tech & the future of democracy

Concerns over the proliferation of "surveillance capitalism", an economic system centred around the commodification of personal data with the core purpose of profit-making, and first described by Shoshana Zuboff, are growing in intensity. It's becoming more and more obvious that large tech corporations ("Big tech" or "GAFA" or "BAT" or the like) have increasing capacity to manipulate individuals and groups not only to maximise profit but also to affect core democratic processes like elections through spreading mis- and disinformation and other targeted, politically motivated campaigns. This has implications for the very core of modern democracies as well as other political governance systems.

CONNECTIONS

Prosperity
Global geopolitics
Social justice
Power & empowerment
Transparency & accountability
Trust

Social justice

How does social justice look in the digital age? Access to the internet and digital tools has the potential to increase diversity and inclusivity, and to empower individuals and communities to participate more equitably in society. On the other hand, the digital has also enabled new forms as well as vehicles for hate and discrimination.

MyData-related technologies like those for digital identities and practices like algorithmic decision-making based on historical (personal) data are to be critically examined from the perspective of whether they promote social justice if we are to build fair digital societies for all.

CONNECTIONS

Fairness
Sustainability
Prosperity
Digital human rights
Power & empowerment
Big Tech & the future of democracy
Artificial intelligence
OurData

5. Journey of Interoperability:

Paths of governance and standards

Introduction

Interoperability is one of the most critical aspects of making MyData happen and making it right. Interoperability across the BLTS is necessary for data to be useful across various (re-)uses; for multiple systems, organisations, and ecosystems; across different business models; and between jurisdictions.

Two major strands of MyData thinking and doing that rely on and call for increased interoperability are in the fields of **standardisation** and **governance**. A dialogue between governance and standardisation is emerging where different parties prefer to emphasise one over the other. The differences in emphasis are driven both by appeal to the perceived practicality and pragmatism as well as by the perceived conceptual primacy of the preferred points of emphasis for reaching the desired goal.

This fictive dialogue illustrates the different points of view of governance and standards on their shared journey towards interoperability.

Governance

Standards

Macro

Technology governance

Meso

Across organisational boundaries

Micro

Enterprise data governance

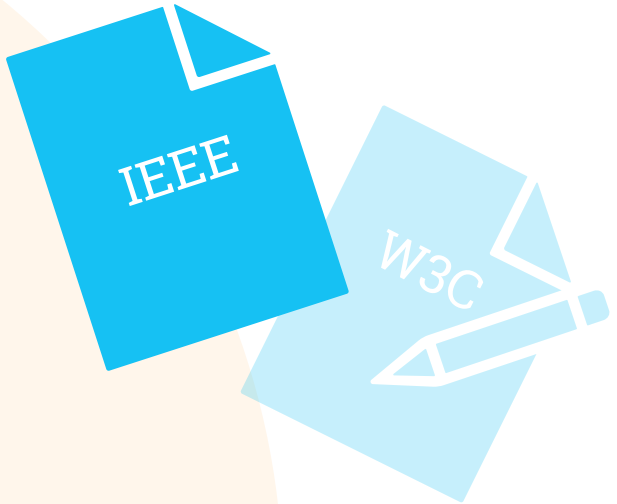
3

People use the term “data governance” to mean a bunch of different things, so let me describe how I’m using it in this context.

On a macro level, there are broad terms like “technology governance” that refers to how technology in general is or should be developed. On the other hand, data governance as part of “internet governance” is usually used to refer to political concepts in international relations.

On a micro level, data governance as “enterprise data governance” is used to refer to the practices and policies governing data handling inside a single organisation.

What I’m talking about here is a kind of meso level of data governance: it involves data handling across organisational boundaries but does not necessarily have an international or political implications.



4

I think that, like data governance, the word “standards” can also be interpreted in different ways. Here, I use the term in a very wide sense. There are technical standards that are developed and maintained by international organisations like IEEE, W3C, and ISO. There are also less strictly technical standards like standard processes, best practices, codes of conduct. This is where, sometimes, the conversation gets confused with what’s also considered governance.

5

Yes, and it's interesting that sometimes, even though we are speaking of very similar things, there can be significant differences of opinion on which of "governance" or "standards" is more primary or important. Take for example the case of interoperability. It's something widely understood as a necessary enabler for much of data innovation, as that innovation depends on the cross-organisational sharing and use of data.

6

You're right! The way that I see interoperability, namely as functioning primarily on the levels of technology and semantics, is impossible without robust technical standards. In fact, there's little need for anything else if the right standards are in place and widely adopted. This will mean that we'll have achieved interoperability. That's why it's so important to focus on standardisation efforts.

7

That's interesting! The way I see it, we need governance in place both before and after standards are effectively developed. It's needed before in order to coordinate various similar efforts. It's also needed after, as the adoption of standards, needed for interoperability, also requires coordinated efforts. And so when I speak of interoperability, I also mean organisational and regulatory aspects. Organisational governance, including work towards interoperable business models, is needed for the management of infrastructure into which standards feed and which they build on. Further, regulatory interoperability on some level is necessary for cross-country and cross-sector data sharing and use to be facilitated by jointly adopted standards.

8

It seems that both standards and governance are needed for different aspects of interoperability to be realised. There might be some cases where the need for standards is more pressing and relevant and other cases where the situation is reversed.

9

Agreed, and I'd go further and say that the balance between the two is always dynamic as technology develops and innovation progresses. Especially in those cases I mentioned, where cross-country or cross-regional data sharing and interoperability become a need, we must find ways of negotiating different interests, and that's to me what governance is about.

11

A fully democratic model of governance is an interesting concept and I would argue that it has some drawbacks. For now, the standards aren't in place that would technically allow for such agents to function. Second, the idea that trust is a bug and can be entirely eliminated seems unlikely. And as long as trust is necessary, as long as direct control over all the data about me is not possible, we need those ways of negotiating different interests I mentioned.

10

For sure. I will say this further thing in favour of emphasising standardisation efforts, though. A truly democratic way of governing data means that each individual, through a self-sovereign identity and a self-sovereign agent, can directly exercise control over what happens with the data about themselves. This can be achieved by a mature set of well-formed standards. And it means that we don't have to rely on, or trust, others to do as they say. Distributed technologies enable us to know that they behave the way they ought to.

12

Yes, and all of that only goes to show that we need more work on standards, development and adoption, for us to eventually reach the goal of full self-sovereignty.

13

As I mentioned, I think a model of governance, which is what full self-sovereignty and direct democracy represent, is not without its drawbacks even in its ideal and fully realised form. To me, it seems to place too much burden on the individual at the centre of the data to make decisions for which most people are not equipped or in which they aren't even interested.

15

So in my view, these clubs or cooperatives are an example of what I mean when I say that we need data governance in place to ensure that the different actors in data ecosystems act in a trustworthy manner.

Another example of what I mean are what the EU Data Governance Act calls "data sharing service providers" or "data intermediaries" and what MyData calls entities with the role of "MyData operator".

14

For sure, not everyone will want to be able to exercise direct control over all aspects of data about themselves. This is why structures like decision-making clubs or cooperatives, which collectively make decisions based on like-minded members' preferences and interests, would serve those who need support.

16

Yes, and when I speak about self-sovereign agents, I mean the person themselves acting in the role of "MyData operator".

17

I understand, so the person themselves might provide for basically all the functional elements of a MyData operator by themselves, as long as the proper standards are in place.

What's missing for me in this picture is the layer of infrastructure, which cannot be provided by self-sovereign individuals. MyData operators can also be understood as providing precisely this infrastructure, and this is why I consider them necessary. Of course the existence of MyData operators infrastructure does not exclude the possibility of self-sovereign agents as operators plugging into that infrastructure and leveraging it to function.

19

Agreed!

18

I see you've introduced a new term into the discussion, "infrastructure". I think that deserves a treatment and a discussion of its own, some other time.

6. Strengthening Trends:

Importance of design & cities as pioneers

The importance of design

The cross-cutting importance of design is emerging as an even stronger trend. Design is becoming recognised more and more widely as much more than plans and specs, shapes and colours; it is becoming highlighted as addressing and embodying fundamental questions of intentions, values, commitments, and biases across the BLTS perspectives.

Key insights from design thinking in MyData

We cannot only think of the experience of the user, but also the experience of the partners and enablers of the ecosystem. *The first customer is the ecosystem.*

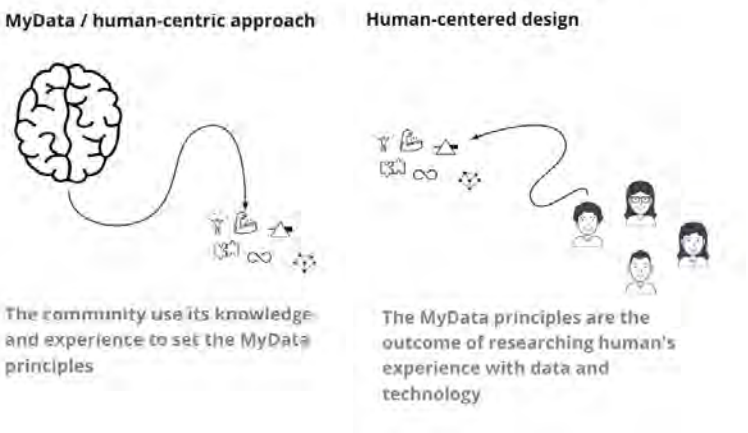
For MyData to become a reality, we need to really engage the enablers, who are not experts. We need to articulate the *human stories of how my data would make people's lives better*, one person at the time, rather than only focus on what the technicalities of MyData solutions are.

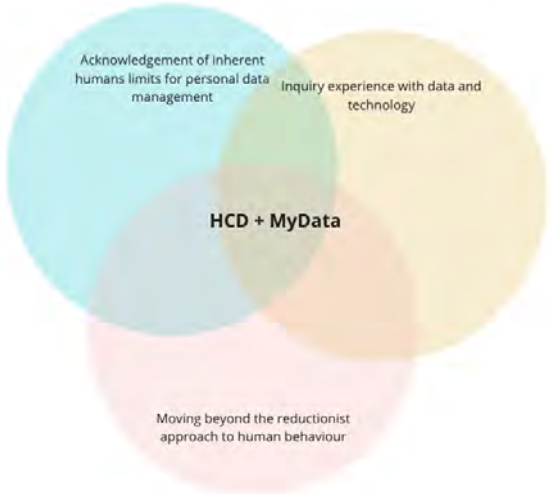
It is not enough that a solution is ethical or MyData-aligned, it must be *enjoyable* (fun, engaging), *easier* (than whatever is there today) and *functional* (no issues). Otherwise people will not use it, even if there is a moral imperative to do so.

Human-centered design (HCD) and MyData design

Combining top-down and bottom-up approaches

- MyData approach aims to give human control by shaping the system according to a set of principles that comes from different fields of knowledge of which system-design is prominent (top-down)
- HCD approach suggests that a system that is designed for humans should also reflect certain values, personal significance and cultural aspects that drive people's relationship with data and technology (bottom-up)





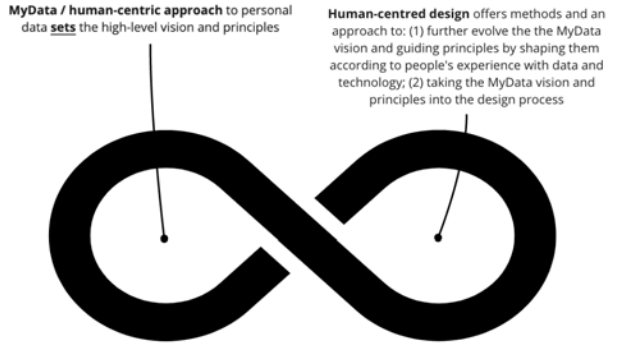
Three lenses of HCD in the MyData field

Applying HCD to the context of MyData

From a HCD perspective, the concept of MyData can emerge at the intersection of 3 ways of looking at the relation between people and data. These are: the role played by (1) inherent human limitations and (2) people's inner motivations and personal values that drive data disclosure behaviour and which (3) may not emerge through the linear cause-and-effect model of behavioural lenses.

Merging approaches: MyData + HCD continuum

- Merging MyData and HCD approaches means to embrace the complexity which lays behind our multi-layered relationship with technology and data
- Doing so requires to apply HCD methods to the context of MyData
- Both approaches are indeed complementary and can benefit from each other — MyData principles need to be tested and reviewed in the light of individuals' experience with data.



Putting "human-centered design" and MyData / human-centric approach to personal data into a continuum

MyData-aligned design methods

User centred = personas

User journey centred = design thinking

Design solution centred = UX blueprint, patterns, building blocks

See more examples

Cities as Pioneers

In recent years, it has become evident that cities can play a significant role in developing proactive data-based services and other innovative practices based on MyData principles. Furthermore, they have an important role in governing data and AI locally and complement national and international governance frameworks and initiatives from the private sector. This is based on three main observations.

First, **cities as urban environments** are fruitful testing grounds to develop and pilot innovative technological solutions and services. People living in a city have various lived experiences in the context of the built environment, transport and mobility, social services etc, that give a basis for a number of use cases to pilot. Furthermore, cities combine a myriad of stakeholders, policies, and technological infrastructures that need to work together to enable a functional city.

Secondly, **cities as public administration entities** are important data holders who have access to a wealth of personal data about their citizens and visitors (in addition to non-personal data about the city). Leveraging that data can give meaningful insights to improve local governments' ability to develop smarter and more functional services and provide value to their citizens and visitors. Local governments have a responsibility to stay accountable to their citizens and a duty to act in those citizens' service. Further, they are more immediately and tangibly present in their citizens' lives than higher level governments like regional and national authorities. This makes cities ideally positioned to carry out duties of data stewardship with the public as their primary beneficiaries. Furthermore, big enough cities can catalyse sufficient investments to realise their strategies to develop more human-centric digital services.

Thirdly, **most cities realise that they are just one city, among others.** To provide value to their citizens, businesses, and visitors, they see a need for interoperability in the wider ecosystem of services (for direct utility, convenience, cost reduction etc.). This is particularly relevant for cross-border cities, where a relevant share of the local population regularly commutes between different cities (and countries). To reduce friction, interoperability across the ecosystem is needed.

Yet, this potential doesn't come without challenges. Questions around trust, governance, and interoperability prevail. How are citizens' data rights protected when providing proactive services through technologies like predictive data analytics, algorithms, and machine learning? Whose voices are heard when developing services and making decisions around their implementation? How are the potentially conflicting interests and responsibilities (crudely put: staying accountable to the public vs. maximising profit) managed in public-private partnerships? To what extent are the technical infrastructures and business models of services provided in one city interoperable with services provided in other local ecosystems?

Several cities and coalitions are seeking answers to these questions and piloting MyData principles in practice. Some forward-thinking cities pioneering human-centric, MyData approaches to personal data are Oulu and Helsinki in Finland; Lyon, La Rochelle, and Nantes in France, Zug in Switzerland, Ghent and Antwerp in Belgium.

Furthermore, many cities are taking up various initiatives for responsible approaches to data and AI, like Barcelona in Spain and Montreal in Canada; New York City organising a Data Assembly to engage citizens toward understanding expectations and co-creating solutions; City of Berkeley enforcing ethical and standardised AI adoption and use, and many others.

Use Case

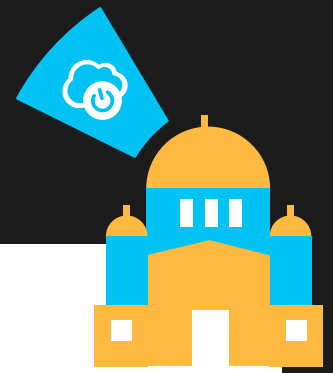
Mobility as a Service

From a human-centric perspective, citizens should be able to use various mobility services seamlessly. To enable that, personal data needs to flow, or roam, between various services, and across city, regional or country borders.

The My Mobility Profile project in France aims to make mobility practices more sustainable and smoothen the user experience for citizens. Furthermore, several cities & regions in Belgium, the Netherlands, Germany and Luxembourg are piloting cross-border personal data sharing use cases between the countries to empower the individual and to reduce friction in mobility. Both of these follow the Mobility as a Service concept.

Use Case

City as an Operator



The city of Helsinki is putting MyData principles at the core of its digitalisation efforts. As an effort to implement these principles in practice, the city seeks to offer its citizens the possibility better to manage the personal data about themselves that the city collects. Partnering with a Finnish company, Helsinki is developing the technical capacities to function in the role of a MyData operator. This capacity will allow for better personal data sharing based on citizens' consent.

As the city wants to ensure interoperability, it's working closely with the Open and Agile Smart Cities (OASC) network to develop Minimal Interoperability Mechanisms (MIMs), i.e., universal tools for achieving interoperability of data, systems, and services between cities and suppliers around the world. The city of Helsinki is leading the work on the Personal Data Management (MIM4).

7. Where do the stars align?

Maturity

Convergence

Tensions

Missing discussions

MyData is an idea that evolves and becomes more clear as we put it into practice and iterate. Although MyData thinkers and doers' viewpoints and approaches might not always align, the community strives to learn from each other and co-create while staying true to the core vision described in the MyData declaration. Here is a summary of the main topics where the MyData community seems to have reached a mutual standing, is yet questioning and debating, and discussions that haven't received much attention as of now.

Maturity

- Operators: from conceptualisation to implementation - more and more service providers have been awarded the MyData Operator 2020 award and embarked on a journey towards interoperability.
- “OurData” and collective aspects of personal data are just as important as the individual aspects.

Convergence

- We need human-centricity embedded in all types of design.
- We need human governance in addition to data and technology governance.
- Data literacy and cultural literacy among professionals as well as individuals and communities more widely are key to the adoption of MyData solutions.
- We need actual use cases now more than ever.

Tensions

- How does MyData exactly relate to issues of privilege and power?
- How do we realise and sustain ethical business models?
- What’s the best path to interoperable MyData ecosystems, an emphasis on governance or on standards? Or both?
- Data commodification and direct monetisation of personal data: friend or foe?
- The MyData slogan is “Make it happen, make it right”. How do we balance between making it “happen” and making it “right”?

Missing discussions

- Where are the lawyers and legal innovators?
- Discussions on specific tech solutions have faded: where’s the cloud, edge computing, blockchain, AI / ML, quantum, federated learning? Are these discussions needed?
- Discussions on indigenous data and governance topics are gaining traction elsewhere, not yet MyData.
- Voices from the Global South are still faint.

8. Calls to action.
We're in this together!

We're in this together

Building a fair, sustainable, and prosperous digital society is not a solo sprint. It's a teamsport and a relay marathon where each of us matter!

SHARE & (RE-)USE

- Let others know about this publication by sharing it in social media and to specific people in your networks!
- Reference this publication in your own work.

INSPIRE & GET INSPIRED

- Join MyData Global Slack workspace (main communication channel for the community) & share your work!
- Participate in the activities of MyData local hubs and thematic groups!
- Stay up to date with key news from MyData community & beyond with the Weekly Digest & MyData Global's newsletter
- Apply for the MyData Operator Award in 2021 (new call opening in the fall).

INFLUENCE & SUPPORT

- Become a member of MyData Global
  - as an individual
  - as an organisation

  MyData Global's work is mostly financed by membership fees and revenue from the MyData conference(s). Your support has tremendous value in realising our mission (see MyData Declaration, Strategy for 2020-2022)
- Explore and sign the MyData Declaration
- Start a MyData thematic group on a topic that needs more work and attention
- Start a local hub for developing MyData in your local ecosystem.

9. Resources

MyData white papers

- MyData White Paper (2020)
- Understanding MyData Operators (2020)
- The Future of Work and Skills (2020)

MyData declaration (2017)

MyData Global Theory of Change (2020)

MyData conferences

- MyData 2016 programme
- MyData 2017 programme
- MyData 2018 programme
- MyData 2019 programme
- MyData Online 2020 programme

Photos

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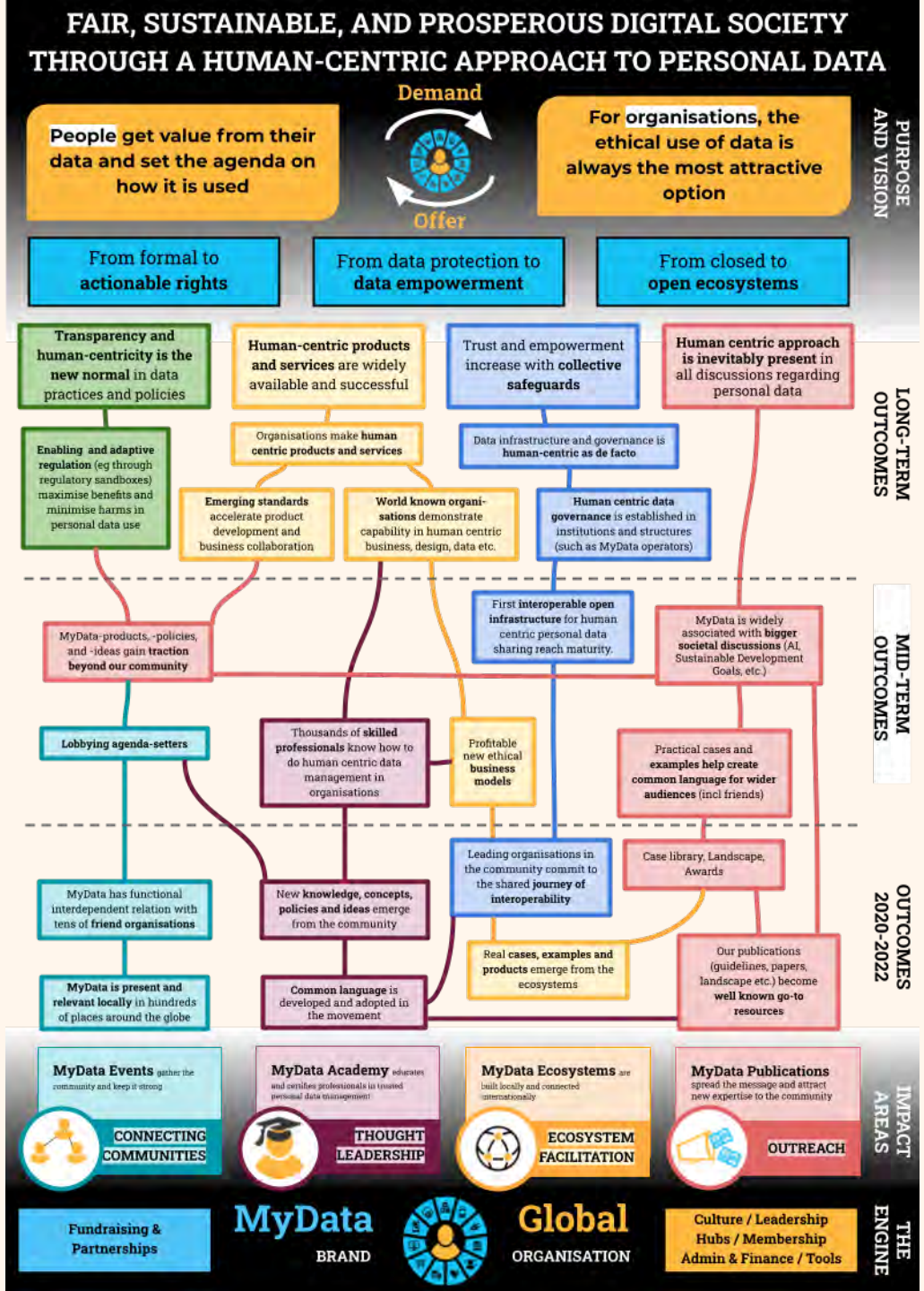
Annex A

MyData Global Theory of Change



FAIR, SUSTAINABLE, AND PROSPEROUS DIGITAL SOCIETY THROUGH A HUMAN-CENTRIC APPROACH TO PERSONAL DATA

PURPOSE AND VISION

People get value from their data and set the agenda on how it is used

Demand

Offer

For organisations, the ethical use of data is always the most attractive option

From formal to **actionable rights**

From data protection to **data empowerment**

From closed to **open ecosystems**

LONG-TERM OUTCOMES

Transparency and human-centricity is the new normal in data practices and policies

Human-centric products and services are widely available and successful

Trust and empowerment increase with **collective safeguards**

Human centric approach is inevitably present in all discussions regarding personal data

Enabling and adaptive regulation (eg through regulatory sandboxes) maximise benefits and minimise harms in personal data use

Organisations make **human centric products and services**

Data infrastructure and governance is **human-centric as de facto**

Emerging standards accelerate product development and business collaboration

World known organi-sations demonstrate capability in human centric business, design, data etc.

Human centric data governance is established in institutions and structures (such as MyData operators)

MID-TERM OUTCOMES

First **interoperable open infrastructure** for human centric personal data sharing reach maturity.

MyData-products, -policies, and -ideas gain **traction beyond our community**

MyData is widely associated with **bigger societal discussions** (AI, Sustainable Development Goals, etc.)

Lobbying agenda-setters

Thousands of **skilled professionals** know how to do human centric data management in organisations

Profitable new ethical **business models**

Practical cases and **examples help create common language for wider audiences** (incl friends)

OUTCOMES 2020-2022

Leading organisations in the community commit to the shared **journey of interoperability**

Case library, Landscape, Awards

MyData has functional interdependent relation with tens of **friend organisations**

New **knowledge, concepts, policies and ideas** emerge from the community

Real **cases, examples and products** emerge from the ecosystems

Our publications (guidelines, papers, landscape etc.) become **well known go-to resources**

MyData is present and relevant locally in hundreds of places around the globe

Common language is developed and adopted in the movement

IMPACT AREAS

MyData Events gather the community and keep it strong

CONNECTING COMMUNITIES

MyData Academy educates and certifies professionals in trusted personal data management

THOUGHT LEADERSHIP

MyData Ecosystems are built locally and connected internationally

ECOSYSTEM FACILITATION

MyData Publications spread the message and attract new expertise to the community

OUTREACH

THE ENGINE

Fundraising & Partnerships

MyData BRAND

Global ORGANISATION

Culture / Leadership
Hubs / Membership
Admin & Finance / Tools

Annex B | MyData Global organisational members

As of April 2021

Annex C

Online and physical

THE MYDATA COMMUNITY IS GROWING

MyData Declaration

underlines the need for human-centricity and agency in the data economy.

11 LANGUAGES

Original MyData white paper

5 TRANSLATIONS

A revised edition made in 2020: "An introduction to human-centric use of personal data"

MyData Global

MyData Global is grounded on local, regional, and national level through the local hubs and the thematic groups unite actors working on similar topics globally.

30 LOCAL HUBS

6 THEMATIC GROUPS

100+ ORGANISATIONS

400+ INDIVIDUALS

We have members from over 50 countries - over 100 organisations and 400 individuals.

The organisational members include Fujitsu, NTT Data, De Volksbank, and the cities of Oulu and Helsinki.

Slack

Slack has nearly 2500 experts, with nearly 400 people active weekly!

2500 EXPERTS

MyData operators

MyData operators provide interoperability at the technical, informational and governance levels to support the flow of personal data across services.

27 MYDATA OPERATORS

About MyData Global

About MyData Global

MyData Global is an award-winning international nonprofit. The purpose of MyData Global is to empower individuals by improving their right to self-determination regarding their personal data. MyData Global facilitates a global community of personal data professionals and enthusiasts, who share a vision of human-centric paradigm towards personal data. This paradigm is aimed at a fair, sustainable, and prosperous digital society, where the sharing of personal data is based on trust as well as balanced and fair relationships between individuals and organisations.

Download this publication at mydata.org/papers/state-of-mydata-2021

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About this publication

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