TALKING ABOUT DATA ABOUT US

Towards a global and local conversation

RSA, ODI and Luminate

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This short paper summarises a series of exercises undertaken by the RSA (Royal Society for the encouragement of Arts, Manufactures and Commerce), the ODI (Open Data Institute) and Luminate over 2019-2020 that sought to interrogate how people feel about the rights and responsibilities needed to govern the use of data about us - and how we realise the value of data about us.

About the RSA

The RSA (Royal Society for the encouragement of Arts, Manufactures and Commerce) believes in a world where everyone is able to participate in creating a better future. Through our ideas, research and a 30,000 strong Fellowship we are a global community of proactive problem solvers, sharing powerful ideas, carrying out cutting-edge research and building networks and opportunities for people to collaborate, influence and demonstrate practical solutions to realise change.

Acknowledgements

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1. The project

Last year the RSA in collaboration with ODI and Luminate produced a report, video, summary and podcast of a project called About Data About Us. This work was designed to test people's understanding about the use of data about them, and what they thought about the rights they have.

Despite being 'About Us', decisions about data use are rarely in our favour, but rather in the favour of the company or public body we are being asked to share data with. While we have rights over how data about us is protected, some policy makers are starting to consider whether framing the challenge as increasing ''ownership' of data would give us greater control.

This project sought to identify whether the concept of ownership chimed with the public, or whether the rights model had greater resonance and required improvement.

1.1 Findings

To do this, we spoke to randomly selected members of the public about their data rights in a series of focus groups and in-person sessions.

One of the top line findings of this work was that there is a surprisingly sophisticated understanding - and some strong opinions - among the general public regarding the collection, use and value of data about them. Indeed, this far exceeds what many experts in the data policy space expect to hear. For instance, the role of GDPR as protection for individuals was well understood, although there was frustration with how cookies and consent were still being approached by some companies.

The drawbacks of the data ownership idea were clearly identified: and there was consensus on the need for promulgated rights around the governance of data about us.

Since publishing our initial report, we have taken the conversation into new arenas; we have conversed with policy makers and experts about the research in meetings and at public events; including two successful conversations at the Conservative and Labour Party Conferences last year.

In addition to this, we reconvened in February 2020 and collaborated with the German not-for-profit think tank Das Progressive Zentrum to host two half-day workshops. One in London and the other in Berlin, where we presented our work and listened to the views of organisations including the Information Commissioner's Office (ICO), Wikimedia, Open Knowledge Foundation Deutschland, Ada Lovelace Institute, Department for Digital, Culture, Media and Sport (DCMS), Google, AlgorithmWatch, Telefónica Germany, Civil Liberties Union for Europe, Centre for Data Ethics and Innovation (CDEI), The Legal Education Foundation and the Freie Universität Berlin, among others.

We asked these experts - just as we did with the public in last year's work - to discuss their personal thoughts and feelings on data, rights, and ownership. We presented and discussed our research, and asked for feedback on what, if anything, they felt it could do to help stimulate wider conversation within their work.
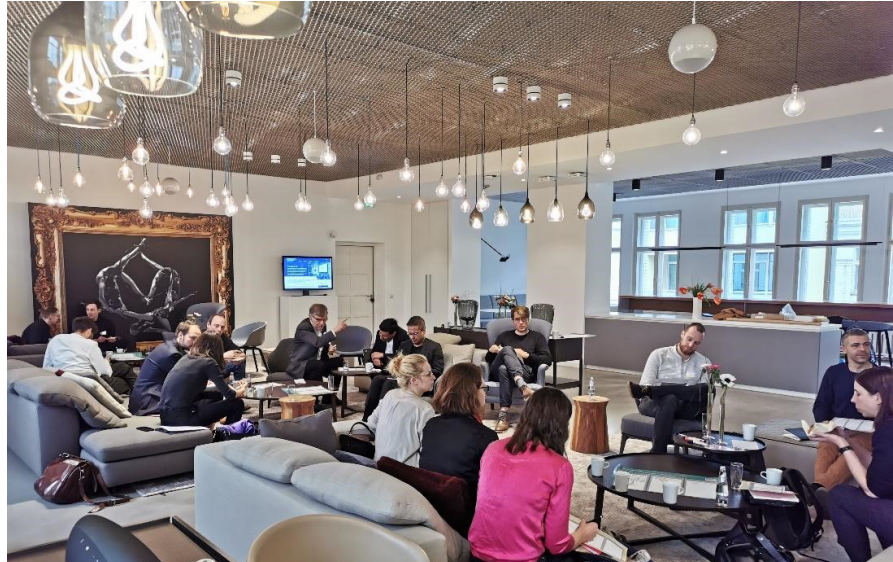
Just as in our original public conversations, points regarding honesty and transparency, rights and responsibilities, agency and control, compliance and enforceability and context and fairness were given as critical facets of the debate around data.

The remainder of this short paper outlines the key discussion points that were raised in our engagements with policy makers and experts and articulates the next areas of work.

Data About Us

2. Discussion points

2.1 Data as democracy

Data is a foundational pillar of democracy: this was embraced and understood by participants across the piste.

In simple terms, it was suggested to us that data trusts, data repositories and other tools for civic engagement and activism should be considered community assets or be subject to some sort of democratic control. There was strong support for the socialisation of data about us across the workshops.

> *"We need to think of data as part of citizenship as opposed to being property"* – **London attendee**

There was also fear; had the horse already bolted? One participant asked, "Is this conversation happening too late?". Given that the workshop was held on the day the EU announced its digital and data rights framework for discussion, the answer must be that this issue is still very much contested.
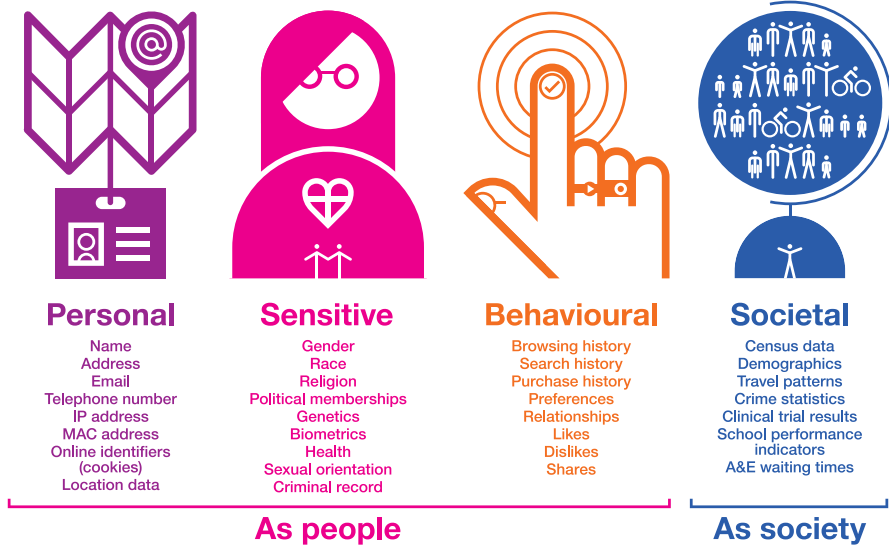
2.2 Literacy and language

A common problem when discussing 'data' is that the word 'data' itself is a catch-all and can mean different things. This confusion about what type of data we are referring to became clear within our research and so gave us a chance to present our 'Types of Data About Us' graphic with the participants to give them greater clarity and simple language to assist with thinking about which types of data they were being asked to share.

The partners have been using the graphic as part of our wider work including the ODI's recent project with the Co-op related to building trust in data.

> *"Trying to get something back off the internet is like trying to take the piss back out of a swimming pool."* – **Citizen**

Types of Data About Us

Personal	Sensitive	Behavioural	Societal
Name	Gender	Browsing history	Census data
Address	Race	Search history	Demographics
Email	Religion	Purchase history	Travel patterns
Telephone number	Political memberships	Preferences	Crime statistics
IP address	Genetics	Relationships	Clinical trial results
MAC address	Biometrics	Likes	School performance
Online identifiers	Health	Dislikes	indicators
(cookies)	Sexual orientation	Shares	A&E waiting times
Location data	Criminal record		

As people — **As society**

It was encouraging to hear that the participants of these sessions saw it is a useful tool to "help frame conversations around use of shared data", and that it would be used by one participant's organisation to help with "definitions to inform [their] approach".
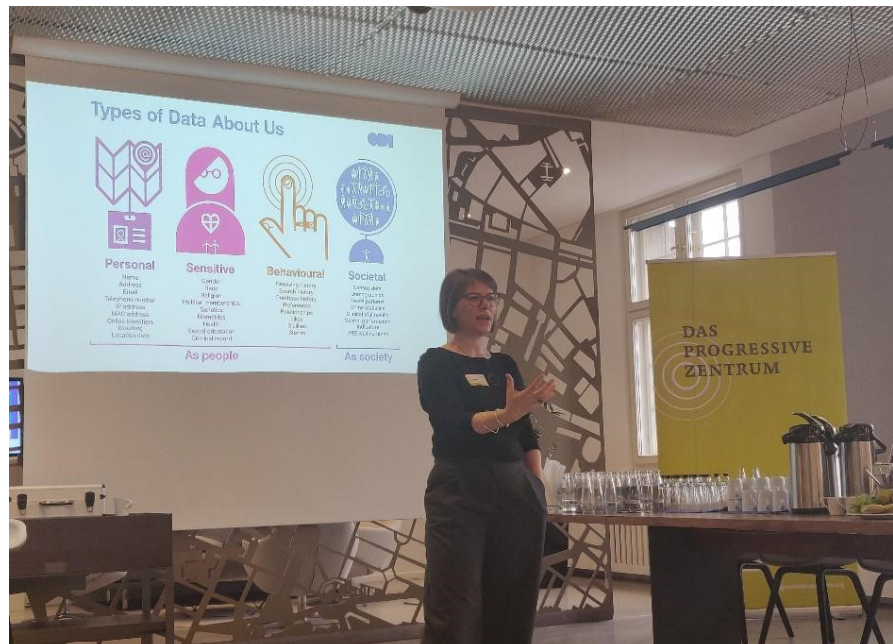
2.3 Next steps for GDPR and data rights

Questions regarding the future of the UK's data protection and alignment with the General Data Protection Regulation (GDPR) since Brexit were also raised.

In Berlin, a participant asked what that would look like and we heard in response, from another participant, that the regulation is likely to be retained, but that Brexit would be an opportunity for further strengthening of data protection rights. This was contested by those present, outlining both the trepidation and also the regard in which GDPR type legislation is held.

Data rights and GDPR were considered essential by the public and the experts we spoke to; an opportunity to retain and strengthen the regulation, and indeed to evolve it, offers a chance to develop some of the key asks the public made to us in our original work. Namely:

- more agency over how data about us is used
- more control over when we opt in, as opposed to opt out, of data sharing and
- more control and insight into how automated decisions are made about us (to name but three).

Such an opportunity would also enable the development of data rights for groups, as well as individuals, and stronger data rights for employees.

Moreover, improving data literacy and further developing the way we speak about, categorise, and identify different types of data will help us to know what information about us is being collected, for what purpose and to whose benefit.

2.4 Discrimination and bias

Bias is a known problem within datasets and can, in many ways, reflect and replicate existing societal bias and discrimination. This was a fact not lost on the citizens we spoke to and there was a nuanced understanding and worry about the potential for discrimination and bias within data that is used to make decisions about their lives.

The fact that citizens knew and understood potential for bias was picked up by policy makers and experts within Berlin and London. They recognised the need to be forthright, open, and honest regarding potential discrimination and bias within data and within the assumptions made about individuals based on their data. Without an understanding of what assumptions are made about citizens there is little chance the public will see or understand any biases present either.

For those in Berlin, in particular, this was an issue not simply for technologists, but a society-wide debate about values: having this conversation with citizens is a chance to both understand and set our standards.

"There's a lot of potential here, not just risks." – Berlin attendee

2.5 A Europe-wide townhall conversation

From an international perspective, it was clear that there are key differences in approach. The vernacular in Germany, for example, often placed emphasis on privacy, while in the UK the focus on the complexity of ownership was prevalent. These differences stem from culture and practice as well as civil or Justinian versus common law traditions.

However, it was also striking how much overlap there was; and how the approach of openly conversing in a democratic way about the new data democracy and its governance was seen as a crucial part of the conversation, not just at an elite or technocratic level but beyond.

> *"We need town halls… a Europe wide conversation. It can't just be experts. This thing is too wide and too important for that."* – Berlin attendee

We concur with this sentiment. If our first project was to test to see whether randomly selected people had useful insight on the data conversation, and if the European workshops were to question whether this insight was useful and shareable across borders, it seems that the next part of this work should be to broaden that conversation – and build new movements from local deliberation and democracy about data about us.

It is through cultural innovations like these – alongside major initiatives or incentive reform – that an environment in which technology is positively received and embedded at every interstice of the health system might be realised.

> *"You have to come back: you have to stay in a community. A one-off helps no one."* – Berlin attendee

3. Reflecting on the future

The opportunity for us to disseminate and discuss our findings to a wider audience outside of the UK and to hear the different areas of emphasis and concern on data policy from London and Berlin has been both useful and informative.

We were encouraged to hear that stronger data rights are widely supported, particularly in relation to people's autonomy, their awareness of how decisions are made and how we can improve data rights for groups as well as individuals.

There are many challenges ahead. At the time of writing this report, coronavirus augurs a new shared social and economic reality, much of which is convened online. With the use and exploitation of data about us, our need for strong rights systems, including a robust method of deliberating them, becomes even more existential.

With greater understanding comes greater engagement and as the use of data about us grows ever more prevalent, ensuring that people are clear on what data is being used, why and for whose benefit is essential. Data rights and data literacy sit at the heart of that. We are pleased that the About Data About Us work has kick-started a conversation that crosses borders, but this is only the beginning.

Now more than ever we realise we are all stakeholders in our society, not only as we battle coronavirus but as we build bridges to the future beyond. Talking about our future is key to resolving the shared challenges we face. Whether these conversations take place in person, or online, at grassroots level or between communities and governments, they need to be happening now and they need to be happening going forward.

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