DARE UK Public Dialogue

Summary of findings from initial workshops

Follow-up workshop, Tuesday 22 February 2022

1. Transparency

- Starting with little understanding of sensitive data use in research it appeared that increased understanding helped lead to increasing acceptance.
- There was a strong desire for "proactive" transparency to build trust.
- That is, more clear understandable information about how data is being used that actually reaches people Not just that information be readily available but actively brought *to* them.
- A question remained about how the public want to get this information rather than going on the research websites.

Q: What is the most important aspect for trust? Is it transparency?

We don't go on your website

Should be learning this at School

Feed back to people whose data used

Targeted communication efforts – use translators, mixed methods, go into community but don't pigeon-hole, use community members as recruiters/researcher

Tell me what my data is getting used for and by who

Transparency from start to finish: What data collected, who by, for what, what happens if breach?

Conduct tours of TREs

Ongoing generalised awareness campaign about the whole data journey

More effort to reach public on own terms

I'm at work/ busy - come to me

Want to receive impact reports/ be told policy changes. Perception that data/research is going to waste

Strong wish to know outcomes of data use – show the public benefits are worth the potential risks

Social media users

Made aware through GPs

2. Public involvement

Q: How can current PPIE be improved?

Q: Who isn't being included?

- There was an ask for a diverse public to be included meaningfully (not "tokenistic or tick box")
- Particularly in deciding whether something is of public benefit or not
- To ensure inclusion and accessibility participants suggested fresh, public-informed methods and efforts to reach people.

Education sessions to build understanding before PPIE session, support control and inclusion in decision-making

Seek us out- come to us with the information, chat to me on social media

Inclusion for full cycle of the data use e.g. Don't forget to report back, show us how our data impacted things.

People most affected by the research need to be part of decision making

Change the make-up of groups- people get habituated

Who decides what is in the public benefit? The public should be able to decide – public approval panel?

Involving young people is really important

Recognition that historical PPIE is self selecting- reach into the "unengaged public"

Groups need to be diverse (e.g. ethnicity, country, SEP)

How are you reaching people with little English? Isolated people, without internet?

3. Security: Storage, sharing and access

Do you agree there was no desire in your group for more restrictions?

- People were relatively satisfied with the suggested storage and access procedures, even the researcher using the data at remotely home, although there was lingering uncertainty.
- Some people suggested more streamlined mode of access for researchers (depending on sensitivity).
- There was an awareness that for some people it's more risky for data to be shared than others… so questions for the public are, do you want: 1) More awareness and trust building? 2) Or data from these people not to be shared? 3)Or higher tiers of security for this data?

Central regulatory body wanted

Lingering doubts about data breaches/ misuse even once explained

Desire to build public understanding of safety. E.g. Offer tours of TREs, teach topic in schools

General awareness of safety procedures needs to be improved

How should it be decided which types of data should be accessed in which way?

And who decides who/what is more vulnerable?

Data helpline to address concerns.

People and data has different levels of vulnerability so should there by different tiers of safety procedures/ approval?. E.g gov. misuse of data within political agenda, or peopl identifiable in small communities e.g. NI

Do you agree that though risk is acknowledged that the benefit is worth it?

4. Four nations approach

Q: Should data be shared across the nations when its deidentified?

- Participants generally approved of sharing data across the UK, Europe and internationally if relevant and in the interest of the public good and to reduce redundancy.
- There were some worries about sharing and benefit being fair to all
- There was some acknowledgement about country-specific needs.

Some country specific uniqueness e.g. smaller communities in NI, therefore identification breaches may be more risky

Benefit is also different across nations; it might not be beneficial across all nations.

"If it's beneficial to the people then share it "

Governance should be nationwide apart from unique legal situations

Tell me if other countries are using my data

Some people wanted to remove red tape, making it easier to share across nations

5. Centralisation

- Many participants talked about centralising access and/or storage processes and cutting red tape-
- This was suggested to speed up important research
- And, so the processes were more understandable, and therefore, people feel more in control of their data

Single process to apply, train for and access data?

Independent regulatory body for the governance of TREs and matters of data security

Quicker process to access data for more urgent projects

Who is deciding which projects to speed through?

Access requirement varies on sensitivity and associated risk?

Central gatekeeper for accessing the data

Single place for storage? Easier to track your own data. Better security?

Streamline data access processes?

6. Who uses the data

- There were wide ranging views about trusting private companies and government researchers to use sensitive data, from satisfaction to mistrust and lack of acceptance.
- Potentially, there was an acceptance as long as the project was transparent, had the most stringent security, and was for public benefit

But who decides what is in the public benefit? The public should be able to decide-would there be a public approval panel?

Private companies should be able to access data so its use is maximised for public benefit

How can we make sure that our information is not being used for the wrong purpose by the government?

What the public believe is ethical is different to what a company believes is ethical

What would make you more comfortable about private access?

Public want to know all potential users of their data- is this when they first give it? Where are they told this and how?

As long as the use is transparent, secure etc, it doesn't matter whether the user is private/public

Overarching need: Sense of Control

What would make people more comfortable and increase sense of control?

- There was a sense of low control over whether people's data is used, what is happening to it, who has it.
- Some participants wanted individual control outside of DARE UK's remit, i.e. an opt out, notifications at point of use.
- Public awareness and transparency appeared to improve public feelings of control over their data.

Data helpline to address concerns.

Informing at each stage of research- making consent to use ongoing rather than one off

Show the benefits of data use are worth it

Tell me before it gets used VERSUS acknowledge the use, report on the use even if can't change it

Tell me what it is getting used for and by who

General awareness campaign of sensitive use and what for

Opt out at point of collection?

Overarching need: Transparency

Feeding into each theme was a strong desire for more information and transparency. A question remained about how the public want to get this information as as a whole they acknowledged they would not naturally go to the research websites.

When someone's data is used, are they notified?

Seek us out- come to us with the information, chat to me on social media

Transparency on what happens if something goes wrong e.g. in storage

What does transparency mean to you?

What is the most important aspect for trust? Is it transparency?

Generally available what is being used, by whom, where and how stored, for what→ then outcomes

Informing at each stage of research- making consent ongoing rather than one off.