



The “My Data” Project.

understanding the perceptions of administrative data usage for research: A public engagement project in partnership with people who used drugs



University
of Dundee



LOUISE MARRYAT
NHS/CSO PPI EVENT

12TH MARCH 2024

@LMARRYAT

Study Background

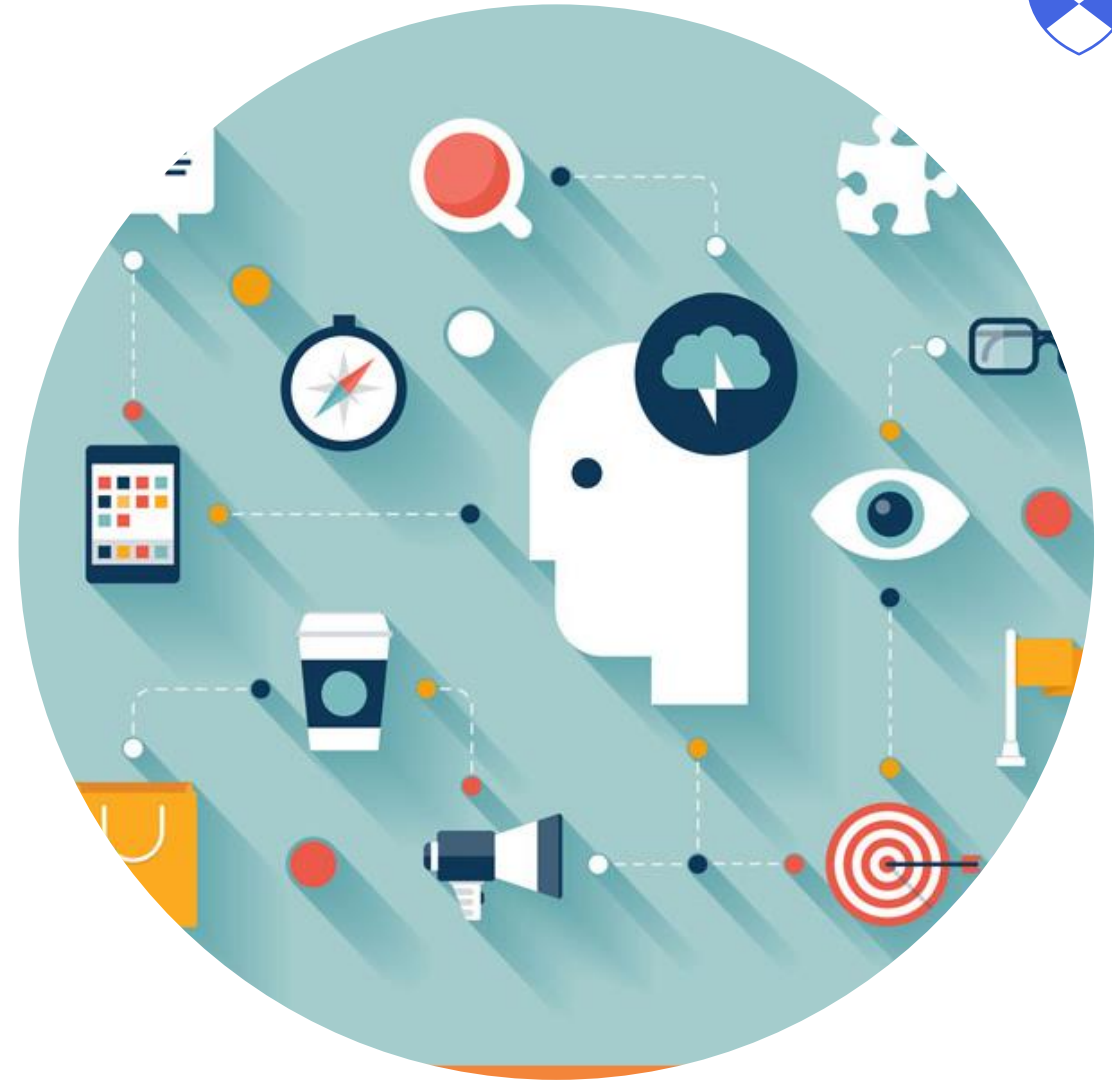
Our group uses administrative data to explore impacts of substance use

→ However, no data on what people who use drugs think about this

Evidence indicates that public mostly supportive of sharing of administrative data for research (Aitken et al., 2016)

→ Those with mental health difficulties were supportive overall, although less supportive of using mental health data (Satinsky et al., 2018)

→ Some evidence that people are more cautious about sharing GP data





Why might people who use drugs have different views?

Stigma experienced often results in distrust of services (Paquette et al., 2018)

→ Unknown how this relates to researchers?

Their data and service use might conceivably be felt to be particularly sensitive

Potentially less knowledge of research

→ Statistically the demographic of this group is different from a mainstream population

→ Low traditional engagement of quant research community with population

What did we aim to do?

Funded by Research Data Scotland's Public Engagement fund

Partnered with Restoration Fife

Aims:

1. Explore the views of using admin data in research held by people who use drugs
2. Work with people who use drugs to create a short film exploring those views
3. Curate a list of people willing to help with future research





Phase 1: Focus Group Methods

Partnership with Restoration Fife

2 focus groups to explore views of use of admin data in research

- n.= 12 / 11 people
- Worked with live illustrator Graham Ogilvie
- Provided information of how data are currently used and processes in Scotland
- Discussion around feelings/views on this
- Traffic light ranking of different types of data and how people felt about sharing them



Findings 1: Perceptions of use of admin data in research

Limited understanding about how data were being used in research and processes

Range of views about data sharing:

- Overall:
 - Happy to share all data
 - Some data off-limits e.g. child social work data, drug and alcohol data
- Reasons for use were important
- There was a view that data should be consented
 - But recognition that this would impede data quality



But the addiction side and all that I don't really care if it's going to help people. But there's some information that I wouldn't like sharing. (G2_Male 2)



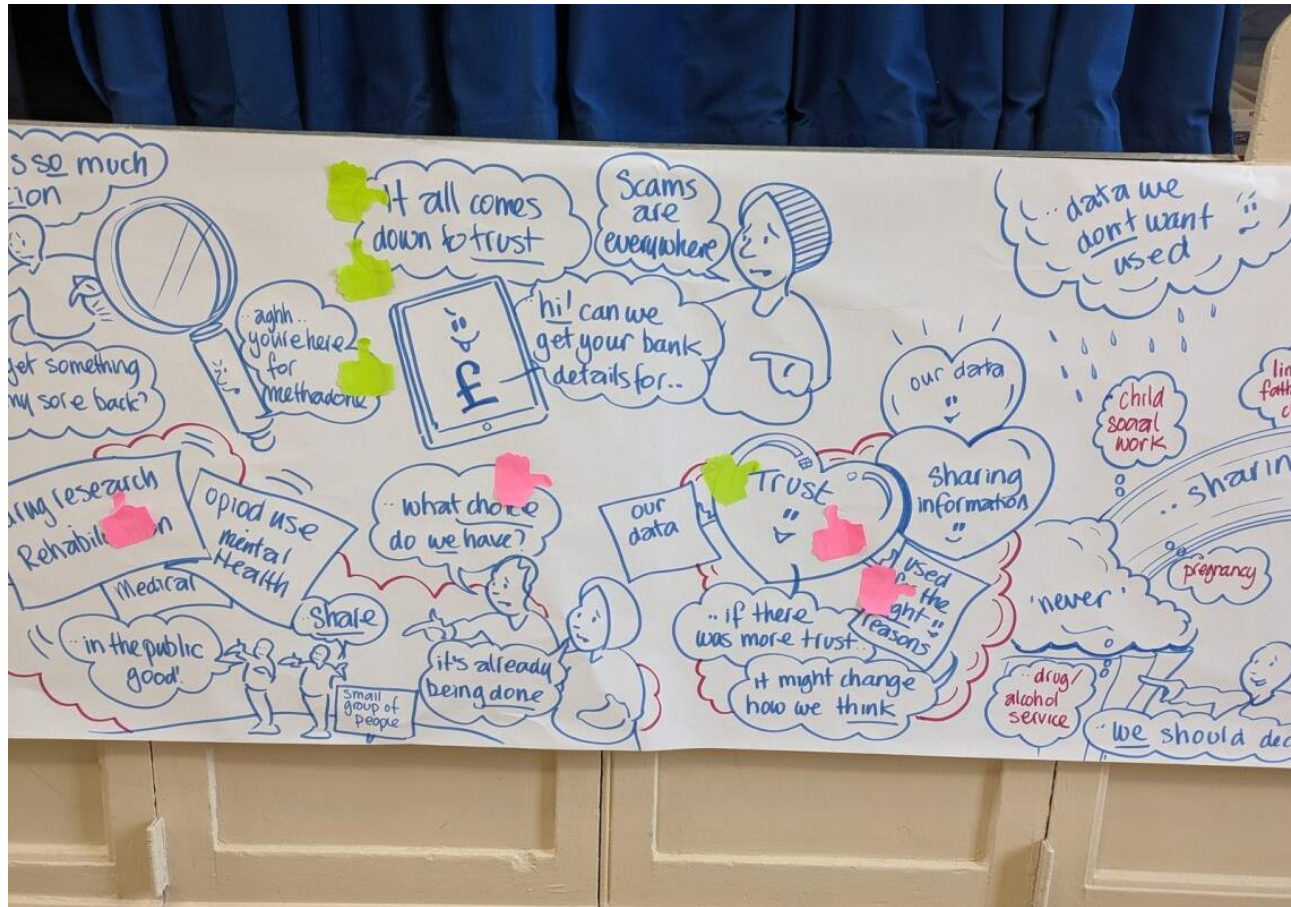
Findings 2: Are data accurate?

Concerns raised about data quality

- People not truthful in reporting e.g. to health visitors
- People not accessing 'usual' services

*I think it's gonna be incomplete and all. That's the thing about who you ask – if you ask an addict your data's gonna be useless because you're not getting the right treatment, not getting the right medication... ..than someone normal. So if you're somebody...people who haven't had addiction or had problems with substances the data's going to be all different than somebody who has had problems. And for me personally [I don't go to the GP] because what's the point if you're not getting the right treatment or they think you're just there to get free whatever...what's the point wasting your time?
(G2_Male1)*

Trust in services vs trust in researchers



Discussion frequently moved between data sharing with/between services and for research

- Trust with services a big issue
- Examples given of stigma by services specifically for people who use drugs
- Also feeling that data sharing might stop people having to retell story
- Trust greater with researchers

Phase 2: Creative Workshop methods



4 creative workshops

→ 2 developing ideas and materials;

→ 1 filming and recording;

→ 1 showing draft film and getting feedback

→ Up to 6 people in each

→ Worked with animator Andrew Low



→ Very much up to participants what went in the film



The film

Feedback from participants

On involvement in PPI...

“enlightening”

“it just goes to show that when you get into recovery you can do anything you put your mind to”

“You start to get involved with groups you wouldn’t normally get involved with”

On learning about admin data...

“Yeah, I think most of us didn't realise how our information was used when this all began.”

“...no one actually knows how your data does get used and (where) it goes to...You can actually access it so....so like now we're a lot more informed after doing this, which we could then pass on other people.”



Key messages

Work with partners

You need lots of hands!

Tell people what you are doing with their data

Think about what is deemed to be 'public good' → who decides?

Funders and institutions need to raise this kind of work up the agenda



Thank you to:



University of Dundee

Research team: Camila Biazus Dalcin (Co-PI); Louise Marryat (Co-PI); Sarah Gray (Co-I); Andrea Mohan (Co-I); Senga Robertson-Albertyn (Co-I); Sreekanth Thekkumkara (Co-I); Hazel Booth (Co-I)

Additional voice-over: Calum Hoggitt (Mental Health Nursing Student); Kay McMahon (Receptionist Fife Campus)

Creative staff

Graham Ogilvie (Conference in pictures – Ogilvie Design)

Andrew Low (Artist)

Restoration Fife

Animation team: Craig Glencross; David Hood; Jade Renton; Maxine Thomson; Ryan Westwood; Stewart Bernard; Sarah Hulin; Robert Doig ; Ashley McMaihin

Restoration Fife staff, particularly Jade Whyte and Vanessa Hamilton

...and everyone at Restoration Fife who shared their views and experiences.



Thank you for listening!

lmarryat001@dundee.ac.uk

Link to film:

