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Mental health service users' perceptions of data sharing and data protection: a short qualitative report

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ABSTRACT

Background   To improve health services, social, economic and health data should be shared and linked to create a full narrative of lived experience. Mental health data sharing is often considered a particularly sensitive area.

Objective   To assess mental health service users' perceptions regarding the current practice of administrative data-driven research.

Method   We conducted a focus group using case study scenarios. Themes and subthemes were analysed using qualitative methods.

Results   Participants were generally happy for data owners to share their health, social and economic data if the purpose was transparent and if the information would inform and improve health policy and practice. Participants were less keen on sharing data through digital applications.

Conclusion   This case study informs a data linkage study protocol. Research teams and database owners should strive to educate service users on data protection and create dissent opportunities.

Keywords: data sharing, data protection, qualitative research, data linkage, mental health, transparency, trust

INTRODUCTION

Sharing and linking data can improve the quality and integrity of information, increase communication across stakeholders and inform health policy. However, data linkage raises concerns on disclosure of sensitive personal information. Research needs to ensure that public benefits outweigh risks of disclosure and that patients' privacy is protected.[1] Whilst previous research has shown public support for data sharing and linkage for research, mental health data remain differentiated as more sensitive.[2]

The University of Southampton and the Mental Health Foundation are setting up a retrospective cohort study to examine the effects of community mental health services on users in England before and after the financial crisis of 2008. The University of Southampton has requested National Health Service (NHS) Digital to create a pseudo-anonymised dataset containing data shared by NHS Digital, the Department for Work and Pensions, Clinical Practice Research Datalink, the Office for National Statistics, the Department of Health and the Care Quality Commission on individuals receiving community mental health services between 2006 and 2016.

To increase transparency and ensure compliance with existent ethical regulation frameworks, we conducted a small focus group case study to assess mental health service users' perceptions regarding use of their administrative data.

METHODS

We undertook a 3-hour focus group to assess service users' opinions on data sharing and data protection. Participants were recruited through a Facebook advertisement (October 2017) calling for service users interested in privacy and data use. Additional participants were recruited through snowballing techniques. Fifteen participants were registered for the focus group but only eight participants attended (five male, three female; age range: 40–65).

The focus group started with introductions to the upcoming research project and data linkage and sharing before splitting into two smaller groups to discuss three case studies (Table 1). An existing framework informed the development of these case studies.[3] Facilitators, one with each breakout group, allowed participants to guide conversations. When discussions faltered, facilitators probed with non-leading questions. After each case study, the group reconvened to discuss responses and key themes. The focus group ended with a discussion of safeguards and measures that would make participants more comfortable having their data used for research, particularly in the context of the upcoming study.

The focus group was audio-recorded; these recordings were transcribed and analysed qualitatively for themes and subthemes. The themes reported are neither exhaustive nor generally applicable to the mental health population in England because of the geographic, age and size limitations of the focus group sample.

RESULTS

Case study A

Participants discussed arguments for and against opt-out systems but unanimously agreed that if their health data could be analysed to positively help others, they were happy with their data being shared for research. P5 said she was fine having her data collected, commenting, 'It doesn't bother me… because that could benefit other people'. P3 added, 'without sharing the information, things don't get identified'.

Some participants expressed wanting control over what data are shared, for instance, if data could endanger employment opportunities. P5 added that she was less comfortable sharing her daughters' information, as she believes children are too young to make those decisions. However, she clarified that she would support her children's administrative data being analysed in a protected research environment if used to help treatment or service planning for others.

Participants stressed the importance of transparency of opt-out systems in the NHS. P3 commented, 'I want to see a report of what decisions, what conclusions have been drawn'. They repeatedly mentioned that data collected need to drive service improvement. P1 commented, 'I just don't think it's going to the right people to assess it, to provide the services that are needed'.

Case study B

Participants agreed that opt-in data collection by mental health charities can provide individuals with information on service availability and direct people to appropriate peer support. However, since disclosure of mental health conditions can drastically affect perceptions of an individual, participants conveyed wanting to feel comfortable with protection measures and with how the organisation planned to use their information; P2 stressed: 'it has to do with how it's going to be used'.

Participants expressed concern over security systems in mental health charities. A charity, as P7 and P2 mentioned, might not have funding to keep data as secure as in a larger governing body. P3 reflected: 'they might not be as, you know, data protection rights-literate'.

As in Case study A, participants expressed feeling more comfortable if they could have access to reports collated based on their data.

Case study C

Six participants said they would not download a mental health app, expressing concerns that apps would not use their information, particularly location data, securely.

Two participants had previously downloaded mental health apps, with P5 adding, 'If it was useful to me or a member of my family, and I thought it was secure, I'd definitely use it'. However, as other participants expressed pervasive concern over sharing data over technology, both participants wavered in their support for telehealth services.

Table 1 Case study presentations

Case study A	The National Health Service collects individual-level data on patients throughout the United Kingdom (UK). It sends data for 1 million patients to a research institution; data includes age, gender, ethnicity, mental health diagnosis, deaths, treatment and treatment response over a 3-year period. As data are collected at General Practitioners under an opt-out system, individuals do not provide consent. Data from various parts of the health and care system are linked for comparison and analysis. The research outcomes and analyses are provided to the government and used to inform national reporting and analysis, commissioning, service planning, monitoring policies and legislation, local and national performance management and benchmarking.
Guiding questions	• What are the benefits? • What are the risks? • Are you okay with your data being used in this way? • Are you more okay with some information being used than others? (Age *versus* diagnosis or treatment?) • What would make you okay with your data being used in this way?
Case study B	A mental health charity organises peer support groups for people at risk of mental-ill health. In order to evaluate the effectiveness of the programme and guide future interventions, the charity collects data on ethnicity, age, sexual orientation, gender, religion, income, employment status, condition and years with the diagnosis. In addition, they have participants take questionnaires to measure wellbeing and depression. The charity runs analyses with the data to look for correlations between demographic factors and mental health. They will publish the research and use the results to inform other programmes.
Guiding questions	• What are the benefits? • Are there any concerns? • What would the charity need to do to make you comfortable sharing this information? • Is there any information you wouldn't want to disclose?
Case study C	Patients with a mental health condition can download an app targeting improved mental health. Individuals can use the app to record feelings and stress, monitor their medication and get advice from online counsellors. When downloading the app, individuals must check that they have read and feel comfortable with a lengthy page outlining the terms and conditions. The terms and conditions mention that the app collects information on age, gender, location, ethnicity, diagnosis and information shared through activity on the app. The information is then provided to research organisations to understand how groups deal with stress, perceive feelings and adhere to medication and treatment. Additionally, the app conducts market research and assesses how engagement with the app drives mental health outcomes.
Guiding questions	• What are the benefits? • What are the risks? • Would you download and use this app? • Would you read the terms and conditions? • What would make you comfortable with using this type of app? • Would you be okay having your information used to improve the app?

Safeguards

Participants expressed the need for better education regarding data sharing and safeguards. Furthermore, participants felt they would be more comfortable sharing their data if they could provide feedback to the research team. Despite the need for greater education and feedback systems, participants were comfortable with the laws and safeguards in place to protect data and ensure secure research.

DISCUSSION

Participants showed little prior awareness of health data uses for research but were largely comfortable sharing their health records. Some participants raised issues of transparency, advocating for clear opt-out options and processes, and others stressed an interest in being part of reference groups to stay up-to-date on findings. These results reflect those of previous research demonstrating patient support for data sharing and linkage in conjunction with education on research, governance practice and safeguards.[2,3]

Participants were comfortable sharing sensitive information for research purposes if they trusted that the organisation collecting data was safeguarded and aimed to provide support for service users. Participants in another health study[4] similarly expressed the importance of weighing institutional trust and social responsibility when providing consent. Public trust is fundamental to the success of large-scale health data projects.

In the last decade, mental health mobile apps have become commercially available, yet only a few have been clinically evaluated.[5] A systematic review suggests that mobile health technology has the potential to reduce symptoms of depression, anxiety, stress and problematic substance use.[6] However, only two participants in this focus group said they would feel comfortable downloading a mental health-based app or using online counselling.

This case study was limited by its small sample size; participants' views may not reflect those of the general mental health service user population. All participants were over 40, which may have impacted views around using digital services. While we were also interested in capturing perceptions on sharing economic data, particularly during Case study B,

these did not come up during focus group conversations. Future focus groups should recruit a larger sample from disparate services, age-groups and geographical areas to provide more diverse input.

CONCLUSION

This case study reflects previous research suggesting individuals may comfortably agree to share their data – even sensitive mental health data – in hopes that their service use history leads to better policy and care. Despite the support for data-sharing, participants lobbied for improved transparency around the use of administrative data for research.

REFERENCES

Individuals should be given the option to opt-out, and results should be disseminated across resources relevant to the given population. Individuals should be made aware of reference groups and opportunities to provide input. The University of Southampton and the Mental Health Foundation have employed these safeguards for their retrospective cohort study.

1. de Lusignan S. Effective pseudonymisation and explicit statements of public interest to ensure the benefits of sharing health data for research, quality improvement and health service management outweigh the risks. *Journal of Innovation in Health Informatics* 2014;21(2):61–3. https://doi.org/10.14236/jhi.v21i2.68. PMid:24841404.

2. Aitken M, Jorre JD, Pagliari C, Jepson R, Cunningham-Burley S. Public responses to the sharing and linkage of health data for research purposes: a systematic review and thematic synthesis of qualitative studies. *BMC Medical Ethics* 2016;17(1):73. https://doi.org/10.1186/s12910-016-0153-x. PMid:27832780; PMCid:PMC5103425.

3. Ipsos MORI Social Research Institute. The one-way mirror: public attitudes to commercial access to health data. *Wellcome Trust* 2016;123–32.

4. Williams H, Spencer K, Sanders C, Lund D, Whitley EA, Kaye J, *et al*. Dynamic consent: a possible solution to improve patient confidence and trust in how electronic patient records are used in medical research. *JMIR Medical Informatics* 2015;3(1):e3. https://doi.org/10.2196/medinform.3525. PMid:25586934; PMCid:PMC4319083.

5. Torous JB, Chan SR, Yellowlees PM, Boland R. To use or not? Evaluating ASPECTS of smartphone apps and mobile technology for clinical care in psychiatry. *Journal of Clinical Psychiatry* 2016;77(6):e734–8. https://doi.org/10.4088/JCP.15com10619. PMid:27136691.

6. Donker T, Petrie K, Proudfoot J, Clarke J, Birch MR, Christensen H. Smartphones for smarter delivery of mental health programs: a systematic review. *Journal of Medical Internet Research* 2013;15(11):e247. https://doi.org/10.2196/jmir.2791