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Mental health service users' perceptions on the use of administrative data for research

Satinsky, E¹, Driessens, C^{2*}, Crepaz-Keay, D¹, and Kousoulis, A¹

¹Mental Health Foundation

²University of Southampton

Background

Recently, opportunities have been created to link health records with data routinely collected by social and economic departments. The ADRC-E (Southampton), in collaboration with the Mental Health Foundation has taken advantage of these opportunities to request information on a retrospective cohort to examine the effects of community mental health services on users in England before and after the financial crisis of 2008.

Objective

To increase transparency the Mental Health Foundation assessed mental health service users' perceptions regarding current practice with the secondary use of their administrative data.

Methods

This three-hour focus group study identified mental health service users' thoughts around the word 'data', data sharing and data protection governance.

Findings

Focus group participants were generally happy to share their health data. Trust was an important factor mentioned in relation to data sharing. Participants expressed a desire for improved transparency around the use of administrative data for research purposes. When discussing safeguards the participants all agreed that they would feel more comfortable sharing their health data if there were better patient education and feedback systems in place.

Conclusion

Mental health service providers should strive to inform individuals using their services that their data might be used for research purposes and communicate the rights to opt out of participation. It is important for researchers and data administrators to draw the service users' attention to relevant studies and opt-out mechanisms as well as enforce data protection and linking policies.

*Corresponding Author:

Email Address: c.m.driessens@soton.ac.uk (C Driessens)