Service user engagement and leadership in mental health research: findings from an occupational therapy supported project

Nicola Hancock, Anne Honey, Justin Scanlan, Bridget Berry, Richard Schweizer, Shifra Waks
The University of Sydney, Sydney, NSW, Australia

Introduction: Internationally, mental health policies and research funding bodies demand greater involvement and control of service-users in research. The value of service-user engagement in research is now well evidenced. Service-user researchers can: prioritise different questions that are more relevant to other service users; enhance acceptability of research designs and methods; facilitate a more nuanced interpretation of results, and enhance knowledge translation and dissemination. Additionally, engagement in research is a meaningful occupation that facilitates mental health recovery.

Objectives: To report a) the within-team and external facilitators and barriers to actualising a service-user led research program; and b) our evolving understanding of what service-user led research actually means.

Method: Service-user researchers and occupational therapy academic researchers collaborated on a service-user led research project. We employed a collaborative autoethnographic methodology to systematically examine, document and reflect on the service-user led nature of our project. Iterative 3-monthly cycles involved individual weekly written reflections, sharing of reflections and whole-of-team focus groups. Data were transcribed and analysed using grounded theory methods.

Results: Central to our findings was a more nuanced understanding of service-user led research; its alignment with, and departure from, co-production methods. Facilitators included shared values, complementary and respected skills, job flexibility, resources, multiple service-users, and time together. Barriers included limited time, mixed understandings, administrative power, and habitual interaction patterns.

Conclusion: Occupational therapists are well suited to leading the way in supporting service-users to actively engage in genuinely collaborative or service-user led research. This presentation provides insights into how they might do so.