Conference Abstract

Online support for integrated care and recovery in mental health: Implications of service user input to design processes

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Abstract

Background: Innovation processes aiming to improve integrated care in mental health need to partner with those having lived experiences of mental illness and service usage. The current study started by the researcher presenting service users and differing levels of mental health services with the question: Can information and communication technologies (ICT) such as Internet and mobile phones improve user involvement and integrated care in community mental health services? If yes, will you participate in designing such a service? A mental health community in Norway committed to participate in the design process.

Theory and methods: Guided by the principles of Community-Based Participatory Research we developed an online tool for integrated care and recovery in mental health. Service users, clinicians, researchers and IT-personnel worked as a team in specifying tool requirements. The process took over a year and started with clarifying and prioritizing answers to very basic questions: Who is the primary target group? What are the aims? What functions are priorities? Roles and responsibilities? What types of evidence can legitimize tool design decisions? In this paper we highlight the views of service users since these emerged as particularly influential in the team's vision for integrated care and evaluation of the tool.

Results: The resulting tool, ReConnect, is ready for testing in two communities starting in 2015. ReConnect has become a tool for those who need coordinated care over long periods of time regardless of their specific condition(s). It is "owned" by service users and aims to support them in gaining greater overview and control, legitimacy, and sense of continuity in relationships with helpers. It has a "my control panel" which depicts status → process → goals. Functionality includes support for: mapping life domains; medication overview; crisis management; coping exercises; secure messaging; and social support. Integrated care is supported by a common communication platform were service users and providers can share relevant, updated information. While the types of evidence that can legitimize design decisions are scattered and indirectly relevant, recent trends in recovery research are guiding further refinements.

Discussion: The concept of integrated care that has emerged from this process is genuinely service user-centered in that it underlines the key role service users play in guiding their lives in the direction they choose. Care providers participate to support service users in this process. The tool invites a proactive approach that is likely to challenge treatment cultures that are reactive, disorder-focused and consultation-based. Service user representatives will need to play central roles in training peers and clinicians in order to increase the likelihood of tool usage in line with intentions. They are working to develop local "service user cafés" as part of the intervention to ensure links to community.

Conclusions, lessons learned, future research: Starting down the path of service user involvement in integrated care design fosters commitment to follow through also in the implementation and research phases. Although time-consuming and less prestigious for researchers, this work is probably vital to increasing the likelihood of success of person-centered service innovations. Researchers need to share the rationales for service design decisions, not just outcomes.

Limitations: We have yet to test the concept in real life practices.

Keywords

internet; online; mental health; recovery; integrated care

PowerPoint presentation

http://integratedcarefoundation.org/resource/icic15-presentations