PARTICIPATORY DESIGN OF AN ONLINE TOOL FOR COPING AND RECOVERY IN MENTAL HEALTH: DOES IT MAKE A DIFFERENCE?

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BACKGROUND
The current project is designing, implementing and evaluating an online Interactive Health Communication tool called PsyConnect. It builds on research and the principles of Community Based Participatory Research (CBPR). Our aim is that users of the tool will experience:

1) greater insight and sense of coherence about issues affecting their personal health and recovery.

2) that their knowledge and experience has greater influence in forming supportive interventions.

3) improved sense of continuity in collaboration with care providers.

Service users and health care professionals are heavily involved in all phases of the research and development. We ask: Does it make a difference?

DIFFERENCES DUE TO PARTICIPATORY APPROACH
The CBPR process has resulted in a number of system requirements for PsyConnect, including:

1) A non-diagnostic focus and language. The system supports services users independent of diagnosis.

2) Focus is on general, research-based coping and recovery strategies.

3) PsyConnect is “owned” by the service users. This includes controlling the access of clinicians and other helpers to the different modules of the site.

4) Optional modules that can be tailored to individual users include: self-guided treatments/exercises, life domain monitoring, social support forums, diary, and evidence-based educational material.

5) User friendly message exchange with medical records.

While difficult to document, these requirements would not have arisen without a participatory approach (e.g. from researchers alone).

METHODS
From the outset a practice-research team was established based on the principles of Community Based Participatory Research (CBPR). This is an extension of shared decision-making into the processes of system design, implementation and evaluation. We use this approach in the development of a HCA called PsyConnect in mental health. Three types of teams collaborate:

First, the development team includes mental health service user representatives, municipal and specialist care providers from an urban and a rural community, experts and researchers in implementation science. This team outlines system requirements based on research and user needs.

In addition, two local implementation teams have been established in two case communities—one rural community and one urban community.

Phases I-III include specifying user requirements, testing, implementation and evaluation. Each phase will take approximately 1 year respectively. In line will CBPR, participants contribute throughout all phases of the project, thus ensuring locally acceptable and feasible solutions both technically and organizationally.

CONCLUSIONS
CBPR processes between multiple stakeholders are challenging and time-consuming. The reward is that stakeholders have arrived at a consensus regarding PsyConnect system requirements and a commitment to the objectives of the system. We believe that the CBPR approach ensures that patient-centered collaborative systems are likely to succeed in the daily lives of service users, as well as in the organizational practices of community mental health.

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