Prioritized research questions in health care and social care for serious mental illness
Based on the James Lind Alliance method

Summary

Background

In 2021, The Swedish Agency for Health Technology Assessment and Assessment of Social Services (SBU) published an inventory of identified evidence gaps in mental health from two databases: The SBU Evidence Gap database and the UK Database of Uncertainties about the Effects of Treatments (DUETs). This inventory identified over 2000 evidence gaps within the field mental health [1]. In order to assess which evidence gaps are the most urgent to address regarding *serious mental illnesses* (SMI), as prioritized by patients, carers, clinicians and practitioner in health care and social care, we conducted a priority setting partnership in accordance with the James Lind Alliance method [2].

Aims

The aim of this priority setting was to highlight what patients, families and carers, clinicians and practitioners consider to be the most important research questions in health care and social care in serious mental illness. The priority setting included the following serious mental illnesses: psychotic disorders, bipolar disorder, eating disorders, self-harm, severe depression, severe anxiety disorders, serious personality disorders, and suicidal behavior. The interventions included prevention, diagnostics, treatment, support and social care as well as service delivery models and coordination of health care and social care. Target groups for the prioritized research questions are researchers, research funders, governmental agencies and authors of systematic reviews.

Method

This priority setting protocol was based on the James Lind Alliance method [2]. Approximately 500 evidence gaps in the field of serious /severe mental illness were aggregated and thematized into 62 indicative research questions. A first prioritization was conducted as an open, anonymous, web survey. Approximately 800 survey responses were received, equally divided between patients, carers and families, clinicians and practitioners. The responses were weighted separately for patients, carers and clinicians/practitioners to ensure equal influence. The final prioritization was conducted in a consensus meeting consisting of 14 representatives from patient- and professional associations and two individual professional representatives.

Table 1 The top 10 prioritized research questions.

1.	Prevention of serious mental illness, including identifying individuals at risk and prevention of suicide.
2.	How can assessments and diagnostic methods in serious mental illness be improved, including suicide risk assessments and evaluations of psychiatric co-morbidity?
3.	What staff training interventions are needed in health care and social care of individuals with serious mental illnesses? What competencies and skills are required for staff in health care and social care of patients with specific psychiatric conditions?
4.	How can shared decision making be structured and improved in care and support of individuals with serious mental illnesses?
5.	Which interventions, activities and occupations are needed within psychiatric inpatient care/mental health wards?
6.	How can different methods and models for coordinated and collaborative care and social care be improved for people with serious mental illness? (e.g. coordination between sectors and disciplines, including monitoring and treating physical health)?
7.	How can health care and social care for individuals with serious psychiatric comorbidities, including addiction, be organized and coordinated to have the best effect?
8.	How is psychoeducation and patient information delivered in the best way?
9.	How is family support and support of next of kin and carers delivered in the best way?
10.	What are the effects of different support interventions, that are provided as a complement to usual care, that are aimed towards recovery, reduce suffering, promote coping mechanisms and improving quality of life? (for example, art therapy, music therapy, dance therapy, yoga, horticultural therapy, animals in health and social care settings)?

Results

In the final priority setting workshop, three main areas were identified as particularly important for future research: early interventions, service delivery/health systems related questions and different support interventions. The top 10 research questions are listed and ranked in the order of priority (1 = highest ranked). The rationale for the prioritized research questions, as concluded by the final prioritization workshop delegates, are presented in the report (www.sbu.se/368).

Discussion

The research questions that were highlighted as the most important to address in this priority setting were selected and prioritized by a very broad and versatile group of people, including individuals with lived experience, carers and families, and several different professional disciplines who work with or come in contact with individuals with serious mental illness. Several of the respondents of the web survey indicated that they had lived experience with several conditions and experience with suicidal ideation. Several respondents also indicated experience from different perspectives, for example both as a patient and family member, or as staff and family member. The final prioritization was conducted by representatives from invited patient- and professional associations.

Several research questions that were highlighted in this report, coincide with research priorities highlighted in other priority setting reports in psychiatry and social work [3–5]. Research needs that have consistently been highlighted have concerned assessments, diagnostics, coordination of care and support between different providers, staff training interventions that improve competence skills, shared decision making, components or care, and different types of support interventions. This report highlights the research questions that are particularly urgent in serious mental illnesses. The research questions are broad and primarily aimed towards research funders, while the underlying evidence gaps are specific and aimed towards researchers in health and social care.

References

1. SBU. Evidence gaps in mental health. An inventory on mental health research needs identified in databases on uncertainties of effects of interventions. Swedish Agency for Health Technology Assessment and Assessment of Social Services; 2021. Available from: www.sbu.se/335

2. James Lind Alliance Guidebook. Available from: https://www.jla.nihr.ac.uk/jla-guidebook/

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5. FORTE. Priorities for research on social services – perspectives from users, policy-makers and practitioners. Swedish Research Council for Health, Working Life and Welfare; 2019. Available from: https://forte.se/en/publication/priorities-for-research-on-social-services/

The full report in Swedish

The full report in Swedish, Prioritering av forskningsfrågor inom vård och stöd vid allvarliga psykiska sjukdomar och tillstånd.

Project management team and priority setting workshop team

The project management team consisted of project managers at SBU, clinicians and practitioners in psychiatry and social care, a patient representative and a family representative. The final priority setting workshop team consisted of 14 representatives from patient- and professional organisations in psychiatry and social care in Sweden, and two individual practitioners (patient organisations for schizophrenia, bipolar disorder, eating disorders, self-harm, suicide and mental health, and professional organizations for adult psychiatry, child psychiatry, mental health nursing, psychologists, social work practitioners, psychiatric care assistants, and social support workers).

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