

A Research Agenda for Bipolar Disorder Developed from a Patients' Perspective

Maassen et al. (2018)

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For which topic were research priorities identified?

bipolar disorder

In which location was the research priority setting conducted?

Europe - Netherlands

Why was it conducted at all?

Diagnosis and treatment of bipolar disorder is complex. Health care is supported by clinical guidelines, which are highly based on scientific evidence. However, such care does not necessarily correspond to preferred care according to patients. In order to narrow the gap between scientifically based guidelines and the patient's perceptions of the best clinical practice, additional research is needed.

What was the objective?

to create a patient based research agenda for bipolar disorder to enhance the alignment between patients' needs and care system

What was the outcome?

a ranking list of 23 research topics

How long did the research prioritization take?

No information provided.

Which methods were used to identify research priorities?

focus group; survey

How were the priorities for research identified exactly?

Step 1: six focus groups: participants discussed challenges of living with BD and aspirations for the future with regard to BD based on fictitious case of young woman with BD who had not yet been diagnosed, participants were then asked to write down everything they hoped for this young woman in all life domains and for health care, participants also asked to formulate research topics or questions they considered important in the field of BD. Step 2: data processing: thematic analysis, list of 23 topics for research clustered into five themes. Step 3: survey: participants were asked to vote by distributing 25 points over 23 topics

Which stakeholders took part?

Patients diagnosed with bipolar disorder, being at least 18 years of age, and not currently in a severe mood episode. Focus groups: 35 participants. Survey: 219 participants.

How were stakeholders recruited?

To recruit participants, questionnaires were sent to 100 randomly selected from a group of patients with BD who were treated at a specialized Dutch outpatient clinic based at a large mental health institution, and who had indicated at an earlier occasion that they would be interested in participating in research. If they expressed an interest for this particular study, they were contacted to participate in a focus group. In addition, participants were recruited via the website of the Dutch patients' organization for Manic Depressive Patients and their Caregivers. For the survey, patients who routinely attended the two specialized outpatient clinics were recruited.

Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.