

Recommendations from NSEPP service users on the best way to use self-report measures

Context

As the NSEPP and early psychosis clinics across Nova Scotia are using more self-reported assessments through GreenSpace, it is important to understand how patients want to share their perspectives with their team and the clinic. We asked 9 NSEPP patients the best way to collect information. We had clinicians and decision makers review this list to make sure it will also work for them, and then had the participants review the final list and identify their priorities. These are their recommendations. Many of these recommendations are already either in process or ongoing, highlighting practices to keep or strengthen. Others may not yet have started, and could be important priorities for ensuring that this way of gathering patient perspectives can be effective. These recommendations are organized by theme, as all are equally important.

An overarching recommendation was to have flexibility, recognizing that different people will prefer different ways of sharing their perspectives, and each person may need something different at a different time. These recommendations are not intended to be “one-size-fits-all”, but rather a guide for what patients want from self-reports.

Top Priority Recommendations from Participants

Questionnaire Format



- Less repetitive questions, more to the point
- Questions with more options than yes or no
- Keep questionnaires short
- Collect as much background on the patient as they are willing to provide
- Asking more “open text” questions where patients can provide a paragraph of information; generalized questions about the patient’s feelings and what they are going through

Time and Place of Collection



- Have the patient fill out tracking questionnaires before the meeting for clinicians to review 15 minutes before seeing the patient
- Patient seeing results/answers to questionnaires over time would be helpful
- Having a way for the patient to track their own symptoms, progress, and ups and downs
- Psychiatrists should also complete questions about their perception of the patient’s wellbeing that can be compared to patient-reported surveys and discussed.

Patient Resources



- Updated collection of resources (e.g., places to get free food, community spaces, activities...)
 - Big brother type program. “It is easier to succeed with role model.”
 - Information on scholarship type programs
- Patient feedback space: patient can share with care team issues and clinician can cross-reference with other patients who may have reported the same thing (e.g. an anonymous feedback box)
- Information on upcoming research studies available in a way that’s easy to access from outside the clinic

79% understand how the ideas would improve their experience of services