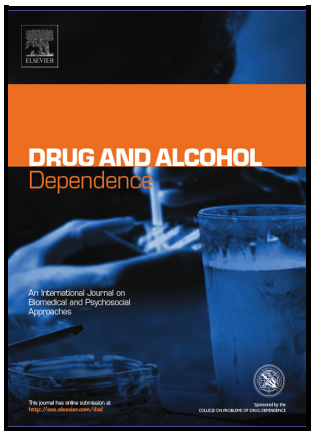
Patient Reported Outcome and Experience Measures (PROMs and PREMs) in substance use disorder treatment services: A scoping review



Charlotte Migchels, Amine Zerrouk, Cleo L. Crunelle, Frieda Matthys, Lies Gremeaux, Kim Fernandez, Jérôme Antoine, Wim van den Brink, Wouter Vanderplasschen

PII: S0376-8716(23)01255-3

DOI: https://doi.org/10.1016/j.drugalcdep.2023.111017

Reference: DAD111017

To appear in: *Drug and Alcohol Dependence*

Received date: 15 September 2023
Revised date: 24 October 2023
Accepted date: 26 October 2023

Please cite this article as: Charlotte Migchels, Amine Zerrouk, Cleo L. Crunelle, Frieda Matthys, Lies Gremeaux, Kim Fernandez, Jérôme Antoine, Wim van den Brink and Wouter Vanderplasschen, Patient Reported Outcome and Experience Measures (PROMs and PREMs) in substance use disorder treatment services: A scoping review, *Drug and Alcohol Dependence,* (2023) doi:https://doi.org/10.1016/j.drugalcdep.2023.111017

Patient Reported Outcome and Experience Measures (PROMs and PREMs) in substance use disorder treatment services: A scoping review.

Charlotte Migchels[a] - charlotte.migchels@vub.be

Amine Zerrouk[b] – elamine.zerrouk@ugent.be

Cleo L. Crunelle[a] – cleo.crunelle@vub.be

Frieda Matthys[a] – frieda.matthys@vub.be

Lies Gremeaux[c] – lies.gremeaux@sciensano.be

Kim Fernandez[c] – kim.fernandez@sciensano.be

Jérôme Antoine[c] – jerome.antoine@sciensano.be

Wim van den Brink[d] – w.vandenbrink@amsterdamumc.nl

Wouter Vanderplasschen[b] - wouter.vanderplasschen@ugent.be

a. Vrije Universiteit Brussel (VUB), Universitair Ziekenhuis Brussel (UZ Brussel), Department of Psychiatry, Laarbeeklaan 101, Brussels, Belgium

b. Department of Special Needs Education, Ghent University (UGent), Ghent, Belgium

c. Department of Epidemiology and Public Health, Sciensano, Brussels, Belgium

d. Amsterdam UMC, Department of Psychiatry, University of Amsterdam, Amsterdam, the Netherlands

Corresponding author:

Charlotte Migchels

Charlotte.migchels@vub.be

Laarbeeklaan 101

1090 Jette

Belgium

Declaration of interest

Wim van den Brink reports a relationship with Takeda Pharmaceutical Company Limited, Camurus AB, and Clearmind that includes: consulting or advisory.

All other authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Abstract

Background

Substance use disorders (SUD) pose significant challenges for healthcare systems, and there is a need to monitor the provision of effective, individualized care to persons accessing treatment. Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs) are increasingly used in healthcare services to measure treatment outcomes and quality of care as perceived by patients, and to guide service improvement.

Objectives

This review aims to identify and characterize international developments regarding the use and systematic implementation of PROMs and PREMs in SUD treatment services.

Methods

A scoping review was conducted searching multiple databases to identify studies on the use and routine implementation of PROMs and PREMs in SUD treatment services.

Results

23 articles were selected, all dating from 2016 onwards. There was large variation in the patient-reported measures that were used, how they were developed and how and when patient-reported data were collected. Treatment providers identified leadership support, the presence of an integrated electronic patient record, and regular feedback to be the most important facilitators of successful implementation of patient-reported measures into clinical practice, whilst dropout and burden to staff and patients were the most important barriers to consider.

Conclusions

PROMs and PREMs are increasingly used in SUD treatment services, but guidance is needed to support researchers and clinicians in selecting and implementing valid, meaningful, and comparable measures if we want to understand the effects of PROM and PREM data collection and feedback on treatment quality and results.

Keywords: Patient-reported outcome measures; patient-reported experience measures; substance use disorder treatment services

1. Introduction

Alcohol and other substance use disorders (SUD) are associated with various adverse personal, social, and economic outcomes, including acute (e.g., overdose, injury) and chronic (e.g., dependence, cardiovascular disease, cirrhosis) mental and physical illnesses (Degenhardt and Hall, 2012). SUD are an important and growing contributor to the global burden of disease, causing morbidity and premature mortality (Castelpietra et al., 2022; Degenhardt et al., 2013; Whiteford et al., 2013). In 2019, drug use was responsible for almost 60,000 years of life lost (YLLs) in Europe (Castelpietra et al., 2022). SUD pose significant challenges for healthcare providers, and improving the coverage and quality of SUD treatment is one of the global priorities outlined in the United Nations Sustainable Development Goals 2020-2030 (Dale-Perera, 2021).

Treatment cohort studies provide valuable information on the effectiveness of treatment for SUD, showing reductions in drug use and improvements in psychopathology and consistently demonstrating more favorable outcomes for those patients who remain in treatment for a longer period of time (Bargagli et al., 2006; Cox and Comiskey, 2009; Fletcher et al., 1997; Gossop et al., 2003; McKeganey N, 2008; Teesson et al., 2008). Traditionally, in this type of studies, objective outcome indicators, such as drug and alcohol use, risk behavior, criminal offences, and mental and physical health outcomes, are used, mainly addressing the medical and economic impact of SUD (Alves et al., 2017; De Maeyer et al., 2009). Lately, there has been a growing emphasis on the importance of also including subjective outcome indicators. These focus on the perspectives of people seeking treatment for SUD, whose concerns are often more diverse than is reflected in the objective outcome measures that are typically used (Alves et al., 2017; Kiluk, 2019; Neale and Strang, 2015; Tiffany et al., 2012). The emergence of these subjective measures is driven by the increasing focus on patient-centered care and shared decision-making in the SUD and mental health field, highlighting the importance of involving patients in both treatment decisions and service evaluation (Davis et al., 2020; Friedrichs et al., 2016; Garnick et al., 2012; Kolind and Hesse, 2017). A consensus document by, among others, the United Nations Office on Drugs and Crime (UNODC) and the World Health Organization (WHO)

identified patient-centered treatment and care as one of the key quality standards in SUD treatment services (Dale-Perera, 2021).

Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) are increasingly introduced in healthcare to measure personal wellbeing and quality of care as perceived by patients, in order to guide treatment and service improvement (Doyle et al., 2013; Gleeson et al., 2016; Valderas et al., 2008). PROMs measure the perceived outcomes of the treatment, including information about symptoms, quality of life, physical functioning, and psychological well-being. PREMs measure how service users experience healthcare and refer to practical aspects of care, such as accessibility, coordination and continuity of care, and patient-provider communication. PREMs differ from satisfaction measures as they capture objective patient experiences, rather than relying on patients' subjective views (Kingsley and Patel, 2017). Broadly speaking there are two different categories of patient-reported measures: condition-specific measures, which capture elements relevant to a particular patient group or condition, such as SUD or cancer, and generic measures, which apply to a wide range of patient groups (Churruca et al., 2021). In recent years, several PROMs and PREMs have been developed for use in SUD treatment services, including the Substance Use Recovery Evaluator (SURE) (Neale et al., 2016), the Patient Reported Experience Measure in Addiction Treatment (PREMAT) (Hinsley et al., 2019; Kelly et al., 2021), and the Patient-Reported Outcomes Measurement Information System (PROMIS) (Pilkonis et al., 2013; Pilkonis et al., 2016; Pilkonis et al., 2015).

Most PROMs were initially developed for use in clinical trials to assess the effectiveness of treatment (Churruca et al., 2021; Kluzek et al., 2022). However, over time, their use has expanded to clinical practice and policy evaluation, where they are used to measure quality of care, improve patient-provider communication, enhance shared decision making, and compare outcomes between health-care providers as a form of benchmarking (Churruca et al., 2021; Gelkopf et al., 2021; Kluzek et al., 2022; Marshall et al., 2006). Considering that most PROMs were not developed for the latter purposes, their potential use and validity in these settings might be limited (Churruca et al., 2021; Kingsley and

Patel, 2017). Similarly, the use of PREMs varies from local initiatives to improve the quality of services, to benchmarking and performance reporting on an (inter)national level (Gleeson et al., 2016).

In various healthcare fields, PROMs and PREMs are widely used and have shown a positive impact on patient-provider communication, processes of care, health status, and patient safety (Doyle et al., 2013; Gleeson et al., 2016; Marshall et al., 2006). Some international organizations, e.g., the OECD (Organisation for Economic Co-operation and Development) and ICHOM (International Consortium for Health Outcomes Measurement), promote the systematic use of patient-reported measures across all healthcare domains. However, implementation of these measures in routine clinical practice in general mental health settings has proven to be a difficult process, requiring a nationwide policy and active involvement and training of all stakeholders (Gelkopf et al., 2021; Roe et al., 2021). Although the number of initiatives focusing on the systematic use of PROMs and PREMs in SUD treatment services is increasing, research on this topic in the SUD field is still in its infancy and seriously fragmented. (Clarke et al., 2021; Davis et al., 2020; Goodman JD, 2013; ICHOM Addiction 2020; Kelly and Mee-Lee, 2019; Myers et al., 2015; Trujols et al., 2013). Like in other healthcare areas, PROMs and PREMs have the potential to improve the quality and effectiveness of SUD treatment services. However, an overview of the measures used in clinical practice and the specific challenges faced when implementing PROMs and PREMs in SUD treatment is currently lacking.

Therefore, this scoping review aims to identify and characterize the international literature on current practices regarding the use and systematic implementation of PROMs and PREMs in SUD treatment services.

The research questions that we intend to explore in this scoping review are:

1. What are the current practices regarding the use of PROMs and/or PREMs in SUD treatment services?
2. What are the known factors that facilitate or hinder the routine implementation of PROMs and/or PREMs in SUD treatment services?

2. Methods

For this scoping review we followed the JBI methodology for scoping reviews (Peters et al., 2015; Peters et al., 2020). Results were reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) (Tricco et al., 2018).

A preliminary search for existing scoping and systematic reviews, conducted on 24th March 2022 in PubMed, Web of Science, APA PsycINFO, Cochrane Database of Systematic Reviews and JBI Database of Systematic Reviews and Implementation Reports, identified that no review addressing the use and implementation of PROMs and PREMs in SUD treatment services is currently available.

2.1 Inclusion criteria

Articles and studies that explicitly reported on the use and/or routine implementation of PROMs and/or PREMs in SUD treatment services were included. We only included articles that used the terms 'patient-reported outcome measures' or 'patient-reported experience measures' and related terms. Studies in which the measures used were not patient-self-reported were deemed ineligible. We included all service settings that treated SUD, including inpatient, outpatient, and community treatment. Studies that were not set in clinical practice or in services not treating SUD were excluded. Reports focused on physical health (e.g., HIV or hepatitis C) or smoking were also excluded. There were no geographical or chronological restrictions.

2.2 Search strategy

An initial search of PubMed and Web of Science databases was undertaken to identify articles on the use of PROMs and/or PREMs in SUD treatment services. The full search strategy was developed in consensus between four of the authors (CM, AZ, CC and WV) using the text words included in titles and abstracts of relevant articles, and the index terms used to describe the articles (see appendix 1). The search strategy was adapted for each included database. The databases searched include PubMed (Medline), Web of Science, APA PsycINFO (Ebsco), Embase, and EBSCO Open Dissertations. Articles

were searched from database inception to 1st August 2023. The final and full search was conducted on 1st August 2023, after which all identified citations were collated and uploaded to EndNote 20 (Clarivate Analytics, PA, USA) and duplicates were removed.

2.3 Article selection

Titles and abstracts were screened independently by two of the researchers (CM and AZ) for assessment against the inclusion criteria. Of the selected papers, full texts were further assessed in detail by both researchers. References of included articles were searched for additional studies. Disagreement between the researchers was resolved through discussion, or with a third author (WV and CC) when needed.

2.4 Data extraction

Relevant data were extracted from the included articles to address the research questions, using the JBI methodology (Peters et al., 2015). Two of the researchers (CM and AZ) charted the data using a data extraction tool developed by the research team (see appendix 2). The following information was extracted from all included studies: author(s), year of publication, country, aim of the study, methodology, study population, sample size, treatment setting, PROMs and/or PREMs reported, method of PROM and/or PREM data collection, barriers and facilitators to PROM/PREM implementation, and relevant key findings.

2.5 Article inclusion

A total of 701 papers were identified. After removal of duplicates and screening of title and abstract, 92 articles remained for full-text review, of which 71 were excluded because they did not address the research question, and one because we were unable to retrieve the full text, despite efforts to contact the authors. The study selection and inclusion process is presented in Figure 1. Through citation

tracking of the articles included, three additional articles were identified, resulting in a total of 23 papers included in this review.

=== Insert Figure 1 here ===

3. Results

3.1 Characteristics of included studies

All included articles were recent, with the earliest ones dating from 2016 and most articles (n=18; 78%) being from 2019 onwards. Table 1 shows an overview of the characteristics of the included studies. The majority of the studies included in this review were conducted in high-income countries (USA n=10, 44%; Norway n=3, 13%; Australia n=2, 9%; Germany n=1, 4%). The only studies from low- or middle-income countries (LMIC) were from South Africa (n=6, 26%) and Bulgaria (n=1, 4%). Almost all studies included only adults (18 years and older), except for one that focused on adolescents (13-17 years old) (Myers et al., 2019a), and three studies did not report any age restrictions (Krasteva et al., 2022; Myers et al., 2022; van der Westhuizen et al., 2021). Fourteen articles reported on the use of PROMs and PREMs to assess patient outcomes and the effectiveness of SUD treatment services. (Amura et al., 2022; Carlsen et al., 2019; Carlsen et al., 2020; Dams et al., 2023; Huhn et al., 2022; Kablinger et al., 2022; Liebmann et al., 2022; Muller et al., 2017; Myers et al., 2022; Ngo et al., 2022; Strada et al., 2019; van der Westhuizen et al., 2021; Wilson et al., 2022; Yi et al., 2022). Implementation of PROMs and PREMs into routine clinical practice was discussed in 8 articles (Bingham et al., 2016; Hawk et al., 2021; Johnston et al., 2016; Krasteva et al., 2022; Myers et al., 2016; Myers et al., 2017; Myers et al., 2019a; Myers et al., 2019b). Of these 8 studies, 4 focused on the clinicians' perspectives (Bingham et al., 2016; Myers et al., 2016; Myers et al., 2017; Myers et al., 2019b), 3 focused on the patients' perspectives (Hawk et al., 2021; Krasteva et al., 2022; Myers et al., 2019a), and 1 study assessed both patients' and clinicians' views on the acceptability and ease of use of PROMs in an SUD treatment setting (Johnston et al., 2016). We included 1 systematic review which examined the

relationship between indicators of patient-centered care, such as the use of PREMs, and patient outcomes in specialized SUD treatment settings (Davis et al., 2020).

=== Insert Table 1 here ===

3.2 Patient-reported measures

Most studies used established, validated measurement tools, both generic and SUD-specific, as patient-reported outcome indicators. An overview of the patient-reported measures used in the different studies can be found in Table 1. Only five instruments were used in more than one study: the Alcohol Use Disorder Identification Test (AUDIT), the Brief Addiction Monitor (BAM), the Short Form Health Survey-12 (SF-12), the General Anxiety Disorder-7 (GAD-7) and the Patient Health Questionnaire-9 (PHQ-9).

Myers et al. (2015) developed their own patient-reported measurement tool, the South Africa Addiction Treatment Services Assessment (SAATSA), a 31-item patient-reported survey which assesses patients' perceptions of the outcome and quality of SUD treatment services. Carlsen et al. (2019, 2020) made use of data that was collected as part of KVARUS, the National Quality Register for Substance Abuse Treatment (NQR-SAT), in Norway. This is a questionnaire that collects PROM and PREM data, incorporating questions from different validated tools, such as the World Health Organization Quality of Life - Brief (WHOQOL-BREF) (Carlsen et al., 2019; Carlsen et al., 2020; Skevington et al., 2004).

Besides the SAATSA and the KVARUS, the only other PREM that was used in the included studies was the Experiences of Care and Health Outcome Survey (ECHO), which was developed specifically for use in mental health and SUD treatment (Daniels et al., 2004; Liebmann et al., 2022). Next to the ECHO, Davis et al. (2020) also identified the Community Oriented Program Environment Scale (COPES) and the Primary Care Assessment Survey (PCAS) as comprehensive and psychometrically validated PREMs suitable for use in SUD treatment.

3.3 Implementation of PROM and PREM in clinical care

3.3.1 Timing of data collection

Patient-reported data were most often collected at the start of treatment. In those studies where follow-up data were collected, the timing varied considerably. In some studies, follow-up data were collected at set times, ranging from one month to twelve months after baseline (Bingham et al., 2016; Dams et al., 2023; Johnston et al., 2016; Kablinger et al., 2022; Muller et al., 2017). In other cases, these measurements were only repeated at or after discharge (Hawk et al., 2021; Ngo et al., 2022; Wilson et al., 2022; Yi et al., 2022). The most common timing for measuring follow-up data was at three months after baseline, in some cases preceded by a measurement point one month after baseline (Bingham et al., 2016; Carlsen et al., 2019; Carlsen et al., 2020; Johnston et al., 2016; Liebmann et al., 2022; van der Westhuizen et al., 2021). Bingham et al. (2016) recommended reducing the time interval between intake, screening, and completion of patient-reported measures. They also suggested encouraging the completion of longitudinal assessments, even if this occurs outside the preferred time frame, as a means to address common challenges in the SUD population, such as relapse, for instance.

Loss to follow-up in the longitudinal studies included in this review varied from 29.3% to 58%. The study by Kablinger and colleagues (2022) showed that, across all diagnostic groups that were assessed, PROM completion was lowest for patients with SUD, suggesting that additional barriers exist for this population (Hawk et al., 2021; Johnston et al., 2016; Kablinger et al., 2022). Several authors have outlined possible reasons for these rates of missing patient-reported data: the voluntary nature of the data collection, clinics' focus on service delivery rather than on data collection, premature treatment dropout, inability to contact patients for follow-up due to non-working or disconnected telephone numbers, incarceration, or relapse (Amura et al., 2022; Hawk et al., 2021; Johnston et al., 2016; Myers et al., 2022). Patients themselves reported lack of interest, concerns over data privacy, and different priorities, such as housing, finances, and medical appointments, as reasons for noncompletion (Carlsen et al., 2019; Hawk et al., 2021). Proactive recruitment of participants and testing participants'

phone numbers were suggested as strategies to minimize missing data and loss to follow-up (Carlsen et al., 2019; Hawk et al., 2021).

3.3.2 Method of data collection

Bingham et al. (2016), Hawk et al. (2021), and Krasteva et al. (2022) assessed the electronic administration of PROMs and concluded that access to and the use of electronic methods are feasible and acceptable for people with SUD. Bingham et al. (2016) recruited participants in an outpatient SUD treatment clinic and provided desktop computers that were reserved for PROM completion (Bingham et al., 2016; Johnston et al., 2016). Hawk et al. (2021) assessed patients with opioid use disorder presenting in the emergency department and made use of an online platform that could be accessed through a personal smart device, or a tablet or laptop provided by the service as needed. Krasteva et al. (2022) included participants with SUD without specifying the setting. They used a mobile application that participants could access on their personal devices. Recommendations were formulated to address some challenges typically associated with electronic data collection, such as difficulties retaining login information, integration into clinical care, and technological issues (Hawk et al., 2021). It is advised to have adequate technology available for data collection, including dedicated computers or tablets, and internet access (Bingham et al., 2016; Hawk et al., 2021; Johnston et al., 2016). When participants need to make use of their personal e-mail and/or mobile devices, having multiple phone chargers available, providing strategies to record and retain login information, and attention to patient preference for telephone, text or e-mail contact can be helpful (Hawk et al., 2021). Another strategy that was proposed to overcome the barriers of electronic data collection is to train research and/or clinical staff to help patients resolve technological issues and to have specialized IT staff available who can easily be contacted when needed (Bingham et al., 2016; Hawk et al., 2021).

Myers et al. (2016, 2019b), who used a pen-and-paper version of the SAATSA in an LMIC setting, found that some centers had developed their own electronic administration system. This offered the advantage of automated electronic reminders for measurement completion, reducing the workload

for treatment providers. Additional advantages of this electronic system included a decrease in social desirability, the ability for remote completion, and faster and easier data processing and feedback (Myers et al., 2016; Myers et al., 2019b). Audio-computer-assisted personal interviewing could also help enable illiterate patients to fill out the survey (Myers et al., 2016; Myers et al., 2019a). However, despite the described advantages of moving to an electronic system, technical issues, such as a lack of available computers, may limit the implementation of this transition (Myers et al., 2016).

3.3.3 Implementation in routine clinical practice

Several studies reported on facilitators and barriers for implementing PROM and PREM data collection and routine use in SUD treatment services. An overview of the most important factors is presented in Table 2.

Myers et al. (2016, 2017, 2019b) conducted three studies focusing on treatment providers' views on the implementation of the SAATSA in routine clinical care in residential and outpatient settings in South Africa and found that, in general, treatment providers deemed it feasible to implement the instrument in their daily practice. Additionally, they found the results to be valuable in guiding service improvement efforts. Timing of assessment proved an important challenge, both for patients, who sometimes felt overwhelmed by administrative procedures when the measurement was performed at first contact, and for clinicians, who needed to adapt their usual processes to incorporate data collection and keep track of when patients needed to complete the measures (Myers et al., 2016). On the other hand, a participatory leadership approach that actively endorsed the implementation of the measurement system seemed to positively influence the staff's readiness to adopt this system. This highlights the importance of an organizational climate that is open to and supportive of implementing new practices (Myers et al., 2017; Myers et al., 2019b).

Difficulties with interpreting the feedback of patient-reported data hindered the use of these data as guidance for quality improvement initiatives (Myers et al., 2019b). To enhance the usefulness and implementation of PROM and PREM data in clinical practice, the results need to be processed and

organized in a way that is understandable and accessible to patients and clinicians. Johnston et al. (2016) generated individual patient reports by downloading the data from their electronic platform and restructuring and assembling them for presentation, displaying the responses to the PROM assessments in both bar graph form and as a table of individual items. Patients and therapists reported that they found this feedback helpful in treatment planning and communication, and that it helped them make treatment decisions (Bingham et al., 2016; Johnston et al., 2016). Dams et al. (2023) pointed out that routine implementation of patient-reported measurements may require a mix of strategies such as clinician education, systemic support, and eliciting clinician feedback.

=== Insert Table 2 here ===

4. Discussion

Based on this scoping review of 23 articles that reported on current practices regarding the use and systematic implementation of PROMs and PREMs in SUD treatment services, we found that the literature on this topic appears to be recent, starting from 2016. There are several possible reasons why we only found recent articles: PROM and PREM are relatively new terms that have become more relevant only in the last decade, as the patient's perspective has become increasingly important. Moreover, PROMs were initially mainly used in research, particularly in clinical trials, and only recently their use has expanded to clinical practice, which was the focus of this review (Churruca et al., 2021). Lastly, in SUD treatment, researchers appear to be hesitant to use self-reported data due to concerns about reliability because of the social undesirability of drug use and possible negative consequences of disclosing use, though research has shown consistently that there is a high agreement between self-report and biological measures of drug use (Bharat et al., 2023).

The majority of the included studies were conducted in high-income countries. The few studies from LMICs came from South Africa and Bulgaria. These countries, however, face distinct difficulties and

therefore findings from research in high-income countries can often not be implemented in LMIC settings (McMichael et al., 2005).

Although the literature on PROMs is expanding, this seems to be less so for PREMs. Of the studies included in this review, only Carlsen et al. (2019, 2020), Liebmann et al. (2022), and Myers et al. (2022) made use of a PREM, alongside outcome indicators. In their systematic review, Davis et al. (2020) describe the limited attention for PREMs compared to patient satisfaction. PREM and patient satisfaction are quality of care concepts that are clearly distinct, with PREMs focusing more on whether certain processes and events occurred, while satisfaction pertains to the affective response to the care received (Davis et al., 2020).

Some of the first validated patient-reported measures stem from the mental health field, dating back to as early as the 1960s, and mental health PROMs are among the most widely used in all healthcare fields, which is likely due to the fact that self-reporting is essential in diagnosing and monitoring mental health conditions (Churruca et al., 2021). The growing interest in incorporating the patient's perspective in assessing treatment outcomes and quality of care, in SUD treatment as well as in other healthcare fields, has resulted in an increasing use of PROMs and PREMs (Churruca et al., 2021; Davis et al., 2020; Trujols et al., 2013). However, it is important to note that 'patient-reported measure' (i.e., PROM and PREM) can be used to describe any self-reported instrument that assesses how patients perceive aspects of the outcome or quality of their treatment. The term describes the patient as the source of the information, which does not necessarily mean that the content of the measure accurately reflects patients' primary concerns (Trujols et al., 2013). The target population of a PROM or PREM should be involved throughout its development if it wants to move beyond traditional instruments and be truly meaningful and relevant to patients, and not just to clinicians or researchers, because, as Trujols et al. (2013) point out, "PROMs that are irrelevant to patients – even if

psychometrically robust – do not ensure a genuinely patient-centered outcome assessment" (Neale and Strang, 2015; Trujols et al., 2013).

In this review we included all studies that used the term Patient-Reported Outcome Measures/PROM and Patient-Reported Experience Measures/PREM and related terms, relying on the authors' interpretation and use of these terms. The measures used in the included studies showed important differences in how they were developed (e.g., with or without user involvement) and for what purpose (e.g., screening, outcome assessment). For example, the AUDIT was developed as a screening instrument to detect harmful alcohol use in a primary care setting and was not intended for outcome assessment (Saunders et al., 1993). Thus, not all patient-reported measures reported here might be equally valid or meaningful in assessing treatment outcome and quality from the patient's perspective. Especially frequently used measures that were developed a long time ago, such as for instance the Addiction Severity Index (ASI), appear to lack patient involvement, and it is likely that the constructs that they assess differ from patients' own views on their treatment needs and health status. It is recommended for researchers who use existing PROMs and PREMs to evaluate that these measures are not just self-reported, but allow for a truly patient-centered assessment, in order to avoid generating outcomes that are not relevant to patients (Neale and Strang, 2015; Trujols et al., 2013).

The studies included in this review varied in data collection methods and timing, indicating a lack of consensus in the SUD field on how and when PROM and PREM data should be collected. There was very little overlap in the instruments used and significant variation in what the measures assessed (e.g., substance use, quality of life, mental health, physical health). Some studies reported high rates of loss to follow-up, which is a known challenge in persons with SUD, increasing the risk of selection/attrition bias. Moreover, it can lead to a decrease in the motivation of treatment providers, who may become less inclined to administer assessments regularly. This, in turn, could compromise the quality and utility of the data (Dams et al., 2023; Johnston et al., 2016; Stark, 1992).

Collection of PROM and PREM data can serve a range of different purposes, from guiding individual treatment to comparing service quality on an (inter)national level. Different objectives require different data collection strategies to ensure robust data and minimize the risk of bias. A more coordinated and standardized approach could generate more useful, comparable data, which in turn could increase motivation to implement such a data collection system (Boyce et al., 2014; Myers et al., 2019b; Roe et al., 2021). For example, ICHOM recently developed a standard set of outcome indicators, termed the Standard Set for Addictions (SSA), focusing on PROM assessment and providing an internationally agreed upon method for measuring patient-reported outcomes in addiction (ICHOM Addiction, 2020). In any case, when interpreting patient-reported data, we need to take into account measurement errors, such as inaccurate data entry and missed measurement scores, that are inherent to this naturalistic method of data collection (Ngo et al., 2022; Yi et al., 2022).

In most cases, patient-reported measures were collected as part of a one-time evaluation of the effectiveness or acceptability of a service or treatment. Some studies, however, reported on the results of PROM and PREM data which were collected regularly, as part of routine clinical practice. This was the case for studies from Norway, the USA, and South Africa. These routinely implemented systems of PROM and PREM assessment demonstrate how these data can be used to guide treatment and identify outcome predictors, targets for quality improvement in services, and directions for future research. For example, Myers et al. (2022) identified patient groups facing greater challenges in accessing SUD treatment, as well as patient groups reporting poorer health outcomes. Additionally, Carlsen et al. (2019, 2020) found that quality of life is an important factor affecting opioid use in patients treated with opioid agonist therapy. These are valuable findings that can enhance the accessibility and quality of services, as well as guide individualized treatment plans. This kind of information can also further stimulate the implementation of PROM and PREM assessment in standard care.

Nevertheless, like in other mental health fields, embedding these measurement systems into daily clinical practice in SUD treatment poses some significant challenges. Attrition and burden for staff and patients are important barriers to implementation to consider, especially in settings where time, staff, and resources are already constrained. On the other hand, leadership support, having an integrated electronic administration system, and providing regular, useful feedback to treatment providers and patients contribute to the successful implementation of PROM and PREM data collection and utilization in routine clinical care. Electronic completion systems offer some important advantages, and it is recommended for organizations to invest in electronic systems for PROM and PREM data completion and interpretation (Foster et al., 2018). Based on the studies included in this review, the use of electronic systems seems feasible and acceptable to people with SUD and to treatment providers. Yet, it is important to highlight that only a few studies have been undertaken in LMIC settings, where access to technology is not as readily available as in high-income countries. Factors that are known to limit people's ability to make use of electronic devices, such as low socioeconomic status, homelessness, and older age, were also not investigated (Myers et al., 2021; Zhai, 2020). Further research on how patients, including those in vulnerable situations, perceive the routine implementation of patient-reported measurement systems could help decrease attrition rates and improve the quality of the collected data.

5. Limitations

Although we conducted a broad search, without any geographical or chronological restrictions, and with no language barriers as all identified articles were in English, it is possible that certain studies have been overlooked. We opted to focus our search on articles using the terms Patient-Reported Outcome Measures/PROM and Patient-Reported Experience Measures/PREM and related terms, but there is little standardization in the use of this terminology, and there may exist relevant articles that applied different terms. During our search, we came across additional PROMs and PREMs available for use in SUD treatment to the ones described here, but they were not included in this review because

their use was limited to clinical studies or psychometrical properties, which was beyond the scope of this review. Lastly, we did not assess the quality of the included studies, given that this was a scoping review and not a systematic review.

6. Conclusions

Improving patient-centered treatment for people with SUD requires direct input from patients on how they perceive health outcomes and quality of care. PROMs and PREMs allow us to collect this feedback in a systematic and meaningful way. This review identified that patient-reported measures are increasingly used in SUD treatment services, but there are substantial differences in the PROMs and PREMs administered, the ways in which they were developed, and how and when they are collected in clinical practice. Guidance is needed for researchers and clinicians to select valid, meaningful, and comparable patient-reported measures. Furthermore, using implementation science in the integration of PROMs and PREMs in SUD treatment could offer valuable insights on how to overcome barriers in using these measures in routine clinical care. If we want to understand and benefit from the impact that PROM and PREM data can have on treatment quality and treatment results, we need standardized and comparable instruments and implementation methods.

Role of funding source

This work was supported by a grant from the Belgian Science Policy Office (BELSPO), research project DR/90.

BELSPO was not involved in the research conducted or in the writing of the manuscript.

Acknowledgements

This work was supported by a grant from the Belgian Science Policy Office (BELSPO), research project DR/90.

Table 1 Characteristics of included articles; OUD=Opioid Use Disorder, OAT = Opioid Agonist Therapy, SUD=Substance Use Disorder, AUD=Alcohol Use Disorder

Study/authors	Country	Methodology	Study population and setting	Patient-reported measures reported
Epidemiology of Hepatitis C Virus Infection Among People Receiving Opioid Substitution Therapy (ECHO) Strada et al., 2019	Germany	Quantitative, cross-sectional study	Adults with OUD in outpatient treatment receiving OAT N=2,176	Brief Symptom Inventory (BSI-18); Opiate Treatment Index Health Symptoms Scale (OTI-HSS); Short Form 12 (SF-12)
Measurement-Based Care (MBC) in	USA, Virginia			

Veterans Health Administration (VHA) Mental Health (MH) Initiative Dams et al., 2023		Quantitative, longitudinal study; T0= admission; T1= discharge	Veterans in residential SUD treatment N=14,070	Brief Addiction Monitor-Revised (BAM-R); Patient Health Questionnaire-9 (PHQ-9); PTSD checklist for DSM (PCL-5); Generalized Anxiety Disorder-7-item scale (GAD-7)
National Quality Register for Substance Abuse Treatment (KVARUS)	Norway			

Carlsen et al., 2019		Quantitative, longitudinal study; T0= baseline; T1-4= every 3 months until 12-month follow-up	Adults with OUD in outpatient treatment receiving OAT N=47	KVARUS (National Quality Register for Substance Abuse Treatment – NQR-SAT)
Carlsen et al., 2020		Quantitative, longitudinal study; T0= baseline; T1-4= every 3 months until 12-month follow-up	Adults with OUD in outpatient treatment receiving OAT N=47	KVARUS (National Quality Register for Substance Abuse Treatment – NQR-SAT)
Norwegian Cohort of Patients in Opioid Maintenance Treatment and Other Drug	Norway			

Treatment (NorComt) Muller et al., 2017		Quantitative, longitudinal study; T0= start of treatment; T1= after 12 months	Adults in outpatient and residential SUD treatment N=338	10-item Quality of Life questionnaire (QOL10)
Patient-Centered Outcomes Research Institute (PCORI) Pilot projects Bingham et al., 2016	USA, Maryland/Pennsylvania	Mixed-methods, cross-sectional study	Treatment providers for patients with chronic illnesses, including SUD	Patient-Reported Outcome Measurement Information System (PROMIS)

			Sample size not reported	
Johnston et al., 2016		Mixed-methods, longitudinal study; T0= start of treatment; T1= after 1 month; T2= after 3 months	Adults with dual diagnosis SUD and psychiatric disorders in outpatient treatment N=225	Alcohol Use Disorder Identification Test (AUDIT); Patient-Reported Outcome Measurement Information System (PROMIS)
Service Quality Measures (SQM) performance measurement system	South Africa			
Myers et al., 2016		Qualitative study	SUD treatment providers N=15	South Africa Addiction Treatment Services Assessment (SAATSA)

Myers et al., 2017		Quantitative, cross-sectional study	SUD treatment providers N=81	South Africa Addiction Treatment Services Assessment (SAATSA)
Myers et al., 2019a		Qualitative study	Adolescents in outpatient and residential SUD treatment N=38	South Africa Addiction Treatment Services Assessment (SAATSA)
Myers et al., 2019b		Mixed-methods study	SUD treatment providers N=81 (quantitative) N=26 (qualitative)	South Africa Addiction Treatment Services Assessment (SAATSA)
Myers et al., 2022		Quantitative, cross-	Patients in outpatient	South Africa Addiction

		sectional study	and residential SUD treatment N=1,097 treatment episodes	Treatment Services Assessment (SAATSA)
Veterans Outcome Assessment (VOA) survey Liebmann et al., 2022	USA, Connecticut	Quantitative, longitudinal study; T0= start of treatment; T1= after 3 months	Veterans in outpatient SUD treatment N=2,788	Short Form 12 (SF-12); Experiences of Care and Health Outcomes Survey (ECHO)
Virtual Intensive Outpatient Program (VIOP) study	USA, Minnesota	Quantitative, longitudinal study;	Adults in intensive outpatient	Patient Health Questionnaire-9 (PHQ-9); General

Ngo et al., 2022		T0= start of treatment; T1= 1 month post-discharge; T2= 3 months post-discharge; T3-5= every 3 months until 12 months post-discharge	treatment for SUD N=3,642	Anxiety Disorder (GAD-7); 5-item Commitment to Sobriety Scale (CSS-5); Desire for Alcohol Questionnaire-6; System Usability Scale; Flourishing scale; Consumer Financial Protection Bureau (CFPB) Financial Well-being Scale; Gratitude Questionnaire-6 item form; Centers for Disease Control Healthy Days Survey; Self-efficacy of Sustained Sobriety Scale; 12-step peer group engagement; Parenting Daily Hassles Scale;

				Modified Children of Alcoholics Screening Test-6; Revised Conflict Tactics Scale; Form-90 Quick Drinking Assessment (Form-90-AQ)
Amura et al., 2022	USA, Colorado	Quantitative, longitudinal study T0= start of treatment; T1= after 6 months	Adults with OUD in outpatient treatment receiving OAT N=1,005	Addiction Severity Index (ASI); General Anxiety Disorder (GAD-7); Patient Health Questionnaire (PHQ-9)
Davis et al., 2020	Australia	Systematic literature review	Patients in specialized SUD treatment	Experiences of Care and Health Outcome Survey (ECHO); Community Oriented Program Environment Scale (COPES); Primary Care Assessment Survey (PCAS)

Hawk et al., 2021	USA, Connecticut	Quantitative, longitudinal study; T0= emergency department visit; T1= 3 days post-discharge; T2= 30 days post-discharge	Adults with OUD in the emergency department N=101	Patient-Reported Outcome Measurement Information System (PROMIS); Treatment Effectiveness Assessment (TEA)
Huhn et al., 2022	USA, Maryland	Quantitative, cross-sectional study	Adults in SUD treatment in the past 3 months N=240	Beck Anxiety Inventory (BAI); Insomnia Severity Index (ISI); Perceived Stress Scale (PSS)
Kablinger et al., 2022	USA, Virginia	Quantitative, cross-sectional study	Adults in outpatient psychiatric treatment N=103	Alcohol Use Disorder Identification Test (AUDIT); Brief Addiction Monitor – Revised (BAM-R); Brief Adjustment

				Scale (BASE-6); Drug Abuse Screening Test (DAST-10); General Anxiety Disorder (GAD-7); Patient Health Questionnaire (PHQ-9)
Krasteva et al., 2022	Bulgaria	Quantitative, cross-sectional study	Patients with SUD N=1,077 completed questionnaires	Questionnaires assessing mood, anxiety, substance use, sleep, medication, social activity, and various symptoms
van der Westhuizen et al., 2021	South Africa	Mixed methods study; T0= emergency department visit; T1= after 3 months	Patients with AUD in the emergency department N=4,847 (quantitative) N=18 (qualitative)	Alcohol, Smoking and Substance Abuse Involvement Screening Test (ASSIST)

Wilson et al., 2022	Australia	Quantitative, longitudinal study; T0= start of treatment; T1= treatment completion	Patients in a general practice and specialist AUD collaborative care program N=152	Australian Treatment Outcome Profile (ATOP)
Yi et al., 2022	USA, Maryland	Quantitative, longitudinal study; T0= admission; T1= discharge	Adults in residential SUD treatment N=961	Brief Addiction Monitor (BAM); PROMIS-Global Health Scale (GHS)

Table 2 Facilitators and barriers to collecting and using Patient Reported Outcome Measurement (PROM) and Patient Reported Experience Measurement (PREM) data

Facilitators	**Barriers**
Compatibility with existing administrative and organizational practices	Burden on clinical staff
Electronic platform	Timing of assessment
Technical/IT support	Attrition and treatment drop-out
Training and awareness of staff	Lack of resources
Leadership support	Difficulties interpreting data feedback

Regular feedback of data	Illiteracy
Perceived utility of the system for improving treatment quality	Delay in receiving paper forms

References

Alves, P., Sales, C., Ashworth, M., 2017. Does outcome measurement of treatment for substance use disorder reflect the personal concerns of patients? A scoping review of measures recommended in Europe. Drug Alcohol Depend. 179, 299-308.

Amura, C.R., Sorrell, T.R., Weber, M., Alvarez, A., Beste, N., Hollins, U., Cook, P.F., 2022. Outcomes from the medication assisted treatment pilot program for adults with opioid use disorders in rural Colorado. Subst. Abuse: Treat. Prev. Policy 17(1).

Bargagli, A.M., Faggiano, F., Amato, L., Salamina, G., Davoli, M., Mathis, F., Cuomo, L., Schifano, P., Burroni, P., Perucci, C.A., 2006. VEdeTTE, a longitudinal study on effectiveness of treatments for heroin addiction in Italy: study protocol and characteristics of study population. Subst. Use Misuse 41(14), 1861-1879.

Bharat, C., Webb, P., Wilkinson, Z., McKetin, R., Grebely, J., Farrell, M., Holland, A., Hickman, M., Tran, L.T., Clark, B., Peacock, A., Darke, S., Li, J.H., Degenhardt, L., 2023. Agreement between self-reported illicit drug use and biological samples: a systematic review and meta-analysis. Addiction 118(9), 1624-1648.

Bingham, C.O., III, Bartlett, S.J., Merkel, P.A., Mielenz, T.J., Pilkonis, P.A., Edmundson, L., Moore, E., Sabharwal, R.K., 2016. Using patient-reported outcomes and PROMIS in research and clinical applications: Experiences from the PCORI pilot projects. Qual. Life Res. 25(8), 2109-2116.

Boyce, M.B., Browne, J.P., Greenhalgh, J., 2014. The experiences of professionals with using information from patient-reported outcome measures to improve the quality of healthcare: a systematic review of qualitative research. BMJ Qual. Saf. 23(6), 508-518.

Carlsen, S.-E.L., Lunde, L.-H., Torsheim, T., 2019. Predictors of quality of life of patients in opioid maintenance treatment in the first year in treatment. Cogent Psychol. 6, 14.

Carlsen, S.-E.L., Lunde, L.-H., Torsheim, T., 2020. Opioid and Polydrug Use Among Patients in Opioid Maintenance Treatment. Subst. Abuse Rehabil. 11, 9-18.

Castelpietra, G., Knudsen, A.K.S., Agardh, E.E., Armocida, B., Beghi, M., Iburg, K.M., Logroscino, G., Ma, R., Starace, F., Steel, N., Addolorato, G., Andrei, C.L., Andrei, T., Ayuso-Mateos, J.L., Banach, M., Bärnighausen, T.W., Barone-Adesi, F., Bhagavathula, A.S., Carvalho, F., Carvalho, M., Chandan, J.S., Chattu, V.K., Couto, R.A.S., Cruz-Martins, N., Dargan, P.I., Deuba, K., da Silva, D.D., Fagbamigbe, A.F., Fernandes, E., Ferrara, P., Fischer, F., Gaal, P.A., Gialluisi, A., Haagsma, J.A., Haro, J.M., Hasan, M.T., Hasan, S.S., Hostiuc, S., Iacoviello, L., Iavicoli, I., Jamshidi, E., Jonas, J.B., Joo, T., Jozwiak, J.J., Katikireddi, S.V., Kauppila, J.H., Khan, M.A.B., Kisa, A., Kisa, S., Kivimäki, M., Koly, K.N., Koyanagi, A., Kumar, M., Lallukka, T., Langguth, B., Ledda, C., Lee, P.H., Lega, I., Linehan, C., Loureiro, J.A., Madureira-Carvalho Á, M., Martinez-Raga, J., Mathur, M.R., McGrath, J.J., Mechili, E.A., Mentis, A.A., Mestrovic, T., Miazgowski, B., Mirica, A., Mirijello, A., Moazen, B., Mohammed, S., Mulita, F., Nagel, G., Negoi, I., Negoi, R.I., Nwatah, V.E., Padron-Monedero, A., Panda-Jonas, S., Pardhan, S., Pasovic, M., Patel, J., Petcu, I.R., Pinheiro, M., Pollok, R.C.G., Postma, M.J., Rawaf, D.L., Rawaf, S., Romero-Rodríguez, E., Ronfani, L., Sagoe, D., Sanmarchi, F., Schaub, M.P., Sharew, N.T., Shiri, R., Shokraneh, F., Sigfusdottir, I.D., Silva, J.P., Silva, R., Socea, B., Szócska, M., Tabarés-Seisdedos, R., Torrado, M., Tovani-Palone, M.R., Vasankari, T.J., Veroux, M., Viner, R.M., Werdecker, A., Winkler, A.S., Hay, S.I., Ferrari, A.J., Naghavi, M., Allebeck, P., Monasta, L., 2022. The burden of mental disorders, substance use disorders and self-harm among young people in Europe, 1990-2019: Findings from the Global Burden of Disease Study 2019. Lancet Reg. Health Eur. 16, 100341.

Churruca, K., Pomare, C., Ellis, L.A., Long, J.C., Henderson, S.B., Murphy, L.E.D., Leahy, C.J., Braithwaite, J., 2021. Patient-reported outcome measures (PROMs): A review of generic and condition-specific measures and a discussion of trends and issues. Health Expect. 24(4), 1015-1024.

Clarke, D.E., Ibrahim, A., Doty, B., Patel, S., Gibson, D., Pagano, A., Thompson, L., Goldstein, A.B., Vocci, F., Schwartz, R.P., 2021. Addiction Medicine Practice-Based Research Network (AMNet): Assessment Tools and Quality Measures. Subst. Abuse Rehabil. 12, 27-39.

Cox, G., Comiskey, C., 2009. Characteristics of opiate users presenting for a new treatment episode: Baseline data from the national drug treatment outcome study in Ireland (ROSIE). Drugs: Educ. Prev. Policy 14(3), 217-230.

Dale-Perera, A., 2021. Quality assurance in treatment for drug use disorders:
key quality standards for service appraisal.
https://www.unodc.org/documents/QA_OCTOBER_2021.pdf

Dams, G.M., Burden, J.L., Resnick, S.G., Forno, J.W., Smith, N.B., 2023. Measurement-based care in Veterans Health Administration mental health residential treatment. Psychol. Serv. doi: 10.1037/ser0000752.

Daniels, A.S., Shaul, J.A., Greenberg, P., Cleary, P.D., 2004. The Experience of Care and Health Outcomes Survey (ECHO): A Consumer Survey to Collect Ratings of Behavioral Health Care Treatment, Outcomes and Plans, The use of psychological testing for treatment planning and outcomes assessment: Instruments for adults, Volume 3, 3rd ed. Lawrence Erlbaum Associates Publishers, Mahwah, NJ, US, pp. 839-866.

Davis, E.L., Kelly, P.J., Deane, F.P., Baker, A.L., Buckingham, M., Degan, T., Adams, S., 2020. The relationship between patient-centered care and outcomes in specialist drug and alcohol treatment: A systematic literature review. Substance Abus. 41(2), 216-231.

De Maeyer, J., Vanderplasschen, W., Broekaert, E., 2009. Exploratory Study on Drug Users' Perspectives on Quality of Life: More than Health-Related Quality of Life? Soc. Indic. Res. 90, 107-126.

Degenhardt, L., Hall, W., 2012. Extent of illicit drug use and dependence, and their contribution to the global burden of disease. Lancet 379(9810), 55-70.

Degenhardt, L., Whiteford, H.A., Ferrari, A.J., Baxter, A.J., Charlson, F.J., Hall, W.D., Freedman, G., Burstein, R., Johns, N., Engell, R.E., Flaxman, A., Murray, C.J.L., Vos, T., 2013. Global burden of disease attributable to illicit drug use and dependence: findings from the Global Burden of Disease Study 2010. Lancet 382(9904), 1564-1574.

Doyle, C., Lennox, L., Bell, D., 2013. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. BMJ Open 3(1), e001570.

Fletcher, B.W., Tims, F.M., Brown, B.S., 1997. Drug Abuse Treatment Outcome Study (DATOS): Treatment Evaluation Research in the United States. Psychol. Addict. Behav. 11, 216-229.

Foster, A., Croot, L., Brazier, J., Harris, J., O'Cathain, A., 2018. The facilitators and barriers to implementing patient reported outcome measures in organisations delivering health related services: a systematic review of reviews. J. Patient Rep. Outcomes 2, 46.

Friedrichs, A., Spies, M., Härter, M., Buchholz, A., 2016. Patient Preferences and Shared Decision Making in the Treatment of Substance Use Disorders: A Systematic Review of the Literature. PLoS One 11(1), e0145817.

Garnick, D.W., Horgan, C.M., Acevedo, A., McCorry, F., Weisner, C., 2012. Performance measures for substance use disorders--what research is needed? Addict. Sci. Clin. Pract. 7(1), 18.

Gelkopf, M., Mazor, Y., Roe, D., 2021. A systematic review of patient-reported outcome measurement (PROM) and provider assessment in mental health: goals, implementation, setting, measurement characteristics and barriers. Int. J. Qual. Health Care 34(Suppl 1), ii13–ii27.

Gleeson, H., Calderon, A., Swami, V., Deighton, J., Wolpert, M., Edbrooke-Childs, J., 2016. Systematic review of approaches to using patient experience data for quality improvement in healthcare settings. BMJ Open 6(8), e011907.

Goodman JD, M.J., DePhilippis D, 2013. Progress monitoring in mental health and addiction treatment: A means of improving care. Prof. Psychol. Res. Pract. 44(4), 231-246.

Gossop, M., Marsden, J., Stewart, D., Kidd, T., 2003. The National Treatment Outcome Research Study (NTORS): 4-5 year follow-up results. Addiction 98(3), 291-303.

Hawk, K., Malicki, C., Kinsman, J., D'Onofrio, G., Taylor, A., Venkatesh, A., 2021. Feasibility and acceptability of electronic administration of patient reported outcomes using mHealth platform in emergency department patients with non-medical opioid use. Addict. Sci. Clin. Pract. 16(1), 66.

Hinsley, K., Kelly, P.J., Davis, E., 2019. Experiences of patient-centred care in alcohol and other drug treatment settings: A qualitative study to inform design of a patient-reported experience measure. Drug Alcohol Rev. 38(6), 664-673.

Huhn, A.S., Strain, E.C., Jardot, J., Turner, G., Bergeria, C.L., Nayak, S., Dunn, K.E., 2022. Treatment Disruption and Childcare Responsibility as Risk Factors for Drug and Alcohol Use in Persons in Treatment for Substance Use Disorders During the COVID-19 Crisis. J. Addict. Med. 16(1), e8-e15.

ICHOM Addiction, June 2020, available at: https://www.ichom.org/portfolio/addiction/. Accessed on 7 Sep 2023.

Johnston, K.L., Lawrence, S.M., Dodds, N.E., Yu, L., Daley, D.C., Pilkonis, P.A., 2016. Evaluating PROMIS® instruments and methods for patient-centered outcomes research: Patient and provider voices in a substance use treatment setting. Qual. Life Res. 25(3), 615-624.

Kablinger, A.S., Gatto, A.J., O'Brien, V.C., Ko, H.Y., Jones, S., McNamara, R.S., Sharp, H.D., Tenzer, M.M., Cooper, L.D., 2022. Effects of COVID-19 on Patients in Adult Ambulatory Psychiatry: Using Patient-Rated Outcome Measures and Telemedicine. Telemed. J. E. Health 28(10), 1421-1430.

Kelly, J.F., Mee-Lee, D., 2019. Quality, accountability, and effectiveness in addiction treatment: The measurement-based practice model, in: Danovitch, I., Mooney, L.J. (Eds.), The assessment and treatment of addiction: Best practices and new frontiers. Elsevier, Amsterdam, pp. 207-217.

Kelly, P.J., Hatton, E.L., Hinsley, K., Davis, E., Larance, B., 2021. Preliminary psychometric evaluation of the patient reported experience measure for addiction treatment (PREMAT). Addict. Behav. 123.

Kiluk, B.D., Fitzmaurice G.M., Strain E.C., Weiss R.D., 2019. What Defines a Clinically Meaningful Outcome in the Treatment of Substance Use Disorders: Reductions in Direct Consequences of Drug Use or Improvement in Overall Functioning? Addiction 114(1), 9-15.

Kingsley C, Patel S., 2017. Patient-reported outcome measures and patient-reported experience measures. BJA Educ. 17(4), 137-144.

Kluzek, S., Dean, B., Wartolowska, K.A., 2022. Patient-reported outcome measures (PROMs) as proof of treatment efficacy. BMJ Evid. Based Med. 27(3), 153-155.

Kolind, T., Hesse, M., 2017. Patient-centred care-perhaps the future of substance abuse treatment. Addiction 112(3), 465-466.

Krasteva, S., Apostolov, Z., Kozhuharov, H., 2022. What ePROs are telling us about patients with substance use disorder. European Psychiatry 65, S166-S166.

Liebmann, E.P., Resnick, S.G., Hoff, R.A., Katz, I.R., 2022. Associations between patient experience and clinical outcomes in substance use disorder clinics: Findings from the Veterans Outcomes Assessment survey. J. Subst. Abuse Treat. 133, 11.

Marshall, S., Haywood, K., Fitzpatrick, R., 2006. Impact of patient-reported outcome measures on routine practice: a structured review. J. Eval. Clin. Pract. 12(5), 559-568.

McKeganey N, B.M., McIntosh J, Neale J, 2008. Key findings from the Drug Outcome Research in Scotland (DORIS) study. University of Glasgow Centre for Drug Misuse Research.

McMichael, C., Waters, E., Volmink, J., 2005. Evidence-based public health: what does it offer developing countries? J. Public Health (Oxf) 27(2), 215-221.

Muller, A.E., Skurtveit, S., Clausen, T., 2017. Building abstinent networks is an important resource in improving quality of life. Drug Alcohol Depend. 180, 431-438.

Myers, B., Govender, R., Koch, J.R., Manderscheid, R., Johnson, K., Parry, C.D.H., 2015. Development and psychometric validation of a novel patient survey to assess perceived quality of substance abuse treatment in South Africa. Subst. Abuse Treat. Prev. Policy 10(44), 15.

Myers, B., Williams, P.P., Johnson, K., Govender, R., Manderscheid, R., Koch, J.R., 2016. Providers' perceptions of the implementation of a performance measurement system for substance abuse treatment: A process evaluation of the Service Quality Measures initiative. S. Afr. Med. J. 106, 308-311.

Myers, B., Williams, P.P., Johnson, K., Govender, R., Manderscheid, R., Koch, J.R., 2017. Readiness to adopt a performance measurement system for substance abuse treatment: Findings from the Service Quality Measures initiative. S. Afr. Med. J. 107(2), 160-164.

Myers, B., Johnson, K., Lucas, W., Govender, R., Manderscheid, R., Williams, P.P., Koch, J.R., 2019a. South African service users' perceptions of patient-reported outcome and experience measures for adolescent substance use treatment: A qualitative study. Drug Alcohol Rev. 38(7), 823-830.

Myers, B., Williams, P.P., Govender, R., Manderscheid, R., Koch, J.R., 2019b. A Mixed-Methods Evaluation of the Implementation of a Performance Measurement System for South Africa's Substance Use Treatment Services. J. Stud. Alcohol Drugs Suppl. Sup 18, 131-138.

Myers, B., van der Westhuizen, C., Pool, M., Hornsby, N., Sorsdahl, K.R., 2021. Responding to COVID-19 threats to trial conduct: lessons learned from a feasibility trial of a psychological intervention for South African adolescents. Trials 22(1), 440.

Myers, B., Koch, J.R., Johnson, K., Harker, N., 2022. Factors associated with patient-reported experiences and outcomes of substance use disorder treatment in Cape Town, South Africa. Addict. Sci. & Clin. Pract. 17, 13.

Neale, J., Strang, J., 2015. Blending qualitative and quantitative research methods to optimize patient reported outcome measures (PROMs). Addiction 110(8), 1215-1216.

Neale, J., Vitoratou, S., Finch, E., Lennon, P., Mitcheson, L., Panebianco, D., Rose, D., Strang, J., Wykes, T., Marsden, J., 2016. Development and validation of 'SURE': A Patient Reported Outcome Measure (PROM) for recovery from drug and alcohol dependence. Drug Alcohol Depend. 165, 159-167.

Ngo, Q.M., Braughton, J.E., Gliske, K., Waller, L.A., Sitar, S., Kretman, D.N., Cooper, H.L.F., Welsh, J.W., 2022. In-Person Versus Telehealth Setting for the Delivery of Substance Use Disorder Treatment: Ecologically Valid Comparison Study. JMIR Form. Res. 6(4), e34408.

Peters, M.D., Godfrey, C.M., Khalil, H., McInerney, P., Parker, D., Soares, C.B., 2015. Guidance for conducting systematic scoping reviews. Int. J. Evid. Based Healthc. 13(3), 141-146.

Peters MDJ, G.C., McIrney P, Munn Z, Tricco AC, Khalil H., 2020. Chapter 11: Scoping Reviews (2020 version), in: Aromataris E, M.Z.E. (Ed.) JBI Manual for Evidence Synthesis.

Pilkonis, P.A., Yu, L., Colditz, J., Dodds, N., Johnston, K.L., Maihoefer, C., Stover, A.M., Daley, D.C., McCarty, D., 2013. Item banks for alcohol use from the Patient-Reported Outcomes Measurement Information System (PROMIS®): Use, consequences, and expectancies. Drug Alcohol Depend. 130(1-3), 167-177.

Pilkonis, P.A., Yu, L., Dodds, N.E., Johnston, K.L., Lawrence, S.M., Daley, D.C., 2016. Validation of the alcohol use item banks from the Patient-Reported Outcomes Measurement Information System (PROMIS®). Drug Alcohol Depend. 161, 316-322.

Pilkonis, P.A., Yu, L., Dodds, N.E., Johnston, K.L., Lawrence, S.M., Hilton, T.F., Daley, D.C., Patkar, A.A., McCarty, D., 2015. Item banks for substance use from the Patient-Reported Outcomes Measurement Information System (PROMIS(®)): Severity of use and positive appeal of use. Drug Alcohol Depend. 156, 184-192.

Roe, D., Mazor, Y., Gelkopf, M., 2021. Patient-reported outcome measurements (PROMs) and provider assessment in mental health: a systematic review of the context of implementation. Int. J. Qual. Health Care 34(Suppl 1), ii28–ii39.

Saunders, J.B., Aasland, O.G., Babor, T.F., de la Fuente, J.R., Grant, M., 1993. Development of the Alcohol Use Disorders Identification Test (AUDIT): WHO Collaborative Project on Early Detection of Persons with Harmful Alcohol Consumption--II. Addiction 88(6), 791-804.

Skevington, S.M., Lotfy, M., O'Connell, K.A., 2004. The World Health Organization's WHOQOL-BREF quality of life assessment: psychometric properties and results of the international field trial. A report from the WHOQOL group. Qual. Life Res. 13(2), 299-310.

Stark, M.J., 1992. Dropping out of substance abuse treatment: A clinically oriented review. Clin. Psychol. Rev. 12(1), 93-116.

Strada, L., Schmidt, C.S., Rosenkranz, M., Verthein, U., Scherbaum, N., Reimer, J., Schulte, B., 2019. Factors associated with health-related quality of life in a large national sample of patients receiving

opioid substitution treatment in Germany: A cross-sectional study. Subst. Abuse Treat. Prev. Policy 14(1), 2.

Teesson, M., Mills, K., Ross, J., Darke, S., Williamson, A., Havard, A., 2008. The impact of treatment on 3 years' outcome for heroin dependence: findings from the Australian Treatment Outcome Study (ATOS). Addiction 103(1), 80-88.

Tiffany, S.T., Friedman, L., Greenfield, S.F., Hasin, D.S., Jackson, R., 2012. Beyond drug use: a systematic consideration of other outcomes in evaluations of treatments for substance use disorders. Addiction 107(4), 709-718.

Tricco, A.C., Lillie, E., Zarin, W., O'Brien, K.K., Colquhoun, H., Levac, D., Moher, D., Peters, M.D.J., Horsley, T., Weeks, L., Hempel, S., Akl, E.A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M.G., Garritty, C., Lewin, S., Godfrey, C.M., Macdonald, M.T., Langlois, E.V., Soares-Weiser, K., Moriarty, J., Clifford, T., Tunçalp, Ö., Straus, S.E., 2018. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. Ann. Intern. Med. 169(7), 467-473.

Trujols, J., Portella, M.J., Iraurgi, I., Campins, M.J., Siñol, N., de Los Cobos, J.P., 2013. Patient-reported outcome measures: are they patient-generated, patient-centred or patient-valued? J. Ment. Health 22(6), 555-562.

Valderas, J.M., Kotzeva, A., Espallargues, M., Guyatt, G., Ferrans, C.E., Halyard, M.Y., Revicki, D.A., Symonds, T., Parada, A., Alonso, J., 2008. The impact of measuring patient-reported outcomes in clinical practice: a systematic review of the literature. Qual. Life Res. 17(2), 179-193.

van der Westhuizen, C., Malan, M., Naledi, T., Roelofse, M., Myers, B., Stein, D.J., Lahri, S., Sorsdahl, K., 2021. Patient outcomes and experience of a task-shared screening and brief intervention service for problem substance use in South African emergency centres: a mixed methods study. Addict. Sci. & Clin. Pract. 16(1), 31.

Whiteford, H.A., Degenhardt, L., Rehm, J., Baxter, A.J., Ferrari, A.J., Erskine, H.E., Charlson, F.J., Norman, R.E., Flaxman, A.D., Johns, N., Burstein, R., Murray, C.J., Vos, T., 2013. Global burden of

disease attributable to mental and substance use disorders: findings from the Global Burden of Disease Study 2010. Lancet 382(9904), 1575-1586.

Wilson, H.H.K., Schulz, M., Mills, L., Lintzeris, N., 2022. Feasibility and outcomes of a general practice and specialist alcohol and other drug collaborative care program in Sydney, Australia. Austr. J. Prim. Health 28(2), 158-163.

Yi, C.M., Huhn, A.S., Hobelmann, J.G., Finnerty, J., Solounias, B., Dunn, K.E., 2022. Integration of Patient-reported Outcomes Assessment Into Routine Care for Patients Receiving Residential Treatment for Alcohol and/or Substance Use Disorder. J. Addict. Med. 16(4), e240-e247.

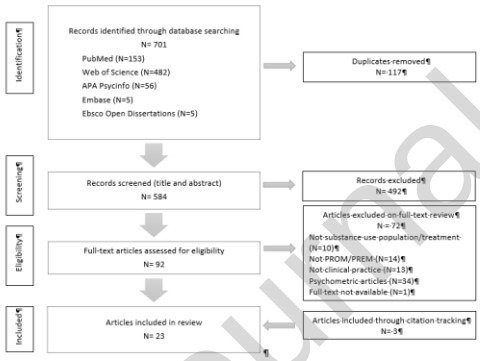


Fig. 1. PRISMA flow diagram of the scoping review process

Contributors

Charlotte Migchels and Amine Zerrouk performed the literature search, screening, and selection. Cleo Crunelle and Wouter Vanderplasschen participated in the selection of included articles. Charlotte Migchels, Cleo Crunelle and Wouter Vanderplasschen prepared the manuscript. All authors contributed to the design and methodology, and reviewed and approved the final manuscript.

Conflict of interest

Wim van den Brink reports a relationship with Takeda Pharmaceutical Company Limited, Camurus AB, and Clearmind that includes: consulting or advisory.

All other authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Highlights

- The use of patient-reported measures can improve addiction treatment services
- Challenges exist for implementing patient-reported measures in addiction services
- Guidance is needed in the selection and collection of patient-reported measures
- Patient-reported data should be used cautiously due to risk of bias and errors