FEDERAL RESEARCH PROGRAMME ON DRUGS

OMER-BE

Outcome Measurement and Evaluation as a Routine practice in alcohol and other drug services in Belgium (BE)

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Contract - DR/90

FINAL REPORT

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As this is a study by a multidisciplinary team of researchers with a background in psychiatry, psychology, special education and public health, we used different terminologies and frameworks throughout the study and this research report. We have tried to be as consistent as possible in using terminology within chapters, but depending on the lead author and the journal where a paper was submitted/published, terminology may differ throughout the report. Consequently, terms like 'addiction', 'substance use disorder' and 'alcohol and drug problems' are used interchangeably in this report, as well as the terms 'alcohol and drug services' and 'substance use (SUD) treatment'. By analogy with the terms PROM and PREM, the term 'patient' is used to refer to users of alcohol and drug services and persons involved in SUD treatment, which are also referred to as 'service users' or 'clients'. We apologise for any inconvenience this may cause, as this interpretation of the term may differ from the reader's interpretation.

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LIST OF ABBREVIATIONS

ACT	Assertive Community Treatment
ADHD	Attention-Deficit/Hyperactivity Disorder
AOD	Alcohol and Other Drugs
ASAM	American Society of Addiction Medicine
ASI	Addiction Severity Index
ASRS	Adult ADHD Self-Report Scale
AUDIT	Alcohol Use Disorder Identification Test
BAM	Brief Addiction Monitor
BSI	Brief Symptom Inventory
CFA	Confirmatory Factor Analysis
CFI	Comparative Fit Index
CoCoTDI	Treatment Demand Indicator Coordination Committee
COPES	Community Oriented Program Environment Scale
DASS	Depression, Anxiety and Stress Scale
ECHO	Experiences of Care and Health Outcome Survey
EMCDDA	European Monitoring Centre for Drugs and Drug Addiction (now EUDA)
EUDA	European Union Drugs Agency
GAD	Generalized Anxiety Disorder
GH	Global Health
GHB	Gamma-Hydroxybutyrate
HSI	Heaviness of Smoking Index
ICHOM	International Consortium for Health Outcomes Measurement
IGDT	Internet Gaming Disorder Test
IRT	Item Response Theory
KCE	Federaal Kenniscentrum voor de Gezondheidszorg (Belgian Health Care Knowledge Centre)
LMIC	Low- or Middle-Income Countries
NQR-SAT	National Quality Register for Substance Abuse Treatment
NSDUH	National Survey on Drug Use and Health
OAT	Opioid Agonist Treatment
OECD	Organisation for Economic Co-operation and Development
OMER-BE	Outcome Measurement and Evaluation as a Routine practice in alcohol and other drug services in Belgium
OMT	Opioid Maintenance Treatment
OST	Opioid Substitution Treatment
OTI-HSS	Opiate Treatment Index Health Symptoms Scale

PC	Psychiatric treatment Center
PCA	Principal Component Analysis
PCAS	Primary Care Assessment Survey
PC-PTSD-5	Primary Care PTSD Screen for DSM-5
PEQ-ITSD	Patient Experiences Questionnaire for Interdisciplinary Treatment for Substance Dependence
PGSI	Problem Gambling Severity Index
PHQ	Patient Health Questionnaire
PREM	Patient-Reported Experience Measure
PREMAT	Patient Reported Experience Measure for Addiction Treatment
PRISMA-ScR	Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews
PROM	Patient-Reported Outcome Measure
PROMIS	Patient-Reported Outcomes Measurement Information System
QoL	Quality of Life
RMSEA	Root Mean Square Error of Approximation
ROM	Routine Outcome Monitoring
ROSC	Recovery-Oriented Systems of Care
SAATSA	South Africa Addiction Treatment Services Assessment
SF	Short Form
SF-12	Short Form Health Survey-12
SSA	Standard Set for Addictions
SUD	Substance Use Disorder
SURE	Substance Use Recovery Indicator
TC	Therapeutic Community
TDI	Treatment Demand Indicator
TLI	Tucker-Lewis Index
TOP	Treatment Outcomes Profile for substance misuse
UNODC	United Nations Office on Drugs and Crime
VIKZ	Vlaams Instituut voor Kwaliteit van Zorg (Flemish Institute for Quality of Care)
VIP²	Vlaams Indicatoren Project (Flemish Indicator Project)
WHO	World Health Organization
WHODAS	World Health Organization Disability Assessment Schedule
WHOQOL-BREF	World Health Organization Quality of Life – Brief
YLL	Years of Life Lost

CHAPTER 1

BACKGROUND, AIMS AND STUDY DESIGN

I. BACKGROUND

1.1. Alcohol and drug problems and its treatment

Alcohol and other drug (AOD) problems are associated with a broad range of negative health, social and economic consequences that affect individuals, families as well as neighborhoods and communities worldwide [1, 2]. AOD problems have a significant impact on the global burden of disease [3] and the co-existence of AOD and other psychiatric disorders poses specific treatment challenges [4]. Housing, judicial and relational problems are also well-documented among this population, including a negative impact on partners, children and parents [5]. Addiction has been characterized as a chronic and relapsing brain disorders [6-8], but an increasing body of literature shows that recovery is possible, despite being a long and individual process requiring a personalized approach and ongoing support.

Treatment outcome studies in the United States (e.g. TOPS, DATOS), Australia (e.g. ATOS, SONAR) and several European countries (e.g. NTORS (England & Wales), DORIS (Scotland), ROSIE (Ireland), VEDETTE (Italy)) have repeatedly demonstrated the benefits of engaging in AOD treatment, typically resulting in improved abstinence and employment rates and less recidivism and psychopathology [9-14]. Multiple studies have compared various treatment modalities (e.g. long-term residential treatment, residential detox and opiate substitution treatment), indicating substantial differences in target populations and outcomes. Yet, consistent evidence shows that treatment retention/completion and participation in aftercare are strong predictors of successful outcomes [15-18].

While treatment may be effective for addressing AOD problems, relapse rates are high and initial positive outcomes tend to decline over time. Most persons (52-58%), however, recover from AOD problems [19], but the time needed to achieve stable recovery (>5 years) varies and may take up to 30 years [20]. The role of treatment in recovery trajectories should not be overestimated and recent research among a large, representative US sample [21] demonstrated that a substantial proportion of persons who have overcome an AOD problem (46%) do so without formal treatment or professional support. Some authors have questioned the severity of these persons' AOD problems and found more severe problems among persons seeking professional treatment [22]. In any case, treatment remains the recommended recovery pathway for those with severe and long-lasting AOD problems [23].

1.2. Treatment evaluation in Belgium and use of PROMs and PREMs

A wide variety of specialized outpatient and residential AOD services is available in Belgium, but little is known about the effectiveness and efficiency of these services, in the absence of outcome studies or specific tools for routine outcome measurement. Available evaluation studies have looked at specific interventions or populations (e.g. family therapy in therapeutic communities [24]; Multidimensional Family Therapy for adolescent cannabis users) [25]) or were limited to a specific setting or region (add ref BFTC study – VDP PZ studie). No systematic monitoring or evaluation of treatment of persons with AOD problems is performed in Belgium, except the pharmacological register and monitoring of opioid substitution treatment (OST). Moreover, available data about AOD users are highly fragmented, since these are usually collected at the regional level (Flanders, Brussels, Wallonia) and/or per sector (e.g. hospitals, specialized drug services, mental health care centres). National data are limited to the EMCDDA Treatment Demand Indicator (TDI), which only covers intake

data of persons with AOD problems. A recent development concerns the implementation of an instrument for measuring support needs across a variety of health and social services (i.c. BEL-RAI, including a specific supplement on addiction), but this tool neither provides specific information on persons with AOD problems nor information on treatment outcomes. Other recent efforts (e.g. Vlaams Indicatoren Project (VIP²)/Flemish Indicator Project; Vlaamse Patiëntenpeiling/Flemish Patient survey) have attempted to measure a few generic outcome indicators for mental health services (including AOD services), but these assessments lacked specificity and a longitudinal scope. As a consequence, very limited information is available on treatment outcomes and experiences of users of AOD services in Belgium.

Treatment outcomes are traditionally evaluated using objective outcome measures (e.g. number of drinking days, days employed or hospitalized), but several authors have emphasized the need to look beyond these socially desirable outcomes and to also incorporate subjective outcome indicators such as quality of life and well-being [26, 27]. A growing body of literature recommends the use of 'patient-reported outcomes' and 'patient-reported experiences' in healthcare research to monitor the provision of effective, individualized care to persons accessing treatment and other services [28-31]. *Patient-Reported Outcome Measures* (PROMs) provide information on the outcomes of the treatment that individuals have received, including information about symptoms, quality of life, physical functioning, and psychological well-being. *Patient-Reported Experience Measures* (PREMs) measure how service users experience health care and refer to practical aspects of care, such as accessibility, coordination and continuity of care and provider-patient communication. Internationally reputed bodies like the OECD (Organisation for Economic Co-operation and Development) and ICHOM (International Consortium for Health Outcomes Measurement) strongly promote the routine measurement of health outcomes as these matter most to service users themselves and contribute to building better lives. Routine monitoring of patient outcomes (PROMs) and experiences (PREMs) is recently strongly promoted in all health care areas, including primary care, psychotherapy, and multidisciplinary mental health care settings (e.g. AOD services). A systematic review showed that the routine use of patient-reported outcome measures (PROMs) is labor intensive, but has the potential to enhance treatment outcomes and management [29].

As opposed to other health care sectors, there is a lack of research on PROMs and PREMs in the AOD field [32]. An international group under leadership of professor Michael Farrell (AU), consisting of well-known international experts (e.g. Wim van den Brink (NL), Joanne Neale (UK), Marica Ferri (PT) and Marta Torrens (ES)) and supported by the EMCDDA (European Monitoring Centre for Drugs and Drug Addiction (recently named European Drugs Agency (EUDA), Lisbon) developed a standard set of outcome indicators for AOD problems in partnership with ICHOM. By bringing together patient representatives, clinical leaders and registry leaders from all over the world, ICHOM develops standard sets of outcome indicators for all types of health disorders. The Standard Set for Addiction (SSA) [33] focuses on patient-centered results (PROM) and provides an internationally agreed upon method for measuring each of these outcomes. Adoption of standardized outcome measures opens possibilities to compare performance not only within regions and countries, but also globally, allowing practitioners to learn from each other, and providing policy makers with tools and evidence to improve the quality and effectiveness of care. The systematic use of patient-reported experiences measures (PREMs) in AOD services is even scarcer [32], although PREMs are also likely to advance the field

towards more personalized and effective support, since they provide a direct evaluation of the accessibility, continuity and coordination of care by service users.

II. AIMS AND OBJECTIVES OF THE STUDY

Given the lack of research on effectiveness and outcomes in AOD services in Belgium and the relapsing nature of AOD problems, longitudinal research on (long-term) outcomes after various AOD treatment modalities is highly needed. International research shows that recovery is a long and individual process that can clearly be advanced by treatment and cumulative treatment experiences [34, 35]. Also other elements play an important role in recovery pathways, relating to personal and social recovery capital and community resources like employment, housing, peer-support groups, etc.. While most outcome research has solely looked at effectiveness using objective, clinical outcome measures, this study aimed to incorporate patient-reported outcomes (PROM) and experiences (PREM) to evaluate and improve the quality of AOD treatment. The OMER-BE study (Outcome Measurement and Evaluation as a Routine practice in alcohol and other drug services in BElgium) intended to introduce systematic measurement of patient-reported outcomes and experiences in AOD services in Belgium and to assess the effectiveness of various treatment modalities for persons with AOD problems.

The overall aim of the project was to improve the quality of AOD services in Belgium through routine measurement and monitoring of patient-reported outcomes and experiences. To achieve this goal, several specific objectives and related work packages were put forward:

I. *Prepare the implementation of measuring treatment outcomes and experiences (WP1)*
   - Adapt, translate and test the ICHOM outcome measurement tool in AOD services in Belgium
   - Assess the implementation of PROMs and PREMs in AOD and other mental health services and review preconditions for their implementation

II. *Measure patient-reported outcomes (PROMs) from a recovery and continuing care perspective in various treatment modalities for AOD service users in Belgium (WP2 & 3)*
   - Assess baseline characteristics of service users and differences between treatment populations and modalities
   - Monitor initial evolutions and progress after 45 and 90 days, controlling for baseline characteristics and treatment modality
   - Assess and compare 6-month outcomes and recovery status, based on established outcome and recovery predictors (e.g. retention, aftercare participation, severity of dependence, extent of social network)

III. *Assess patient-reported experiences (PREMs) in diverse treatment modalities for AOD users (WP4)*
   - Document and monitor treatment experiences among a large sample of AOD service users to evaluate various aspects of quality of care
   - Conduct an in-depth assessment of service users' treatment and recovery experiences

IV. *Evaluate the feasibility of routine measurement of PROMs and PREMs and discuss the perceived quality of care and effectiveness of various AOD treatment modalities (WP5)*
   - Prepare and test the routine use of the outcome measurement tool in daily practice
   - Provide recommendations for future routine implementation of PROMs and PREMs in AOD services in Belgium

III. STUDY METHODOLOGY AND DESIGN

The OMER-BE project aimed to address the lack of outcome and effectiveness research in the AOD field in Belgium by setting up a non-randomized, naturalistic, longitudinal cohort study in various treatment modalities for persons with AOD problems, starting from a recovery and continuing care perspective. Considering health authorities' and service providers' increasing interest in patient-reported outcomes (PROMs) and experiences (PREMs) [29] and the Belgian Health Care Knowledge Centre's advice to implement these indicators routinely in health care services [31], this outcome study in AOD services introduced PROMs and PREMs to evaluate effectiveness and enhance routine use of these measures. ICHOM, the International Consortium for Health Outcomes Measurement, plays a prominent role in advancing health outcome measurement and quality of care by providing standard sets of PROMs for various types of health problems. The ICHOM Standard Set for Addictions [33] was released in 2020. It was constructed by various renowned experts in the AOD field, with support from the EMCDDA. PREMs were measured using one of the few validated tools for measuring patient-reported experiences (i.e. PREMAT) [32].

The ICHOM Standard Set for Addictions has been developed to represent the most relevant treatment outcomes according to persons with AOD problems themselves [33]. It is a brief collection of validated and internationally comparable indicators, selected by an international expert panel based on user-friendliness and methodological quality. The standard set consists of background ('case-mix') and outcome variables, covering demographic, clinical and intervention variables ('case-mix' variables), severity of dependence (symptoms, frequency and quantity of alcohol/drug use) and global functioning and quality of life (social, physical and psychological functioning) (see table 1.1) [36]. Administration of the instrument takes about 30 minutes and is intended for routine use by service providers. In this study the instrument was administered by trained researchers to validate the tool and monitor its implementation and to map routine implementation requirements. Part of the study (WP5) focused on the feasibility of PROM/PREM implementation in real-life settings.

Despite the complex and lengthy nature of AOD problems, a single treatment episode was taken as starting point for this cohort study and for following up individuals over a six-month period (with the option to monitor this cohort over longer periods of time). The study cohort was assessed at baseline and patient-reported outcomes and experiences were measured after 45, 90 and 180 days. To reduce drop-out, the first follow-up moment was planned after 45 days, as opposed to the ICHOM guideline to plan the first follow-up after 3 months. Case-mix variables were only measured at baseline, while PROMs and PREMs were measured at all follow-up points. Figure 1.1 provides an overview of the quantitative data collection process and the topics measured at each follow-up moment.

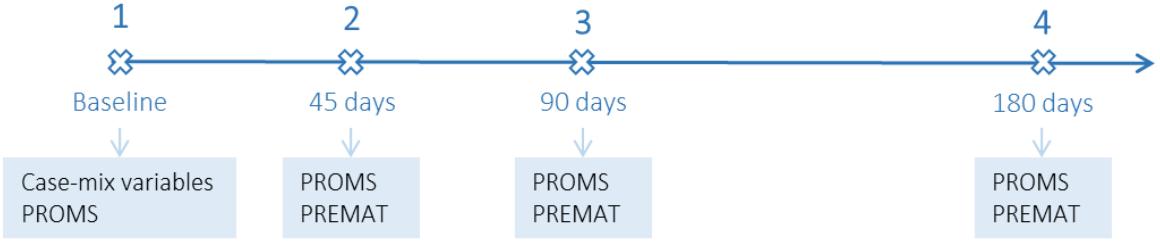

Figure 1.1 – Timeline quanitative data collection process

Originally, we proposed to recruit the study cohort in five treatment modalities, representing the most established and commonly used treatment options for persons with AOD problems in Belgium:

- **Outpatient drug-free treatment.** This generic category of outpatient treatment consists of various types of outpatient services, based on regular individual consultations or group sessions with a counsellor or psychiatrist, without providing agonist treatment. This type of treatment is provided in mental health care centers and specialized services and by individual therapists and coaches, lasting typically 3 to 6 months. As the focus of this study was on services, participants were not recruited through individual counsellors and psychologists.
- **Outpatient substitution treatment.** The most commonly provided treatment for people who use drugs in the EU [37], consisting of opioid agonist treatment (OAT) usually combined with multidisciplinary (medical, psychological & social) support. OAT is available in Belgium through specialized medical-social care and day centers and through GPs. As the focus of the study was on services, participants were not recruited through GPs.
- **Long-term residential treatment.** This common type of residential treatment [38] consists of long-term (2-3 months) treatment in a psychiatric hospital and focuses on (medically assisted) abstinence and rehabilitation after initial detoxification. Most of these programs target persons with alcohol problems.
- **Therapeutic Communities (TCs).** Residential TC programs are rooted in principles of social learning ('community as method'), mutual aid and recovery and focus on building a healthy drug-free lifestyle [39]. TC programs in Belgium usually take approx. 6 months to program completion and are followed by a staged re-entry process.
- **Assertive community treatment (ACT).** Assertive outreach teams ('Mobiele teams 2B') were recently established as part of a mental health care reform in Belgium and reach out to persons with (chronic) mental health problems (including AOD problems) in the community. The support these teams provide is closely linked to what is internationally referred to as (Flexible) Assertive Community Treatment [37]. Despite being a new type of treatment in Belgium, we considered it important to include this type of treatment, as it represents the transition to more community-based care and is considered a missing link between in- and outpatient treatment [40].

It soon turned out, however, that it would not be possible to recruit a sufficient number of participants in ACT teams, as a substance use disorder is seen as an exclusion criterion for support by an ACT team in several mental health networks. Moreover, given the heterogenous composition of the target population of these outreach teams, it would be very challenging to systematically recruit all persons with AOD problems.

While the quantitative cohort study can be considered the core of the OMER-BE research project (WP2-4), the study consisted of a multi-method design, also including qualitative research methods (i.e. in-depth interviews with service users (WP4)), a scoping review of the literature (WP1) and an implementation study in selected AOD settings (WP5)). The interdisciplinary composition of the academic research team (with an equal number of female and male supervisors) was complemented by the involvement of an expert by experience/co-researcher at UGent (P. Tomlinson) and the inclusion of service users' and service providers' voices in various work packages. Figure 1.2 provides a global overview of the research plan and all work packages.

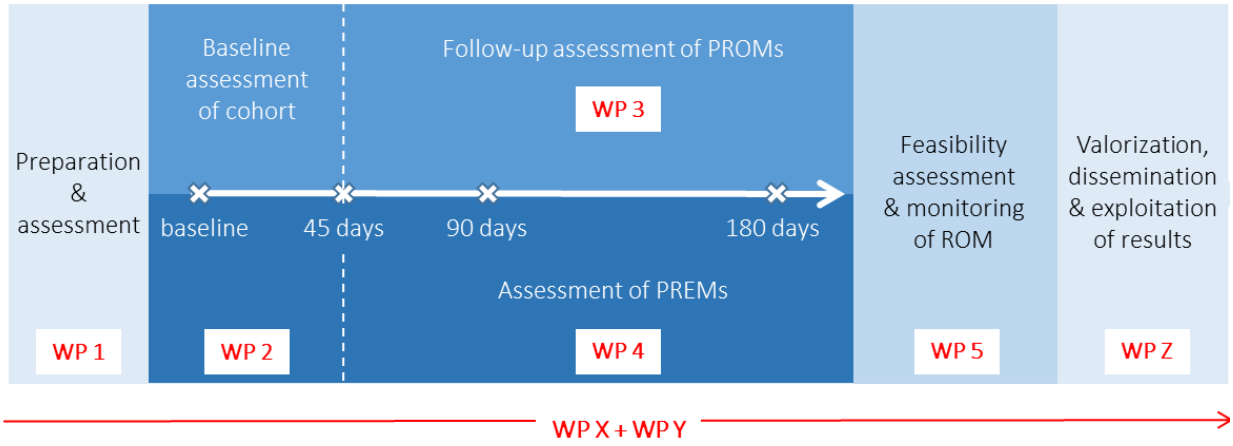

Figure 1.2 – Overview of the OMER-BE research plan and work packages

WP 1 – Preparation of the outcome measurement tool and assessment of existing practices

The project started with a brief inventory of existing practices using PROMs and PREMs in AOD and other mental health services by contacting key informants (e.g. clinical coordinators of large AOD treatment networks, coordinators of mental health networks, umbrella organizations of AOD services) in Flanders, Brussels and Wallonia to identify plans or current attempts to measure outcomes and/or experiences. These practices were contacted to explore instruments that are used in these settings and how they are integrated in the daily routines (if any). The information resulting from this brief assessment was used to prepare the selection of participating services (WP1) and the feasibility study (WP5).

Adapting, translating and testing the outcome measurement tool

The ICHOM Standard Set for Addictions (2020) is a set of brief, validated questionnaires to measure and monitor treatment outcomes routinely in AOD services. The tool consists of case-mix and outcome variables and offers great potential for routine use, since it has been specifically developed for persons with AOD problems, can be administered easily and is applicable in a wide range of treatment settings. The instrument is based on existing questionnaires of which some are available in multiple languages, but not all parts of the ICHOM SSA are available in French/Dutch. Therefore, items and questionnaires not available in Dutch/French were first translated. We used forward/backward translation principles as recommended in the international literature [41] *(see Chapter 3)*.

Besides translating items/questionnaires that are not yet available in Dutch/French, some minor adaptations/additions were made, given the ICHOM recommendation [33] to take into account contextual differences and differences in service user populations. As the focus of the ICHOM Standard Set for Addictions (2020) is limited to PROMs, we added a brief (33 items) instrument (PREMAT, [32]) to assess patient-reported experiences. Consequently, the OMER-BE outcome measurement tool consisted of three sections (described below and in table 1.1).

The first section, i.e. case-mix variables, is designed to collect data on sociodemographic, clinical and intervention factors that may influence treatment outcomes. After consultation of all project partners and the international expert, we included additional screening instruments to assess substance use &

treatment history and comorbid problems that are likely to affect treatment outcomes (e.g. anxiety and depression (DASS-21, [42]), ADHD (ASRS-v I.I, [43]), trauma (PC-PTSD-5, [44])). Given the scope of the call and the study, we decided to omit three measures from the ICHOM standard set: the Problem Gambling Severity Index (PGSI), Ten-Item Internet Gaming Disorder Test (IGDT-10) and KIDSCREEN-10 Index), as the focus of these instruments was not on AOD problems among adults, but on gambling, gaming and adolescents respectively. The second section of the tool is focused on patient-reported outcomes (PROMs). To extend the focus on well-being, we added an instrument to assess subjective quality of life and overall well-being (i.e. WHOQOL-BREF, [45]). The third section of the OMER-BE outcome measurement tool is not part of the ICHOM Standard Set, but concerns a patient-reported experience measure (PREM) to assess service users' experiences regarding the treatment they followed (i.e. PREMAT, [32]).

As several of the selected assesments were not yet available in Dutch and French, the research team conducted a rigorous translation process for the set of questionnaires using both forward and backward translation to ensure accuracy and cultural relevance. The forward translation was carried out by two experts fluent in both the source and target language, also taking into account clarity and linguistic precision of the phrasing while maintaining the original meaning. Afterwards, an independent translator, unaware of the original text, performed the backward translation to compare it with the source material. This step allowed us to identify any discrepancies, ambiguous wording, or unintended shifts in meaning. Some phrases did not translate seamlessly due to cultural or linguistic differences, necessitating revisions and refinements. Through discussions with the translators and subject-matter experts, we adjusted wording to improve clarity and contextual appropriateness. Additionally, pilot testing with native speakers provided valuable feedback, revealing minor misunderstandings or awkward phrasing that we corrected. Overall, while the process was time-consuming, it was crucial in ensuring the reliability and validity of the translated questionnaires. The final version retained the original meaning while being fully comprehensible and culturally appropriate for the target audience. This meticulous approach helped minimize misinterpretations and ensured that responses accurately reflected participants' perspectives. Two of these translated questionnaires were further validated *(see sections 3.1 and 3.2)*.

The adapted and translated instrument was tested to check clarity, user-friendliness and length among 5 inpatient service users in one AOD service in Brussels, allowing to test it among Dutch and French speaking persons. Based on this test assessment, the outcome measurement tool was further discussed within the research team and resulted in a final set of variables. The WHODAS12 (WHO Disability Assessment Schedule 2.0) [46] was eventually excluded due to substantial overlap with other instruments and to reduce the length of the tool. For similar reasons, only 2 (out of 10) items from the PROMIS-GH-10 (PROMIS Scale v1.2 – Global Health) [47] were retained. After making final changes, the OMER-BE measurement tool was converted into a digital entry form to facilitate data-collection and self-assessment at follow-up.

Instrument	Part of ICHOM SSA?	Number of items	Available languages
Case-mix variables			
Socio-demographic factors			
Year of birth, sex, highest level of education completed, work/education status, housing status, ethnic minority	yes	-	Dutch, French
Clinical factors			
Substance use history	yes	10	Dutch, French
Treatment history and hospitalisations	yes	2	Dutch, French
PC-PTSD-5 *(Primary Care PTSD Screen for DSM-5)* ***[44]***	yes	5	English, Dutch, French
DASS-21 *(Depression, Anxiety, Stress Scale)* ***[42]***	no	21	English, Dutch, French
ASRS-v1.1 *(Adult ADHD Self-report Scale)* ***[43]***	no	6	English, Dutch, French
Intervention factors			
Intervention setting + type	yes	-	Dutch, French
Patient-Reported Outcome Measures (PROMS)			
PROMIS-Alcohol *(PROMIS SF v1.0 – Alcohol Use 7a)* ***[48]***	yes	7	English
PROMIS-Substance (*PROMIS SF v1.0 – Severity of Substance Use 7a)* ***[49]***	yes	7	English
PROMIS-Smoking *(PROMIS SF v1.0 – Smoking Nicotine Dependence for All Smokers 8a)* ***[50]***	yes	8	English
HSI *(Heaviness of Smoking Index)* ***[51]***	yes	2	English
TOP-S1 (*NHS Treatment Outcomes Profile for Substance Misuse – Section 1)* ***[52]***	yes	7	English
PROMIS-GH-10 *(PROMIS Scale v1.2 – Global Health)* ***[47]***	yes	2	English
SURE *(Substance Use Recovery Evaluator)* ***[53]***	yes	26	English
WHOQOL-BREF *(WHO Quality of Life Scale)* ***[45]***	no	26	English, Dutch, French
Patient-Reported Experience Measures (PREMS)			
PREMAT *(Patient Reported Experience Measure for Addiction Treatment)* ***[32]***	no	33	English

Table 1.1 - Overview of item and instruments in the OMER-BE outcome measurement tool

Selection of participants and treatment services

We recruited participants in four of the above-mentioned treatment modalities, targeting a diverse sample of persons with a primary alcohol and/or drug use disorder and a substantial proportion of female service users (at least one third). Given the exploratory nature of the project, we did not intend to recruit a representative sample of service users in AOD treatment modalities. We engaged and followed up a naturalistic cohort of persons with AOD problems as they presented themselves in selected AOD services. Potential research locations were purposefully selected based on their interest in the study, their capacity to recruit a sufficient number of participants and geographical spread. As we anticipated a certain degree of attrition at follow-up (20-30%), we aimed to recruit 50 participants in each treatment modality, resulting in a minimal sample size of 35 respondents per treatment

modality. Table 1.2 shows the anticipated number of services that we deemed necessary to reach the number of participants per treatment modality.

Treatment modality	Targeted number of settings (n)	Number of participants per modality (n)
Residential therapeutic Communities	4	50
Residential psychiatric treatment	4	50
Outpatient substitution treatment	3	50
Outpatient drug-free treatment	3	50

Table 1.2 - Original recruitment plan per treatment modality (intended sample = 200)

Given the low patient turnover in long-term residential facilities, we oversampled in these facilities. Eventually, it turned out to be very difficult to recruit study participants in outpatient settings and – after consultation of the guidance committee – we decided to recruit 80 participants in both types of residential services instead of 50. We also aimed to recruit participants in Dutch as well as French speaking services, by engaging at least one French speaking AOD service per modality. We encountered little enthusiasm to participate in the study in French speaking services and eventually only one French speaking service partipated in WP 2 – 4.

Scoping review of the literature

To assess current practices, prerequisites and do's and don'ts regarding the implementation of PROMs and PREMs, we performed a scoping review of the literature. A scoping review is a systematic review methodology and type of research synthesis that aims to map the broad literature on a particular topic. It provides insight in key concepts within a short period of time [54]. Commonly used bibliographical databases (Web of Science, PubMed) were searched, following scoping review guidelines and using following search terms: patient-reported, outcomes, experiences, PROM, PREM, implementation, etc. Relevant hits were studied and analyzed, looking for factors and requirements facilitating/hindering the routine implementation of PROMs and PREMs in a variety of substance use disorder services. These findings are reported in Chapter 2 and were used to formulate recommendations for the routine implementation of PROMs and PREMs in AOD services and for the feasibility study in WP5.

WP 2 – Baseline assessment of the study cohort

Baseline data collection

Data collection targeted 200 adults with AOD problems who started a new treatment episode in one of the selected services/treatment modalities. Eligibility criteria were: (1) have a documented AOD problem (e.g. substance use disorder diagnosis, previous AOD treatment), (2) be at least 18 years old, (3) be able to communicate in Dutch or French, and (4) have started treatment not longer than 14 days ago. 'New' as well as 'known' cases were considered eligible for this cohort study, as long as they started a new treatment episode during the recruitment period. Upon treatment entry, service users were informed about the aims and design of the OMER-BE study through posters, leaflets and staff members of the selected treatment settings. From the start date of the study onwards, all consecutive new treatment entries were checked for eligibility and asked for consent to participate. When service

users agreed to take part in the study, staff members contacted the researchers to notify them about a new eligible candidate. During the initial meeting with the researcher, participants were informed extensively about the study and implications of study participation and were asked for written informed consent to participate. At each subsequent follow-up moment, informed consent to further participate in the study was checked.

When service users agreed to participate, the baseline data-collection started with the assessment of all case-mix variables (sociodemographic, clinical and intervention data) and outcome variables (cf. Figure 1, supra). Baseline data were collected during a face-to-face contact with study participants at the treatment center where they were recruited. Administering the entire set of baseline variables and instruments took approx. 30-45 minutes. At the end of this first assessment, contact details of the participants were collected to facilitate contact at the 45-, 90- and 180-day follow-up moments. Participants received a voucher of 10 EUR for participation in each baseline and follow-up assessment.

WP 3 – Follow-up assessment of patient-reported outcomes (PROM) in AOD services

Study participants were contacted again after 45, 90 and 180 days for follow-up data collection. A 15- (after 45 days) and 30-day time window was permitted at these follow-up assessments, as not all interviews could be done simultaneously, nor were all participants available at the same time. The researchers contacted study participants, either directly by phone or through the treatment setting where they were enrolled in the study or through other contact information they have provided. At each follow-up moment, informed consent to further participate in the study was checked before the start of the interview. Data were collected using online assessment of the outcome measurement tool. Follow-up assessments focused on PROMs (severity of dependence, global functioning and quality of life) and PREMs (see WP4) and took 20 to 30 minutes per assessment.

WP 4 – Patient-reported experiences (PREM) in AOD services

Despite the importance of monitoring patient-reported experiences, the development of quantitative instruments for measuring PREMs in the field of AOD treatment is still in its infancy. Hinsley and colleagues recently developed the PREMAT, a 33-item questionnaire that aims to capture service users' perspectives on the AOD treatment they received [32]. More precisely, the following topics are addressed in the PREMAT: access to care, respect for expressed needs and values, physical comfort, emotional support, involvement of family and friends, continuity and transition, and coordination of care. The PREMAT was adapted and translated (see Chapter 3.2) and was administered at all follow-up moments (45, 90 and 180 days after the first interview (cf. Figure 2, supra), if the participant was still in treatment in the baseline facility or recently left treatment. For example, if a participant stopped treatment after 50 days, the PREMAT was only administered at the 45- and 90-day follow-up moments.

The quantitative data collected with the PREMAT provided global information on service users' experiences with each AOD treatment modality and could be linked to baseline characteristics and PROMS. This quantitative view was complemented with in-depth qualitative interviews. To gain deeper understanding of participants' treatment experiences related to their treatment and recovery trajectories, a subsample of 20 to 25 participants was recruited purposefully from the OMER-BE study

cohort, taking into account following criteria: (1) a balanced number of male and female participants, (2) inclusion of participants from Dutch and French speaking services, and (3) proportional numbers per treatment modality. These qualitative data were collected following the 6-month follow-up interview (180-240 days after quantitative baseline assessment). During this in-depth interview, following topics will be discussed: treatment history, recovery experiences, helping and hindering factors in recovery, and experiences with various treatment modalities. These qualitative interviews lasted 45 to 90 minutes and participants received a 20 EUR voucher for participation in this additional data-collection moment. All interviews were audio-recorded and transcribed verbatim. We made use of NVivo to analyse these data, performing a thematic analysis.

WP 5 – Feasibility of routine outcome measurement and monitoring in AOD services

To assess the feasibility of the routine implementation of the outcome measurement tool, one of the project partners (Sciensano) developed a detailed protocol and tested an online version of the OMER-BE monitoring tool and explored possibilities to link this tool to the registration of AOD service users with the TDI (Treatment Demand Indicator). Two tracks were followed in this WP: one resulting in an intermediate solution, the second one anticipating a long-term, structural integration in the existing TDI-structures.

The integration of the tool in the TDI required thorough discussion within the existing TDI Coordination committee (CocoTDI) and needed to be approved by the Belgian Data Protection Authority. As opposed to WP 2-4, the researchers did not administer the outcome measurement tool in this work package, but trained and supported practitioners for its implementation. Following the experiences in WP2 and 3, a draft protocol was developed. In 5 AOD services (2 in Flanders, 1 in Brussels and 2 in Wallonia; different from the ones in WP2-4), 4 service users were selected (after being fully informed and having provided informed consent) to test the outcome measurement tool which was made consistent with the TDI-protocol. This PROM/PREM-module was not mandatory as is the case for other parts of the TDI. A new secured online application was developed, allowing these 20 service users to complete the baseline and follow-up versions of the outcome measurement tool (after 45, 90 and 180 days, consistent with WP2-4). Service users used a mobile device (phone, laptop, tablet…) to fill out the tool. Service providers and service users were interviewed about their experiences with this online tool. Findings and feedback from other WPs were also taken into account when developing, testing and implementing this tool routinely. Collected data were stored in a secured database separate from the TDI, with a (secured) link to the TDI-data through a unique code. Service providers and practitioners could use the tool for clinical purposes and discuss PROMs and PREMs with service users to optimize individual treatment trajectories. Since the main objective of this phase was to test the protocol and the technical implementation of a computerized tool, service users' data were not analyzed as part of WP3-4, but only to provide individualized feedback and to check accuracy and appropriateness of the data collection. Finally, all necessary steps were taken to prepare the long-term legal and technical integration of this tool into the existing TDI-structure and to make the outcome measurement tool available for voluntary routine use by treatment centers that are participating in the TDI data collection.

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CHAPTER 2

SCOPING REVIEW ON IMPLEMENTATION OF PROMS AND PREMS IN ALCOHOL AND DRUG SERVICES

Based on:

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I. 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 [1]. SUD are an important and growing contributor to the global burden of disease, causing morbidity and premature mortality [2, 3, 4]. In 2019, drug use was responsible for almost 60,000 years of life lost (YLLs) in Europe [2]. 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 [5].

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 [6-11]. 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 [12, 13]. Lately, there has been a growing emphasis on the importance of also including subjective outcome indicators. The latter 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 [12, 14-16]. 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 [17-20]. A recent 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 [5].

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 [21-23]. 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 [24]. 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 [25]. In recent years, several PROMs and PREMs have been developed for use in SUD treatment services, including the Substance Use Recovery Evaluator (SURE) [26], the Patient Reported Experience Measure in Addiction Treatment (PREMAT) [27-28], and the Patient-Reported Outcomes Measurement Information System (PROMIS) [29-31].

Most PROMs were initially developed for use in clinical trials to assess the effectiveness of treatment [25, 32]. 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

[25, 32-34]. Considering that most PROMs were not developed for the latter purposes, their potential use and validity in these settings might be limited [24, 25]. 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 [22].

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 [21, 22, 34]. 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 [33, 35]. 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 [17, 36-41]. 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, we performed a scoping review 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 chapter 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?

II. METHODS

For this scoping review we followed the JBI methodology for scoping reviews [42-43]. Results were reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) [44]. A preliminary search for existing scoping and systematic reviews was 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 and identified that no review addressing the use and implementation of PROMs and PREMs in SUD treatment services is currently available.

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.

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. 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.

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 (WVDP and CC) when needed.

Relevant data were extracted from the included articles to address the research questions, using the JBI methodology [42]. Two of the researchers (CM and AZ) charted the data using a data extraction tool developed by the research team. 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.

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

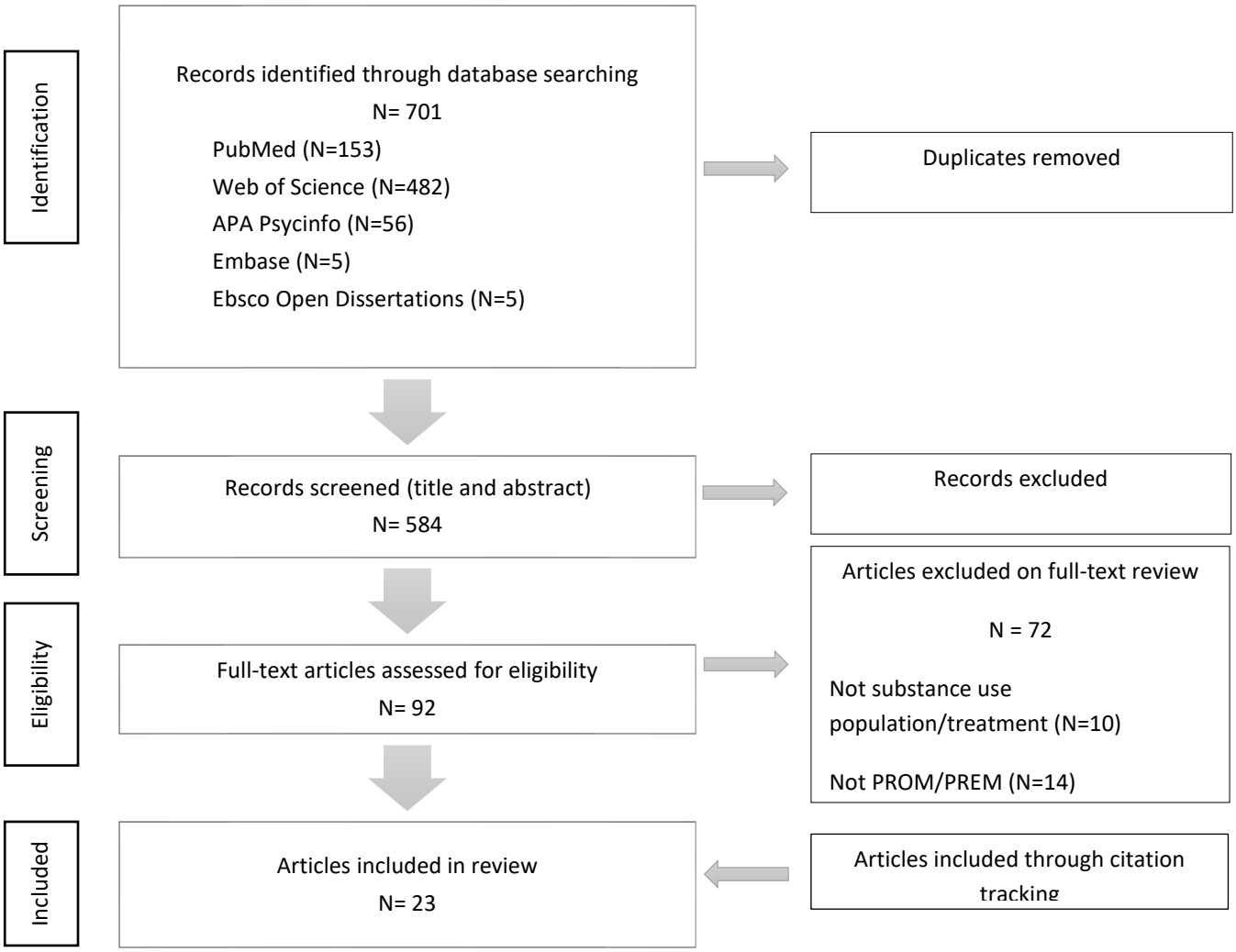

Figure 2.1. PRISMA flow diagram of the scoping review process

III. RESULTS

3.1 Characteristics of included studies

All included articles were recent, with the earliest ones dating back to 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) [45], and three studies did not report any age restrictions [46-48]. Fourteen articles reported on the use of PROMs and PREMs to assess patient outcomes and the effectiveness of SUD treatment services [47-60]. Implementation of PROMs and PREMs into routine clinical practice was discussed in 8 articles [45, 46, 61-66]. Of these 8 studies, 4 focused on the clinicians' perspectives [61, 64-66], 3 focused on the patients' perspectives [45, 46, 62], and 1 study assessed both patients' and clinicians' views on the acceptability and ease of use of PROMs in an SUD treatment setting [63]. 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 [17].

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 and colleagues [40] 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. [50, 51] 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) [50, 51, 67].

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 [55, 68]. Next to the ECHO, Davis et al. [17] 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 [52, 54, 56, 61, 63]. In other cases, these measurements were only repeated at or after discharge [57, 59, 60, 62]. 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 [48, 50, 51, 55, 61, 63]. Bingham et al. [61] 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.

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 Veterans Health Administration (VHA) Mental Health (MH) Initiative Dams et al., 2023	USA, Virginia	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) Carlsen et al., 2019	Norway	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 Treatment (NorComt) Muller et al., 2017	Norway	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	USA, Maryland/Pennsylvania			
Bingham et al., 2016		Mixed-methods, cross-sectional study	Treatment providers for patients with chronic illnesses, including SUD *Sample size not reported*	Patient-Reported Outcome Measurement Information System (PROMIS)
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-sectional study	Patients in outpatient and residential SUD treatment N=1,097 treatment episodes	South Africa Addiction Treatment Services Assessment (SAATSA)
Veterans Outcome Assessment (VOA) survey	USA, Connecticut			
Liebmann et al., 2022		Quantitative, longitudinal study;	Veterans in outpatient SUD treatment N=2,788	Short Form 12 (SF-12); Experiences of Care and Health Outcomes Survey (ECHO)

		T0= start of treatment; T1= after 3 months		
Virtual Intensive Outpatient Program (VIOP) study Ngo et al., 2022	USA, Minnesota	Quantitative, longitudinal study; T0= start of treatment; T1= 1 month post-discharge; T2= 3 months post-discharge; T3-5= every 3 months until 12 months post-discharge	Adults in intensive outpatient treatment for SUD N=3,642	Patient Health Questionnaire-9 (PHQ-9); General 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 2.1 Characteristics of included articles (n=23)

OUD=Opioid Use Disorder, OAT = Opioid Agonist Therapy, SUD=Substance Use Disorder, AUD=Alcohol Use Disorder

Loss to follow-up in the longitudinal studies included in this review varied from 29.3% to 58%. The study by Kablinger and colleagues [54] 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 [54, 62, 63]. 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 [47, 49, 62, 63]. Patients themselves reported lack of interest, concerns over data privacy, and different priorities, such as housing, finances, and medical appointments, as reasons for noncompletion [50, 62]. Proactive recruitment of participants and testing participants' phone numbers were suggested as strategies to minimize missing data and loss to follow-up [50, 62].

3.3.2 Methods of data collection

Bingham and colleagues [61], Hawk and colleagues [62], and Krasteva and colleagues [46] 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. [61] recruited participants in an outpatient SUD treatment clinic and provided desktop computers that were reserved for PROM completion [61, 63]. Hawk et al. [62] 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. [46] 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 [62]. It is advised to have adequate technology available for data collection, including dedicated computers or tablets, and internet access [61-63]. 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 [62]. 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 [61, 62].

Myers et al. [64, 66], 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 [64, 66]. Audio-computer-assisted personal interviewing could also help enable illiterate patients to fill out the survey [45, 64]. 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 [64].

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. [64-66] 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 [64]. 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 [65, 66].

Difficulties with interpreting the feedback of patient-reported data hindered the use of these data as guidance for quality improvement initiatives [66]. 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. [63] 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 [61, 63]. Dams et al. [52] 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.

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

Table 2.2 Facilitators and barriers to collecting and using Patient Reported Outcome Measurement (PROM) and Patient Reported Experience Measurement (PREM) data

IV. 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 [25]. 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 [69].

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. [50, 51], Liebmann et al. [55], and Myers et al. [47] made use of a PREM, alongside outcome indicators. In their systematic review, Davis et al. [17] 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 [17].

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 [25]. 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 [17, 25, 41]. 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 [41]. 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. [41] point out, "PROMs that are irrelevant to patients – even if psychometrically robust – do not ensure a genuinely patient-centered outcome assessment" [15, 41]. 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 [70].

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 [71]. 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 [15, 41].

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 [52, 63, 72].

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 [35, 66, 73]. 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 [38]. 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 [57, 60].

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. [47] identified patient groups facing greater challenges in accessing SUD treatment, as well as patient groups reporting poorer health outcomes. Additionally, Carlsen et al. [50, 51] 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 [74]. 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 [75, 76]. 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.

Limitations of this review

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.

V. CONCLUSION

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.

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CHAPTER 3

TRANSLATION AND ADAPTATION OF PROM AND PREM TOOLS

Based on:

Migchels, C., van den Brink, W., Zerrouk, A., Matthys, F., De Ruysscher, C., Debeer, D., Vanderplasschen, W. & Crunelle, C.L. (2025). Psychometric Evaluation of the Dutch version of the Substance Use Recovery Evaluator (SURE-NL). *European Addiction Research, 31,* 13-22.

Migchels, C., van den Brink, W., Zerrouk, E.-A., Matthys, F., De Ruysscher, C., Vanderplasschen, W., & Crunelle, C. L. (2024). Psychometric evaluation of the Dutch version of the patient-reported experience measure for addiction treatment (PREMAT-NL). *Drug and Alcohol Review*, *43*(7), 2021–2034.

Chapter 3.1
Validation of the Dutch version of the Substance Use Recovery Evaluator (SURE-NL)

Based on:

Migchels, C., van den Brink, W., Zerrouk, A., Matthys, F., De Ruysscher, C., Debeer, D., Vanderplasschen, W. & Crunelle, C.L. (2025). Psychometric Evaluation of the Dutch version of the Substance Use Recovery Evaluator (SURE-NL). *European Addiction Research, 31,* 13-22.

I. INTRODUCTION

Outcome measures in SUD treatment traditionally focus on abstinence or the reduction of drug use, overlooking other important domains impacted by drug and/or alcohol use, such as general health, well-being, and relationships [1-3]. It has been recommended to routinely include these other domains of functioning as essential outcomes in SUD treatment studies [1, 2, 4]. Existing outcome measures, however, do not always target the problems experienced by patients with SUD and their loved ones, but rather reflect the perspectives of clinicians and researchers [5]. Recently, the use of patient-reported outcome measures (PROMs) has increased in all healthcare areas, emphasizing the significance of patients' own views on health and well-being [5-7]. PROMs are questionnaires that collect information on health outcomes, including symptoms, functional status, and quality of life, directly from patients [6]. PROMs are an important source of information that can be used for a wide range of purposes, from clinical practice and clinical trials to public health and policy evaluation [8]. Developing PROMs that represent and incorporate the patient's perspective and are psychometrically robust is a complex but necessary process, if we aim for a truly patient-centered assessment [5, 7, 8].

The emerging recovery paradigm in the SUD field illustrates a similar trend and focus beyond abstinence, and is increasingly being integrated in SUD research, policy, and practice [9, 10]. Recovery is viewed as a deeply personal and dynamic process of change, encompassing several life domains [11]. It entails multiple interrelated aspects, including clinical recovery (e.g., reduced substance use, abstinence), functional recovery (e.g., housing, daily activities, employment), personal recovery (e.g., connectedness, hope, identity, meaning, empowerment), and social recovery (e.g., overcoming stigma, inclusive citizenship) [10, 12, 13]. From this perspective, abstinence is not the only possible pathway to recovery, shifting the emphasis towards building on available strengths, expanding recovery capital, and creating nurturing contexts in which persons can transit from active addiction to recovery [14, 15].

In 2016, Neale and colleagues introduced the Substance Use Recovery Evaluator (SURE), a PROM developed with service user input to monitor the recovery journey and assess treatment outcomes in people with SUD [9]. The SURE is a 21-item questionnaire with a total score and five relatively independent factors: 'substance use', 'self-care', 'relationships', 'material resources', and 'outlook on life'. To the best of our knowledge, the only validated translation of the SURE that is currently available is a German version with 20 (instead of 21) items, and three (instead of five) factors: 'psychological and physical well-being', 'daily functioning', and 'substance use' [16]. These differences underscore the importance of validating instruments before their application in a culturally and linguistically different population from the original context in which they were developed.

Since several years, addiction recovery has gained increasing attention in SUD treatment in Belgium and the Netherlands [15]. A psychometrically sound translated version of the SURE could enable patient-centered routine assessment of recovery indicators in people with SUD in Dutch-speaking populations. Therefore, the objective of this study was to translate the SURE to Dutch (SURE-NL) and evaluate the psychometric properties of this translation in a sample of Dutch-speaking patients from various SUD treatment settings in Belgium. The psychometric evaluation included statistical analyses (a) to establish the underlying factor structure of the SURE-NL and (b) to assess the reliability (Cronbach's α) of the different subscales, and correlational analyses to (c) explore the concurrent validity of the SURE-NL using the World Health Organization Quality of Life questionnaire – brief

(WHOQoL-BREF) and (d) the discriminant validity using the Depression, Anxiety, Stress Scale (DASS-21) [17, 18].

II. METHODS

2.1 Translation

The original SURE questionnaire was translated from English to Dutch using forward-backward translation in accordance with international guidelines [19]. Forward translation was conducted by CC and WVDB, native Dutch speakers and experts in the SUD field. Next, an independent back translation was performed by a native English speaker. Following each step, translations were discussed by an expert committee and adapted accordingly. The preliminary translated questionnaire was used for pilot testing in five native Dutch-speaking patients who were in inpatient treatment for SUD. The pilot testing was reviewed by the expert committee and no modifications were deemed necessary, resulting in the final translated version of the questionnaire, the SURE-NL.

2.2 Measures

2.2.1 Demographic and clinical characteristics

Participants provided demographic information including age, sex, education level, and ethnicity. Self-completed clinical information included treatment history, participation in opioid agonist treatment (OAT), and main substance(s) used, with the option to select multiple substances if applicable.

2.2.2 Substance Use Recovery Evaluator (SURE)

The SURE consists of 21 items, that are completed using a 5-point Likert type response scale, but scored on a 3-point scale (1-3). The decision to use this 3-point rating scale was based on the low response probabilities of the two extreme response categories. The first 2 response options correspond to a score of 3, the third response option to a score of 2 and the finale 2 response options to a score of 1. Response options for the first 3 questions are ‘never’, ‘on 1 or 2 days’, ‘on 3 or 4 days’, ‘on 5 or 6 days’, and ‘every day’, while for the remaining questions response options are ‘all of the time’, ‘most of the time’, ‘a fair amount of the time’, ‘a little of the time’, and ‘none of the time’. Total scores range from 21 to 63, with higher scores indicating more recovery strengths. Based on the factor analysis of the original SURE study, the 21 items are grouped in five subscales: ‘substance use’ (6 items), ‘self-care’ (5 items), ‘relationships’ (4 items), ‘material resources’ (3 items), and ‘outlook on life’ (3 items) [9]. In a sample of current and former outpatient SUD service users in the UK, the SURE showed good construct validity and internal consistency was found to be acceptable to high for all subscales (Cronbach’s α= .68 to .87) and high for the total score (Cronbach’s α= .92) [9].

2.2.3 World Health Organization Quality of Life questionnaire – brief (WHOQoL-BREF)

The WHOQoL-BREF is a 26-item abbreviated version of the WHOQoL-100 assessment, assessing four domains of quality of life: ‘physical health’ (7 items), ‘psychological health’ (6 items), ‘social relationships’ (3 items), and ‘environment’ (8 items). All items are scored on a 5-point Likert type response scale (1-5). Response options, from lowest to highest score, are ‘very poor/very dissatisfied/not at all/never’, ‘poor/dissatisfied/a little/seldom’, ‘neither poor nor good/neither satisfied nor dissatisfied/a moderate amount/moderately/quite often’, ‘good/satisfied/very

much/mostly/very often', and 'very good/very satisfied/an extreme amount/extremely/completely/always'. Higher total and subscale scores indicate higher quality of life. The first 2 questions are scored separately, and 3 items are reverse-scored. In an international sample of healthcare users and people from the general population, the WHOQoL-BREF showed good construct and discriminative validity, and internal consistency was acceptable for all WHOQoL-BREF domains (Cronbach's α= .68 to .82) [17].

2.2.4 Depression, Anxiety, Stress Scale (DASS-21)

The DASS-21 is a 21-item questionnaire, assessing self-reported symptoms of depression, anxiety, and stress. It consists of three subscales ('depression', 'anxiety', and 'stress') with 7 items each. The questions are rated on a scale from 0 (did not apply to me at all) to 3 (applied to me very much) [18]. Sum scores are calculated by adding up the scores on the individual items and multiplying them by a factor 2. In a Dutch population of SUD patients in residential detoxification, the DASS-21 total score was found to have high reliability (Cronbach's α= 0.92) [20].

2.3 Participants

A convenience sample of N=171 participants was recruited as part of the Outcome Measurement and Evaluation as a Routine practice in alcohol and other drug services in Belgium (OMER-BE) study: a naturalistic multicenter study assessing SUD treatment services using patient-reported outcome and experience measures (PROMs and PREMs) [21]. Participants were included between July 2022 and September 2023 if they met the following inclusion criteria: (i) started treatment for SUD in the participating center less than 3 weeks before study inclusion; (ii) over 18 years old; and (iii) Dutch-speaking.

Participants were included from different inpatient (N=149) and outpatient (N=22) treatment modalities. Participants in inpatient treatment were recruited from three psychiatric centers and four therapeutic communities in Flanders. Therapeutic communities for SUD are "a drug-free environment in which people with addictive problems live together in an organized and structured way in order to promote change and make it possible for them to lead a drug-free life in the outside society" [22]. The five participating outpatient treatment centers offered individual treatment, with three centers also providing OAT.

The majority of participants were male (N=142, 83%), and the average age was 34.7 years (SD 9.5). For most, their highest level of education was secondary education (N=105, 61.4%). Of the participants, 87.2% (N=149) was in inpatient treatment and 12.8% (N=22) in outpatient treatment. 81.3% (N=139) had received previous treatment for SUD, and 16.4% received OAT at the time of assessment. Cocaine (52.1%) and alcohol (52.1%) were the most frequently used substances and 60.5% of the participants reported using more than one substance, with a median of 2 substances (range: 1-7). Table 3.1 provides an overview of the demographic and clinical characteristics of the participant sample.

Upon treatment entry, participants were asked by their treatment provider if they were interested in participating in the study. If they agreed to participate, the treatment provider contacted the researchers. Participants were given a tablet by the researcher on which they self-completed sociodemographic data, clinical information, and outcome measures, including the SURE-NL, the

WHOQoL-BREF, and the DASS-21, using an online survey administered through LimeSurvey [23]. Participants filled out the questionnaires independently, but a researcher remained present throughout the assessment to respond to any queries from the participants. After completing all questionnaires, participants received a gift card with a value of €10.

	Mean	**SD**
Age	34.74	9.49
	N	**%**
Sex		
Male	142	83
Female	29	17
Country of birth		
Belgium	164	95.9
Other	7	4.1
Education level		
Primary education	40	23.4
Secondary education	105	61.4
Higher education	26	15.2
Type of treatment center		
Psychiatric inpatient center	69	40.4
Therapeutic community	80	46.8
Outpatient treatment	22	12.8
Opioid agonist therapy	28	16.4
Previous treatment for SUD	**139**	**81.3**
Main substance(s) of use[ab]		
Cocaine	87	52.1
Alcohol	87	52.1
Cannabis	56	33.5
Amphetamines	42	25.2
Opioids	29	17.4
Ketamine	20	12
Benzodiazepines	19	11.4
Gamma-hydroxybutyrate (GHB)	13	7.8
Other	5	3

Table 3.1 Demographic and clinical characteristics of participant sample (N=171)
[a] Some participants reported more than one main substance used;
[b] Data missing for 4 participants (total N=167)

2.4 Statistical analyses

All data analyses were conducted using IBM SPSS statistics version 29 and R statistical software (package lavaan) [24]. We opted for analyses based on classical test theories over those based on Item Response Theory (IRT) due to our limited sample size of N=171, which may be insufficient for robust IRT modelling. Normality of data distribution was assessed. Demographics and clinical data were analyzed using descriptive statistics. Confirmatory Factor Analysis (CFA) was performed to test whether previously obtained factor structures of the original English SURE and the German translation of the SURE showed a good fit for the SURE-NL [9, 16]. Responses to the items were considered ordered categorical and diagonally weighted least squares was used. Model fit was assessed using

measures of both absolute and relative fit, i.e. the Root Mean Square Error of Approximation (RMSEA, values less than .08 indicate an acceptable fit), the scaled χ^2 test, the scaled version of the Comparative Fit Index (CFI, values of .90 and higher indicate an acceptable fit), and the Tucker-Lewis Index (TLI, values of .90 and higher indicate an acceptable fit) [25]. Reliability of the SURE-NL in terms of internal consistency was assessed by calculating Cronbach's α. Values between .70 and .95 indicate good reliability [26]. To examine concurrent validity, Spearman's correlations were used to assess the relationship of the SURE-NL total and subscale scores with the four subscales of the WHOQoL-BREF. Discriminant validity was assessed by examining Spearman's correlations of the SURE-NL total and subscale scores with the three DASS subscale scores. Participants' scores on the SURE-NL were calculated and a Mann-Whitney U test was used to assess whether there were differences in SURE-NL scores between participants in inpatient and outpatient treatment.

III. FINDINGS AND DISCUSSION

This chapter examined the validity and reliability of the Dutch translation of the SURE, the SURE-NL, for measuring indicators of personal recovery and recovery capital in people with SUD in a Dutch-speaking population of patients in inpatient and outpatient SUD treatment in Belgium. The SURE was originally developed in English by Neale et al. (2016) as a 21-item instrument with a total score and five subscales, based on factor analysis with Promax oblique rotation [9]. The German translation by Reichl et al. (2023), using a factor analysis with Oblimin oblique rotation, had 20 items and three factors [16]. We performed a confirmatory factor analysis (CFA), showing that the original 5-factor structure as proposed by Neale et al. (2016) had an acceptable fit for our data [9].

Observed correlations between the SURE-NL subscales ranged from .19 to .54. The 'relationships' and the 'outlook on life' subscales were strongly inter-correlated (r= .54), suggesting considerable overlap between these two concepts (see Table 3.2). A possible explanation for this is that having a supportive network has a positive impact on quality of life, which is assessed in the 'outlook on life' subscale. In comparison, inter-scale correlations in the original English SURE ranged from .40 to .70, and those in the German version from .39 to .54 [9, 16]. All subscales a strong positive correlation with the total score (correlations between .51 and .77), indicating that the SURE-NL subscales assess a common underlying concept. Therefore, a 1-factor structure was considered, but the CFA indicated a better fit for the 5-factor model. We used both subscale scores, which provide detailed information on specific dimensions of recovery, and the total score, which offers a measure of the overall construct of recovery.

SURE-NL	Substance use	Self-care	Relationships	Material resources	Outlook on life
Self-care	.39				
Relationships	.31	.44			
Material resources	.28	.19	.19		
Outlook on life	.26	.45	.54	.19	
Total score	.72	.77	.68	.51	.68
α	.62	.76	.66	.61	.76

Table 3.2 SURE-NL observed subscale and total score correlations

Internal consistencies of the SURE-NL subscales 'material resources', 'substance use', and 'relationships' were relatively low (Cronbach's α <.70), while the SURE-NL 'self-care' and 'outlook on life' subscales had good internal consistency (Cronbach's α = .76). Internal consistency of the total score of the SURE-NL was good: Cronbach's α= .83. For the original SURE, Cronbach's α of the total score was .92 and for the five subscales this ranged from Cronbach's α= .68 ('material resources') to Cronbach's α= .87 ('outlook on life') [9]. The three subscales of the German translation by Reichl et al. (2023) all showed good internal consistency: 'psychological and physical well-being' (8 items, Cronbach's α = .86), 'daily functioning' (7 items, Cronbach's α = .76), and 'substance use' (5 items, Cronbach's α = .85), and had a Cronbach's α of .89 for the total score [16]. These higher internal consistencies found in the German version might be (partly) explained by the larger number of items in each subscale.

Regarding concurrent validity, we found mostly positive correlations of the SURE-NL total and subscale scores with the WHOQoL-BREF subscales. However, for the total and inpatient sample, these correlations were smaller than those found by Neale et al. (2016), especially for the SURE-NL 'substance use' and 'material resources' subscales correlation coefficients were small. This is likely due to treatment setting, which strongly influences access to substances, housing, and money, which are topics assessed in these subscales. This observation is further supported by the stronger correlations between the SURE-NL and the WHOQoL-BREF subscales in our outpatient sample, which were similar to those found in the outpatient study by Neale et al. (2016) [9]. Additionally, our findings show that the SURE-NL is not correlated with the DASS-21, a measure for psychopathology, suggesting that these constructs are distinct from recovery, supporting the discriminant validity of the SURE-NL. The only small (but significant) negative correlation we found was between the SURE-NL 'outlook on life' subscale and the DASS-21 'anxiety' subscale, which might be due to symptoms of anxiety influencing people's response to questions such as 'I have felt positive'.

In the entire sample, the median total score on the 21-item SURE-NL was 54 (IQR 48-58). Neale et al. (2016) found a median total score of 41.8 (min. 22 – max. 63) in their sample [9]. Although it was suggested by Neale et al. (2016) that questions such as 'having stable housing' and 'managing money well' would be influenced by the structure of an inpatient setting, we found no significant difference in the magnitude of the scores between participants in inpatient and outpatient treatment for the SURE-NL 'material resources' subscale. Furthermore, we observed that scores on the 'substance use' subscale of the SURE-NL were significantly higher for participants in inpatient treatment than for those in outpatient treatment, indicating less substance use in those in inpatient treatment. This is to be expected considering that abstinence is required in inpatient settings and motivation for change is a prerequisite to start treatment. We also found a significant difference in SURE-NL 'self-care' scores between participants in inpatient treatment and those in outpatient treatment, which is likely due to the fact that inpatient participants scored higher on questions such as 'eating a good diet' and 'having a good daily routine'. Finally, the higher scores for participants in inpatient treatment on the SURE-NL 'substance use' and 'self-care' subscales seem to explain the significantly higher total scores on the SURE-NL for participants in inpatient treatment compared to those in outpatient treatment, even though both groups were in the same early stage of treatment.

3.1 Limitations of the study

The relatively low number of outpatients compared to inpatient participants and the heterogeneity of the participant sample included in this study is a limitation to consider. Although the SURE was initially developed for use in community-based services, most of the participants (87.2%) were in inpatient treatment. This is important since inpatients were not included in the original study because the SURE was developed for an outpatient population and several items of the SURE assess aspects that are likely influenced by treatment settings, for example diet, daily routine, and housing. Therefore, it is important to investigate the impact of the treatment setting on the SURE-NL scores carefully, and to interpret results in their context. The CFA was conducted on a sample that included both inpatient and outpatient participants. While it would be beneficial to perform a multigroup analysis to establish subgroup measurement invariance, this would require a larger sample, particularly for the outpatient subgroup. The relatively small sample (N=171) is another limitation to consider. Validity testing guidelines vary, suggesting respondent-to-item ratios anywhere between 5:1 and 30:1, with our sample size being towards the lower end of this spectrum with a respondent-to-item ratio of 8:1 [19]. Although our choice for classical test theories over IRT analyses limits the depth of item-level analysis, our use of CFA, reliability, and validity testing still provided a solid assessment of the psychometric properties of the SURE-NL, which can be compared to previous research. On the other hand, the investigated sample was diverse in terms of substances used, age, and education level. To the best of our knowledge, this study is the first to offer a psychometrically validated instrument for evaluating the recovery process in people with SUD in Dutch, which was developed with extensive service user input. It is only the second psychometrically validated translation of the SURE available, and the first to investigate its use in a sample of participants that were predominantly in inpatient treatment.

IV. CONCLUSION

Overall, the original 5-factor structure of the SURE showed an acceptable fit for our data. While our findings showed acceptable to good reliability and validity for the SURE-NL ‘self-care’, ‘relationships’, and ‘outlook on life’ subscales and the total score, this was not the case for the ‘substance use’ and ‘material resources’ subscales. This is probably related to the fact that our sample predominantly consisted of participants in inpatient treatment settings, while the SURE was developed for use in an outpatient population. Although treatment setting seemed to have an impact on the results, especially on some of the subscale scores, we conclude that the SURE-NL is appropriate for use in Dutch-speaking treatment-seeking people with SUD, in particular inpatients, but subscales should be used and interpreted with caution. Future research should assess the SURE-NL in larger samples of Dutch and Belgian outpatients. The development of a separate version for use in inpatient settings, for which the results of the current study can provide relevant input, should be considered.

V. REFERENCES

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Chapter 3.2
Validation of the Dutch version of the Patient-Reported Experience Measure for Addiction Treatment (PREMAT-NL)

Based on:

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I. INTRODUCTION

In patient-centred care, people who receive treatment are actively involved in making healthcare decisions and their individual preferences, values, and needs are taken into consideration [1, 2]. This approach has become increasingly important in the past decade in all healthcare areas. In a consensus document published in 2021, which included contributions from the United Nations Office on Drugs and Crime (UNODC) and the World Health Organization (WHO), patient centred treatment and care were recognized as key quality standards within addiction treatment services [3]. Patient-centred care is associated with increased patient well-being and improved healthcare quality and outcomes both in general healthcare and in addiction treatment [2, 4-7]. A study in the United States found that patient-centred care in addiction treatment is associated with greater service utilisation [7]. Moreover, a review by Davis et al. (2020) showed significant positive relationships between indicators of patient-centred care (i.e. patient satisfaction and patient reported experience measures) and improved outcomes (i.e. substance use and service use) in people receiving specialized treatment for addiction [2]. Conversely, negative treatment experiences can contribute to early treatment drop-out and may have an impact on future treatment utilization [8]. This is particularly relevant in addiction treatment settings, where treatment drop-out and relapse rates are high [9].

Traditionally, patient-centred care has been measured using patient satisfaction measures, but their value in driving quality improvement in addiction treatment services has been questioned [2, 10, 11]. Satisfaction measures relate to the person's affective response to the care received and are dependent on personal expectations, often resulting in more positive ratings and overlooking problems with specific processes that impact the quality of care that is delivered [2, 11, 12]. Patient-reported experience measures (PREMs), on the other hand, are standardized questionnaires that measure patient experiences related to practical aspects of care, such as accessibility, coordination and continuity of care, and patient-provider communication [2, 13, 14]. To ensure that PREMs effectively assess patient centred care, the target population should be actively involved throughout its development [14].PREMs provide more actionable information than satisfaction measures for improving service quality and can be used as a common measure for performance reporting and benchmarking [15, 16]. Nonetheless, two recent reviews revealed that the use of PREMs in addiction treatment is rare compared to the use of satisfaction measures, which might be due to the limited availability of psychometrically sound PREMs for addiction treatment [2, 14]. Although there are some PREMs that have been developed for use in addiction treatment, such as the Experience of Care and Health Outcomes (ECHO) and the Patient Experiences Questionnaire for Interdisciplinary Treatment for Substance Dependence (PEQ-ITSD), as well as some questionnaires that were developed in a specific national context (e.g., the South African Addiction Treatment Services Assessment (SAATSA)), there is currently no standard PREM for measuring patient experiences in addiction treatment [2, 14, 17-19].

In 2019, Hinsley and colleagues developed the Patient Reported Experience Measure in Addiction Treatment (PREMAT) to assess the experiences of people in residential addiction treatment, consisting of 31 items scored on a 5-point Likert scale and two open-ended questions [10]. The development process of the PREMAT included extensive input of service users through focus groups [10]. In 2021, Kelly and colleagues performed a preliminary psychometric evaluation of the PREMAT [12]. Using principal component analysis (PCA) with Promax oblique rotation, they identified six factors: 'individualised support', 'self-determination & empowerment', 'program structure', 'treatment

environment', 'coordination of care', and 'personal responsibility'. Eight items were removed from the questionnaire because they were deemed unfitting in terms of content or statistical relevance, resulting in a 23-item PREMAT, for which they calculated total scores and proposed categorizations of treatment experience based on z-scores [12]. Their results provided preliminary support for the PREMAT as a valid and reliable measure of patient experience in residential addiction treatment settings [12]. To our knowledge, no translated and validated version of the PREMAT is currently available in any other language than English.

An expert report published in 2018 recommended the routine use of PREMs in health care in Belgium to support the shift toward patient centred care and improve the quality of patient care [20]. Initiatives in Flanders and the Netherlands aim to measure quality indicators from patients' perspectives in hospitals and other care centres, using surveys which were adapted for use in mental health and/or addiction treatment settings [21-23]. However, to our knowledge, no PREM specifically developed for use in addiction treatment services is currently available in Dutch. To facilitate the measurement of patient experiences of Dutch-speaking people in addiction treatment, the aim of this study was to translate the PREMAT into Dutch (PREMAT-NL) and to evaluate the psychometric properties of this translated version in a sample of Dutch-speaking people in residential addiction treatment services in Belgium. The psychometric evaluation included statistical analyses to establish the underlying factor structure and to assess the internal consistencies (Cronbach's α) of the different subscales and the total score of the PREMAT-NL. Additionally, associations of the PREMAT-NL total score with demographic and clinical variables were explored.

II. METHODS

2.1 Translation

An initial translation of the original PREMAT questionnaire from English to Dutch was made using forward-backward translation in accordance with international guidelines [24]. Forward translation was conducted by co-authors CC and WvdB, both native Dutch speakers and experts in the addiction field. Next, an independent back translation was performed by a native English speaker. Following each step, translations were discussed by an expert committee, consisting of co-authors CM, WvdB, AZ, FM, WVDP and CC, all experts in the field of addiction with diverse backgrounds in psychiatry, psychology, special needs education, psychotherapy, and epidemiology. Translation of the items was discussed until consensus was reached. The preliminary translated questionnaire was used for pilot testing in five native Dutch-speaking individuals who were in residential treatment for addiction. The pilot testing was reviewed by the expert committee and no modifications were deemed necessary, resulting in the final translated version, the PREMAT-NL.

2.2 Measures

2.2.1 Demographic and clinical characteristics

Participants provided demographic information including age, sex, education level, and ethnicity at baseline. Self-completed clinical information included treatment history, participation in opioid agonist treatment (OAT), and main substance(s) used.

2.2.2 Patient Reported Experience Measure for Addiction Treatment (PREMAT)

The PREMAT is a self-report measure designed to evaluate the experiences of people in addiction treatment [10]. The measure consists of 23 statements, which are completed using a 5-point Likert scale: 1 (strongly disagree), 2 (disagree), 3 (neither agree nor disagree), 4 (agree), and 5 (strongly agree), with total scores ranging from 23 to 115 and higher scores indicating a more positive experience. Additionally, the PREMAT includes 2 open-ended questions ('How could your experience at this service have been improved?' and 'What have been the best things about your experience here?'), which allow respondents to elaborate on certain aspects of the questionnaire, or add topics that are not included in the PREMAT statements [10]. Based on PCA with Promax oblique rotation, the 23 items are divided into six subscales: 'individualised support' (5 items), 'self-determination & empowerment' (5 items), 'program structure' (4 items), 'treatment environment' (4 items), 'coordination of care' (3 items), and 'personal responsibility' (2 items). Correlations between the subscales range from 0.22 to 0.48 [12].

2.3 Participants

A total of 93 participants filled out the PREMAT-NL as part of the Outcome Measurement and Evaluation as a Routine practice in alcohol and other drug services in Belgium (OMER-BE) study: a naturalistic multicentre prospective study assessing patient reported outcome and experience measures (PROMs and PREMs) in addiction treatment services [25]. Participants were included between July 2022 and September 2023 if they met the following inclusion criteria: (i) started treatment for substance use disorder in a participating centre less than three weeks before study inclusion; (ii) over 18 years old; and (iii) Dutch-speaking. Participants were recruited from three psychiatric centres and four therapeutic communities in Belgium where long-term treatment is offered. Participating psychiatric centres had one or more specialised addiction treatment wards. Therapeutic communities for addiction are "a drug-free environment in which people with addictive problems live together in an organized and structured way in order to promote change and make it possible for them to lead a drug-free life in the outside society" [26] (p9).

Upon treatment entry, eligible participants were asked to participate by their treatment provider, after which the researchers were contacted. One of the researchers then visited the participant and, after obtaining written informed consent, participants self-completed demographic data and clinical information on a tablet provided by the researchers. About 45 days after filling out the baseline questionnaires, participants were contacted by the researchers via e-mail or telephone, regardless of whether they were still in treatment at that time, and were asked to fill out another set of questionnaires online, which included the PREMAT-NL. The PREMAT-NL questions referred to the treatment centre where the participants had started treatment at the time of baseline measurement, regardless of whether they were still in treatment in that centre at the time when they completed the 45-day follow-up measurement. Participants received a gift card with a value of €10 after both the baseline and 45-day follow-up measurements as remuneration for their participation. Ethical approval was obtained from the UZ Brussel ethics committee on 11th of May 2022 (BUN 1432022000071).

A total of 149 participants in residential addiction treatment filled out the baseline questionnaires and 93 (62%) of them also filled out the 45-day follow-up questionnaires, which included the PREMAT-NL. Of the 56 remaining participants, we were unable to reach 51 participants and thus did not receive responses from them to the 45-day follow-up questionnaires, 3 participants dropped out of the study,

and responses to the PREMAT-NL were incomplete for 2 participants. Both groups did not differ substantially, except for age and education level (with drop-outs being younger and having a lower educational status (see table 3.3).

	Participants N=93	**Non-participants N=56**	***p* value[c]**
	Mean (SD)	**Mean (SD)**	
Age	36.0 (9.2)	31.7 (9.5)	**0.007 (t-test)**
	N (%)	**N (%)**	
Sex			0.639
Male	77 (83)	48 (86)	
Country of birth			1.000 (Fisher)
Belgium	89 (96)	53 (95)	
Education level			**0.038**
Primary education	16 (17)	19 (34)	
Secondary education	60 (65)	32 (57)	
Higher education	17 (18)	5 (9)	
Type of treatment center			0.320
Psychiatric center	46 (49.5)	23 (41)	
Therapeutic community	47 (50.5)	33 (59)	
Opioid Agonist Therapy	13 (14)	7 (13)	0.798
Previous treatment for addiction	78 (84)	45 (80)	0.584
Main substance(s)[a,b]			
Alcohol	54 (59)	24 (44)	0.077
Cocaine	47 (51)	31 (56)	0.535
Cannabis	26 (28)	24 (44)	0.057
Amphetamines	19 (21)	13 (24)	0.671
Opioids	15 (16)	8 (15)	0.776
Benzodiazepines	15 (16)	5 (9)	0.217
Gamma-hydroxybutyrate (GHB)	9 (10)	2 (4)	0.211 (Fisher)
Ketamine	8 (9)	10 (18)	0.090
Other	3 (3)	6 (11)	0.080 (Fisher)
In same treatment center after 45 days	68 (73)		
Criminal justice referral	7 (8)		

Table 3.3 Demographic and clinical characteristics of the PREMAT sample (N=149) and comparison between participants who completed the 45-day follow-up (N=93) and those who did not (N=56)

[a] Some participants reported more than one main substance;
[b] Data missing for 2 participants (total N=147; participants N=92; non-participants N=55);
[c] Differences between groups were assessed using Pearson χ^2 test or Fisher's exact test/t-test where specified; Significant values (p<.05) are in bold.

2.4 Statistical analyses

Data analyses were conducted using IBM SPSS statistics version 29. Normality of data distribution was assessed, and demographic and clinical information was analysed using descriptive statistics. Characteristics of those who completed the 45-day follow-up measurement and those who did not were compared using Pearson's χ^2 test, Fisher's exact test, or t-test. PCA with Promax oblique rotation was used to examine the factor structure of the PREMAT-NL. Bartlett's Test of Sphericity was used to determine whether the items of the PREMAT-NL were suitable for PCA. Factors were extracted using the Kaiser criterion, dropping the least important factors from the analysis based on eigenvalues <1.0. Component loadings greater than or equal to 0.40 were deemed relevant [27]. Reliability of the PREMAT-NL in terms of internal consistency was assessed by calculating Cronbach's α. Values between 0.70 and 0.95 indicate good reliability [28]. Participants' total scores on the PREMAT-NL were calculated and z-scores were generated. In accordance with the classifications proposed by Kelly et al., 'poor experience' was defined as scores falling >1 standard deviation below the mean, 'average experience' as between 1 and 0 standard deviations below the mean, 'good experience' if scores were between 0 and 1 standard deviation above the mean, and 'very good experience' if scores were >1 standard deviation above the mean [12]. Additionally, we explored the relationship of PREMAT-NL scores with demographic and clinical variables using Pearson's and point-biserial correlation coefficients.

III. FINDINGS AND DISCUSSION

The PREMAT is a 23-item PREM developed to evaluate the experiences of people in residential addiction treatment services [12]. Building on the work done by Hinsley et al. (2019) and Kelly et al. (2021), we translated the PREMAT to Dutch (PREMAT-NL) and examined its psychometric properties in a sample of Dutch-speaking people in various residential addiction treatment settings in Belgium [10, 12]. The PREMAT-NL was assessed as part of a follow-up measurement, which was completed about 45 days after treatment entry, by 93 participants who participated in the OMER-BE study [25]. While Kelly et al. (2021) identified a 6-factor structure for the PREMAT using PCA with Promax oblique rotation, the same analysis showed a 4-factor structure for the PREMAT-NL [12]. The four factors found in this analysis were labelled 'treatment environment and support', 'autonomy and empowerment', 'program structure', and 'access to resources' (see Table 3.4).

There were considerable similarities as well as some differences between the 6-factor solution of Kelly et al. (2021) and the 4-factor solution observed in this study for the PREMAT-NL [12]. The first PREMAT-NL factor, 'treatment environment and support', encompassed four out of five items of the 'individualised support' factor and two of the four items of the 'treatment environment' factor found by Kelly et al. (2021), as well as single items from the PREMAT 'personal responsibility', 'program structure', and 'coordination of care' factors. The second PREMAT-NL factor, 'autonomy and empowerment', included four out of five items of the 'self-determination and empowerment' factor and two items from the 'treatment environment' factor from the PREMAT, as well as single items from the 'individualised support' and 'personal responsibility' factors. The third factor, 'program structure',

consisted of two out of four items of the PREMAT factor 'program structure' and one item out of the five items of the factor 'self-determination and empowerment' found by Kelly et al. (2021). Finally, the fourth factor, 'access to resources', encompassed one item out of the four items from the 'program structure' factor and two out of the three items from the 'coordination of care' factor found by Kelly et al. (2021). Given this overlap but also the differences between the factor structures of the PREMAT and the PREMAT-NL, additional analyses were performed looking at the 5- and 6-factor solutions of the PREMAT-NL (see Appendix 3 and Appendix 4). However, the overlap between the 5- and 6-factor solutions of the PREMAT-NL and the 6-factor solution reported by Kelly et al (2021) did not improve substantially. Based on these findings, although there are similarities between the factor structure of the PREMAT-NL and the original PREMAT factor structure found by Kelly et al. (2021), it is premature to draw final conclusions regarding the factor stability of the PREMAT. The different factors appear to be rather closely related in terms of content, which was also evidenced by the 1-factor solution suggested by the scree plot and the moderate to strong positive intercorrelations between the subscales.

All PREMAT-NL subscales demonstrated good internal consistency, with Cronbach's α ranging from 0.71 to 0.90, and a Cronbach's α of 0.94 for the PREMAT-NL total score. This is comparable with the results found by Kelly et al. (2021), who found Cronbach's α for the 6 subscales ranging from 0.72 to 0.85, and a Cronbach's α of 0.92 for the PREMAT total score [12].

We also examined the distribution of the total scores of the 23-item PREMAT-NL and found this to be negatively skewed, suggesting that the PREMAT-NL might better capture positive experiences with treatment for addiction rather than negative ones. This was also the case for the PREMAT scores found by Kelly et al. (2021), who suggested that this was likely due to the positive wording of the items [12]. We calculated z-scores, establishing categories that can be used to interpret how patients experienced their treatment in a particular service. We identified a similar distribution of experience rating categories as Kelly et al. (2021), who found 15% of participants were classified as having had a 'poor experience', 33% as an 'average experience', 38% a 'good experience' and 14% a 'very good experience', while this was 12%, 36%, 35% and 17% respectively in our analysis [12].

Additionally, correlations between PREMAT-NL total scores and demographic and clinical characteristics of the participants showed that participants in treatment in addiction wards in psychiatric centres tended to report higher scores, reflecting a more positive treatment experience, while those who had received previous treatment for addiction were more likely to report lower scores, indicating a less positive current treatment experience. However, these were small correlations, and further research is needed to investigate whether this is replicated and, if so, whether this is associated with differences in treatment outcome. We observed no correlations with any of the other demographic or clinical characteristics. Participants who did not complete the follow-up measurement were younger and less educated than those who did, possibly because less educated people have less access to electronic resources, the preferred method for contact and completing the questionnaire. Young people, on the other hand, may engage more with social media rather than email and telephone, which were the primary methods used to contact participants. However, age and education level were not associated with PREMAT-NL scores, and, therefore, selective drop-out from the study did not influence the overall results of the study.

Items (in English)[a]	4-factor model				1-factor model
	Treatment environment and support	Autonomy and empowerment	Program structure	Access to resources	
3. I have been supported to start doing things that I want to do	0.23	0.38	0.26		**0.71**
4. I feel better about myself because of this program		**0.76**	0.13		**0.77**
5. I am more aware of myself because of this program	-0.32	**0.65**	**0.60**		**0.69**
6. I have enough privacy here		**0.73**	-0.21	0.18	**0.61**
7. I am given enough space by other people in this program	0.32	**0.40**	-0.11	0.32	**0.75**
10. I better understand why I have used drugs and/or alcohol because of this program		0.35	**0.69**	-0.21	**0.63**
11. I have enough one-to-one sessions	**0.80**		-0.16		**0.64**
12. I am supported to look after my health, financial, and legal problems	**0.67**				**0.73**
13. I can get help for any difficulties I have	**0.58**		0.21	0.11	**0.79**
14. I know what the rules are and what will happen if I don't follow the rules	**0.61**	0.35		-0.32	**0.65**
15. I think the rules make sense	**0.44**	**0.65**	-0.14	-0.13	**0.74**
16. My day is structured here		-0.25	**0.84**	0.18	**0.57**
17. I am provided with a schedule so that I know what to do with my time	0.17		**0.66**		**0.68**
18. I am provided with opportunities to exercise			0.31	**0.44**	**0.53**
19. I am provided with fresh fruit and vegetables	**0.62**	-0.35	**0.44**		**0.55**
20. I think this place is clean and hygienic	**0.45**	0.13	0.30		**0.70**
21. I feel supported and understood by other people in this program		**0.44**		0.39	**0.68**
24. Staff treat me like a person and not an addict	**0.74**	-0.16	0.21	0.12	**0.75**
26. I am supported to focus on my recovery	**0.60**	0.36			**0.80**
27. My family and friends have been provided with information about recovery	**0.52**			0.28	**0.67**
28. I am more able to cope with my everyday life outside the program		**0.72**		0.13	**0.63**
30. I have been linked up with other services to support me when I leave this program	-0.15	0.11		**0.82**	**0.54**
31. I can get information from staff about where else I can go for help	0.21	0.20		**0.65**	**0.71**
Eigenvalue	10.61	1.68	1.17	1.06	10.61
% of variance	46.13	7.30	5.10	4.62	46.13
α	0.90	0.89	0.77	0.71	0.94

Table 3.4 Promax Factor Structure of the 23-item PREMAT-NL

[a]Item numbering follows the original 31-item PREMAT.
Note: Loadings <0.1 are not displayed. Significant factor loadings (>0.4) are in bold.

3.1 Strengths and limitations of the study

One of the important strengths of the current study is that the sample included participants who had left treatment at the time of completing the PREMAT-NL. People who leave treatment early may have distinct experiences and perspectives that are not captured when they are excluded from studies. By including these participants, the findings become more representative and applicable to a broader population. Additionally, the study had very limited exclusion criteria, resulting in a diverse sample in terms of age, education level, and substances used. However, the study results need to be viewed in the context of some limitations. One limitation of our study is the potential for selection bias due to the lack of data on participants who were invited but declined to participate at baseline or who were deemed too ill by treatment providers to be invited to participate. While this may impact the generalisability of our results, potentially skewing the findings towards healthier or more motivated individuals, it is reflective of regular care settings where these people would also be unlikely to complete the questionnaire. The most important limitation is the relatively small sample size. Whereas respondent-to-item ratios of 5:1 to 30:1 are recommended in validity testing guidelines, our sample size of N=93 corresponds to a respondent-to-item ratio of 4:1 [24]. This limits the interpretation of the score categories and the correlations between the scores and demographic and clinical variables considering that some subgroups were small.

IV. CONCLUSION

The 23-item PREMAT-NL total score demonstrated good validity and reliability, rendering it a useful instrument for assessing the experiences of Dutch-speaking people in residential addiction treatment services. However, the factor structure of the PREMAT is not fully established and needs further investigation, making it difficult to determine the appropriate use of subscales. The availability of an instrument such as the PREMAT is important for monitoring patient centred care in addiction treatment services. The proposed categories derived from z-scores can be helpful to interpret PREMAT-NL scores and how patients perceived treatment but should be used with caution. Future research should include longitudinal studies testing the predictive validity of the PREMAT-NL with treatment retention and treatment outcomes as the main criteria. Some of the questions of the PREMAT are not applicable in outpatient settings, limiting its use to residential addiction treatment services. The development of an adapted version, focusing on outpatient addiction treatment services, would be helpful.

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CHAPTER 4

PARTICIPANT CHARACTERISTICS AND BASELINE ASSESSMENT OF PROMS AND CASE-MIX VARIABLES

Based on:

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I. METHODOLOGY

1.1 Study settings

The OMER-BE study is a naturalistic, longitudinal, multicenter cohort study, in which 189 individuals with SUDs were followed up over a 6-month period in various residential and outpatient treatment modalities in the Dutch- and French-speaking region of Belgium. Data collection for the study started in July 2022. Participants were recruited from eight residential services (four psychiatric treatment centers (PCs) and four therapeutic communities (TCs)) and nine outpatient treatment services.

Specialized wards of PCs offer long-term (3 to 6 months) residential care that provides intensive medical and psychological support, addressing SUDs and in some cases co-occurring mental health disorders. Treatment consists of group counseling, psychoeducation, individual psychotherapy, and occupational activities.

TCs for addictions have a long history and were set up for individuals with SUDs, complementing traditional mental health care services that were traditionally not open to persons with drug problems [1]. In a TC, individuals with SUDs live together in a structured environment, typically for a period of 6 to 12 months, aiming for positive changes that lead to a drug-free life in society. The TC approach centers around the concept of “community as a method”, thus, highlighting the influential role of peers and the power of mutual support in fostering recovery [2, 3].

Outpatient treatment services provide more autonomy to service users and offer various non-residential care options consisting of drug-free counselling interventions and harm-reduction approaches like Opioid Agonist Therapy (OAT) and needle exchange programs. OAT refers to the use of opioid replacement medication such as methadone or buprenorphine to help manage withdrawal symptoms and reduce craving, often combined with some form of counseling and social support. Drug-free counselling focuses on psychosocial interventions, such as motivational interviewing and cognitive-behavioral therapy, aimed at helping individuals develop coping strategies and support systems to become/remain abstinent.

1.2 Study population

The OMER-BE study aimed to follow up a naturalistic cohort of service users with SUDs as they started a new treatment episode in a selected number of SUD treatment services, focusing on individuals with a primary alcohol and/or primary (illicit) drug problem. Eligibility criteria were: (i) having a documented SUD (e.g. a DSM-5 diagnosis of a SUD or previous treatment for a SUD), (ii) being at least 18 years old, (iii) being able to communicate in Dutch or French and (iv) having started treatment no longer than 21 days ago. First-time as well as returning service users are considered eligible for this cohort study, as long as they start a new treatment episode during the recruitment period [4].

Upon treatment entry, service users were informed about the aims and design of the OMER-BE study through posters, leaflets and staff members of the selected treatment facilities. During the initial meeting with the researcher, participants are informed extensively about the (follow-up) study and implications of study participation and are asked for written informed consent to participate [4].

1.3 Study procedure

1.3.1 Baseline assessment

Sociodemographic and clinical factors (see Table 1.1) were assessed at baseline, followed by the assessment of PROMs. Data were collected through self-report using a tablet provided by one of the researchers, who are available throughout the assessment to address any questions participants may have. Administering the set of baseline variables and PROMs took between 20 and 45 minutes. After completion of the baseline assessment, participants received a voucher of 10 EUR as remuneration.

1.3.2 Follow-up assessments

Study participants were contacted again 45, 90 and 180 days after the baseline assessment (see Figure 1.1). We used a time window of four weeks for the 45- and 90-day follow-up and five weeks for the 180-day follow-up assessment to collect and complete the questionnaires. Researchers contacted all study participants either via email, text messages, directly by phone, or through the treatment setting where they were enrolled in the study. Participants could complete the online survey via a personalized link provided by e-mail or during a face-to-face or telephone interview, depending on their preference. The follow-up assessments included a measurement of both PROM and PREM variables (see Table 1), taking 20 to 30 minutes to complete. Participants receive a 10 EUR voucher for each completed follow-up assessment.

As the OMER-BE project is a naturalistic study, some participants were no longer in treatment at the 45-, 90- or 180-day follow-up. Consequently, the PREM-instrument was only administered when service users are still in treatment and at the first follow-up moment after leaving treatment. For example, if a participant stops treatment after 50 days, the PREM questionnaire will be administered at the 45- and 90-day follow-up moments.

1.4 Instruments

The baseline and follow-up assessments (see Table 1.1) were largely based on the ICHOM Standard Set for Addictions (ICHOM SSA) [5], a set of brief, existing, validated questionnaires to measure and monitor treatment outcomes routinely in SUD services that was developed by an international panel of SUD specialists. The ICHOM SSA focuses on patient-centered outcome indicators and provides an internationally agreed upon method for measuring a variety of outcome domains. The tool offers potential for routine use since it is relatively short and has been specifically developed for and validated in the population of SUD service users. It can be easily administered and is applicable in a wide range of treatment settings [5]. To facilitate its application in Belgium, non-translated questionnaires were translated into French and Dutch using forward/backward translation, following guidelines provided by [6], and subsequently validated. Compared to the ICHOM SSA procedure, we added a 45-day follow-up assessment which allowed to have an additional measurement point, keep participants more engaged in the study and reduce attrition.

The OMER-BE measurement tool consisted of three sections (see Table 1.1): (1) sociodemographic and clinical factors, (2) PROMs, and (3) PREM.

1.4.1 Sociodemographic and clinical factors

The first section of the tool included sociodemographic and clinical factors that may influence treatment outcomes. Following sociodemographic variables were assessed: age, sex, education level, current living situation, country of birth of the participants and country of birth of their parents.

Clinical factors included questions regarding SUD treatment history and three validated and widely used screening instruments to assess common comorbid psychiatric disorders (trauma, depression/anxiety and ADHD) that are likely to affect treatment outcomes. These clinical factors were included to ensure a comprehensive understanding of how these variables influence recovery trajectories and are not part of the ICHOM SSA tool.

PC-PTSD-5 (Primary Care PTSD Screen for DSM-5)

The Primary Care Posttraumatic Stress Disorder Screen (PC-PTSD-5) [7] was developed to assess the occurrence of symptoms of posttraumatic stress disorder (PTSD) over the last month. This five-item screening tool is rated on a binary scale (No = 0, Yes = 1). Higher total sum scores suggest the presence of more PTSD symptoms. The reliability of the English version has been found satisfactory in a sample of people with SUDs, as measured by a Cronbach's α value of 0.73 [8].

DASS-21 (Depression, Anxiety, Stress Scale)

The Depression, Anxiety and Stress Scale (DASS-21) [9] is a commonly used instrument consisting of 21 items, divided into three subscales (depression, anxiety and stress), each containing seven items. Each question is rated on a scale from 0 ('did not apply to me at all') to 3 ('applied to me very much'). Subscales and total scores are calculated by adding up the scores on the items and multiplying these by a factor 2. In a population of Dutch-speaking SUD service users in the Netherlands, Beaufort et al. [10] found the total score to be highly reliable (Cronbach's α = 0.91).

ASRS-v1.1 (Adult ADHD Self-report Scale)

The Adult ADHD-Self-report Scale v1.1 (ASRS) consists of several questions encompassing each of the 18 symptoms cited in the DSM-IV [11]. The current study uses the short version, consisting of six items which have been found the most predictive of an attention-deficit/hyperactivity disorder (ADHD) diagnosis. These items are rated on a scale from 0 ('never') to 4 ('very often'). Scores equal to or higher than 2 for items 1-3 and equal to or higher than 3 on items 4-6 are indicative for a diagnosis of ADHD. A Spanish study by Daigre et al. [12] showed a sensitivity of 0.88 and a specificity of 0.69 for a diagnosis of ADHD in a sample of outpatients with SUDs. In an international study among treatment seeking in- and out-patients with a SUD, very similar results were obtained with a sensitivity of 0.83 and a specificity of 0.68 for DSM-5 ADHD [13].

1.4.2 Patient-Reported Outcome Measures (PROMs)

The second section of the tool focuses on PROMs and is based on the ICHOM SSA [5]. To extend the focus to subjective well-being beyond substance use and health outcomes, we added a widely used instrument to assess quality of life and overall well-being (i.e., WHOQoL-BREF).

PROMIS SF-Alcohol (Patient-Reported Outcomes Measurement Information System (PROMIS) Alcohol Use Short Form 7a)

The PROMIS Alcohol Use Short Form [14] is a seven-item self-report questionnaire, derived from the 37-item PROMIS Alcohol Use item bank. This tool is designed to assess alcohol use in the last 30 days. Respondents were instructed to complete the seven questions only if they consumed alcohol in the last 30 days. Answers are rated on a 5-point scale ranging from 'never' (0) to 'almost always' (4). The internal consistency of the total score has proven to be excellent in participants from the general population and a clinical sample of service users in treatment for SUDs (Cronbach's α = 0.95) [14].

PROMIS SF-Substance (PROMIS SF v1.0 – Severity of Substance Use 7a)

The PROMIS Severity of Substance Use Short Form [15] consists of seven items and is a shorter version of the 37-item PROMIS Severity of Substance Use item bank. This tool is designed to assess severity of substance use in the last 30 days. Answers are rated on a 5-point scale ranging from 'never' (0) to 'almost always' (4). The internal consistency of the total score was found to be excellent in participants from the general population and a clinical sample of service users in treatment for SUDs (Cronbach's α = 0.94) [15].

HSI (Heaviness of Smoking Index)

The Heaviness of Smoking Index (HSI) consists of two items: "How soon after waking up do you usually have your first smoke?" and a question assessing the number of cigarettes smoked each day. The first question was rated on a 4-point scale ranging from 'more than 60 minutes' (0) to 'less than 5 minutes' (3). The second question was replaced by an assessment of the number of cigarettes smoked in the last 30 days to maintain consistency with the assessment of the other substances. Internal consistency for the total HSI score was found to be relatively low in a sample of males with SUDs and nicotine dependence (Cronbach's α = 0.49) [16].

TOP-S1 (NHS Treatment Outcomes Profile for Substance Misuse – section 1)

The Treatment Outcomes Profile (TOP) [17] is a multi-dimensional assessment instrument for monitoring outcomes in SUD treatment. This questionnaire measures four key life domains (substance use, crime, health and social functioning). For this study, we only assessed the substance use domain and made modifications to the time frame in line with the other questionnaires. Specifically, participants were asked about their primary substances of use and the number of days and quantity consumed over the past 30 days.

PROMIS-GH-10 (PROMIS Scale v1.2 – Global Health)

The PROMIS Global Health (PROMIS-GH) consists of ten items, scored on a 5-point scale. Due to overlap with other questionnaires, and in accordance with the ICHOM SSA, we only included two items of this scale relating to physical and mental health. The response options of these items are 'excellent', 'very good', 'good', 'fair' and 'poor'. Its psychometric properties were evaluated using a sample of 4370 individuals from the Dutch general population. Results indicated a 2-factor structure with good internal consistency. The subscales 'Global Mental Health' and 'Global Physical Health' had a Cronbach's α of 0.83 and 0.78, respectively [18].

SURE (Substance Use Recovery Evaluator)

The Substance Use Recovery Evaluator (SURE) [19] is a self-report questionnaire consisting of 21 items, which is completed on a 5-point scale but scored on a 3-point scale (1-3). The first 2 response options correspond to a score of 3, the third response option to a score of 2 and the final 2 response options to a score of 1. Response options for the first 3 questions are 'never', 'on 1 or 2 days', 'on 3 or 4 days', 'on 5 or 6 days', and 'every day', while for the remaining questions response options are 'all of the time', 'most of the time', 'a fair amount of the time', 'a little of the time', and 'none of the time'. Higher total sum scores suggest greater recovery strengths. The items are categorized into five subscales: 'substance use', 'relationships', 'self-care', 'outlook on life' and 'material resources'. Internal consistency of the SURE total score was found to be high in a sample of current and former SUD service users (Cronbach's α = 0.92) [19]. Psychometric properties of the translated Dutch version of the SURE (SURE-NL) showed good internal consistency (Cronbach's α = 0.83) [20].

WHOQoL-BREF (WHO Quality of Life Scale)

The brief version of the World Health Organization Quality of Life questionnaire (WHOQoL-BREF) [21] consists of 26 items and is a short version of the WHOQoL-100 questionnaire. Questions are rated on a 5-point scale (1-5) and response options, from the lowest to highest score, are 'very poor/very dissatisfied/not at all/never', 'poor/dissatisfied/a little/seldom', 'neither poor nor good/neither satisfied nor dissatisfied/a moderate amount/moderately/quite often', 'good/satisfied/very much/mostly/very often', and 'very good/very satisfied/an extreme amount/extremely/completely/always'. Higher sum scores are an indication of a better quality of life. The items are grouped in four domains: 'psychological health', 'physical health', 'environment' and 'social relationships'. The WHOQOL-BREF has demonstrated good internal consistency with Cronbach's α values for each of the domains ranging from 0.66 to 0.84 [22].

1.4.3 Patient-Reported Experience Measures (PREMs)

As the objectives of the OMER-BE study also included the measurement of PREMs, the third section of the OMER-BE measurement tool looked beyond the ICHOM SSA. We used a recently validated PREM, the Patient Reported Experience Measure for Addiction Treatment (PREMAT) (see chapter 3.2), to assess service users' experiences regarding the treatment they received.

PREMAT (Patient Reported Experience Measure for Addiction Treatment)

The PREMAT is a recently developed relatively brief (23-item) questionnaire that aims to capture the experiences of people in residential SUD treatment services [23, 24]. More precisely, the following topics are addressed in the PREMAT: 'Individualized support', 'Self-determination and Empowerment', 'Program structure', 'Treatment environment', 'Coordination of care' and 'Personal responsibility' [24]. The instrument consists of 23 statements rated on a 5-point Likert scale: 1 (strongly disagree), 2 (disagree), 3 (neither agree nor disagree), 4 (agree), and 5 (strongly agree). The total score ranges from 23 to 115, with higher scores reflecting a more positive experience. Additionally, the PREMAT includes 2 open-ended questions ('How could your experience at this service have been improved?' and 'What have been the best things about your experience here?'), which allow respondents to elaborate on certain aspects of the questionnaire or discuss topics that are not covered by the PREMAT items [23]. Internal consistency for the total score was found excellent in a sample of participants from specialist residential SUD treatment services in Australia (Cronbach's α = 0.91) [24].

1.5 Ethics and dissemination

This study was granted ethical approval from the Medical Ethics Committee of the University Hospital of Brussels on 11th of May 2022 (UZ Brussel; BUN: 1432022000071). The participants were informed about the confidentiality of the data they provided and written informed consent was acquired from all participants before being included in the study. All data were treated confidentially and reported anonymously. This study was conducted in accordance with the Declaration of Helsinki.

1.6 Data analysis of baseline characteristics

This chapter presents baseline characteristics of the study cohort and comparative analyses between participants from different treatment modalities. For categorical demographic and patient characteristics, significant differences between treatment modalities were assessed using either the Chi-square test or Fisher's exact test when the data did not meet the assumptions required for the Chi-square test. For continuous variables, we used ANOVA to assess group differences. Welch t-test was used when the assumption of equal variances was not met. Post hoc comparisons between groups were made using Tukey test when variances were equal or Games-Howell test when the assumption of equal variances was violated. All statistical analyses were conducted using IBM SPSS statistic version 29. Additional analyses will center on longitudinal changes in PROMs and PREMs, using repeated measures and mixed model analyses. The role of mediating and moderating variables (e.g., socio-economic status, comorbidity, recovery strength) will be assessed, along with differences between treatment modalities. All statistical analyses will be conducted using R studio and IBM SPSS statistic version 29.

II. FINDINGS

In total, 189 individuals participated in the OMER-BE study, of which 161 participants (85.2%) undergoing residential treatment (81 treated in a SUD treatment ward in a psychiatric facility and 80 in a drug-free TC). Additionally, 28 participants (14.8%) were recruited in outpatient services. Details regarding the baseline sociodemographic and clinical characteristics of the participant sample are presented in Table 4.1. The average age was 35.5 years (SD = 9.9) at baseline. The majority of participants were males (N=156, 82.5%), completed secondary education as their highest level of education (N=114, 60.3%) and lived alone (N=90, 47.6%). Most participants were born in Belgium (N=178, 94.2%) and resided in psychiatric facilities (N=81, 42.9%) and therapeutic communities (N=80, 42.3%) during the baseline assessment. 153 participants (81.0%) had received previous treatment for SUDs. The most frequently reported main substances are alcohol (N=100, 53.8%), cocaine (N=81, 43.5%) and cannabis (N=64, 34.4%), indicating the presence of many problematic poly-substance users.

Initial comparisons were made between the three treatment modalities (Table 4.1). When considering sociodemographic and clinical characteristics, no significant differences were found in terms of age, sex, living situation and country of birth. However, significant differences were observed regarding education level, history of SUD treatment, OAT and the primary substances reported. Post hoc analyses revealed that participants in the PC group have the highest level of education, followed by those in the outpatient group and finally the individuals from the TC group. On average, 82.7% of participants from the PC and 85.0% of the participants TC group had a history of SUD treatment, with no statistically significant difference between the two groups. Moreover, a significantly higher

percentage of participants in the outpatient group (46.4%) was engaged in some form of OAT. This is followed by participants in TC group (18.8%) and lastly the PC group (11.1%). In terms of substance use, alcohol was more frequently reported as the primary substance in the PC group, followed by TC and outpatient groups. In contrast, opioids were most frequently reported in the outpatient group, followed by TC and PC groups. Amphetamine, cocaine and GHB were significantly more reported in the TC group, followed by the outpatient and finally the PC group. A significantly higher percentage of participants in the TC group reported more than one primary substance, followed by the outpatient and PC group.

Variables	**Total n = 189**	**PC n = 81**	**TC n = 80**	**Outpatient n = 28**	**Ch-square**
Age *mean* (SD)[d]	*35.5* (9.89)	*36.6* (11.6)	*34.1* (7.9)	*36.5* (9.3)	.201
Gender					
Male	157 (82.6%)	64 (78.0%)	71 (88.8%)	22 (78.6%)	.165
Education level					
Primary	45 (23.7%)	14 (17.1%)	23 (28.7%)	8 (28.6%)	**.036**
Secondary	115 (60.5%)	48 (58.5%)	51 (63.7%)	16 (57.1%)	
Higher	30 (15.8%)	20 (24.4%)	6 (7.5%)	4 (14.3%)	
Current living situation					
Alone	91 (47.9%)	37 (45.1%)	39 (48.8%)	15 (53.6%)	.384[c]
Alone with children	9 (4.7%)	4 (4.9%)	5 (6.3%)	0 (0.0%)	
Living together with partner & children	18 (9.5%)	8 (9.8%)	6 (7.5%)	4 (14.3%)	
Living together with partner without children	13 (6.8%)	8 (9.8%)	2 (2.5%)	3(10.7%)	
Living together with others	59 (31.1%)	25 (30.5%)	28 (35.0%)	6 (21.4%)	
Country of birth					
Belgium	179 (94.2%)	75 (91.5%)	76 (95.0%)	28 (100.0%)	.271[c]
Country of birth (father)					
Belgium	157 (82.6%)	65 (79.3%)	65 (81.3%)	27 (96.4%)	.107
Country of birth (mother)					
Belgium	162 (85.3%)	69 (84.1%)	66 (82.5%)	27 (96.4%)	.188
Previous treatment for SUD					
Yes	154 (81.1%)	68 (82.9%)	68 (85.0%)	18 (64.3%)	**.047**
Opioid Agonist Therapy (OAT)	37 (19.5%)	9 (11.0%)	15 (18.8%)	13 (46.4%)	**<.001**
Main substance(s) (n=187)[a, b]					
Alcohol	100 (53.5%)	52 (63.4%)	38 (48.7%)	10 (37.0%)	**.032**
Amphetamines	41 (21.9%)	9 (11.0%)	23 (29.5%)	9 (33.3%)	**.006**
Benzodiazepines	20 (10.7%)	8 (9.8%)	12 (15.4%)	0 (0.0%)	.078
Cannabis	64 (34.2%)	23 (28.0%)	31 (39.7%)	10 (37.0%)	.281
Crack	33 (17.6%)	9 (11.0%)	19 (24.4%)	5 (18.5%)	.084
Codeine + Promethazine	2 (1.1%)	2 (2.4%)	0 (0.0%)	0 (0.0%)	.632[c]
Cocaine	81 (43.3%)	21 (25.6%)	50 (64.1%)	10 (37.0%)	**<.001**
GHB	14 (7.5%)	1 (1.2%)	10 (12.8%)	3 (11.1%)	**.015**
Hallucinogens	3 (1.6%)	0 (0.0%)	2 (2.6%)	1 (3.7%)	.202[c]
Ketamine	20 (10.7%)	13 (15.9%)	5 (6.4%)	2 (7.4%)	.129
New Psychoactive Substances	6 (3.2%)	2 (2.4%)	3 (3.8%)	1 (3.7%)	.869[c]
Opioids	35 (18.7%)	10 (12.2%)	14 (17.9%)	11 (40.7%)	**.004**
Number of main substances (n=187) [a, b, d]	*2.2* (1.40)	*1.8* (1.31)	*2.7* (1.38)	*2.3* (1.38)	**<.001**
More than one main substance (n=187) [a, b]	111 (59.4%)	33 (40.2%)	60 (76.9%)	18 (66.7%)	**<.001**

Table 4.1 - Overview of sociodemographic and clinical characteristics of the participant sample

[a] *Some service users reported more than one main substance used*
[b] *Data missing for 3 participants*
[c] *Fisher exact test*
[d] *ANOVA*

Further comparisons were made regarding comorbid psychiatric conditions and PROMs at baseline (Table 4.2). No significant differences were found in levels of PTSD, depression, anxiety, and stress scores between the treatment modalities. However, significant differences were observed in scores on the ADHD self-report scale, with participants in the outpatient group scoring significantly lower compared to the TC group. No significant differences were found in general health and QoL scores. In contrast, the total score on the SURE questionnaire revealed significant differences at baseline between the groups, with participants in the outpatient group scoring lower overall than those in the other groups. This trend was significant in the subdomains of 'Substance Use,' 'Self-care,' and 'Outlook on Life'.

Questionnaires	**Total n = 189**	**Psychiatry n = 81**	**TC n = 80**	**Outpatient n = 27**	***p***
PC-PTSD-5	2.23 (1.99)	2.10 (1.92)	2.51 (2.07)	1.78 (1.89)	.185
DASS 21:					
- Depression	18.90 (10.90)	17.61 (10.73)	20.23 (10.80)	18.89 (11.63)	.313
- Anxiety	13.99 (9.49)	12.90 (9.07)	15.53 (9.96)	12.71 (9.03)	.163
- Stress	19.22 (10.13)	17.93 (10.43)	21.00 (9.72)	17.85 (10.01)	.117
ASRS 18Q	3.43 (1.68)	3.35 (1.72)	3.75 (1.50)	2.74 (1.91)	**.022**
PROMIS Alcohol Use					
PROMIS Severity SU					
PROMIS Nicotine					
PROMIS GH					
- Physical	2.78 (.86)	2.73 (.92)	2.85 (.83)	2.70 (.78)	.608
- Mental	2.59 (.92)	2.61 (.94)	2.61 (.88)	2.48 (.98)	.795
SURE TOTAL	52.05 (7.70)	52.10 (7.98)	54.03 (5.46)	46.04 (9.48)	**<.001**[a]
- Substance use	14.98 (2.87)	15.04 (2.98)	15.60 (2.42)	13.00 (3.01)	**<.001**
- Self-care	12.02 (2.78)	11.79 (2.99)	12.91 (1.97)	10.07 (3.12)	**<.001**[a]
- Relationships	10.91 (1.60)	10.98 (1.59)	11.13 (1.26)	10.07 (2.23)	.075[a]
- Material Res.	7.56 (1.76)	7.72 (1.72)	7.48 (1.80)	7.30 (1.77)	.483
- Outlook on life	6.58 (1.89)	6.57 (1.93)	6.91 (1.66)	5.59 (2.10)	**.007**
WHOQOL BREF					
- QoL	2.94 (.82)	2.93 (.77)	2.95 (.87)	2.96 (.85)	.974
- Health	2.86 (.95)	2.91 (.91)	2.81 (.98)	2.81 (1.04)	.771
- Domain 1	13.56 (2.61)	13.36 (2.77)	13.85 (2.41)	13.31 (2.70)	.425
- Domain 2	11.43 (2.81)	11.67 (2.66)	11.33 (2.88)	11.01 (3.06)	.526
- Domain 3	12.14 (3.70)	12.54 (3.74)	11.65 (3.55)	12.40 (3.96)	.291
- Domain 4	13.25 (2.86)	13.72 (2.83)	12.98 (2.85)	12.61 (2.88)	.117

Table 6.2 - Comparison of comorbidity and PROMs at baseline between participants in psychiatric centres (PC) and therapeutic communities (TC)

[a] Welch test

III. DISCUSSION

The use of PROMs and PREMs in SUD treatment services is limited to date and no systematic monitoring system of patient-reported outcomes in Belgium is currently available [4]. Therefore, the OMER-BE study has been set up to assess PROMs and PREMs systematically and to improve the quality of SUD services through the routine measurement and monitoring of patient-reported outcomes and experiences at regular times during and after treatment.

Preliminary comparisons across the three treatment modalities at baseline revealed some noteworthy differences and similarities. While no significant differences are observed in age, sex, living situation, or country of birth, significant variations in education levels, history of SUD treatment, engagement in OAT, and primary substance of problematic use are observed. Regarding co-occurring mental health

disorders, no significant differences were found in PTSD, depression, anxiety, and stress scores between the treatment modalities. However, significant differences were noted in ADHD scores, with the TC group scoring significantly higher than the outpatient group. These differences can be attributed to several factors. TCs may be more suitable for individuals with more severe ADHD symptoms, as these environments provide the structured support and comprehensive care needed to manage both SUDs and co-morbid symptoms like impulsivity. This setting allows for intensive monitoring and interventions, which are crucial for individuals struggling with ADHD symptoms. In contrast, outpatient settings typically cater to individuals with milder symptoms who require less intensive support.

Regarding the PROM scores, no significant treatment modality differences were found in the domains of general health and QoL, but significant differences were observed in recovery strengths, with participants in the outpatient group scoring lower overall than those in the other groups. These differences, particularly noted in the subdomains 'Substance Use', 'Self-care', and 'Outlook on Life' suggest that the structure of the treatment environment play a role in shaping recovery trajectories. For example, we observed that participants in residential treatment score significantly higher on the 'substance use' subscale compared to those in outpatient treatment, suggesting lower levels of substance use among those in residential settings. This difference can be attributed to the structured and controlled environment in residential treatment settings, where strict measures are often in place to encourage abstinence and limit access to substances. The supervision and supportive community in residential facilities may also play a crucial role in reducing substance use, which is less enforceable in outpatient settings where individuals have more autonomy and access to substances. The significant difference in the 'Self-care' subscale, with residential participants scoring higher, may reflect the comprehensive care and empowering support provided in residential settings. These environments typically offer structured daily routines and more intensive psychological and physical care. In contrast, outpatient treatment often places a greater emphasis on self-management, which can be challenging for individuals with limited resources or support networks. Participants in residential treatment also score significantly higher on the 'Outlook on Life' subscale, which may be attributed to the supportive environment of residential treatment settings, where participants are provided with continuous care and peer support, all of which contribute to a more positive and optimistic outlook on life. Notably, the group difference in the 'Relationship' subscale was close to significant. As participants were assessed in the first weeks of treatment, it is possible that participants in residential facilities don't have enough time to build a meaningful relationship with other service users and providers.

3.1 Study limitations

The OMER-BE study also has several limitations. First, recruiting participants in outpatient facilities proved to be extremely challenging, leading to a limited number of participants from these settings. One significant obstacle was the presence of long waiting lists, resulting in a limited number of new treatment episodes and low turnover rates. Additionally, in many outpatient facilities, the frequency of contact between potential participants and service providers was limited. Some service users have only weekly or biweekly appointments. This restricted availability posed significant scheduling constraints since participants had to complete the baseline questionnaires within three weeks of treatment initiation. Moreover, there was a high occurrence of no-shows for scheduled appointments with the researchers, which resulted in missed opportunities to engage potential participants. To

address these challenges, considerable efforts were made. Researchers provided flyers and posters in waiting areas to inform potential participants about the study. They were present at the facilities, addressed potential participants, and checked appointments in advance to ensure their attendance. Regular contact was maintained (through e-mail and phone) with service providers to remind them of the study and discuss potential participants. Despite these efforts, maintaining long-term contacts with outpatient treatment centers was particularly difficult, which resulted in some outpatient centers dropping out from the study. Consequently, future comparative analyses will only focus on the residential treatment services due to the limited number of outpatient participants. Second, recruiting facilities and participants from the French-speaking regions of Belgium proved to be challenging. Although some success was achieved, practical challenges such as staffing shortages and significant differences in the treatment programs of other potential centers hindered broader participation. Despite repeated attempts to engage additional French-speaking services, responses were limited, and further recruitment efforts were not successful. The study is further limited by the lack of standardized diagnostic assessment of participants entering the study. Inclusion was based on previous treatment of SUD, clinical assessment or a history of substance use rather than a clinical diagnoses of a substance use disorder. This lack of structural diagnosis may have introduced variability in our findings and may limit generalization to other populations.

Yet, this study is one of the first studies to explore the assessment of PROMs and PREMs in SUD treatment services using the ICHOM SSA set of instruments. By systematically and routinely monitoring PROMs and PREMs, the project aimed to empower service providers and give them tools to evaluate subjective treatment outcomes and experiences. This approach can provide service providers and policymakers with benchmarks for assessing outcomes and experiences during and after treatment across various treatment modalities. By applying an internationally validated tool, the study allows international comparison with similar interventions and treatment modalities globally. Future analyses will explore longitudinal changes in PROMs and PREMs, with a particular focus on the influence of baseline mediating and moderating variables (e.g., socio-economic status, comorbidity, recovery strength) and differences between treatment modalities. The findings from this study will offer new perspectives and insights into the effectiveness of different SUD treatment modalities and their impact on diverse service user populations. This shift towards patient-centered care not only supports better recovery outcomes, but also fosters continuous improvement and innovation in SUD treatment services. Ultimately, systematically monitoring PROMs and PREMs has the potential to enhance the quality of care by offering a comprehensive understanding of service users' needs and treatment effectiveness.

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CHAPTER 5

LONGITUDINAL ASSESSMENT OF PROMS AND PREMS IN ALCOHOL AND DRUG SERVICES IN BELGIUM

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Chapter 5.1
Longitudinal analyses of PROM data in residential AOD services

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I. INTRODUCTION

Alcohol and other substance use disorders (SUDs) are associated with a range of negative psychological, physical, and social outcomes. Due to their chronic and relapsing nature, SUDs often lead to issues related to judicial problems, housing instability, and social relationships, affecting not only individuals with SUDs but also their social environment and the wider community [1-4]. SUDs are recognized as a major and growing determinant of adverse health outcomes, significantly impacting global morbidity and mortality rates [5-7].

Although treatment is not the only recovery pathway, a wide variety of specialized outpatient and residential SUD treatment options exist. Residential treatment programmes, in particular, are considered a beneficial treatment option, especially for individuals with severe substance use issues and complex psychosocial challenges. This treatment modality offers intensive support and care in a drug-free, 24-hour residential community environment, designed to assist individuals with severe and complex substance use disorders [8, 9]. Several authors [10] have highlighted key advantages of inpatient settings, including a therapeutic environment allowing individuals to focus on recovery away from harmful external influences, consistent access to medical and psychiatric support and opportunities for self-reflection, all of which can positively influence recovery outcomes. However, residential programs vary significantly in their approach, intensity and length of treatment. Key examples of residential treatment settings are psychiatric treatment centers (PCs) and therapeutic communities (TCs). Within PCs, specialized psychiatric wards deliver extended residential care, typically spanning three to six months, offering intensive medical and psychological interventions for SUDs and, in some cases, co-existing mental health disorders. Treatment generally includes psycho-education, group counseling, individual psychotherapy and occupational activities. Drug-free TCs or TCs for addictions have a long history and were set up as long-term, specialized treatment modalities for individuals with SUDs [11]. TCs provide a drug-free environment where individuals live together in a structured setting, typically for 6 to 12 months. The aim of the program is to facilitate personal growth and recovery, promoting positive outcomes such as social reintegration and self-efficacy, and ultimately to lead to a drug-free life in society [12, 13]. The core principle of the TC approach is "community as a method", indicating that peer influence, mutual support, and the sense of connectedness within the community play a vital role in fostering recovery. By modelling positive behavior and engaging in community living, participants support one another in their recovery journey, creating a powerful collective environment that promotes change and healing [11, 14]. A substantial bulk of research has examined the effectiveness of residential substance use treatment services. While several studies have demonstrated the benefits of inpatient SUD treatment, such as higher abstinence rates, reduced levels of psychopathology and better social integration [15-18], other studies provide limited evidence for the effectiveness of residential SUD services. Additionally, challenges such as high relapse and drop-out rates remain and underscore the necessity for further research [19]. SUD treatment outcomes are traditionally assessed using objective measures such as drug-free days, re-arrest/reincarceration rates, or provider-reported indicators including treatment compliance and symptom reduction. Treatment effectiveness is often measured by assessing either abstinence or significant reductions in substance use and related harm. The growing focus on incorporating service users' perspectives in assessing treatment outcomes has recently resulted in the introduction of Patient-Reported Outcome Measures (PROMs) in SUD and other mental health services [20-23]. PROMs capture individual, subjective treatment outcomes, including aspects such as quality of life, recovery capital, psychological well-being and physical health. The implementation of

PROMs is recommended as a means to systematically monitor and enhance the provision of patient-centered care and support shared decision-making, practices that are not yet widely established in SUD and other mental health services [21, 22, 24-29]. Also, lived experience is increasingly regarded as a valuable source of knowledge, besides academic knowledge and practical expertise.

The aim of the study is to monitor the evolution of PROMs among individuals starting residential SUD treatment. By assessing how PROMs evolve over time, this study seeks to provide a deeper understanding of how treatment setting, duration, and participant characteristics — such as age, gender, and education level — affect recovery outcomes. Understanding the evolution of PROMs over time is essential for capturing recovery progress, as changes in these measurements may reflect significant changes in mental, physical and social health, which are key indicators of successful recovery from SUDs.

II. METHODS

2.1 Participants

Data collection started in July 2022 (until June 2024) and individuals with SUDs were followed up over a 6-month period in various residential treatment services (four psychiatric treatment centers (PCs) and four therapeutic communities (TCs)). The study included a baseline sample of 161 participants who started residential treatment. The sample size decreased to 102 after 45 days (36.6% dropout), 98 after 90 days (39.1% dropout) and 89 after 180 days, indicating a total drop-out rate of 44.7%.

2.2 Instruments

To measure patient-reported outcomes in this sample, scores on three instruments were analyzed at various follow-up moments.

PROMIS-GH-10 (PROMIS Scale v1.2 – Global Health)

The PROMIS Global Health (PROMIS-GH) questionnaire comprises ten items, rated on a 5-point scale. To avoid redundancy with other questionnaires and in line with the ICHOM SSA, only two items were included, focusing on physical and mental health. The response options for these items were 'poor', ‘fair’, ‘good’, ‘very good’ and 'excellent'. The questionnaire's psychometric properties were assessed in a sample of 4370 individuals from the Dutch general population, demonstrating a 2-factor structure with good internal consistency. The subscales for 'Global Mental Health' and 'Global Physical Health' yielded Cronbach’s α scores of 0.83 and 0.78, respectively [30].

SURE (Substance Use Recovery Evaluator)

The SURE [31] is a self-report questionnaire with 21 items, completed on a 5-point scale but evaluated on a 3-point scale (1-3). The first two response options are scored as 3, the third as 2, and the final two as 1. For the first three questions, the response options were ‘never’, ‘on 1 or 2 days’, ‘on 3 or 4 days’, ‘on 5 or 6 days’, and ‘every day’.

For the remaining questions, responses are ‘none of the time’, ‘a little of the time’, ‘a fair amount of the time’, ‘most of the time’ and ‘all of the time’. Higher total scores reflect greater recovery strengths. The questionnaire is divided into five subscales: ‘substance use’, ‘self-care’, ‘relationships’, ‘material resources’ and ‘outlook on life’. In a sample of current and former SUD service users, the total score

demonstrated strong internal consistency (Cronbach's α = 0.92) [31]. Similarly, the Dutch version of the SURE (SURE-NL), which was used in this study, showed good internal consistency (Cronbach's α = 0.83) [32].

WHOQoL-BREF (WHO Quality of Life Scale)

The WHOQoL-BREF (World Health Organization Quality of Life-BREF) [33] is a shortened version of the WHOQoL-100, comprising 26 items. The items are rated on a 5-point scale, with response options ranging from 'not at all' to 'completely', 'very poor' to 'very good', 'very dissatisfied' to 'very satisfied', 'not at all' to 'extremely/completely' and 'never' to 'always', depending on the question. Higher overall scores indicate a better quality of life. The items are divided into four domains: 'psychological health', 'physical health', 'social relationships' and 'environment'. The WHOQoL-BREF has demonstrated good internal consistency, with Cronbach's α values for the four domains ranging from 0.66 to 0.84 [34].

2.3 Ethics and dissemination

We received ethical approval for this study from the Medical Ethics Committee of the University Hospital Brussels on May 11th, 2022 (UZ Brussel; BUN: 1432022000071). All participants were informed about the confidentiality of their data, and written informed consent was obtained prior to their inclusion in the study. The data were handled with strict confidentiality and are reported anonymously. The study adheres to the principles of the Declaration of Helsinki.

2.4 Data analysis

This paper presents the baseline characteristics of the study cohort, with comparisons made between study participants from residential psychiatric centres and therapeutic communities. Categorical demographic and patient characteristics were reported using frequency counts and percentages of participants in each category and analysed for significant differences using either the Chi-square test or, where the assumptions of the Chi-square test were not met, Fisher's exact test. For continuous variables, descriptive statistics (mean, standard deviation) were reported and ANOVA was used to assess group differences. If equal variances were not assumed, the Welch t-test was used.

A linear mixed models approach for repeated measurements was used to analyze changes in PROM scores from baseline to the 6-month follow-up. This method is appropriate for analyzing longitudinal data, particularly when there is substantial dropout or missing data. Satterthwaite's corrected F-test was used to test the main and interaction effects. Age and time were centered and p-values below 0.05 were considered to be statistically significant. Statistical tests were two-sided. All statistical analyses were conducted using IBM SPSS statistic version 29.

III. RESULTS

3.1 Sociodemographic and clinical characteristics

A total of 161 participants were included in the study, with 81 from PCs and 80 from TCs. The average age of the participants was 35.3 years (SD = 10.0), with no significant difference in age between the PC (M = 36.6, SD = 11.7) and TC (M = 34.1, SD = 7.9) group (p = .115). Most participants were male

(83.2%), and while the proportion of males was higher in the TC group (88.8%) compared to the PC group (77.8%), this difference was not statistically significant (p = .062).

Variables	Total n = 161	PC n = 81	TC n = 80	Chi-square
Age *mean* (SD)[a]	*35.3* (10.0)	*36.6* (11.7)	*34.1* (7.9)	.115[b]
Sex				
Male	134 (83.2%)	63 (77.8%)	71 (88.8%)	.062
Education level				
Primary	37 (23.0%)	14 (17.3%)	23 (28.7%)	**.007**
Secondary	98 (60.9%)	47 (58.0%)	51 (63.7%)	
Higher	26 (16.1%)	20 (24.7%)	6 (7.5%)	
Current living situation				.375[c]
Alone	75 (46.6%)	36 (44.4%)	39 (48.8%)	
Alone with children	9 (5.6%)	4 (4.9%)	5 (6.3%)	
Living together with partner & children	14 (8.7%)	8 (9.9%)	6 (7.5%)	
Living together with partner without children	10 (6.2%)	8 (9.9%)	2 (2.5%)	
Living together with others	53 (32.9%)	25 (30.9%)	28 (35.0%)	
Country of birth				.360
Belgium	150 (93.2%)	74 (91.4%)	76 (95.0%)	
Country of birth (father)				.722
Belgium	129 (80.1%)	64 (79.0%)	65 (81.3%)	
Country of birth (mother)				.805
Belgium	134 (83.2%)	68 (84.0%)	66 (82.5%)	
Previous treatment for SUDs				.694
Yes	135 (83.9%)	67 (82.7%)	68 (85.0%)	
Opioid Agonist Therapy (OAT)				.174
Yes	24 (14.9%)	9 (11.1%)	15 (18.8%)	
Main substance(s) (n=159) [d, e]				
Alcohol	90 (56.6%)	52 (64.2%)	38 (48.7%)	**.049**
Amphetamines	32 (20.1%)	9 (11.1%)	23 (29.5%)	**.004**
Benzodiazepines	20 (12.6%)	8 (9.9%)	12 (15.4%)	.295
Cannabis	54 (34.0%)	23 (28.4%)	31 (39.7%)	.131
Crack	28 (17.6%)	9 (11.1%)	19 (24.4%)	**.028**
Codeine + Promethazine	2 (1.3%)	2 (2.5%)	0 (0.0%)	.497[c]
Cocaine	71 (44.7%)	21 (25.9%)	50 (64.1%)	**<.001**
GHB	11 (6.9%)	1 (1.2%)	10 (12.8%)	**.004**
Hallucinogens	2 (1.3%)	0 (0.0%)	2 (2.6%)	.239
Ketamine	18 (11.3%)	13 (16.0%)	5 (6.4%)	.055
New Psychoactive Substances	5 (3.1%)	2 (2.5%)	3 (3.8%)	.678[c]
Opioids	24 (15.1%)	10 (12.3%)	14 (17.9%)	.324
Number of main substances (n=159) [a, d, e]	*2.3* (1.4)	*1.9* (1.3)	*2.7* (1.4)	**<.001**[a]
More than one main substance (n=159) [d, e]	93 (58.5%)	33 (40.7%)	60 (76.9%)	**<.001**

Table 5.1. Overview of the sociodemographic and clinical characteristics of the participant sample (n=161)

[a] *ANOVA*
[b] *Welch test*
[c] *Fisher exact test*
[d] *Some service users reported more than one main substance used*
[e] *Data missing for 2 participants*

Significant differences in education level were observed between the two groups (p = .007). A higher percentage of participants in the PC group completed higher education (24.7%) compared to the TC group (7.5%), whereas a larger proportion of TC participants had completed only primary education

(28.7% vs. 17.3% in PC). No significant differences were found between the groups regarding living situation, country of birth, or treatment history for SUDs (p > .05).

3.2 Comorbidity

Comorbid mental health conditions were assessed using the PC-PTSD-5, DASS-21 and ASRS instruments (*see Chapter 4*). Approximately half of the participants (50.3%) had three or more PTSD symptoms in the last month, with no statistically significant difference between PCs and TCs (p = .070). Severe anxiety scores on the DASS-21 were significantly more frequent among TC participants (51.2%) compared to PC participants (32.1%) (p = .014), while depression and stress levels did not differ significantly between both groups. More than half of the participants (56.5%) showed 4 or more ADHD symptoms, with no significant difference between both groups.

Questionnaires	Total n = 189	PC n = 81	TC n = 80	Chi-square
PC-PTSD-5				
>=3 out of 5 DSM sympt.	81 (50.3%)	35 (43.2%)	46 (57.5%)	.070
>=4 out of 5 DSM sympt.	58 (36.0%)	24 (29.6%)	34 (42.5%)	.089
DASS 21:				
- Depression (severe)	70 (43.5%)	32 (39.5%)	38 (47.5%)	.306
- Anxiety (severe)	67 (41.6%)	26 (32.1%)	41 (51.2%)	**.014**
- Stress (severe)	47 (29.2%)	21 (25.9%)	26 (32.5%)	.359
ASRS (4 or more sympt.)	91 (56.5%)	43 (53.1%)	48 (60.0%)	.376

Table 5.2. Overview of comorbidities

3.3 Baseline PROM comparisons and longitudinal evolution of PROMs

At baseline, most PROM scores didn't show significant differences across the treatment modalities. The SURE total score was high and revealed no significant difference between PCs and TCs; however, the 'Self-care' subscale showed higher scores among TC residents (M = 12.91; SD = 1.97) than in PC participants (M = 11.81; SD = 3.00) (p = .007). No significant differences were found in WHOQOL-BREF and PROMIS-GH domain scores between both groups.

Questionnaires	Total n = 189	PC n = 81	TC n = 80	*p*
PROMIS GH				
- Physical Health	2.79 (.88)	2.73 (.92)	2.85 (.83)	.380
- Mental Health	2.61 (.91)	2.62 (.94)	2.61 (.88)	.973
SURE TOTAL	53.10 (6.90)	52.19 (7.99)	54.03 (5.46)	.090[a]
- Substance use	15.34 (2.72)	15.07 (2.98)	15.60 (2.42)	.221
- Self-care	12.36 (2.59)	11.81 (3.00)	12.91 (1.97)	**.007**[a]
- Relationships	11.05 (1.44)	10.98 (1.60)	11.13 (1.26)	.510
- Material Res.	7.60 (1.77)	7.72 (1.73)	7.48 (1.80)	.388
- Outlook on life	6.76 (1.80)	6.60 (1.92)	6.91 (1.66)	.278
WHOQOL BREF				
- Perception QoL	2.94 (.82)	2.93 (.77)	2.95 (.87)	.853
- Perception Health	2.86 (.95)	2.91 (.91)	2.81 (.98)	.499
- Physical Health	13.59 (2.60)	13.33 (2.77)	13.85 (2.41)	.209
- Psychological Health	11.50 (2.77)	11.68 (2.67)	11.33 (2.88)	.420
- Social Relationships	12.12 (3.66)	12.59 (3.72)	11.65 (3.55)	.102
- Environment	13.36 (2.86)	13.74 (2.84)	12.98 (2.85)	.090

Table 5.3. Comparisons of PROMs at baseline using ANOVA

[a] *Welch test*

A series of linear mixed models was applied to analyze the evolution of PROM scores over a period of 6 months (see Table 4). The analyses revealed distinct longitudinal trends across PROM domains.

SURE

Substance Use. Neither time, treatment modality, nor demographic variables (age, gender, and education level) showed statistically significant effects, suggesting no observable changes in substance use recovery scores over time across different treatment settings or demographic groups in this study.

Self-care. The effects of time, treatment modality and demographic variables (age, gender, and education level) were not statistically significant. However, the interaction effect between time and treatment modality was significant (b=-.321, p=.002), suggesting that the evolution of self-care scores varied between TCs and PCs. When analyzing treatment modalities separately, no significant effect of time was found for the PC group (b=.060, p=.319). However, time had a negative significant effect in the TC group (b=-.271, p=.001), suggesting a significant decrease in self-care scores over time.

Relationships. No effects were found for any variable in this domain, indicating stability in relationships over time and no differences between demographic groups or treatment modalities.

Material resources. Although time, treatment modality, gender and education level were not statistically significant, age showed a positive significant effect (b=.029, p=.005), suggesting higher material resources in older participants.

Outlook of life. Neither time nor other predictors showed significant effects in these domains, indicating limited changes in participants' overall outlook on life over the study period. However, a significant interaction effect between time and modality was found (b=-.144, p=.032), suggesting a different evolution of 'Outlook of Life' scores between participants in TCs and PCs. When analyzing these groups separately, time had a negative effect in the TC group and a positive effect in the PC group. However, both effects were not significant (respectively, b=-.081, p=.110 and b=.064, p=.146).

Total score. Neither time nor other individual predictors showed a significant effects in this domain, indicating limited changes overall in participants' total SURE scores over the study period. However, the interaction effect between time and modality was found significant (b=-.755, p=.008). When analyzing treatment modalities separately, no significant effect of time was found for the PC group (b=.280, p=.105). However, time had a significant negative effect in the TC group (b=-.491, p=.037), suggesting a decrease in the total SURE-NL scores over time.

WHOQoL-BREF

Perception of QoL. A significant positive trend over time was found (b=.079, p<.001), indicating a linear improvement in perceived QoL during the study period. Other covariates had no significant effect.

Perception of Health. Both the linear (p=.010) and quadratic (p=.034) effects of time were significant, showing an initial increase in perceived health with a levelling off effect over time.

Physical Health. Age had a significant negative effect (b=-.093, p=.001), indicating that older participants reported lower physical health scores on the WHOQoL-BREF. Similar to 'Perception of Health', both the linear (p=.015) and quadratic (p=.044) effects of time were significant, demonstrating an initial increase in perceived health that plateaued over time.

Psychological Health. A strong positive effect of time (b=.313, p<.001) and a significant quadratic effect (b=-.075, p=.015) highlighted substantial improvements in psychological health that leveled off over time. Treatment modality had a significant negative effect (b=-1.226, p=.012), with participants in TCs reporting lower psychological health scores. Gender had a positive significant effect (b=1.126, p=.047), suggesting on average higher scores in male participants.

Social Relationships. Time did not significantly affect social relationship scores. However, treatment modality had a significant negative effect (b=-1.036, p=.046), suggesting lower social relationships scores in the TC group.

Environment. A significant positive trend over time was found for the study cohort regarding perceived quality of their living environment (b=.149, p=.011). Other predictors were not significant.

PROMIS-GH-10

Physical Health. Time had a positive impact on participants' physical health perceptions (b=.070, p=.002), indicating improved physical health at the follow-up moments. Age had a negative effect on physical health scores (b=-.013, p=.044), consistent with the findings of the WHOQoL-BREF physical health domain.

Mental Health. Time also had a significant positive effect on participants' mental health (b=.076, p=.003), with a quadratic time effect (b=-.030, p=.008), indicating improvements in mental health perceptions which stabilized over time. Gender and other demographic factors did not significantly influence these mental health scores.

Dependent variable	Parameter	Estimate	SE	df	t	Sig	95% Confidence Interval	
							Lower Bound	Upper Bound
SURE								
Substance Use	Intercept	15.448	.535	157.737	28.901	<.001	14.392	16.504
	Time	.133	.078	99.199	1.700	.092	-.022	.288
	Modality (TC)	.077	.393	147.677	.196	.845	-.700	.854
	Age	.019	.019	160.026	.982	.327	-.019	.057
	Gender (Man)	.024	.507	154.249	.047	.963	-.979	1.026
	Education level (higher/uni)	.766	.541	147.659	1.417	.159	-.303	1.835
	Education level (primary)	-.344	.447	161.306	-.770	.443	-1.227	.539
	Time*Modality	-.182	.112	103.346	-1.626	.107	-.403	.040
Self-care	Intercept	11.896	.540	152.903	22.020	<.001	10.828	12.963
	Time	.064	.069	95.868	.926	.357	-.073	.202
	Modality (TC)	.048	.391	145.563	.123	.903	-.726	.822
	Age	.007	.019	157.227	.370	.712	-.031	.045
	Gender (Man)	.488	.515	151.871	.946	.346	-.531	1.506
	Education level (higher/uni)	-.374	.550	145.516	-.681	.497	-1.461	.713
	Education level (primary)	-.396	.454	158.404	-.873	.384	-1.292	.500
	Time*Modality	-.321	.099	99.801	-3.235	.002	-.518	-.124
Relationships	Intercept	10.951	.327	441	33.457	<.001	10.308	11.594
	Time	-.041	.043	441	-.934	.351	-.126	.045
	Modality (TC)	-.102	.242	441	-.422	.673	-.579	.374
	Age	-.012	.012	441	-.989	.323	-.035	.011
	Gender (Man)	-.364	.310	441	-1.173	.241	-.973	.246
	Education level (higher/uni)	.475	.330	441	1.440	.150	-.173	1.124
	Education level (primary)	.054	.274	441	.197	.844	-.484	.592

	Time*Modality	-.081	.062	441	-1.301	.194	-.204	.041
Material Resources	Intercept	8.025	.272	114.931	29.461	<.001	7.485	8.564
	Time	.084	.044	82.905	1.909	.060	-.004	.172
	Modality (TC)	.022	.192	117.613	.114	.910	-.358	.401
	Age	.029	.010	130.895	2.824	.005	.009	.048
	Gender (Man)	-.061	.265	119.722	-.230	.818	-.585	.463
	Education level (higher/uni)	.300	.279	111.569	1.076	.284	-.253	.854
	Education level (primary)	-.171	.236	132.504	-.725	.470	-.638	.296
	Time*Modality	.016	.063	85.581	.252	.802	-.109	.141
Outlook on Life	Intercept	6.638	.392	154.834	16.944	<.001	5.864	7.412
	Time	.065	.046	100.641	1.403	.164	-.027	.156
	Modality (TC)	-.192	.281	148.703	-.685	.495	-.748	.363
	Age	.001	.014	159.571	.043	.966	-.027	.028
	Gender (Man)	.283	.375	154.700	.753	.452	-.458	1.023
	Education level (higher/uni)	-.240	.401	148.676	-.600	.549	-1.032	.551
	Education level (primary)	-.114	.330	160.644	-.347	.729	-.766	.537
	Time*Modality	-.144	.066	104.616	-2.176	.032	-.274	-.013
Total	Intercept	53.042	1.566	166.091	33.876	<.001	49.950	56.133
	Time	.288	.196	92.196	1.470	.145	-.101	.678
	Modality (TC)	-.149	1.184	151.476	-.126	.900	-2.489	2.190
	Age	.056	.055	157.966	1.015	.312	-.053	.164
	Gender (Man)	.238	1.464	154.574	.163	.871	-2.653	3.130
	Education level (higher/uni)	.787	1.568	149.927	.502	.616	-2.312	3.886
	Education level (primary)	-1.243	1.285	159.542	-.968	.335	-3.781	1.294
	Time*Modality	-.755	.280	96.521	-2.695	.008	-1.312	-.199
WHOQoL-BREF								
Perception QoL	Intercept	3.313	.168	150.604	19.748	<.001	2.982	3.645
	Time	.079	.022	94.013	3.547	<.001	.035	.123
	Modality (TC)	.013	.121	142.859	.108	.914	-.227	.253
	Age	-.004	.006	156.805	-.718	.474	-.016	.008
	Gender (Man)	-.092	.160	150.435	-.574	.567	-.409	.225
	Education level (higher/uni)	-.016	.171	143.271	-.095	.925	-.354	.321
	Education level (primary)	-.047	.141	158.161	-.332	.740	-.326	.232
	Time*Modality	-.006	.032	98.293	-.176	.860	-.069	.058
Perception Health	Intercept	3.198	.189	440	16.906	<.001	2.826	3.569
	Time	.068	.026	440	2.581	.010	.016	.120
	Time*Time	-.023	.011	440	-2.127	.034	-.045	-.002
	Modality (TC)	.015	.154	440	.100	.920	-.287	.318
	Age	-.008	.007	440	-1.224	.222	-.021	.005
	Gender (Man)	.131	.172	440	.760	.448	-.207	.469
	Education level (higher/uni)	-.077	.182	440	-.419	.675	-.435	.282
	Education level (primary)	-.006	.152	440	-.040	.968	-.305	.293
	Time*Modality	.044	.038	440	1.175	.241	-.030	.118
	Time*Time*Modality	-.006	.016	440	-.387	.699	-.037	.025
Physical Health	Intercept	14.140	.584	440	24.200	<.001	12.991	15.288
	Time	.146	.059	440	2.453	.015	.029	.263
	Time*Time	-.061	.030	440	-2.018	.044	-.120	-.002
	Modality (TC)	-.624	.463	440	-1.347	.179	-1.535	.286
	Age	-.044	.020	440	-2.186	.029	-.084	-.004
	Gender (Man)	.265	.536	440	.495	.621	-.788	1.319
	Education level (higher/uni)	-.203	.572	440	-.354	.723	-1.327	.921
	Education level (primary)	-.677	.472	440	-1.436	.152	-1.604	.249
	Time*Modality	-.150	.085	440	-1.777	.076	-.317	.016
	Time*Time*Modality	.097	.043	440	2.268	.024	.013	.181
Psychological Health	Intercept	12.397	.614	440	20.181	<.001	11.189	13.604
	Time	.313	.061	440	5.171	<.001	.194	.432
	Time*Time	-.075	.031	440	-2.452	.015	-.135	-.015
	Modality (TC)	-1.226	.484	440	-2.535	.012	-2.177	-.275
	Age	-.001	.021	440	-.062	.951	-.043	.040
	Gender (Man)	1.126	.565	440	1.992	.047	.015	2.236

	Education level (higher/uni)	-.286	.603	440	-.474	.636	-1.472	.900
	Education level (primary)	-.831	.497	440	-1.672	.095	-1.807	.146
	Time*Modality	-.132	.086	440	-1.535	.125	-.301	.037
	Time*Time*Modality	.059	.043	440	1.369	.172	-.026	.145
Social Relationships	Intercept	13.542	.731	148.766	18.516	<.001	12.097	14.987
	Time	.059	.086	101.530	.690	.492	-.111	.230
	Modality (TC)	-1.036	.514	148.255	-2.016	.046	-2.051	-.020
	Age	-.040	.027	159.556	-1.513	.132	-.093	.012
	Gender (Man)	-1.021	.707	152.412	-1.446	.150	-2.417	.375
	Education level (higher/uni)	.139	.751	144.466	.185	.854	-1.347	1.624
	Education level (primary)	.010	.624	160.708	.016	.987	-1.221	1.241
	Time*Modality	.011	.124	105.761	.090	.929	-.234	.256
Environment	Intercept	14.395	.564	145.540	25.522	<.001	13.281	15.510
	Time	.149	.057	90.797	2.608	.011	.035	.262
	Modality (TC)	-.571	.395	145.244	-1.444	.151	-1.352	.211
	Age	-.018	.020	154.671	-.873	.384	-.058	.023
	Gender (Man)	-.314	.545	148.803	-.577	.564	-1.390	.762
	Education level (higher/uni)	.622	.581	141.626	1.071	.286	-.526	1.770
	Education level (primary)	-.851	.479	155.564	-1.776	.078	-1.797	.096
	Time*Modality	-.033	.082	94.837	-.398	.691	-.195	.130
PROMIS-GH-10								
Physical Health	Intercept	2.900	.176	145.896	16.507	<.001	2.553	3.247
	Time	.070	.022	98.244	3.171	.002	.026	.114
	Modality (TC)	-.013	.127	136.612	-.102	.919	-.265	.239
	Age	-.013	.006	151.955	-2.031	.044	-.025	.000
	Gender (Man)	.164	.168	146.102	.977	.330	-.167	.495
	Education level (higher/uni)	.036	.179	139.228	.199	.843	-.318	.389
	Education level (primary)	.065	.148	153.228	.441	.660	-.227	.357
	Time*Modality	-.012	.032	102.618	-.377	.707	-.075	.051
Mental Health	Intercept	2.803	.201	440	13.921	<.001	2.407	3.199
	Time	.076	.025	440	3.034	.003	.027	.125
	Time*Time	-.030	.011	440	-2.674	.008	-.052	-.008
	Modality (TC)	-.276	.165	440	-1.668	.096	-.600	.049
	Age	.001	.007	440	.190	.850	-.012	.015
	Gender (Man)	.321	.182	440	1.765	.078	-.036	.678
	Education level (higher/uni)	.097	.194	440	.503	.615	-.283	.478
	Education level (primary)	-.171	.160	440	-1.068	.286	-.485	.144
	Time*Modality	-.021	.036	440	-.581	.562	-.090	.049
	Time*Time*Modality	.030	.016	440	1.867	.063	-.002	.062

Table 5.4. Overall PROM scores and domain PROM scores regressed on Time (month)

3.4 Post-hoc exploratory analyses of SURE-NL Scores

Given the limited longitudinal changes observed in the SURE scores, particularly when compared to other measures, post-hoc exploratory analyses were conducted to better understand potential explanations for these findings. The baseline data demonstrated generally very high scores across all SURE subdomains, with median scores approaching the maximum possible values: 'Substance Use' (16/18), 'Self-care' (13/15), 'Relationships' (12/12), 'Material Resources' (8/9), and 'Outlook on Life' (7/9) (Table 1, Figure 1). These high baseline scores suggest a ceiling effect, reducing the likelihood of observing substantial improvements over time. Also, from a recovery perspective maintaining these high scores across the study period is considered beneficial.

To account for the fact that the SURE questionnaire captures experiences from the week preceding the assessment and considering that participants in the OMER-BE study could complete the baseline questionnaires up to three weeks after starting treatment, we explored the hypothesis that the

number of days in treatment prior to completing the questionnaire may have influenced the (lack of) longitudinal changes observed in the SURE-NL scores. A linear regression analysis was conducted to assess whether the time in treatment before the baseline assessment predicted baseline SURE scores. Interestingly, the results indicated that the number of days since treatment initiation significantly predicted higher total baseline SURE scores (b = .11, p = .047). This suggests that participants who had been in treatment longer prior to completing the baseline questionnaire reported higher SURE-scores and stronger perceived recovery strengths.

	Mean	Median	SD	Range (Min-Max)	Pc 25	50	75
Substance Use (6-18)	15.34	16.00	2.72	6-18	14.00	16.00	18.00
Self-care (5-15)	12.36	13.00	2.59	5-15	11.00	13.00	15.00
Relationships (4-12)	11.05	12.00	1.44	4-12	11.00	12.00	12.00
Material Resources (3-9)	7.60	8.00	1.77	3-9	7.00	8.00	9.00
Outlook on Life (3-9)	6.76	7.00	1.80	3-9	6.00	7.00	8.00
TOTAL (21-63)	53.10	54.00	6.90	30-63	50.00	54.00	58.00

Table 5.5. Descriptives of baseline SURE scores for participants in residential settings (n=189)

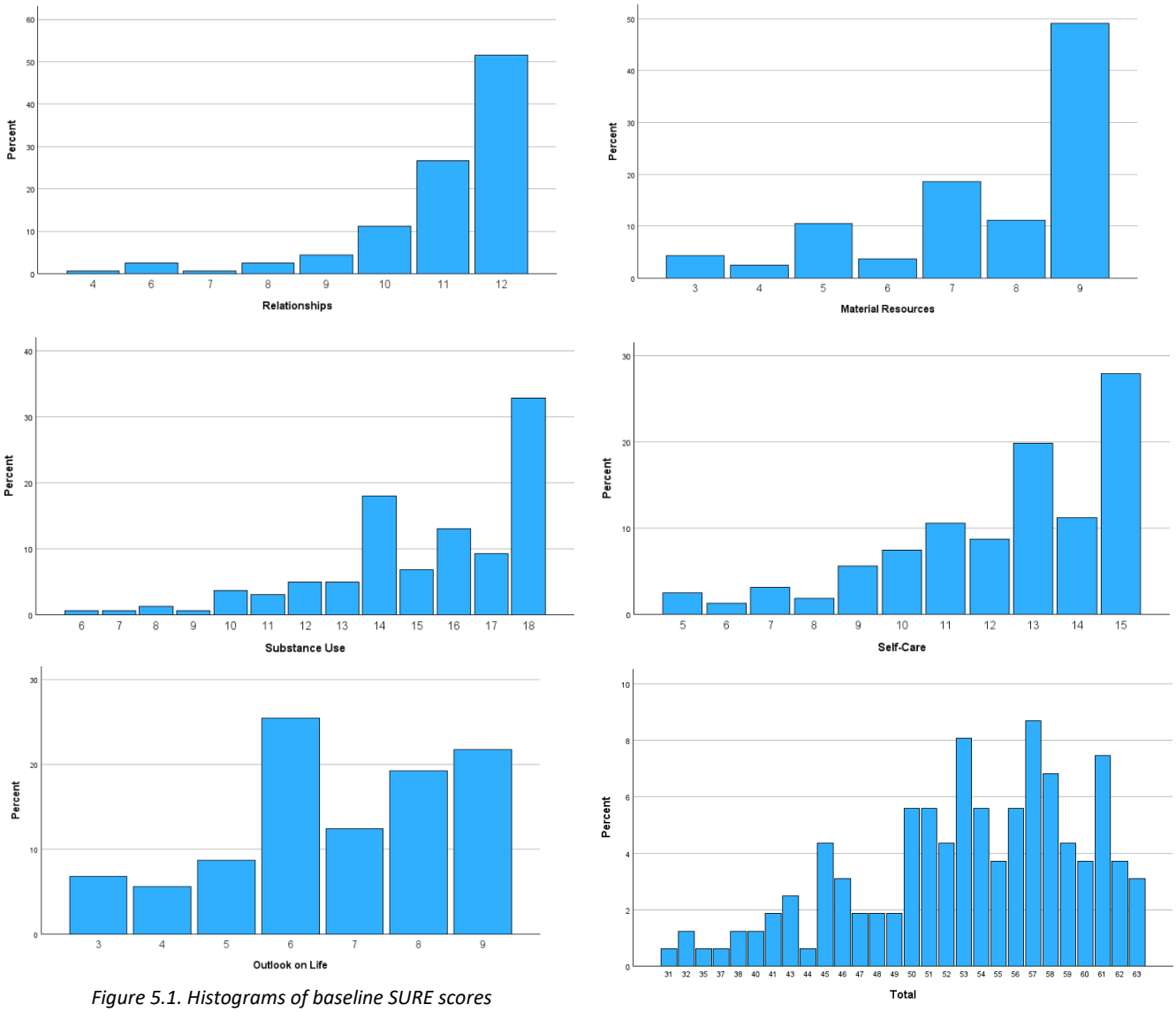

Figure 5.1. Histograms of baseline SURE scores

	B	SE	Beta	t	p-value
(Intercept)	49.35	2.71		18.18	<.001
Gender	-.10	1.55	-.01	-.07	.947
Age	.07	.06	.11	1.29	.201
Education level (higher/uni)	-.16	1.65	-.01	-.10	.923
Education level (primary)	-1.13	1.35	-.07	-.84	.401
Days since start treatment	.11	.06	.16	2.00	.047

Table 5.6. Linear regression analysis of total baseline SURE score

To further explore this hypothesis, a subgroup analysis was conducted, focusing on participants who completed the baseline SURE within 12 days of starting treatment (i.e. median value). This analysis revealed a significant positive time effect on the total SURE scores (b = .52, p = .010), indicating that for participants who completed the baseline assessment earlier, improvements in recovery strengths were more detectable over time, compared to the entire sample.

IV. DISCUSSION

This chapter examined the evolution of PROMs among 161 individuals with SUDs undergoing residential AOD treatment in psychiatric centres and drug-free therapeutic communities in Belgium over a 6 month period. By assessing changes and stability in the early recovery stage, this research sought to examine how treatment setting, time, and demographic and background variables influence recovery outcomes across multiple domains, including self-care, social relationships, and quality of life.

Overall, significant improvements were observed on several PROM measures, particularly the PROMIS-GH-10 and WHOQoL-BREF, which showed significant improvements over time on all domains, except for social relationships. Linear improvements over time were found for the domains 'Perception of QoL' and 'Environment', indicating that longer time (in months) was linked with higher perception of QoL and satisfaction with environmental factors. Additionally, a quadratic time effect was found for physical and psychological health, suggesting initial improvements followed by stabilization at later assessment moments. This pattern indicates that most improvements in these domains occur early in treatment/recovery, with gains leveling off at later moments. These findings align with studies suggesting that the most substantial recovery gains in/after addiction treatment often occur in the initial stages, stabilizing over time [35].

Age and gender were significant covariates in some domains. In general, older participants reported lower physical health, which reflects age-related physical health decline. Gender differences were observed in the psychological health domain of the WHOQoL-BREF, with male participants reporting higher scores than females. This is consistent with research indicating that women in treatment services often experience more mental health issues [36-38].

With regard to recovery strength, results suggest distinct trajectories, highlighting the complex, multifaceted nature of SUD treatment. Distinct recovery trajectories were observed for self-care domain of the SURE, with participants in TCs demonstrating a decline in self-care over time, whereas participants in PCs showing stable self-care scores over time. Additionally, the significant interaction effect between treatment modality and time on the outlook on life domain of the SURE indicates differing trajectories between participants in TCs and PCs. While TC participants exhibit a decline in scores over time, those in PCs show a positive trend. However, neither effect reaches statistical

significance when groups were analyzed separately. Overall, total SURE scores showed a significant negative time effect for TC participants and no time effects for PC participants.

Dependent variable	Parameter	Estimate	SE	df	t	Sig	95% Confidence Interval	
							Lower Bound	Upper Bound
SURE								
Total	Intercept	52.34	2.08	77.35	25.19	<.001	48.20	56.48
	Time	.52	.19	45.13	2.70	.010	.13	.91
	Modality (TC)	.99	1.72	77.34	.58	.567	-2.43	4.40
	Age	.01	.09	78.78	.17	.867	-.16	.18
	Gender (Man)	.86	1.93	76.21	.44	.659	-2.99	4.70
	Education level (higher/uni)	.95	2.21	74.80	.43	.668	-3.46	5.36
	Education level (primary)	-2.94	2.14	83.20	-1.37	.174	-7.21	1.32
	Time*Modality	-.54	.33	49.84	-1.64	.107	-1.19	.12

Table 5.7. Mixed model analyses of participants who filled in the baseline questionnaires before or at 12 days after starting treatment

The results of the exploratory analyses provide some insights into the limited longitudinal changes observed in the SURE scores. The exploratory analyses highlight that methodological factors (particularly the timing of baseline assessments) and the influence of structured treatment environments, likely partly contributed to the limited longitudinal changes. Considering that the SURE assesses experiences in the week preceding the questionnaire, participants who had been in treatment longer before completing the baseline assessment may have already experienced initial changes, resulting in elevated baseline scores. Furthermore, certain SURE items—such as those addressing substance use, sleep, and food intake—may have been influenced by the structured environment of residential treatment facilities. Within these settings, participants were likely abstinent in the week leading up to the assessment due to rules of most treatment services requiring abstinence. Moreover, daily routines and rules in these facilities enforced regular sleep schedules and provided consistent, structured meals, often contributing to healthier dietary patterns. These environmental factors likely contributed to high baseline scores in relevant domains. To better capture recovery progression, future assessments should adjust assessment intervals or prioritizing early baseline assessments, ideally within the first few days of treatment initiation. To better capture recovery progression, future assessments should prioritize early baseline measurements, ideally conducted within the first few days of treatment initiation and/or adjust assessment intervals.

This study has several limitations. First, the six-month follow-up period may be insufficient to capture long-term recovery trends, as SUD recovery often extends over a longer period. Future research with extended follow-up could provide a more comprehensive view of how PROMs evolve beyond this period. Second, the sample's gender composition, predominantly male, may limit the generalizability of findings across genders.

The integration of PROMs into addiction treatment services represents a significant step toward patient-centered care. By systematically assessing subjective outcome measures alongside traditional clinical metrics, PROMs provide a more comprehensive evaluation of treatment effectiveness and can improve treatment engagement in service users. This study contributes valuable insights into the recovery trajectories of individuals in residential SUD treatment. While significant improvements were observed in domains of QoL, physical and mental health, the limited longitudinal changes in SURE scores underscore the importance of methodological considerations when implementing PROM in

SUD treatment services. By optimizing assessment strategies and tailoring interventions to specific recovery needs, addiction treatment services can refine patient-centered care and long-term recovery outcomes. Further research is needed to examine long-term PROM trends and to develop targeted strategies for improving retention and recovery outcomes.

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Chapter 5.2
PREM assessment and predictors of recovery in residential alcohol and drug services

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I. INTRODUCTION

Given the critical role of patient-centered care in addiction treatment and the scarcity of validated PREM tools in this field, this study aims to assess patient experiences and evaluate the predictive value of the PREMAT in residential addiction treatment settings. Specifically, we aimed to: (1) examine PREMAT total and item scores of participants undergoing SUD treatment in residential treatment settings; (2) compare PREMAT scores between participants who remained in treatment at the 45-day follow-up and those who dropped out, assessing whether treatment retention is associated with different patient-reported experiences; and (3) investigate whether PREMAT scores predict recovery strengths as measured by the Substance Use Recovery Evaluator (SURE-NL), providing insights into the relationship between patient-reported experiences and recovery outcomes. By addressing these objectives, this study seeks to contribute to the implementation of standardized experience measures in addiction treatment services and to enhance the understanding of how service user experiences shape treatment engagement and recovery trajectories.

II. METHODS

2.1 Participants

Data collection began in July 2022. People with SUDs were assessed over a 6-month period in several residential treatment settings. The study was conducted in four psychiatric treatment centers (PCs) and four therapeutic communities (TCs). A total of 161 participants were enrolled at baseline. Over the course of the study, participant retention declined, with 102 individuals filling in the 45-day follow-up (dropout rate of 36.6%).

2.2 Questionnaires

PREMAT (Patient Reported Experience Measure in Addiction Treatment)

Hinsley and colleagues [1] developed the Patient Reported Experience Measure in Addiction Treatment (PREMAT) to assess the experiences of people in residential addiction treatment, consisting of 31 items scored on a 5-point Likert scale and two open-ended questions. The development process of the PREMAT included extensive input of service users through focus groups. In 2021, Kelly and colleagues [2] performed a preliminary psychometric evaluation of the PREMAT. Using principal component analysis (PCA) with Promax oblique rotation, they identified six factors: ‘individualised support’, ‘self-determination & empowerment’, ‘program structure’, ‘treatment environment’, ‘coordination of care’, and ‘personal responsibility’. Eight items were removed from the questionnaire because they were deemed unfit in terms of content or statistical relevance, resulting in a 23-item PREMAT, for which they calculated total and norm scores. The following experience categories were identified ‘Poor experience’ (23-74), ‘Average experience (75-87), ‘Good experience’ (88-99) and ‘Very good experience’ (100-115)’. As part of this study, a Dutch version of the PREMAT (PREMAT-NL) was validated and used for PREM-assessment [3].

SURE (Substance Use Recovery Evaluator)

The SURE [4] is a self-report questionnaire designed to assess recovery strengths in individuals with SUDs. The tool consists of 21 items, each rated on a 5-point scale and scored using a 3-point system (1-3). The first two response options receive a score of 3, the middle option is scored as 2, and the last

two options are scored as 1. For the first three questions, response options include: 'never', 'on 1 or 2 days', 'on 3 or 4 days', 'on 5 or 6 days', and 'every day'. The remaining items have the following response choices: 'none of the time', 'a little of the time', 'a fair amount of the time', 'most of the time', and 'all of the time'. Higher total scores reflect stronger recovery strengths. The questionnaire is divided into five subscales, measuring different aspects of recovery: 'substance use', 'relationships', 'self-care', 'outlook on life', and 'material resources'. Previous studies have demonstrated strong internal reliability for the total SURE score (Cronbach's α = 0.92) in a sample of current and former SUD service users [4]. The Dutch version (SURE-NL) has also shown good internal consistency (Cronbach's α = 0.83) [5].

2.3 Ethics and dissemination

Ethical approval for this study was granted by the Medical Ethics Committee of the University Hospital Brussels on May 11, 2022 (UZ Brussel; BUN: 1432022000071). Before participating, all individuals were fully informed about data processing and confidentiality, and written informed consent was obtained. The study ensured strict confidentiality and all findings are reported anonymously.

2.4 Data analysis

ANOVA analyses were done to compare PREMAT item and total scores of people who were still in treatment at 45 days and those who dropped out. A multivariate linear regression analysis was conducted to establish the relationship between SURE-NL total scores and PREMAT-NL scores at 45, 90 and 180 days, while controlling for gender, age, and education level. All model assumptions were met and no significant multicollinearity was found. Analyses were conducted using SPSS version 27. The standard for statistical significance was set at $p < .05$.

III. RESULTS

3.1 Sociodemographic and clinical characteristics

The study included 161 participants, with 80 starting treatment in TCs and 81 in PCs. The average age of the participants was 35.3 years (SD = 10.0) and the majority of participants were male (83.2%). Most participants had a secondary education level (60.9%). The vast majority of participants (93.2%) was born in Belgium, and most had at least one parent being born in Belgium (80.1% father, 83.2% mother). A significant proportion of the sample (83.9%) had received previous treatment for SUD. Regarding substance use, alcohol (56.6%) was the most commonly reported primary substance, followed by cocaine (44.7%), cannabis (34.0%), and amphetamines (20.1%). Polysubstance use was common, with 58.5% of participants reporting more than one primary substance of use. On average, participants reported 2.3 substances (SD = 1.4) as their primary drug(s).

3.2 PREMAT scores

Items. The analysis of PREMAT scores (table 5.8) revealed generally positive patient experiences, with the highest-scoring items being "I am held responsible for my behavior" (M = 4.47, SD = 0.71), "I know my recovery is up to me because of this program" (M = 4.45, SD = 0.71), and "I felt welcome when I started this program" (M = 4.46, SD = 0.69). Other high rated items were "I am provided with a schedule so that I know what to do with my time" (M = 4.37, SD = 0.82), "I am provided with fresh fruit and vegetables" (M = 4.31, SD = 0.80), and "This place is clean and hygienic" (M = 4.27, SD = 0.88).

	PREMAT items	Total M (SD) n = 102	In treatment (45D) n = 79	Dropout n = 23	*p*
1	Wait-time to get into program	3.82 (1.17)	3.92 (1.17)	3.48 (1.12)	.109
2	Felt welcome	4.46 (.685)	4.54 (.55)	4.17 (.984)	.096[a]
3	**Have been supported**	3.90 (1.00)	4.01 (.98)	3.52 (.99)	.038
4	Better about myself	3.97 (1.02)	4.09 (.89)	3.57 (1.31)	.083[a]
5	More aware of myself	4.18 (.87)	4.27 (.73)	3.87 (1.22)	.149[a]
6	Enough privacy	3.39 (1.20)	3.44 (1.21)	3.22 (1.17)	.428
7	**Enough space by others**	3.74 (.89)	3.90 (.82)	3.14 (.91)	<.001
8	**Held responsible for my behavior**	4.47 (.71)	4.56 (.62)	4.17 (.94)	.023
9	**Know recovery is up to me**	4.45 (.71)	4.56 (.57)	4.09 (1.00)	.040[a]
10	Better understand why I've used	3.97 (.959)	4.05 (.95)	3.70 (.97)	.119
11	Enough one-to-one sessions	3.12 (1.20)	3.11 (1.21)	3.13 (1.18)	.954
12	Supported to look after my health, fin., legal pro	4.01 (.84)	4.09 (.79)	3.74 (.96)	.078
13	**Can get help for any difficulties**	3.85 (.97)	3.96 (.90)	3.48 (1.12)	.034
14	**Know what the rules are**	4.38 (.78)	4.52 (.62)	3.91 (1.08)	<.001
15	**Rules make sense**	3.96 (1.04)	4.11 (.99)	3.43 (1.08)	.005
16	My day is structured	4.39 (.77)	4.45 (.70)	4.19 (.98)	.172
17	Provided with a schedule	4.37 (.82)	4.41 (.73)	4.24 (1.09)	.393
18	**Opportunities to exercise**	4.23 (.78)	4.32 (.71)	3.90 (.94)	.029
19	Fresh fruit and vegetables	4.31 (.80)	4.33 (.75)	4.24 (1.00)	.632
20	**This place is clean/hygienic**	4.27 (.88)	4.41 (.69)	3.83 (1.27)	.045[a]
21	Feel supported and understood	3.99 (.90)	4.08 (.87)	3.70 (.93)	.073
22	**Inspired by others in recovery**	3.90 (1.07)	4.03 (1.04)	3.48 (1.08)	.030
23	**Staff genuinely cares about me**	4.02 (.87)	4.14 (.78)	3.61 (1.03)	.009
24	Staff treats me like a person	4.19 (.92)	4.30 (.81)	3.78 (1.17)	.054[a]
25	Can connect with family and friends	3.93 (1.12)	4.01 (1.13)	3.62 (1.02)	.153
26	**Supported to focus on recovery**	4.11 (.82)	4.20 (.72)	3.78 (1.04)	.030
27	Family and friends have been provided with info	3.66 (1.09)	3.68 (1.09)	3.57 (1.08)	.648
28	Able to cope with everyday life	3.71 (1.01)	3.78 (.98)	3.43 (1.08)	.145
29	I will be ok when I leave	3.79 (1.02)	3.85 (1.03)	3.61 (.99)	.323
30	**Been linked up with other services when I leave**	3.50 (1.23)	3.66 (1.19)	2.96 (1.22)	.015
31	**Can get info about where else I can go for help**	3.82 (1.00)	4.00 (.91)	3.22 (1.09)	<.001
Total 23 items		91.29 (14.51)	93.42 (12.79)	83.38 (17.85)	.004
Total 31 items		124.22 (18.97)	127.09 (16.49)	113.57 (23.76)	.003

Table 5.8. ANOVA analysis: comparison of PREMAT-NL items for people who were still in treatment at 45 days vs. drop-outs

[a] *Welch test*

Conversely, the lowest rated items were "I have enough one-to-one sessions" (M = 3.12, SD = 1.20), "I have enough privacy here" (M = 3.39, SD = 1.20) and "I have been linked up with other services to support me when I leave this program" (M = 3.50, SD = 1.23).

Total. On average, participants scored 124.22 (SD=18.97) on the 31-item version of the PREMAT. The mean total score for the 23-item PREMAT was 91.29 (SD=14.51), which is rated as an overall 'good experience' by service users based on the psychometric analysis of Kelly and colleagues [2].

3.3 Comparison between participants still in treatment and those who dropped out before the 45-day follow-up

A comparison of PREMAT-NL scores between participants who remained in treatment at 45 days (n = 79) and those who dropped out before the 45-day assessment point (n = 23) revealed significant differences in total PREMAT scores and several domains (see Table 5.8 and Figure 5.2). Overall, participants who were still in treatment reported more favorable experiences and perceptions compared to those who had dropped out.

Items. People who remained in treatment generally scored higher on items relating to personal responsibility (item 14 and 15), coordination of care (item 30 and 31) and program structure (item 18 and 26). This was also found in some items relating to treatment support (item 3, 7 and 13). Additionally, people who remained in treatment scored higher on the item 'I think this place is clean and hygienic'. However, no significant differences were found in items related to self-determination and empowerment.

Total. The total score for the 23 PREMAT items was significantly higher for retained participants (M=93.42, SD=12.79) compared with drop-outs (M=83.38, SD=17.85, p=0.004). Based on the psychometric analysis of Kelly et al. [2], people who continued treatment had a 'good experience', while those who quit had an 'average experience'. Similarly, the total score for all 31 PREMAT items was significantly higher for participants in treatment (M=127.09, SD=16.49) than for drop-outs (M=113.57, SD=23.76, p=0.003).

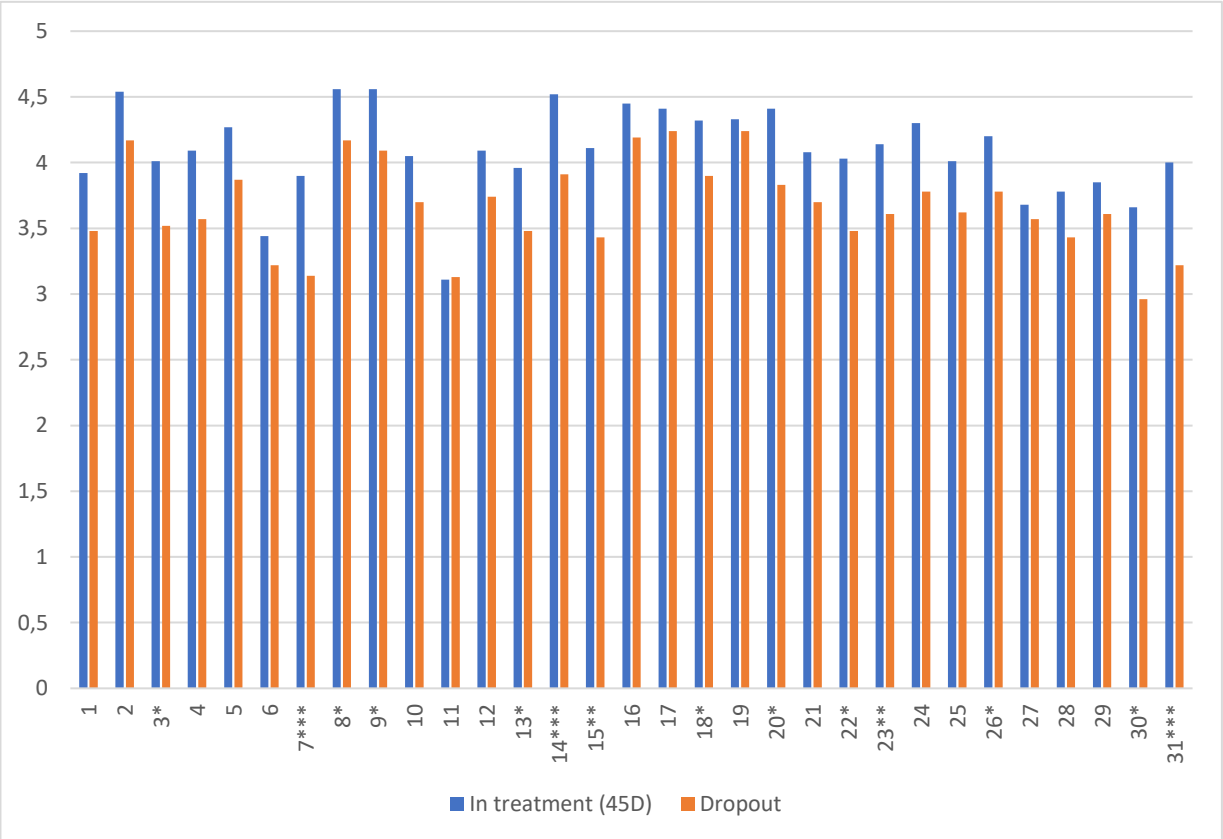


Figure 5.2. Comparison of persons who stayed in treatment at 45 days vs drop-outs (item level)

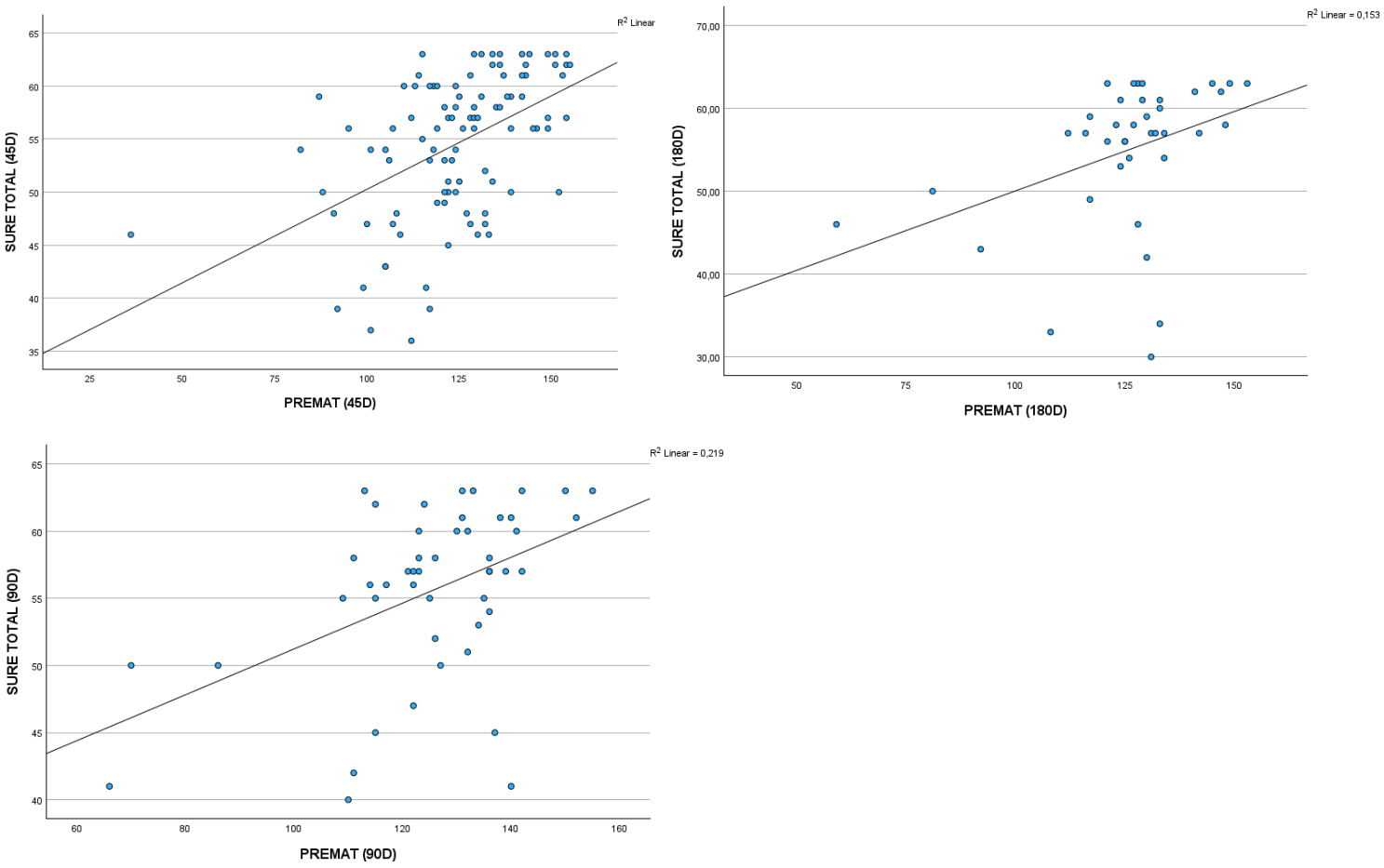
**p<.05, **p<.01, ***p<.001*

3.4 The PREMAT total score as predictor of recovery strength

We examined the predictive value of PREMAT scores on recovery strengths using multivariate regression analyses (Tables 5.9 - 5.11) and scatter plots (Figure 5.3). Scatter plots show a positive relationship between PREMAT and SURE scores at the 45-, 90- and 180-day follow-up assessments. To confirm these relationships, a series of multivariate linear regression analyses were conducted at each follow-up interval while controlling for gender, age, and education level. At the 45-day follow-up, PREMAT scores significantly predicted total SURE scores (B = .18, p < .001), explaining approximately

24.6% of the variance in recovery strength (F(5,93) = 6.07, p < .001). A similar trend was observed at 90 days, where PREMAT scores remained a significant predictor of SURE scores (B = .17, p = .001), explaining 23.4% of the variance (F(5,42) = 2.57, p = .041). At the 180-day follow-up, the predictive value of PREMAT scores remained significant (B = .20, p = .011), explaining 30.0% of the variance in SURE scores (F(5,33) = 2.83, p = .031). Additionally, gender emerged as a significant predictor at this time point, with male participants reporting higher SURE scores (B = 10.75, p = .042). These findings indicate that participants who reported more positive treatment experiences also reported stronger recovery strengths in different stages of treatment.

Figure 5.3. Scatter plots and fit line of SURE and PREMAT scores at 45-, 90-, and 180-day follow-up



IV. DISCUSSION

This study examined patient-reported experiences and its predictive value on treatment drop-out and recovery strengths among individuals in residential addiction treatment. Participants expressed high levels of positive treatment experiences, as reflected in high scores for items related to daily routines, structured schedules, and opportunities for exercise. They also appreciated the cleanliness and hygienic standards of the settings, felt welcomed and demonstrated a clear understanding of the program rules. Participants acknowledged that recovery was their responsibility and felt accountable for their behaviors. Items that were scored lower highlighted some potential for improvement. These included concerns about insufficient privacy, limited access to one-on-one sessions, and a lack of linkage to other services upon discharge. Overall, participants reported a 'good experience' of

treatment as rated with the 21-item PREMAT total score. In line with previous research [6], participants who dropped out of treatment before the 45-day follow-up had significantly lower total treatment experience scores than those who were still in treatment. They reported lower scores in areas such as feeling they had enough personal space, perceiving the rules as fair and meaningful, and drawing inspiration from others in recovery. Additionally, they scored less on items related to feeling supported overall, accessibility of information about alternative services, and feeling that the staff cared about their well-being. Furthermore, our findings demonstrate that higher PREMAT scores significantly predicted greater recovery strengths, as measured by the SURE, at multiple follow-up points. This suggests that positive treatment experiences are linked to stronger recovery trajectories, which is in line with a review by Davis et al. [7].

	B	SE	Beta	t	p-value
(Intercept)	31.03	5.77		5.37	<.001
Gender	.91	1.74	.05	.52	.601
Age	.01	.07	.01	.10	.919
Education level (higher/uni)	.87	1.71	.05	.51	.611
Education level (primary)	.14	1.67	.01	.08	.936
PREMAT (45D)	.18	.03	.50	5.35	<.001

Table 5.9. Prediction of total SURE-NL score (45 days) using linear regression (n=99)

	B	SE	Beta	t	p-value
(Intercept)	36.93	7.79		4.74	<.001
Gender	-.29	2.52	-.02	-.12	.908
Age	-.08	.11	-.11	-.73	.467
Education level (higher/uni)	-.23	2.68	-.01	-.09	.932
Education level (primary)	.53	2.25	.03	.23	.817
PREMAT (90D)	.17	.05	.47	3.43	.001

Table 5.10. Prediction of total SURE-NL score (90 days) using linear regression (n=48)

	B	SE	Beta	t	p-value
(Intercept)	10.46	13.43		.78	.44
Gender	10.75	5.08	.42	2.12	.042
Age	.29	.18	.30	1.66	.107
Education level (higher/uni)	-.62	4.48	-.02	-.14	.891
Education level (primary)	2.08	3.56	.09	.58	.56
PREMAT (180D)	.20	.07	.40	2.68	.011

Table 5.11 Prediction of total SURE-NL score (180 days) using linear regression (n=39)

These findings have the potential to improve patient-centered care in addiction treatment services. First, integrating structured patient experience assessments into routine clinical practice could allow service providers to identify early risk factors for drop-out and tailor interventions accordingly. Second, given the association between PREMAT scores and recovery strengths, improving key treatment experience domains (such as individualized support, program structure and empowerment) may enhance patient engagement and long-term recovery outcomes. Addressing concerns such as privacy, perceived fairness and meaningfulness of rules and overall support could be beneficial in increasing overall patient experiences and reducing drop-out rates.

This study has several limitations. First, the follow-up period of six months may be insufficient to capture long-term recovery trends, as SUD recovery often extends over a longer period. Future research with extended follow-up periods could provide a more comprehensive view of how PROMs evolve beyond this period. Second, the study sample was predominantly male and born in Belgium.

This may limit the generalizability of the findings to other demographic groups, who may experience residential SUD treatment differently. Third, the study did not account for other potentially important factors, such as external social support and personal motivation, which could influence both patient experiences and treatment outcomes.

In sum, this study contributes to the growing body of evidence supporting patient-centered approaches in addiction treatment. The integration of validated PREM tools such as the PREMAT could serve as an essential instrument for monitoring treatment experiences, guiding service improvements, and optimizing long-term treatment engagement and recovery outcomes. Future studies should explore which specific patient experience factors have the greatest impact on recovery trajectories and examine potential mediators and moderators.

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CHAPTER 6

LIVED EXPERIENCES OF SERVICE USERS IN OUTPATIENT AND RESIDENTIAL ALCOHOL AND DRUG SERVICES IN BELGIUM

Based on:

Migchels, C., De Ruysscher, C., van den Brink, W., Fernandez, K., Zerrouk, A., Matthys, F., Vanderplasschen, W., & Crunelle, C.L., (submitted for publication). Understanding treatment and recovery experiences of patients with a substance use disorder: a qualitative study.

I. INTRODUCTION

Many people recover successfully from a SUD [1, 2]. Recovery is recognized as a long and dynamic process influenced by relational and contextual factors, encompassing individual, functional and social domains [3-7]. While there are various pathways to recovery, engaging in professional SUD treatment has been consistently associated with positive outcomes in substance use, mental health, and social functioning [1, 2, 8, 9].

Perspectives on recovery often vary among patients, between patients and professionals, and across different treatment modalities [3, 5, 10-13]. As a result, patients and professionals may not always agree on treatment goals and on what constitutes recovery-supportive treatment (e.g., abstinence-oriented or not, the role of peer support) [13-19]. Understanding patients' treatment needs and desired outcomes is therefore crucial for delivering patient-centered care, a key quality standard in SUD treatment [20-22].

Previous qualitative research has explored how patients perceive SUD treatment, emphasizing the importance of social relationships with therapists and peers, as well as the need for individualized support as key aspects of the treatment experience [18, 23-27]. Other studies have examined the role of treatment in the long-term recovery process from the perspective of people with SUD [5, 10, 19, 28]. In this qualitative study, we investigate how patients seeking treatment for SUD in various treatment modalities perceive the support they receive with a particular focus on their personal views on SUD recovery and its feasibility and assess how their treatment experiences and outcomes converge with long-term recovery goals. To achieve a profound and contextual understanding of these treatment and recovery experiences, we used in-depth qualitative interviews.

II. METHODS

2.1 Participants and data collection

Participants were recruited as part of the OMER-BE study (Outcome Measurement and Evaluation as a Routine practice in alcohol and other drug services in Belgium), a naturalistic multicenter prospective study using patient-reported outcome and experience measures (PROMs and PREMs) in patients with SUD [29]. The OMER-BE study included a total sample of 189 participants who started a new SUD treatment episode less than three weeks ago. Participants of the OMER-BE study were recruited from residential specialized wards in psychiatric centers, therapeutic communities, and outpatient treatment centers. Inclusion criteria were: (i) having a documented SUD and (ii) being over 18 years old.

For this qualitative study, we purposefully recruited a subsample of 21 Dutch-speaking participants, matching the proportion of participants per treatment modality to the OMER-BE cohort study (three psychiatric centers, N=8; four therapeutic communities, N=8; four outpatient centers, N=5). Data were collected from the participants between April 2023 and February 2024, after they reached the 6-month follow-up for the cohort study. They were invited via email and/or telephone to participate in an in-depth interview until the desired number of participants was reached. The aim was to obtain a diverse sample in terms of treatment modality, treatment trajectory (i.e., still in (same) treatment or not), and gender. In-depth semi-structured interviews were conducted, focusing on experiences with and views on recovery from SUD and experiences with SUD treatment. Examples of interview

questions are presented in Table 6.2. The interviews were conducted by three researchers (CM, AZ, and LS), either individually or in pairs. CM is a psychiatrist, AZ is a clinical psychologist and LS is a master student in special needs education. On average, interviews lasted 90 minutes and took place in different locations depending on the participant's preference: at the treatment center, at a university building, or at the participant's home. The interviews were audio recorded and transcribed verbatim. Participant characteristics are presented in Table 6.1.

		N
Sex	Male	17
	Female	4
Age (years)	[20-29]	2
	[30-39]	9
	[40-49]	6
	[50-59]	4
SUD treatment at time of OMER-BE cohort study inclusion	Outpatient individual treatment	5
	Therapeutic community	8
	Residential treatment in psychiatric center	8
SUD treatment at time of interview	Outpatient individual treatment	4
	Therapeutic community	4
	Residential treatment in psychiatric center	4
	Outpatient group treatment in psychiatric center (following residential treatment)	3
	None	
	Treatment drop-out	2
	Involuntarily discharged	1
	Medically discharged	3
Main type of substance use	Legal substances (alcohol and benzodiazepines)	7
	Illegal substances	9
	Mix of legal and illegal substances	5
Opioid Agonist Therapy	Yes	1
	No	20
Involuntary treatment	Yes	1
	No	20

Table 6.1. Characteristics of in-depth interview participants

The study was approved by the UZ Brussel ethics committee on 11 May 2022 (BUN 1432022000071). Written informed consent was obtained from each participant and participants received a €20 gift card as remuneration for their participation.

2.2 Data analysis

Data were analyzed thematically, following the guidelines proposed by Braun and Clarke (2006), adopting an inductive, reflexive approach [30, 31]. For reporting our data we adhered to the guidance by Neale et al. (2015) [32]. The first author (CM) familiarized herself with the data by reading the transcripts and cross-checking them against the original audio recordings. Initial codes were then generated and recorded using NVivo 14 software [33]. To enhance the rigor of the coding process, a subset of ten interviews was independently coded by two researchers, and the coding structure was discussed during regular meetings. To further increase reflexivity, the first author engaged in repeated discussions with the co-authors, refining the codes based on these discussions and on subsequent reviews of the interviews. She then defined and refined the themes through an iterative process, incorporating feedback from the co-authors. This collaborative and iterative approach culminated in the final thematic structure.

Topic	Question
Recovery	Do you currently see yourself as in recovery from addiction? Why (not)?
	What does 'recovery' or 'getting better' mean to you?
	Who supports you in your recovery process?
	How do you view the role of treatment or professional support in your continued recovery journey?
Treatment experiences	Did the support you received at [treatment service] help you in your recovery trajectory?
	What were the most helping/hindering factors of [treatment service]? Why?
	How do you think [treatment service] could be improved?

Table 6.2. Examples of interview questions during the qualitative in-depth interviews

III. RESULTS

Based on this thematic analysis, participants underscored the importance of a comprehensive, patient-centered approach in SUD treatment that addresses both the personal and social dimensions of recovery. This was reflected in the four themes emerged from the analysis: (1) feeling connected, valued and respected, (2) understanding and managing substance use, (3) finding balance in life, and (4) directing your own care pathway. We captured ambivalent experiences within each theme, highlighting the specific and personal needs and recovery journeys of patients in SUD treatment.

3.1 "In good company": Feeling connected, valued and respected

Most participants described that, in treatment, they felt free to speak openly about their substance use and the difficulties it caused them. This sense of recognition and acceptance by both peers and professionals enhanced their self-confidence and self-worth. This was in contrast with the stigma and shame they often experienced in society and their personal environment.

> *"Most importantly, (…) I was able to speak candidly about it here. (…) you really did not have to be ashamed here, because everyone was addicted. Getting past the shame and being able to be yourself again. (…) Not being the addict, but just being who you are in a group. That did me a lot of good, to be able to let it all out once and break that taboo." (*Female, 52 years, psychiatric center)

Although connections that were formed with fellow patients helped some participants in residential group treatment to break out of their isolation, it also posed some challenges, such as difficulties with finding space and time to relax with enough privacy, and being affected when others relapsed or left treatment. Additionally, forming genuine connections with other patients was more difficult when participants felt they could not relate to them, for example because of differences in severity or type of substance use, or gender (with women often being a minority in SUD treatment services).

> *"(…) the people that I lived with. (…) those are people that I would never talk to in everyday life. Lots of different personalities and people that I really felt I could not trust at all, that they weren't genuine with me. That they actually just wanted attention for the sake of getting attention from a lady, so to speak. But that they did not genuinely want me to get better or something. That's what I found hindering."* (Female, 26 years, psychiatric center)

This need for sincerity was also apparent in relation to professionals. A non-judgmental and empathic attitude fostered trusting therapeutic relationships. Especially in low-threshold individual outpatient

treatment centers, participants felt at ease and assured that they would not be judged for their substance use.

> *"Here you can be yourself without any problems. (…) Here you are just a person like any other and how much [methadone] you take is not important. You are working on your problem, and that's what counts." (*Male, 52 years, outpatient individual treatment)

In residential treatment, particularly in psychiatric centers, different professionals are involved in a person's care. For some participants this had the benefit of having one or more professionals who they could confide in and who supported them in their personal process, although this was not necessarily the professional that was assigned to them as their individual counsellor. Nevertheless, some participants reported that therapists were unable to spend enough time with them individually, for example due to staff shortages, preventing them from establishing a meaningful therapeutic relationship. Several participants also described feeling looked down upon by professionals and a lack of room to express their own concerns and opinions. This often improved over time, with participants attributing this change to earning the respect of therapists by working on their substance use and maintaining sobriety.

> *"(…) the further you go in your trajectory, the more respect they have [for you], because in fact a lot of people come in, and a lot give up. (…) As you do your best and as they see that you participate in the system, that they see that you mean well, that your evaluations are good, you always get a bit more respect as well, and a bit more freedom."* (Female, 52 years, psychiatric center)

Being in treatment also allowed many of the participants to reconnect with their families, as these relationships were often severely affected by substance use. Supportive friends and family were crucial for most participants, and some emphasized the importance of maintaining these contacts during treatment, particularly when preparing to return home from residential treatment. On the other hand, a few participants reported how some friends and family members severed ties with them when they went into treatment or after they were discharged. Overall, having healthy and meaningful relationships was an important recovery goal for participants.

Most treatment settings offered family counseling or educational sessions for families, enabling restorative conversations, and increasing knowledge and awareness about SUD. However, not all participants made use of this offer, often because they did not want to burden their families and felt they had to deal with their substance use problem on their own.

> *"It is not necessary because I (…) am here for myself (…), to get to know myself again too. You really have to work on yourself here, instead of outside. Outside is important, other people, but you first have to grow within yourself."* (Male, 36 years, psychiatric center)

Severing ties or reducing contact with people in active substance use was often encouraged or demanded by residential treatment centers. Although many participants believed this strict regime was necessary for them to make changes in their substance use and work toward abstinence, for some, particularly in therapeutic communities, it led to feelings of isolation and contributed to their decision to leave treatment prematurely.

> *Researcher: "So, for example, you didn't have any contact with your girlfriend?" Participant: "No (…) she also had an addiction problem. She is sober now, but she was also in a therapeutic community. (…) And also because of that I left (…). I just wanted to be with her."* (Male, 21 years, therapeutic community)

Finally, many participants expressed a wish to make a valuable contribution to society, often referring to having a job and being able to help other people with (substance use) problems.

3.2 "Learning the ropes": Understanding and managing substance use

Some participants in residential treatment saw treatment as an opportunity to fully concentrate on their recovery process, away from the responsibilities and challenges of everyday life. Being in a protected environment, where they did not have access to substances, where they could undergo a safe detoxification, and where they had professional support available, enabled them to become abstinent, which in turn allowed them to gain insight into and focus on their own goals and needs.

> *"It has given me space to think and (…) take time to detox and deal with everything. (…) it has taken me out of society for nine months."* (Male, 30 years, psychiatric center)

Most participants found it important that the underlying reasons for their substance use were explored in treatment, for example by investigating and treating underlying trauma and co-morbid psychiatric disorders. Educational sessions were considered helpful in understanding the mechanisms behind and the impact of SUD, but participants mostly valued the insights they gained into their personal reasons for using substances, and the practical guidance on how to recognize and change the patterns that led to their problems with substance use. Guidance of professionals with expertise in SUD was seen as an important part of treatment. However, several participants in residential group treatment reported a lack of individual support and limited experience of certain professionals as shortcomings in their treatment.

> *"I think I missed a lot of that, the individual aspect of it. That I felt the need often to say: 'hey but that's not how it is with me', or 'I want to be able to work around me, not about how addiction works in general, I know how it is with me and I want to do something about that'".* (Male, 34 years, psychiatric center)

Besides individual professional guidance, peer support was considered a vital part of treatment, especially by participants in therapeutic communities, where the community itself is viewed as an essential part of treatment. Despite being challenging, confrontations with peers and hearing about their experiences were seen as valuable learning opportunities offering insights into participants' own pitfalls and strategies to address them. Peer support workers were part of the staff in all the therapeutic communities and some of the psychiatric centers and outpatient centers. They were generally viewed as an important asset, providing a unique combination of lived experience and professional expertise.

> *"If you yourself have had (…) an addiction problem, (…), you know how that person feels, what they need, how best to redirect them, (…), support them, care for them. That is all very important. (…) If you study for it then it's just certain things, but you can't know everything. A peer support worker knows more than when you studied for it. And only such people can help you properly."* (Female, 53 years, therapeutic community)

Most participants viewed abstinence as an important recovery goal. However, it is notable that most participants had either completed or were currently in residential abstinence-oriented treatment, or were considering (re-)entering such programs. This may have resulted in a participant group biased towards those viewing sobriety as a key aspect of their recovery approach. While not everyone aimed for complete abstinence, many valued the ability to overcome difficult situations without using substances and saw gaining control of their substance use as essential to recovery. A few participants pursued this goal with OAT or other medications to manage withdrawal symptoms and reduce the risk of relapse.

> *"There are going to be difficult moments (…). And that I'm not going to revert to my old patterns, drugs or whatever as quick satisfaction, no. (…) developing a good resilience to become resistant to that. And to be able to vent in a good way. Not completely knocking myself down."*
> (Male, 36 years, psychiatric center)

3.3 "On solid ground": Finding stability in life

When discussing what it means to live a meaningful life, most participants expressed a desire for 'a stable, normal life'. For most this involved stable housing and employment, financial stability, reliable transportation, and good health. Additionally, they aimed to find pleasure in their daily lives and sought to invest in personal interests, such as hobbies and travelling.

> *"Stability, shelter, a flat or a house. Regular employment, structure in my life, that's very important, a hobby, my girlfriend. Just a good vibe, little car, nice, just stability."* (Male, 21 years, therapeutic community)

Having a supportive employer was perceived as helpful, enabling participants to focus on their recovery with the reassurance that they could return to their job. A few participants also started working during their admission or received assistance from professionals in finding a job.

Most participants further highlighted the importance of a structured daily routine, considering it a vital aspect of their treatment and something which they sought to integrate into their everyday lives. Admission ensured that basic needs - such as food, housing, and hygiene, which had sometimes been neglected by participants - were met, and this was a reason for some participants to opt for residential rather than outpatient treatment.

> *"It has given me structure again. (…) I had no job then, stopped working (…). My days were not planned, I had complete freedom and then in two years I destroyed everything I had built up. So, it has given me back structure and a place where I can be safe."* (Male, 35 years, psychiatric center)

Being in residential treatment also involved adhering to certain rules and some participants felt this left them faced with the choice of either complying with the rules or leaving the program. Some participants mentioned that they believed that treatment providers should intervene when peers did not follow the rules.

> *"I can still choose to leave here whenever I want, after all, I am here voluntarily. But not without obligation (…). So, if I want to be here, I still must follow the rules (…). And I still must stick to the framework and the structure of the program."* (Male, 32 years, therapeutic community)

Although this structured, regulated environment was generally perceived as helpful, it also constrained participants' autonomy and freedom. Participants' daily lives were heavily controlled by treatment protocols and professionals' decisions, which were not always perceived as consistent. This lack of flexibility deterred some participants from (re-)entering residential treatment. Consequently, successful engagement in residential programs largely depended on participants' adherence to the imposed structures, as well as their motivation and willingness to comply with the rules and recovery philosophy of the treatment center.

> *"(…) but it's also very, very focused on survival of the fittest, if I may put it that way. It's very focused on motivation. If you are not motivated there, you won't get out of there."* (Male, 45 years, psychiatric center)

Although most residential treatment centers granted participants more freedom as they progressed through treatment and approached discharge, the transition from this heavily structured environment to everyday life was perceived by some participants as abrupt and destabilizing. Especially when participants left treatment prematurely, they felt like they were left on their own.

> *"(…) I haven't had any support after that. I asked for it, but nobody helped me anymore." (*Male, 40 years, therapeutic community)

3.4 "All in good time": Directing your own care pathway

Most participants agreed that SUD is a chronic condition and, even if they were no longer actively using substances, they felt the need to remain vigilant. Therefore, it was important to them that treatment was long-term and that they had continued access to support when needed.

> *"I will continue to need a safety net. I think it's really important for me to know that I have somewhere to turn to." (*Female, 44 years, psychiatric center)

Participants particularly appreciated a smooth transition when changing treatment settings and valued the ability to consult professionals they knew from previous treatment episodes.

> *"I'm a person who doesn't talk easily, so it was just stress (…). But because you already know that person a little bit you actually start telling them more than you would to a person you have never seen in your life."* (Male, 40 years, outpatient individual treatment)

Different treatment settings were perceived as more or less suitable depending on participants' goals and the stage in their recovery process. For instance, although recovery from SUD has been shown to entail much more than managing substance use, abstinence is still often viewed as a prerequisite to achieving recovery, and residential treatment was seen by many participants as essential to achieving abstinence, with outpatient treatment generally being regarded by these respondents as a form of aftercare. However, access to care was often hindered by factors such as waiting lists, financial costs, and distance.

> *"I can take one step toward treatment, but then it's back to waiting. (…) That frustrates me enormously. (…) if I really have to wait for an admission, then we're still three to four months away. But if I have to continue at this pace for three to four months without any help, then I'm just not there anymore. It's as simple as that." (*Male, 33 years, individual outpatient treatment)

In this regard, low-threshold outpatient centers occupy a unique and invaluable role in SUD treatment by offering affordable, accessible, and continuous care, alongside harm-reduction strategies that do not require patients to pursue or maintain abstinence.

IV. DISCUSSION

In this qualitative study, in which we included people who had recently accessed treatment for SUD in various treatment modalities in Belgium, we gained insights into participants' perceptions of the support they received and their personal views on what SUD recovery entails. Our results generally align with previous research on SUD treatment experiences and recovery frameworks, such as recovery capital and the CHIME model (Connectedness, Hope, Identity, Meaning, and Empowerment), while also highlighting some important new findings [7, 34].

Our findings underscore the crucial role of social support, identity, and social integration in the SUD recovery process (i.e., social recovery capital) [7, 34-37]. While peer influence is widely acknowledged as an essential component of SUD care, several participants reported that difficulties in identifying with peers - due to factors such as gender, treatment history or socio-economic status - can negatively affect this social support [23, 25, 38-44]. In line with previous research, some participants also highlighted the importance of shielding themselves from negative peer influences as a strategy for overcoming SUD [45]. Supportive relationships with knowledgeable staff are known to be vital to treatment experience and adherence [18, 23, 24, 45]. However, some participants in our study, particularly those in residential settings, felt that respect and support from professionals were conditional upon adherence to the treatment service's rules. They felt they had to prove themselves by conforming to the structures and goals set by the treatment service, even if these did not align with their own views. This was not the case for participants in low-threshold individual outpatient treatment centers. This difference might be attributable to the need for a more structured and regulated environment in residential treatment to accommodate living in a group. Moreover, in residential treatment, the time professionals can spend with patients individually is often limited, for example because of staff shortages or administrative tasks, hindering the development of close therapeutic relationships taking into account patients' personal goals and needs. Nonetheless, our findings highlight the importance of investing in these meaningful therapeutic relationships to deliver more individualized care.

Participants also emphasized the value of understanding their personal reasons for substance use and developing alternative coping mechanisms and patterns in treatment, which increased confidence in their skills and gave them a sense of control over their lives. This is in line with previous research, which proposes lifestyle changes and self-competence as important components of effective SUD treatment, and acknowledges empowerment and the acquirement of skills (i.e., human recovery capital) as key aspects of recovery [7, 28, 34, 38-41]. Additionally, psychiatric comorbidities are highly prevalent among people with SUD, underscoring the need for an integrated treatment approach that addresses both SUD and co-occurring psychiatric disorders, as participants in this study also pointed

out [46]. Yet, despite recent reforms, people with SUD struggle to access mental health care services in Belgium, and find that treatment is often not tailored to their needs [47].

Seeking stability was another recurring theme, both in treatment and in the wider recovery process. This included financial stability, which is referred to in the recovery capital literature as physical capital, and which enables people to pursue personal interests and live autonomous lives, but also facilitates access to treatment [34]. A recent study by Beaulieu et al. (2024) found that the availability of material and financial resources was limited in the recovery processes of people with persistent SUD who had been in treatment [28]. Furthermore, these findings support the notion that employment and other meaningful activities are important recovery goals for people with SUD [7, 12, 48]. Therefore, the return to, or search for, employment and other activities should be integrated into treatment practices.

While many participants appreciated the structured environment that residential treatment provided, they were also aware that successful completion of the treatment program depended on compliance with the treatment center's rules and recovery philosophy. This restricted their ability to express their personal needs and recovery goals, for example regarding abstinence or maintaining contact with people outside of treatment. This is especially important considering that those who left treatment prematurely often did so without access to continued or alternative support, essentially forcing them to choose between adhering to a treatment approach they might not fully agree with or being without formal support. An important finding of this study is the expressed need for continuing care and an easy return to treatment, even following discharge against medical advice. This underscores the necessity for a broad, accessible, and coordinated network of SUD treatment services that can provide continuing support services [1, 2, 10, 47, 49-51].

4.1 Strengths and Limitations

We included a diverse sample of participants from various stages and modalities of SUD treatment in Belgium. However, the possibility of selection bias should be considered because of the use of convenience sampling, which may have resulted in mostly people who were satisfied with the treatment they received or were in later stages of their recovery process to respond to the call to participate. On the other hand, the inclusion of people who left treatment early is one of the strengths of this study. The participant sample was limited to Dutch-speaking participants in Belgium; perspectives of French-speaking Belgian patients and therefore care should be taken when generalizing these results. Additionally, although we aimed for a balanced gender representation, women made up only a small part of our sample.

V. CONCLUSION

Persons with SUD value individualized, continuing care that acknowledges the diverse aspects of recovery and addresses the impact of SUD across various life domains. Our findings indicate that access to treatment and quality of therapeutic relationships with professionals, especially in residential treatment, are often dependent on how closely patients adhere to the treatment service's views on treatment and recovery. As a result, patients may not receive treatment that aligns with their personal goals and needs. A variety of SUD treatment services that allow for easy transitions between services and provide continuous care based on the person's needs and objectives at the time can contribute to more accessible and individualized SUD treatment.

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CHAPTER 7

FEASIBILITY OF ROUTINE COLLECTION OF PROMS AND PREMS IN ALCOHOL AND DRUG SERVICES IN BELGIUM

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I. BACKGROUND

Patient Reported Outcomes Measures (PROMs) and Patient Reported Experience Measures (PREM) are often considered complementary and part of the same shift strategy toward a more global and 'patient-centred' approach to care [1, 2]. PROMs and PREMs are the subjects of a growing body of literature, but there are still very few examples of successful implementation in routine daily clinical practice at the national level [1] despite some recent initiatives such as the PaRIS project [2]. Implementing such tools is considered to be harder in the field of mental health care [3,4] and additional barriers must be considered in the field of substance use disorder (SUD) treatment [5,6]. Indeed, even if the concepts behind PROMs and PREMs seem quite simple and straightforward, their implementation is not easy. It raises several questions and creates various difficulties [7].

While the identification of barriers and facilitators has already been the subject of a number of studies [1,8,9], these studies often face various limitations. The available literature offers useful guidelines for studying the feasibility of this type of implementation, but the recommendations are often very general in nature and may suffer from a lack of familiarity with the reality of daily practice and the specificities of the national/local context. Furthermore, there are very few studies available on alcohol and drug services and these studies do not provide a clear picture on the challenges posed in a wide variety of services, particularly in Belgium.

Considering the complexity of the implementation of PROMs and PREMs in routine practice, an analysis of the context, barriers and facilitators of such data collection is an important step. This report focuses on the identification of opportunities and conditions for successful implementation, taking into account barriers and possible strategies to overcome these and to determine whether PROM and PREM implementation is desirable within the current policy framework and available resources. This chapter is structured around three research questions and different research methods will be applied to assess them.

- What are the prerequisites for implementing a routine, nationwide PROM/PREMs data collection in SUD treatment centres?
- How to implement PREM data collection and under what conditions?
- How to implement PROM data collection and under what conditions?

II. METHODS

2.1 Literature search

A literature search on the practical issues of PROMs and/or PREMs implementation in SUD or mental health services was conducted to identify the main aspects to be considered in this feasibility study and in the construction of the test protocol. Articles published in peer-reviewed journals reporting on experiences of PROMs and/or PREMs implementation were consulted, with particular attention paid to articles describing the barriers and facilitators of such projects and the possible strategies to overcome them. Articles dealing with implementation in the mental health field were included to overcome the lack of references on the specific case of SUD treatment. The inclusion of mental health settings in our research is also very relevant to the Belgian context as more than 50% of all new treatment episodes for substance use problems are registered in general mental health centres (TDI register, 2023). In addition, grey literature was consulted, including reports or online documents.

2.2 Survey among practitioners

The Treatment Demand Indicator (TDI) is a tool for collecting information on treatment episodes of people with substance use problems. This data collection started in 2011 and gathers socio-demographic and treatment-related data and information on patterns of substance use in about 150 treatment centres in Belgium.

An online survey was set up to question a wide range of clinicians, researchers and funding authorities to ask their opinion on different aspects of the current data collection and its further expansion. 168 professionals responded to the survey. One of the topics was about interest in PROMs/PREMs in SUD treatment. The question was formulated as follows: "*How do you evaluate the following possible new functionalities that could be developed in TDI? Complementary module for the registration of patient-reported treatment experiences and treatment outcomes (PREMs/PROMs)*". Responses were gathered on a 4-points scale (1=Interesting; 2=Possibly interesting; 3=Not interesting; and 4=No opinion). The results of this survey were used as an additional source of data to assess the interest of clinicians in PROM and/or PREM implementation.

Following this global assessment, a subgroup of participants was consulted on some topics through a Delphi survey in two rounds of consultation in December 2021 (n=32) and January 2022 (n=25). Among other questions, a question on inclusion of PROMs and PREMs in TDI was discussed among the participants. The question asked was: "*Should it be possible to incorporate patient assessment of clinical outcomes and treatment experience should be possible to incorporate into the TDI?"* Responses were rated on a 5-points scale (*0= No response; 1=Totally disagree; 2=Disagree; 3=Agree nor disagree; 4=Agree; 5=Totally agree).* During this Dephi survey, comments justifying the choices that were made were also collected. (Sciensano, unpublished)

2.3 Study of the context

Semi-structured interviews were conducted with representatives of treatment centres in the three Belgian regions, with special attention for including different types of treatment centres: therapeutic communities, outpatient services, day centres and general mental health services. A total of 10 interviews was conducted in 10 different services (2 outpatient services, 2 day centres, 1 crisis unit, 1 psychiatric hospital and 4 therapeutic communities). For each interview, the director of the service, a person involved in service provision, and where appropriate, the person responsible for the quality of care were invited to participate. The interview guide was elaborated based on the difficulties around PROM and PREM implementation identified in the literature search. Three additional interviews were conducted with organizations that have already implemented PREM data collection in mental health care settings (VIKZ, ASPE and Inghelburch). The interviews were transcribed and analyzed using thematic analysis.

2.4 PREM tool testing

Routine implementation was assessed by running a cross-sectional survey in five different facilities of four alcohol and drug treatment centres: two in Flanders, two in Wallonia and one in Brussels. We aimed to recruit different types of treatment services (two outpatient services, two long-term residential treatment services and one psychiatric hospital) to be able to compare the implementation barriers and obstacles between organizations.

A two-month data collection was planned for psychiatric hospitals and long-term residential treatment where there is less patient turnover due to longer-term treatment, while a one-month data collection was planned for the other type of centres. After discussion with the outpatient services, it was eventually decided to set a two-month data collection period for all the services, as they feared they would not reach enough patients in one month. During this period, the participating centres were asked to propose all patients who met the inclusion criteria to complete the PREM questionnaire. The inclusion criteria were: to be at least 18 years old on the day of participation and to be about to leave the centre after completing treatment. Discharge was more complicated to define for outpatient centres without a time-restrained treatment program. In this case, participants were selected among patients who visited the centre since at least three months and who attended the centre at least three times during the last three months.

Respondents were recruited by a staff member who explained the aim of the questionnaire to potential participants. The questionnaire was self-administered by participants on paper or in an electronic version. To reproduce the conditions of routine registration as much as possible, the research team was not involved in the recruitment and data collection. The total number of discharged patients and their repartition by gender, age category, and primary substance were requested from the centres to enable completion rate calculation.

The questionnaire used was the PREMAT [6,10] (Patient Reported Experience Measure for Addiction Treatment) also used in WP2, specially developed and validated for SUD treatment settings. After sharing the results on PREMs indicators with the centre, two semi-structured interviews in each participating centre were conducted: one with a member of the management team to collect their perspective on the potential use of the survey/associated feedback for quality improvement initiatives and one with a clinician/worker who was involved in the data collection to review the challenges associated with routine implementation in organisation.

2.5 PROM tool testing

Three residential services took part in the study: one in Flanders and two in the Walloon region. These alcohol and drug services asked any patient starting treatment who was 18 years or more and who could speak and read French or Dutch to participate in the study. Recruitment stopped after reaching seven participants in each centre or two months after the start of the recruitment phase. The total duration of the recruitment period could not exceed five months and the goal was to reach a total of 20 participants. The ICHOM Standard Set for Addictions [11], a set of brief and validated questionnaires specially developed to monitor patient-reported outcomes among people with a substance use disorder, was also chosen as PROM-tool in the feasibility study. The questionnaire was administered at three different time-points: 1) at the start of treatment, to assess participants' status regarding various symptoms and relevant information about their situation, 2) during treatment, at a point previously determined by the centre and relevant to the treatment pathway; and 3) at discharge. The participant completed the questionnaire during a routine consultation with their service provider using a tablet. The patient was informed that their answers were accessible by Sciensano and their personal therapist. A standard report presenting the results of the questionnaires in a comprehensible way (calculating summarized indicators, identifying risk levels) and summarizing the evolution of the patient's situation at the different time points was automatically generated in an electronic format. This report could be used by the therapist to be integrated (or not) in his practice. The therapists chose

to give participants a copy of the report. At the end of the study, a semi-structured interview was conducted in each participating centre on the PROM indicators with a clinician/worker who was involved in the data collection to review the challenges associated with routine implementation of PROMs in their current work.

III. RESULTS

3.1 Preconditions for implementing a routine, nationwide PROM or PREM data collection in SUD treatment centres?

3.1.1 Defining clear objectives

PROMs and PREMs are tools that can be associated with multiple objectives that are sometimes quite far away from clinical use, if not potentially incompatible [1,12,13]. It can be used for example to improve the quality of care of an institution, to evaluate the outcome of a treatment program, or to compare good practices between facilities [1] (Table 1). Different objectives might require different prerequisites. For example, if the objective at the facility level is to identify areas of improvement for patient experiences and clinical practices, it seems much more appropriate to have centre specific indicators rather than a generic tool. Furthermore, there is a huge variety of SUD treatment facilities differing by the type of setting, therapeutic approach, and the offer of treatment/follow-up proposed. Each of these characteristics will have an impact on the area of interest for the centre, the perceived relevant questions to ask, as well as the quality or the success of care definitions. In that perspective, the centre's preferences for specific indicators contrast with the need for a generic instrument that underlies the pursuit of benchmarking objectives.

Table 7.1 details different levels of implementation and associated objectives and implementation prerequisites and allows to generate a clearer view on the potential incompatibilities between the different levels of implementation [1].

Level of implementation	Objective	Tool	Prerequisites
Health system / Research	- System-wide performance assessment	PROMs PREMs	- Fixed indicators - Importance of representativity
	- Determining value for money	PROMs	- No identification of facilities - Ad-hoc data collection
Commissioners/ health insurance	- Contracting /Pay-4-performance	PROMs- PREMs	- Fixed indicators in every treatment setting - Case-mix adjustment to allow proper comparison of settings with different populations - Importance of a high completion rate. - Annual campaign of data collection and feedback - Mandatory participation - Possibility to discuss/ comment/contest results - Results publicly reported, benchmarking
	- Monitoring quality	PROMs- PREMs	
Facility level	- Clinical audit	PROMs- PREMs	- Indicators adaptable to the treatment setting/program, clinical practice and themes of interest - Limited annual data collection campaign could be sufficient
	- Quality improvement	PROMs- PREMs	

			- Free participation
Clinical practice	- Screening and diagnosis	PROMs	- Indicators adaptable to the
	- Health needs assessment and monitoring	PROMs	treatment setting/program, clinical practice and themes of interest
	- Patient choice	PROMs	- Tool needs to be used routinely and
	- Shared decision making	PROMs	as part of the treatment - Questionnaire should be completed at different meaningful moments of the treatment and possibly after discharge to evaluate the long-term outcome. - Completion should be electronic to provide instantly, clear, and ready to use feedback - Free participation

Table 7.1: Prerequisites associated with different levels of implementation and objectives of PROM & PREM implementation (Desomer et al., 2018)

In addition to the incompatibilities in terms of data collection and the types of information collected, these different objectives are not perceived in the same way by treatment centre professionals. Benchmarking objectives and publication of results are generally not very positively perceived by treatment centres [14]. However, both as producer and user of the data in a quality improvement strategy, taking the perspective of treatment centres and patients into account is central for routine implementation project [15–18].

3.1.2 Acceptance by practitioners

Practitioner acceptance is crucial, as the collection and use of good quality data depends largely on them [15,19]. The results of the survey of stakeholders as part of the TDI survey showed that only a small minority consider that integrating PROMs or PREMs into their data collection is perceived as interesting (21% of the 67 questioned clinicians found it interesting) (Sciensano, unpublished).

The interviews carried out during the additional study also show a certain lukewarmness on the part of a good number of professionals. However, the extent to which centres support an implementation project is partly influenced by the objectives that these tools claim to pursue. In fact, in all the interviews carried out, the practitioners interviewed shared a reluctance to use PROMs and PREMs for the purpose of comparing results between centres (benchmarking), or even between departments within the same institution. This consensus was observed regardless of the type of service considered, the experience of the practitioners encountered with this type of tool or their participation in the test protocol. Two main reasons were mentioned.

First, the perceived lack of relevance of the indicator comparison was due to the wide variability of centres, the diversity of therapeutic objectives they pursue and the different populations they care for.

> *« It's true that there are very low-threshold services, but we're not so low-threshold, there are long-stay services, and we're in something where there's no waiting list, so it's difficult to compare things that are intrinsically different. »* (Director, Day-centre, participant to the test protocol)

According to the practitioners we met, using PREMs results or making them publicly available without putting them into context or without prior knowledge of the therapeutic choices and orientations, could lead to apparent differences in results.

> *« We were talking about intimacy earlier, but in a therapeutic community, you're bound to get a low score. You can try to improve it, but comparing centres on that basis isn't quite right. […] You really have to put the item being assessed in context […]. If you're running to increase the quality of an item, you're perhaps going to... in relation to intimacy, you're perhaps going to lose your essence. »* (Assessment manager, Therapeutic community, participant to the test protocol)

> *« For example, there are other places here in Brussels that offer much longer treatment times than we do. So, they have their own specificity, which is very interesting for certain patients. The problem is that, because they have longer waiting times, they have a waiting list. So, in the questionnaire on 'was it quick to get in', this is likely to be less important. »* (Director, Day-centre, participant to the test protocol)

The idea of using PROMs for comparison purposes poses this problem even more prominently. The very definition of what constitutes an improvement or a 'cure' can vary considerably depending on the practitioner or the treatment centre. There are also huge differences in terms of the populations served, and therefore the improvements that can be expected.

> *« Here […] if we manage to reissue an identity card it's already […] just a big victory. Or just that the person goes to a drug treatment centre or takes shelter for a while. You take a post-cure […] with people who haven't been using for a while […] it's just a completely different path. And it's really not easy to objectify what's involved in the treatment itself? The environment, at last... the resources? The person? It would be so...terribly simplistic to base it on an indicator or even indicators. »* (Practitioner, Crisis centre)

Secondly, practitioners also expressed concerns that comparing indicators would lead to competition between services. According to the people we met, making services compete against each other by comparing results could encourage a reductionist view of care and tend towards homogenization of the care offer, ultimately hampering service users' interests.

> *« If it's just a matter of comparing ourselves and making the results available to other places, then no, because the risk is that it won't help improve care. We really want to be able to create more bridges and, above all, to ensure that patients arrive in the right place at the right time. So, if this is supported by a cohesive approach based on joint reflection and comparison, i.e. 'we work this way, you work that way', how can we use these differences to better guide patients according to their needs. That would be good. And not for it to be a comparison that leads to a kind of standardization […] because we must aim for the same results for the same scales. »* (Practitioner, Day-centre, participant to the test protocol)

> *« And that greatly reduces the complexity of what's happening in the clinic to just 'happy', 'not happy', 'recovery', 'no recovery' and that distorts the reality in the field, even more so if you start comparing services. […] Or it […] simplifies too much the expectations we may or may not have of care. »* (Practitioner, Psychiatric hospital)

This rejection of the use of PROM and PREM tools for comparison or benchmarking purposes is not tantamount to an outright rejection of these tools. In the case of PREMs, questionnaires had already been implemented in some centres we visited, although their use for quality improvement purposes was limited. Among the treatment centres that had not implemented this type of questionnaires, some showed a desire to implement this type of tool to objectify their 'good work' or to respond to a perceived, increasingly pressing institutional demand. Yet, this partial interest was conditional on the implementation of these tools for the benefit of the patient and on its adaptation to the realities of the field to make their clinical use possible.

> « *There will be an obligation to do it, and it will be a tool that will not be incorporated but a tool that will be imposed. And it's going to be filled in incorrectly, because you absolutely have to do it, so it'll be good, there you go, fill in your questionnaire, go and fill it in, thank you, and bin it. […] The thing must be articulated in the clinic, it must be part of the care, it must not be the administrative parenthesis at the end, the middle, the beginning'. »* (Practitioner, psychiatric hospital)

A focus on clinical use and usefulness is therefore preferable, with a view on encouraging practitioners to adopt the tool.

3.1.3 No standardized approach

The KCE report on the implementation of PROMs and PREMs [1] suggests that collaboration between the actors behind the most important PROM and PREM initiatives and the pooling of their efforts would be an appropriate approach for a national implementation project, as well as a move towards standardizing data collection and the instruments used.

The interviews conducted in SUD treatment centres revealed several obstacles to this type of strategy. In the case of PREMs, there is considerable heterogeneity in the objectives associated with existing data collection. For example, the strategy adopted by the VIKZ project in Flanders to stimulate the use of quality indicators is to allow patients to compare settings between one another. Other initiatives such as the ASPE project are focusing more on clinical purposes and allow them to share their experiences between care structures belonging to the same network.

PROMs are less widely used than PREMs, mainly because they are more complex to implement, requiring follow-up measures to be organized and integrated into clinical practice and the necessity to identify and follow up patients over time. Isolated care providers using this type of tool tend to share their experience with other treatment centres in their network but use different instruments. These actors remain attached to the tools they use, which are now an integral part of their clinical practice.

This coexistence of objectives, instruments and differentiated networks is therefore hardly compatible with the standardisation of PROM and PREM data collection as part of a top-down approach. This observation is even more acute if we consider the wide variety of types of structures involved in SUD treatment and the significant heterogeneity of resources, particularly from the point of view of the collection, management and use of electronic data.

Recently, an international study tried to develop a large-scale study protocol and a clinical form to monitor Opioid Maintenance Treatment (OMT) outcomes to improve survival, health, and quality of life of people who use opioids, while promoting non-stigmatizing patient-physician relationships. Although they made the effort to gather as much opinions as possible on the form from OMT patients and OMT professionals (n=477) through a Delphi process, the implementation of such a tool is only meant to be used at the clinical level [20].

In addition, practitioners repeatedly expressed their fear of an imposed tool that does not correspond to the daily reality, stressing the importance of implementation as part of an internal and more global reflection on the quality of care, involving the whole team. Obligation is seen as potentially useless, not only because it increases the risk of collecting irrelevant items and following a protocol that does

not meet clinical needs, but also because it prevents a good appropriation of the tool and its objectives by the teams.

Key points

- The **objectives** for a nationwide implementation of structural PROMs and PREMs data collection must be **clearly stated and these objectives must be compatible with each other**. Absence of a clear objective or multiple objectives is not advised.
- **Practitioner acceptance is crucial** for successful data collection which implies a bottom-up approach. In this context, centres should be the owners of the data they collect.
- **Large-scale benchmarking of outcomes is not recommended** considering the high diversity of treatment settings and the competition between facilities this might induce.
- **The clinical usefulness** of tools must be at the heart of the implementation objective in order to support clinicians in their daily activities.
- A strictly standardized approach is not recommended. Both **protocols and tools proposed must be at least partly adaptable** to centre characteristics and orientations.

3.2 How to implement PREM data collection?

3.2.1 Practical challenges of PREM implementation

A light protocol for better acceptance

The tested protocol was designed so that data collection would be as brief as possible and easily adaptable to the organisational constraints of the centres. The research team's involvement in the data collection phase was minimal to allow the centres to collect data with their existing resources and knowledge.

Most of the centres reported that they were able to follow the data collection protocol without major difficulties. The part considered most burdensome was the collection of the informed consent forms, which in some cases crystallized the mistrust or fear of certain patients. Two centres encountered problems recruiting patients due to their distrust of data collection by an outside institution. Only one centre encountered difficulties that prevented it from collecting data that could be used to construct a personalized report on the service. These difficulties concerned two types:

- Organisational issues: the staff was not aware of patient discharges, which were decided by doctors without being communicated to the rest of the department.
- Patient acceptance: patients were reluctant to participate and did not return the questionnaire and consent form once they had been given to them.

Furthermore, the organisation of the work and brief stays at the centre did not allow for repeated reminders to patients to recall them to read the informed consent form and to complete and return the questionnaire. Repeated reminders and raising patients' awareness of the survey were considered crucial for collecting enough questionnaires. The centres in the test protocol emphasized that

although the introduction of a questionnaire at the end of treatment was generally straightforward, a certain investment by the team was necessary to achieve a sufficient response rate. Presenting the study and collecting the consent form was therefore not enough to achieve a response rate deemed acceptable, and regular reminders to patients and practitioners responsible for collecting the forms were seen as necessary, including, in some cases, the fear of insisting too much.

> *« It could indeed be improved because in the end I would tell them to hand in the sheet when they moved on to the second floor [...] in the end they would say 'yes yes' but […] I couldn't find any questionnaire. »* (Practitioner, Psychiatric hospital, participant to the test protocol)

> *« P: There was no follow-up after they gave him the paper. He received it. But did we have to do it in an office and stay in the vicinity to make sure that it was done. […] Because I think there are a lot of people who may have left it deep in the bag and that's it. (...)*
>
> *D: [Patients feel it] a bit like a test. But if you do that, well, it's a bit peculiar, I think, you force the patient to evaluate your work while you're in the area. »*
> (Practitioner (P) and director (D), Day-centre, participant to the test protocol)

Right moment for data collection

Even without trying to set aside a specific time during the treatment to complete the questionnaire, all participants in the tool test protocol pointed out the difficulties they had in finding the right time to complete the questionnaire. These difficulties were of two kinds:

- On the one hand, the questionnaire had to be administered close enough to the end of treatment for patients to have sufficient distance from the treatment, while at the same time encouraging the participation of patients who had not completed the entire course of treatment. In fact, administering the questionnaire at the very end of treatment rather than at a more intermediate stage would be tantamount to ignoring the experience of patients who have had a break in treatment, and therefore whose experience is very likely to be different from that of patients who have completed their entire course of treatment. This twofold imperative meant that the centres had to find a balance in the timing of the questionnaire, and therefore opted for a degree of flexibility with regard to the protocol.
- On the other hand, the work had to be organized in such a way that the person or persons in charge of data collection could be aware of the patient's forthcoming discharge, or more generally that the time for handover had come. This was not an easy task in certain contexts, where discharges could be decided from one day to the next and where there were already communication difficulties within teams (sometimes made up of many people, each working on very specific aspects of care and not having an exhaustive view of the position of patients within the different phases of treatment).

> *« So, I asked the department's psychologist, who theoretically should see the patients […] [and] are supposed to know more or less when the patients are leaving, to give them the questionnaire more or less around the time of their discharge, even though there's always a huge risk that one morning the psychologist will arrive: 'I see that and that patient at that and that time'. […] [The patient] is not coming. […] They'll ask downstairs : 'well no, he left the day before yesterday'. Often, they're not necessarily the first to know »* (Practitioner, psychiatric hospital, participant to the test protocol)

Electronic vs paper completion

Paper questionnaires were widely preferred, mainly for practical reasons:

- Centres in the test protocol reported difficulties in managing the tablet so that it could be charged in time and be easily accessible at the right time for the practitioner/patient who needed it.
- Centres also felt that the use of the tablet would require more support for patients to complete the questionnaire due to errors or patients' difficulties with this type of tool. This mode of completion therefore required the presence of a staff member nearby, which was not the case with the paper questionnaire.
- Finally, the use of an expensive device such as a tablet required the presence of a staff member to ensure that the tablet was returned. In some cases, staff felt uncomfortable about the risk of the equipment being lost.

Furthermore, a technical aspect that appeared during the set-up of the protocol was to find a way to block access to other internet websites than the one used for the questionnaire. Indeed, internal rules of certain centres do not allow the use of the internet at any time.

The use of electronic tools required data collection to be more closely monitored and supervised by practitioners and created therefore more work during the data collection phase. Also, it would have been necessary to reorganize procedures at the centres so that tablets could be made available or patients could be accompanied to complete the questionnaire on a computer in the centre. Most centres opted for the paper questionnaire, especially as the research team was responsible for encoding and processing the data.

However, most practitioners admitted that electronic data collection could be interesting in the long term if PREMs were to be implemented routinely in the centre, but that patients must have the option of using a paper version, as some patients were not comfortable with electronic completion. According to some centres, the tool developed for the test protocol is not yet user-friendly enough for routine use. In addition, data processing and report generation could not be fully automated. Taken together, these two factors indicate that additional work is needed before electronic completion can fully fulfil its promise of removing constraints associated with data management.

3.2.2 Are the PREM data collected relevant and useful?

Interest in indicators

During the background study, practitioners' main fear regarding the implementation of a standardized PREM tool was the lack of relevance of the items to the reality in the field. These concerns were mainly of two kinds:

- That the items were not of interest because they did not question relevant dimensions of patients' experience of the proposed treatment.
- That the lack of specificity of the items does not make it possible to identify the causes of bad patient experiences and therefore to translate the results of the survey into concrete action to improve the quality of care.

A comparison of the PREM questionnaires or satisfaction questionnaires that were used by the centres shows a wide variety of questions and topics. The literature review also showed that the lack of relevance of items to the realities of professionals' work was one of the major obstacles to translating the results of PREM-type surveys into concrete actions to improve the quality of care [21–23]. One of the challenges of the test protocol was therefore to see whether the PREMAT items were relevant to practitioners, even though they were standardized and collected in different types of centres.

We found that the PREMAT questionnaire was very well received by the participants in the test protocol. All centres emphasized its completeness in terms of the dimensions covered and its simplicity both in terms of wording and in terms of brevity. These findings were confirmed by the patients recruited in the first part of the study. Yet, the centres noted that the questionnaire could be expanded on certain aspects, but the gaps that were identified varied greatly from one centre to another. Among the points raised were the duration of treatment, communication within the therapeutic team and proper circulation of information related to treatment, and the arrangements put in place to welcome families and friends. The centres further emphasized that while the application of a standardized questionnaire was possible and relevant, a degree of flexibility regarding the questionnaires in the event of a national implementation project would be important. It was stressed that the option of adding certain items for specific centres, depending on the specific problems encountered in the field, could be a good solution, in addition to the standardized items.

The reports produced for the participants were generally well received and were considered to be clear and easy to understand. In two centres, however, practitioners felt that the proposed presentation, which focused solely on numerical results (see example in Figure 1), could focus more on interpreting the results, or at least describing them to make it easier to share these with all team members who were not necessarily familiar with numerical elements.

> *« For the rest of the team, I get the impression that they're not going to take the time to look at each element and be interested in it. I think that perhaps in the form of a summary somewhere... more text... and not graphics... even if it means seeing the graphics in an appendix... »* (Practitioner, Psychiatric hospital, Participant to the test protocol)

Résultats du questionnaire: respect des préférences, valeurs et besoins exprimés

	n	mean	median
Grâce à ce traitement, je sais que je suis responsable de mon propre rétablissement.	7	4,7	5
On m'a tenu responsable de mon comportement.	7	4,4	5
Les autres participants à ce traitement me laissaient suffisamment d'espace.	7	3,6	4
J'ai bénéficié d'une intimité suffisante.	7	3,3	4
J'ai une meilleure conscience de moi grâce à ce traitement.	7	4,6	5
Je me sens mieux par rapport à moi-même grâce à ce traitement.	7	4,6	5
J'ai été soutenu(e) pour faire les choses que je veux faire.	7	4,3	5
Total: respect des préférences, valeurs et besoins exprimés		4,2	

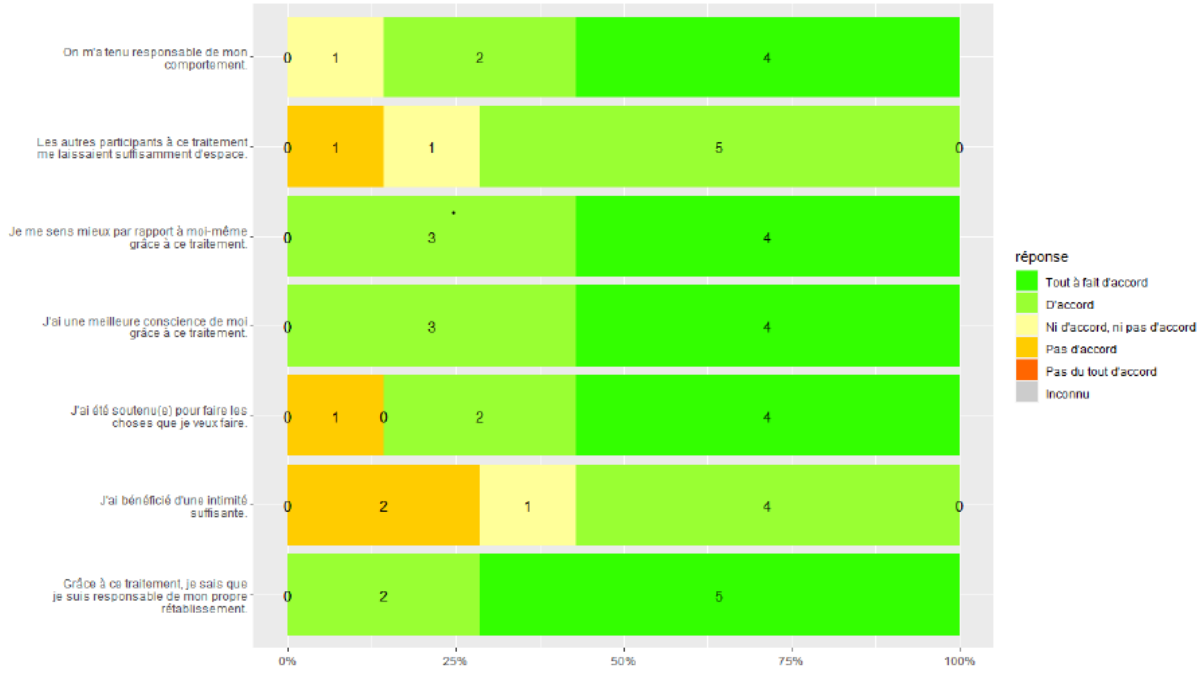

Figure 7.1 : Screenshot of a feedback report based on the PREMAT questionnaire

PREM data quality

Apart from the one centre that was unable to collect responses, the other four centres reported overall modest participation rates ranging from 39% to 53%. These response rates were also calculated excluding people who had been excluded or had left voluntarily before the end of their treatment. These relatively low participation rates illustrate the recruitment difficulties already mentioned, as well as the need for intensive monitoring of data collection to achieve acceptable response rates that can at least claim to indicate certain trends in patient experiences. It should also be noted that while the questionnaires that were collected were fully completed, with very low non-response rates for multiple choice questions, but open questions were largely ignored. However, answers to open questions were highly valued by practitioners, who saw it as a means of obtaining richer and more complete feedback on patient experiences.

These response rates also represent another problem linked to the quality of the data and its interpretability, namely the *de facto* exclusion of people who are excluded or voluntarily leave the facility before the end of their treatment. This problem, already mentioned in the literature [24–26]

was confirmed here. Participants in the test protocol were specifically asked to try to recruit people who had left the program, but rather than being a challenge, this would be an inherent limitation that is difficult to overcome in the case of standard data collection.

> *« If they left very angry, we weren't going to do it. But we could still ask for it to be completed. Now I think that in reality we've mostly had people who were really at the end of their treatment. Because if someone leaves very impulsively, it's often not that simple, so we noticed that it was difficult to give them this questionnaire. »* (Practitioner, Therapeutic community, participant in the test protocol)
>
> *« P1: [...]How do we manage to get the broadest possible opinions and take into account people who aren't happy.*
>
> *D: Generally, they've left and we don't have access to them anymore. Because sometimes when they leave, it's overnight*
>
> *P1: They just drop out...*
>
> *P2: Yes, or they blow a fuse and decide to... I'm thinking of a patient recently who said 'Hello, I'm leaving, I won't be back, you won't see me again'. Go and get him to fill in now, when that would be the most interesting thing.*
>
> *P1: Yeah, you have to ask!*
>
> *P2: Yeah, but you tell him, 'Well, sorry, if you want to fill it in', he'll say 'but no', it's still very complicated. »*
> (Practioners (P1 & P2) and medical director (D), Day centre, participant in the test protocol)

For the centres that identified this problem, it was regaded as a major bias in data collection, which generally led to positive overall opinions. According to a practitioner in another centre, the most dissatisfied patients were, on the contrary, the most willing to fill out the questionnaire. However, this hypothesis could not be verified, as no valid questionnaire could be collected at that time.

> *« R: And is it a large number of people who leave like this?*
>
> *P: Yes, it varies a lot. But last week, for example, I think three people left.*
>
> *Q: And how many left in a positive way?*
>
> *P: Just one. There's a certain turnover, yes. »*
> (Researcher (R), Practitioner (P) and quality officer (Q), Therapeutic community)

Practical implementation of PREM results

As already mentioned, the centres generally found the indicators relevant, and although the representativeness of the data was questioned, it was generally accepted that the information was nonetheless interesting and indicative of patient experiences. However, this does not automatically guarantee that the results can be effectively translated into practice, for example by adopting measures to improve quality. This difficulty, also widely identified in the literature, was identified by all participants in the test protocol.

> *« [...] If we see that patients say 'well, not really, I wasn't supported, I wasn't informed', when I read that, I say to myself 'yes, it should be evaluated'. But how do we then get back into the system, to say 'well many patients say that their treatment wasn't explained to them'. Who*

> *should do it at some point and how? »* (Practitioner, psychiatric hospital, Participant to the test protocol)

> *« This is one of the difficulties that I, as a quality officer, encounter when I'm in the therapeutic community from time to time. It's when I see data, how do I use it, how do I feed it back into the treatment? »* (Quality officer, Therapeutic community, participant to the test protocol)

Several factors were identified that hampered the translation of the findings into actual changes. For example, it was not always possible to identify the source of the problem:

> *« There are obvious things [to fix, for example the] lack of planning, you know who you're going to see to improve things with. But if you hear 'I'm not well informed about my condition', who screwed up? […] Is it the doctor who doesn't talk, or is it the team that isn't psycho-educational enough? That's more complex. »* (Practitioner, Psychiatric hospital, participant in the test protocol)

This difficulty is particularly linked to the lack of specificity of the items, which may prevent the practitioner from effectively identifying the sources of the problem, the services or the practices behind them. The tension that can exist between therapeutic objectives or practices, which practitioners assume to be necessary, but which can potentially be detrimental to the patient's experience, is also one of the obstacles identified in relation to the effective translation of results:

> *« And I think we can also look at the areas where we don't have good results, and whether that's also part of the programme, for example: 'there's not much contact with the family', where results are more limited. So, you might think 'we should think about increasing that a little bit'. But the idea is to stay consistent with yourself. They want to go for more walks to clear their head, okay. Maybe, but in reality, the intention isn't to clear your head. The intention is to have a little pressure, not exaggerated but still a little, so that you can look at yourself. »* (Practitioner, Therapeutic community, Participant in the test protocol)

This type of difficulty is more particularly highlighted in residential therapeutic communities, where the rules and constraints, linked in particular to accommodation and community living, can be at odds with the experiences and aspirations of some patients, thus creating tensions among patients.

Finally, some practitioners pointed to the lack of useful information derived from this approach, given the almost always overwhelmingly positive feedback. This was noted in all participating centres that were able to collect usable questionnaires.

> *« And then I thought 'well, there's green, that's cool, so now what do we do?'. So, I wondered if in the end it was discriminating enough... You see green and you say 'bah that's cool, there's nothing to change' and we just wanted to say 'ok what do we have to change'. »* (Medical director, Day-centre, Participant in the test protocol)

The potentially low discriminatory power of this type of questionnaires, already identified in the case of satisfaction questionnaires [27], must then be a point of attention, as it could affect its usability in the long term. Rather than an opportunity to improve care in concrete terms, some participants in the survey saw it more as an opportunity to objectify their 'good work' in the eyes of subsidiary institutions, or to enhance the work of professionals, who receive few direct feedback about their work from patients.

3.2.3 How to facilitate PREMs implementation?

PREMs as part of a broader reflection around quality of care

One of the points on which all the participants in the PREMs test protocol agree, is that their primary mission is to provide care and that the resources available, whatever their type, are and will be allocated first and foremost to this primary mission. In this sense, the collection of PREMs seems to many practitioners to be secondary to this primary mission, in any case as far as concrete, positive impact on care or, more generally, the usefulness of this type of collection is not perceived as such.

> *« And secondly, we can also see the difficulty, perhaps, in wearing a carer's hat, of going into something that's not care and pushing someone to do something that isn't care. [...] Maybe it was too much to say to yourself, I don't want to force the other person to do this when it's not care. »* (Director, Day-centre, participant in the test protocol)

On the one hand, the collection of PREM data cannot be considered independently from a more global approach to improving the quality of care, of which it is only one of the many tools that can be implemented. In other words, the tool and the objectives it is supposed to pursue might not be confused. On the other hand, to consider that quality improvement processes, or more generally evaluation processes, are part of a care process or that they play a part in it requires acculturation or a 'change of perception' on behalf of certain practitioners.

> *« And we need to change the way we think about things by saying that evaluating the quality of care is part of care, it's part of continuous improvement, it's part of care practices »* (Medical Director, Day centre, participant in the test protocol)

This change in perception would involve training practitioners in the evaluation of care and the value of these approaches to their care mission.

> *« The training aspect I think is really important, because I was accompanied [...] to be able to set up the evaluation tools [...]. So, it's really a spirit and you have to maintain that spirit. And being alone in maintaining that spirit, […] it's not something easy. So, I think it's really important to have support, both internally and externally, around the evaluative spirit because, from you to me, it's not something that comes naturally. »* (Quality officer, Thearapeutic community, participant to the test protocol)

This aspect is largely confirmed by the interviews conducted in centres that did not participate and testified a lack of knowledge and training in this type of approach. In addition to training practitioners, implementing quality improvement initiatives cannot be a mission limited to a few quality managers, and therefore requires broader involvement of various team members.

> *« It mustn't be limited to a purely administrative level, which I think is the case at the moment. For me, I'm simplifying, I have the impression that it's a bit of a management issue, which remains at the management level and doesn't fully filter down to the field. »* (Practitioner, Psychiatric hospital, participant in the test protocol)

> *« What could help is to help us to make it participative so that it allows everyone to discuss. So that it doesn't cut off our means of discussion and that it allows us to discuss more, to implement an evaluative spirit. »* (Quality office, Therapeutic community, participant to the test protocol)

The implementation of PREMs can therefore not be an end goal in itself and should be part of a wider reflection on the quality of care within the various treatment centres, involving the therapeutic teams

as a whole. An accreditation system for SUD centres could be an interesting driving force for the generalisation of this type of approach, as it would enable a global and coordinated approach to be taken to improve the quality of care. One of the criteria for accreditation should be the inclusion of all teams in the discussions on improving quality, as well as patients.

> *« P: Because on the one hand we have the PROMs and PREMs to objectively measure this this this, with the tool that we hand over, that we analyze and that we have to discuss. But in reality, some patients, who then become part of the user representatives, will report what they have experienced. So, it's an indirect PREMs that's done elsewhere, and that exists [...]*
>
> *R: It might also mean, for example, including user representatives in the discussion and in the reception of the results.*
>
> *P: I think it's necessary. And it's going to become the norm if it isn't already the case in Belgium. »* (P: Practitioner, R: Researcher, Psychiatric hospital, participant in the test protocol)

From direct support to network coordination: heterogenous needs in support

Support needs are primarily internal. Although the need to involve all team members is generally recognized, solid support from management teams and project coordination by a designated person were identified as essential elements for the success of this type of initiatives, which was also found in the literature [28].

> *« It needs to be a drill, and once it's up and running, we can't just say it's going to run itself, we'll just let it run. No, you have to keep reminding people, keep the thing going all the time, and coordinate the effort. »* (Practitioner, Psychiatric Hospital)

However, while there was some agreement on this observation, opinions on the need for or the type of external support to facilitate the implementation of a quality approach differed. The need for training, already discussed above and on which there was a relative consensus, was one of the aspects that could be covered by an external institution. Another aspect also mentioned was the organisation of a network focusing on quality of care, enabling practitioners to share their practices in this area.

> *« R: Looking a bit at being more in a network in which there are several of you setting up this process, and being able to talk about how it works and exchange practices. Would that be something interesting or not?*
>
> *MD: If it's part of a process involving meetings, reflection and a shared desire to improve... yes, that's clear. It would also be a way of questioning our clinical practices. »* (R : Researcher, MD : Medical Director, Day-centre, participant to the test protocol)

For half of the services taking part in the PREM test, the fact that the encoding, processing and analysis of the data was carried out by an external partner was ideal from the point of view of the time saved and the lack of internal resources needed for handling and analyzing the data. For two other centres, data management support was not considered necessary, as the resources were already available within the centre. It should be noted, however, that the exploratory interviews did reveal difficulties for most of the centres in collecting, storing and analysing data.

The needs of the centres in terms of external intervention are therefore very different, with each centre having different resources and being more or less advanced in thinking about mechanisms to improve the quality of care. A support system that focuses only on certain specific aspects, such as data analysis or training, does not seem to be well suited for the Belgian situation, where a service

that can provide different types of support adapted to the needs and individual situations of the centres seems to be more appropriate.

Funding

The cost of implementing a collection of PREM data, or more broadly a policy for monitoring the quality of care, should not be underestimated and is often mentioned as one of the main barriers to the success of this type of projects [28]. This is even more important as the results of this study show the need for a long-term project that can incorporate acculturation and health professional objectives. Given the cost to the centres for implementing this type of practice, the introduction of financial incentives is mentioned as a possible way of encouraging its spread. Although the centres acknowledge a lack of resources or manpower to carry out their care missions, financial incentives are not favoured. According to some, any incentive would be accompanied by an obligation to complete the questionnaire and quantified targets for the number of questionnaires collected.

> *« […] It would be great but also, well here I'm deliberately going for the negative every time. […] Who will benefit behind it if we are paid it's because there are issues behind it and conversely, if there is funding well, there will be an obligation to do it and it will be a tool that won't be incorporated but a tool that will be imposed. And it's going to be filled in incorrectly, because you absolutely have to do it, so it'll be good to go and fill in your questionnaire, go and fill it in, thank you, and bin it. »* (Practitioner, Psychiatric Hospital)

Incentives are more likely to be found in standardised data collection processes following a precise timetable which is not necessarily compatible with the gradual integration of a quality-of-care policy and reflection around it.

Material support to ensure that centres have the equipment to collect data electronically is therefore perceived more positively, as is the provision of a monitoring service to help them with coding, data analysis, report creation and team training.

Key points

- Developing a **flexible, light registration protocol** that can be adapted to a variety of treatment realities, including restricted periods of data collection, different timeframes when collecting data and a mix of paper-based and electronic registration.
- Allowing centres to **select relevant topics to include** in the questionnaire and **add topics relevant for specific treatment settings**.
- It is important to **involve the full team in the development, processing and reporting** of the tool to ensure maximum acceptance by the staff and integrate it in a broader quality-of-care process.
- **Practitioner training and network coordination** must be part of the implementation strategy.
- Allow **sufficient resources** to develop this kind of project by providing adapted support to the participating centre.

3.3 How to implement PROM data collection?

3.3.1 A tool that needs improved handling and practical use

The creation of a PROM data collection tool, based on the ICHOM questionnaire, attempted to follow three primary recommendations in the literature:

- The questionnaire should be easy for patients to understand and complete
- Patient results should be quickly available, if possible, instantly
- The results must be easy for practitioners to understand and interpret.

Overall, feedback from the practitioners who took part in the protocol test shows that these three objectives were achieved. The questionnaire did not pose any major difficulties for the patients who completed it, the results were available within one working day and were found to be generally easy to understand. However, the processing of patient data and the sending of feedback to practitioners by the research team could not be fully automated. The possibility to generate automatic reports was limited in the available softwares (RedCAP, Limesurvey) and the data storage service used by Sciensano did not allow feedback mechanisms to be set up for clinicians.

In order to create a report that met the requirements of readability, interpretability and simplicity, the research team developed a computer script. However, although the creation of the document was automated, its launch and distribution when new data was made available was not. The research team had to monitor each day whether a new questionnaire had been completed, run the script and send the document to the practitioner. This process, which therefore required the team to be constantly available and closely monitor the completion of the questionnaires, would be difficult to implement outside of a research project and would need to be fully automated before routine use could be considered. The integration of the data collection tool and data reporting into the electronic patient system of the centre could overcome this problem, but would require adaptations to each existing system. This costly solution could not be implemented in smaller structures where no integrated system is available.

Other practical difficulties encountered during the collection of PROMs were rather related to the use of the tablets provided and the management of the equipment, and sometimes to electronic bugs which made it difficult for some patients to complete the forms. Time management, as with the PREMs, was also a point raised by the practitioners who took part in the test protocol. It was difficult for them to administer the follow-up questionnaires at the right time, especially when the time of the follow-up questionnaire was not defined by a strategic moment in the treatment (e.g., the change from one department to another or the end of an introductory period) but by the setting of a time limit. The PROM tool would therefore benefit from a reminder system, for example via the electronic patient system interface, to ensure consistency in the timing of follow-up questionnaires.

3.3.2 Are the indicators measured perceived as useful in clinical practice?

The items from the ICHOM set were generally perceived as interesting, with practitioners showing more interest in the so-called ‘clinical’ items, in particular the depression, anxiety and stress scales and the PTSD and ADHD screening items. Two of the three centres participating in the test protocol emphasized that these items were already known when the clinical interviews were carried out correctly, although they did not take the form of numerical indicators.

> *« It can also bring up subjects that normally would theoretically be the subject if the clinical interview is well done. These are themes that should be addressed, but it really allows to highlight specific points that could be drowned out in the rest of the interview if we didn't pay attention to them »* (Practitioner, Psychiatric hospital, participant to the test protocol)

The potential of the ICHOM tool to recognize points of attention so that practitioners are not drowned by the mass of information is recognized, in particular when it would allow to detect specific problems which the practitioner can easily follow up.

> *« This Anxiety, Stress and Depression scale which, in a way, already gives you an indication of possible mood disorders which you could then possibly investigate further. And above all the ADHD test for the presence of attention deficit disorder, which also gives an indication of the need for further investigation, and I have to say that in two of the six people, I think there were two with it. [...] This was then investigated further using another screening instrument and it was retained anyway, but it was mainly this mood disorder and attention deficit disorder that I found interesting. Quality of life indicators are something we do anyway. »* (Practitioner, Therapeutic community, participant to the test protocol)

However, some limitations were raised regarding the indicators and their presentation. First, while the indicators that are fairly obvious because of their construction, such as the depression scales and the ADHD indicators, which clearly indicate whether or not subjects are at risk and/or require further investigation by practitioners to confirm/invalidate a diagnosis, the results of the SURE are much less indicative, since they do not really provide an indication of severity, nor are the dimensions defined precisely.

The actual use of the results may therefore be potentially limited.

> *« But what do you do with it afterwards once you know that your patient has scored 35 on the stress scale? And that's already good because there are little phrases to help with reading, colors to give indications, but you need to have some ideas for action, especially if the tests aren't known. [...] And here on SURE, well OK we can see that it's decreasing, but still? What does that mean? What do I do with it? I'm already asking the patient about these elements, so apart from that, what do we do? Well, in my opinion, it can't work if we just have a questionnaire and that's it. Because a questionnaire, well it's just a questionnaire... it has no effect in itself, it's how you get information from it and how you act afterwards that's going to have an effect. »* (Practitioner, Psychiatric hospital, participant to the test protocol)

The indicators measured would therefore potentially benefit from being coupled in advance with suggestions for action, based on patient's results and recommendations based on scientific/expert advice. Although the literature confirms this finding, this aspect remains complex to develop and requires further research. It was also pointed out by a practitioner that although the various PROM scales used could provide interesting avenues of investigation, these scales do not have diagnostic value and it is important to train professionals in their application.

> *« Well, you'd have to look at it in a global way. So, […] for example these scales, there are elements that will only be known by a few CBT specialists. But if you present them to system therapists or to psychoanalysts, well, they're really not going to talk to them. So, first of all, the people who are potentially going to have to use it have to be able to really do it and do it well. So, they need to be trained in how to do it, and to be able to see the benefits and potential uses of it. »* (Practitioner, Psychiatric hospital, participant to the test protocol)

3.3.3 Limited use of feedback in clinical practice

The centres participating in the feasibility study were given a series of instructions concerning data collection. However, the actual use of the results was not guided, and practitioners were left free to use them in any way they considered appropriate. It was requested, however, that patients would be given access to individualized feedback on request. However, none of the participating patients received a copy of the report, either because they did not request it, or because they left in a hurry, or because the therapeutic team forgot to pass on the results.

In addition to not sharing the feedback, all practitioners involved in the test protocol acknowledged that they had not made use of the report.

> *« I must honestly admit that I've read it, but in practice we haven't done much with it [...]. But I do see possibilities. »* (Practitioner, Therapeutic community, Participant to the test protocol)

> *« Because we're a therapeutic community and we're constantly in contact with the residents, we already have a lot of material to deal with. So the items were interesting but weren't really more compared to the content we already have. »* (Practitioner, Therapeutic community, Participant to the test protocol)

Reasons given for not using the results vary according to the practitioners interviewed, including the large amount of information and redundant information that was gathered:

> *« Q: [These are information we already have.] Because for example when you take mental health […] that's data that we work with directly and when the carers become aware of something with the person, well, there's the psychiatrist, so the carer goes to the psychiatrist with the person and they discuss it at that level, so that's it. It didn't add anything. It's information that we're already picking up on.*
> *R: Yeah yeah... same for quality of life and so on?*
> *Q: Yes, yes, quality of life, that's information we pick up […]. »*
> (Q: Quality officer, R: Researcher, Therapeutic community, Participant to the test protocol)

Further reasons were the lack of experience in using questionnaires and the difficulty of including a not widely know tool in a clinical routine. Also organisational difficulties linked to communication issues regarding patients' schedules, a large proportion of patients leaving on a break and also the pseudonymization of questionnaires, which required the practitioners to search for the name associated with the identifier entered on the feedback form.

3.3.4 Potential generalization of PROM tool and preconditions

Cost-effectiveness?

The PROM monitoring tool was used with a small number of patients, with the objective of testing the potential interest of the approach with practitioners already familiar with and interested in this type of practice. At the end of the test protocol, most practitioners deemed the generalization of the tool to be complicated. Moreover, the interviews conducted with a wider group of professionals revealed major challenges in the dissemination of this type of tool to a larger and more diversified number of centres.

While many consider the approach to be theoretically interesting, the longitudinal monitoring of patients that the implementation of PROMs requires is considered by many to be very costly in terms of resources in a sector that is already under time and financial pressure.

> *« P: I just thought it was very interesting, but if I were offered it right now...*
>
> *R: You wouldn't have the time?*
>
> *P: Not at all, hahaha »*
> (R : Researcher, P1 : Practitioner, Day centre)

> *« Well, I'm quite amazed when I see what Europ-ASI does and the impact it has, because they can really assess a patient's level of self-assessment on different themes when they arrive: family, consumption, health. After 3 months, after reception, they re-evaluate this with the same person, after 6 months, they re-evaluate this and so they really have a tool which identifies, by means of graphs, which really make it possible to see the average, what impact of centre X in the programme and so we had taken the training in the late 90s, early 2000 saying we were going to start there but with the centre things have changed so much and the fact that we are ambulatory is really a big difficulty for us compared to residential. And it takes an incredible amount of time. Time that we don't have. They have a dedicated part-time nurse. We have a queue of patients and a lack of staff. »* (Director, Day-centre)

Administering a PROM questionnaire after patients had left the care centre, as envisaged before the test protocol was launched, was most often considered impossible. This was mainly due to the amount of work required to find and contact former patients, in combination with the low success rates among persons with SUD. The cost in terms of resources of a PROM-approach is questioned, as the cost-benefit ratio of this approach is considered uncertain.

> *« P: So I don't think that for the public with whom we work it's something interesting. […]*
>
> *D: Yeah, and they're not going to fill it*
>
> *P: No, and we're also going to feel uncomfortable asking them to fill in the questionnaire, which is likely to be the case, and we might not talk about it systematically. »*
> (P: Practitioner, R: Researcher, D: Director, Therapeutic community)

Moreover, the facilities also employ other, less restrictive or more appropriate tools for monitoring patients' symptoms and individualizing care, such as clinical interviews, informal interviews with significant others, multidisciplinary team meetings, other routine outcome measures (ROM) (e.g. EuropASI) or individual support plans.

> *« It's always interesting, but you have to see the investment it requires. It's always interesting to see that it's mainly on the physical aspect of quality of life that we have power, well a power in inverted commas, but is the effort it would take to be able to have this data worth it? By the quality-price ratio whatsoever. »* (Practitioner, Therapeutic community, Participant in test protocol)

Even more than PREMs, the routine implementation of PROMs – as far as they directly affect clinical practice – will always depend on the perceived added value of the approach compared with other monitoring tools. Awareness about this type of practice remains limited and systematic training of professionals in this type of approach could enable its wider implementation, while guaranteeing the therapeutic freedom of professionals.

For a limited number of patients?

In addition to the difficulties associated with the centres' resources and the perception that the cost-effectiveness of implementing PROMs was not appropriate, there were also difficulties associated with patient recruitment. The centres involved in testing the PROM protocol were all residential treatment centres with medium to long duration of stay (≥2 months). The results of the interviews with a large number of professionals in the first phase of the feasibility study already highlighted the difficulties involved in monitoring patients in outpatient services or crisis units at regular intervals:

> *« We have people coming and going, and it's impossible for us to determine, for anyone, what's going to happen next. It's really this factor, this unknown factor, that forces us to try not to delay until tomorrow what we can do on the day itself, from any point of view. Because the next day the person will no longer be there, and sometimes won't be for some time. »* (Practitioner, Crisis unit)

> *« You don't know who you see for a session, who stops for 4 months and then comes back. There's no stability, it's totally unpredictable. Without knowing it, the person can go back to prison, be forced to stop all treatment or follow-up, and come back very badly, or not at all. »* (Medical Director, Specialised Outpatient Centre)

Although the centres recruited for testing the PROM protocol were high-threshold residential centres, the introduction of this type of tool in facilities serving more vulnerable populations (e.g. low threshold or methadone centres) is seen as even more complex for several reasons. First, patients may not be in a condition to complete a questionnaire and a relationship of trust needs to be established, which can take time to build up. In such a context, asking patients to fill out a questionnaire at specified times may prove to be unrealistic, potentially counter-productive and difficult to generalize.

> *« I think it's fairly easy to involve patients like that [without any serious mental health problems] in this relationship, but we do have some very psychotic patients who sometimes have a very particular relationship to this, who are very paranoid and very suspicious of anything that involves encoding data. »* (Practitioner, Therapeutic Community)

Second, difficulties related to reading, writing or handling electronic equipment may be more common in low-threshold settings.

> *« Because, in any case, in terms of difficulties here too, it's everything to do with, language barriers, writing barriers to fill in documents, forms and so on. There are, it depends on the day, but there are days when there are people who come to the centre for whom French is not at all their language of origin, their temporality is not the same either, and so filling in standardised questionnaires without revising them with them is often something very complicated. »* (Practitioner, Crisis Unit)

> *« And then there's the difficulty, too, that there's nothing self-reported in the programmes, well it's done in the course of a discussion, it's oral. Otherwise impossible, for the TDI for example. »* (Practitioner, Crisis Unit)

Finally, lack of trust regarding data collection is something that is generally noticed and which was also explicitly mentioned by one of the participants. This mistrust on the part of service users also raises questions about the management of health data (and combination about it), which, even when pseudonymized, raises issues of compliance with the regulations in force by centres that are

sometimes poorly equipped or have little expertise in information technology. Consequently, technical and legal support needs to be considered.

Consequently, a degree of rigidity in applying the PROM protocol and minimal requirements of literacy may exclude a potentially large proportion of service users when implementing PROMs. Under these conditions, rather than generalizing the use of PROMs to all services, the wider dissemination and training of practitioners in a patient-centred approach may have proven most relevant. These findings further underline the fact that the use of PROMs may be better suited to the population and conditions in residential centres or day centres. Moreover, additional efforts are needed to open up the implementation of PROMs to as many people as possible: translation into languages other than Dutch, French and English; creation of paper models that can easily be processed; more advanced applications that are easily accessible by practitioners and patients, etc..

Key points

- The need to develop a **trusted, secure, user-friendly system** providing direct feedback (to patients and practitioners) including the possibility to follow-up patients over time and facilitate data collection.
- **Accessibility of the tool** is a major point of attention in terms of its cost to the centre and use by patients: different languages and a paper version must be available.
- The tool should be part of clinical practices and not be overlapping with existing systems. It should also be supported by **guidelines explaining how to make use of the information collected**.
- Practitioner training (both initial and ongoing) is crucial for the dissemination of PROMs

IV. DISCUSSION AND CONCLUSION

This chapter provides important insights into the implementation of PROMs (Patient-Reported Outcome Measures) and PREMs (Patient-Reported Experience Measures) in substance use disorder (SUD) treatment centres in Belgium. A first consideration is that PROM and PREM questionnaires are flexible tools that can serve a variety of purposes at different organizational levels. It is essential to define the objective of such projects in advance as each objective entails specific requirements that influence the data collection protocol, targeted population, analysis, and interpretation. Attempting to address several objectives for a PROM/PREM data collection can create conflicting demands, complicating its implementation [1,29,30]. Notably, clinical objectives aimed at improving the quality of care at the centre level emerged as particularly relevant, offering feasibility, practical utility, and better data quality thanks to better adherence of practitioners to this type of purpose. A bottom-up approach for the development of these tools, supported by practical and methodological guidance for existing initiatives, is recommended. Awareness-raising regarding potential applications of PROMs and PREMs is also crucial. However, the implementation of a standardized, large-scale PROMs tool would require considerable resources and a highly secure data collection infrastructure, especially given the need for unique patient identifiers.

Good practices for PREM implementation include adapting protocols to the operational constraints of individual centres. Flexibility in planning and monitoring are essential to achieve high response rates. The need for intensive follow-up of patients to ensure their participation may lead some centres to

prefer time-limited data collection rather than routine integration of PREMs. It was also stressed that finding the right time to administer the questionnaire and identifying people who are about to leave the center was quite challenging. Further, the need was highlighted to identify a referent person in the centres who is most likely to know how patients are progressing with their treatment, or to put in place mechanisms to identify the right time to carry out the data collection. While the literature highlights electronic data collection as a means of reducing administrative burden [31–33], centres preferred paper-based methods for their simplicity and flexibility. To maximise participation, offering PROM measures on paper and electronically is essential.

Despite the provision of measurement tools, even accompanied by external support, there is no guarantee that data collected through PREMs will be used in practice. Challenges such as data quality issues, misalignment with clinical realities, and limitations associated with convenience sampling persist [12,34]. Regarding the alignment of the questionnaire with clinical realities, the PREMAT questionnaire tested was generally well received by professionals in the field for its compactness, comprehensibility and completeness. Some flexibility in the questions included could still improve its adoption by clinicians. Considering issues related to convenience sampling, it was stressed that patients who leave the centre abruptly generally don't answer this type of questionnaires. This is an important bias to consider, especially as the proportion of patients who drop out from treatment is high in SUD treatment centres [35,36].

The use of a PREMs tool in clinical practice to improve quality of care is not guaranteed to be successful due to a lack of confidence in the measurement tool or the use of data, low level of involvement of various professionals in the teams, or insufficient support of the project at the organizational level [37–39]. The process of implementing PREMs must therefore be part of a more global approach of improving quality of care. In this regard, integrating this measurement in a kind of accreditation project may prove to be interesting. The therapeutic teams must be involved as much as possible in the discussions about the results provided by this tool. In addition, treatment centres need to be supported in implementing these approaches according to their specific needs: technical, methodological or material. Organizing discussion moments between different treatment centres around quality of care and providing training are also important elements of an implementation strategy.

For the use of PROMs, a nationwide implementation project with clinical objectives may be less relevant due to logistical challenges, such as the longitudinal nature of data collection and the need for continuous patient follow-up. Current technical solutions lack the automation necessary for efficient data processing and reporting. Furthermore, the perceived cost-effectiveness of PROMs is limited, as they require significant changes in therapeutic practices.

To encourage broader adoption of PROMs, further efforts should focus on training and raising awareness about patient-centred care and utility of PROMs. Securing clinicians' confidence and support is essential before investing in resource-intensive technical developments such as bespoke digital platforms.

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CHAPTER 8

GENERAL DISCUSSION AND RECOMMENDATIONS

I. INTRODUCTION

Alcohol and other substance use disorders (SUDs) are linked to a range of adverse psychological, physical, and social consequences [1]. The chronic, relapsing nature of SUD and related economic, judicial, housing and relational problems impact individuals, but also families, neighbourhoods and whole communities [2-5]. SUDs have a significant and growing impact on global morbidity and mortality [6-8]. Worldwide, harmful alcohol use causes 3 million deaths annually, representing 5.3% of all deaths, and accounts for 5.1% of the global burden of disease [9]. Recent findings from the annual National Survey on Drug Use and Health (NSDUH) showed that 10.5% of the US population aged 12 or older met DSM-5 criteria for having an alcohol use disorder in the past year, and 8.5% met the criteria for a drug use disorder [10].

The American Society of Addiction Medicine [11] considers addiction, the most severe form of SUD [12], as "a treatable, chronic medical disease involving complex interactions among brain circuits, genetics, the environment, and an individual's life experiences. People with addiction use substances or engage in behaviours that become compulsive and often continue despite harmful consequences". Besides prevention and law enforcement, treatment and harm reduction are regarded valuable public health measures to decrease the impact of substance use and related problems [1, 13, 14]. The efficacy and efficiency of substance use and addiction treatment is often debated due to high relapse and drop-out rates and small to moderate effect sizes of most interventions and treatment modalities [15-17]. Yet, numerous studies have established a clear association between the time spent in treatment (retention) and successful outcomes, as well as the importance of continuing care and support for maintaining and consolidating change [18, 19]. Data on this subject are largely missing in Belgium.

II. BACKGROUND OF THE STUDY

The OMER-BE study started from the above observations, (positive) findings from treatment cohort studies in the US and Europe comparing outcomes across treatment modalities and the lack of similar research in Belgium. Although some initiatives have been taken to systematically implement monitoring of treatment outcome and experience indicators in Flanders/Belgium (e.g. patient surveys, Flemish indicator project, BELRAI-registration), these efforts mostly concern single indicators and/or are limited to some health services and deemed not specific enough for AOD services. The recommendation by the Belgian Health Care Knowledge Centre [20] to crank up the use of patient-reported outcome and experience measures in patient care and policy was a further impetus to set up this study. *Patient-Reported Outcome Measures* (PROMs) refer to information on treatment outcomes as perceived by service users, including information about symptoms, quality of life, physical functioning, and psychological well-being. *Patient-Reported Experience Measures* (PREMs) focus on service users' experiences of health care services and concern practical aspects of care, such as accessibility, information and decision making, and continuity of care.

The use of patient-reported outcomes and experiences as part of routine outcome monitoring (ROM) practices is relatively new and brings in a service-user perspective, which may differ substantially from the service provider or proxy perspectives. In Belgium, the monitoring of treatment progress at macro-level is non-existent and besides a few initiatives at service and institutional level, monitoring of treatment outcomes is not mandatory nor common in Belgium. In Flanders, a number of quality/outcome indicators were collected voluntarily during the VIP² project, while the BELRAI-tool

has been introduced as a standardized assessment tool across various social welfare and health care services, including a specific module for AOD services. Yet, an outcome/monitoring version of this tool is not available.

Our systematic review of the literature [21] showed that, although the implementation of PROMs and PREMs in SUD treatment services is increasing, its application is still in its infancy and seriously fragmented [22-27]. These patient-reported measures have the potential to improve the quality and effectiveness of SUD treatment services, but it is unclear which measures are best used in clinical practice and what are specific challenges when implementing PROMs and PREMs, including hindering and facilitating factors. Based on a review of 23 international studies, it appeared that the use of PROMs is relatively new and disperse. Its application is mainly limited to research projects and not common in clinical practice. The use of PREMs is even more scarce, also due to a lack of instruments. Substantial differences can be observed in the way PROMs and PREMs are administered, the way in which they have been developed, and how and when they are collected in clinical practice. Additional guidance is needed for clinicians and researchers to select valid, meaningful, and comparable patient-reported tools, as we did in this study, and to offer valuable insights on how to overcome barriers in using these measures in routine clinical care [21]. Consequently, we used standardized and comparable instruments and implementation methods based on the ICHOM SSA tool to better understand and benefit from the impact of PROM and PREM data on treatment quality and treatment outcomes. New and unvalidated instruments were translated and adapted to the Belgian context and validated in Dutch (SURE-NL and PREMAT-NL) [28, 29].

As opposed to earlier treatment outcome studies, the OMER-BE study started from a recovery perspective instead of an acute care approach. We monitored study participants regularly (with 45 and 90 day intervals) over a 6-month period after starting a new treatment episode [30]. Typically, addiction treatment has been evaluated using an acute care approach, evaluating individuals' functioning after treatment and assuming that these outcomes (will) last after treatment. The emerging literature around addiction recovery shows that recovery often takes time and that people require various treatment episodes before they can eventually be considered in 'stable recovery' (>5 years) [31-33]. Although we used a residential treatment episode as starting point for measuring patient-reported outcomes and experiences in this study, we extended the traditional scope of outcome studies by assessing various life domains related to health, well-being and citizenship (beyond substance use) and a dimensional rather than a dichotomous (abstinence/relapse) approach to recovery. Recovery was measured at various points in time (45, 90 and 180 days after initial assessment) to observe how individuals evolve after initial treatment participation and which covariates affect service users' outcomes and experiences [30].

In 2015, a shift to recovery-oriented care and support was introduced in substance use treatment in Flanders [34], which followed similar evolutions in general mental health care that were initiated in 2012 with the title 107 reform [35]. The recovery model includes an important shift away from a purely medical model of treatment to a personal recovery approach viewing addiction recovery as an individual, non-linear process requiring individualized support that might change over time, a continuing care perspective and attention for individuals' well-being, quality of life and social connections [32].

III. BASELINE CHARACTERISTICS OF THE STUDY SAMPLE

In total, 189 individuals participated in the OMER-BE study, 81 treated in a SUD ward in a psychiatric hospital, 80 in a drug-free TC and 28 participants (14.8%) were recruited in outpatient services. The average age of study participants was 35.5 years at baseline and the majority was male (82.5%), completed secondary education (60.3%) and lived alone (47.6%). Most participants (81%) had undergone previous treatment for SUDs. The most frequently reported problem substances were alcohol (53.8%), cocaine (43.5%) and cannabis (34.4%), also indicating frequent presence of poly-substance use [30].

Initial comparisons were made between the three treatment modalities. When considering sociodemographic and clinical characteristics, no significant differences were found in terms of age, sex, living situation and country of birth. However, significant differences were observed regarding education level, treatment history, OAT involvement and primary substances reported. Post hoc analyses revealed that participants in the PC group had the highest level of education, followed by those in the outpatient group and finally the individuals from the TC group. On average, 82.7% of participants from the PC and 85% of the participants TC group had a history of SUD treatment, with no statistically significant difference between the two groups. A significantly higher percentage of participants in the outpatient group (46.4%) was engaged in some form of OAT. In terms of substance use, alcohol was more frequently reported as the primary substance in the PC group. In contrast, opioids were most frequently reported in the outpatient group. Amphetamine, cocaine and GHB were significantly more reported in the TC group. A significantly higher percentage of participants in the TC group reported more than one primary substance.

While background (case-mix) variables differed between the three treatment modalities in terms of education level, treatment history and primary substance, no differences were found regarding co-occurring mental health problems, except for ADHD being more prevalent among persons in therapeutic communities [30]. PROM scores at baseline were similar across treatment modalities, except for the SURE-NL scores which were significantly higher among participants in residential AOD facilities as compared with those in outpatient services, in particular regarding ‘substance use’, ‘self-care’ and ‘outlook on life’. Attrition analyses showed substantial drop-out rates at initial and subsequent follow-up assessments (36.5%), in particular in outpatient services. Comparisons between participants who completed the 45-day follow-up and those who did not revealed several significant differences. Those retained in the study were significantly older, had a higher education level, were more likely to live alone, and were more likely to have parents (mother) being born in Belgium and to report alcohol as primary problem substance. Additionally, persons participating in follow-up assessments scored higher on ‘material resources’ (SURE-NL), including questions about stable housing, steady income, and effective financial management. Our findings are in line with studies that suggest that factors such as lower education level, younger age, unemployment, and financial instability are associated with higher attrition at follow-up assessments [36,37]. Moreover, as we opted for digital follow-up assessments (through mobile phones, computers or tablets) lower participation in persons with low socioeconomic status may be attributed to limited digital skills and individuals’ inability to use electronic devices [21, 38, 39].

IV. FINDINGS AT FOLLOW-UP MEASUREMENTS

Longitudinal analyses of PROMs in residential AOD services showed high initial recovery scores as measured with the SURE-NL, a recently developed recovery measure [28, 40], leaving little room for further improvements. Moreover, the extent of recovery strengths was related to the time when the questionnaire was administered. Since participants stayed in a safe and closed environment, they scored high on the 'substance use' scale of the SURE-NL and these scores were higher when individuals had been in treatment for more days. Using linear mixed modeling, the evolution of PROM scores at the various follow-up points was analyzed, as well as the role of time, treatment modality, age and gender. In general, recovery scores remained high over the 6-month follow-up period, indicating that most participants maintained the initially high scores on various recovery indicators. No or few differences were observed between participants from PC and TCs, except that TC participants who had higher initial scores for 'self care' scored lower on this measure over time and also had lower total SURE-NL scores at the follow-up moments compared to the PC group. These significant differences may be attributed to greater problem severity and lower educational attainment among persons in TCs and to the lack of specificity and sensitivity of the SURE-NL scale. This measure uses a one week time window, while participants could be – for pragmatic reasons – assessed at baseline during the first 21 days of treatment, leaving ample space for overlooking inter- and intrapersonal differences. Importantly, the PC and TC group were not matched at the baseline assessment, nor did we use a controlled study design, which does not allow any inference about differences between treatment modalities (PC vs. TC) nor causal attributions related to the treatment modality where individuals began treatment.

Significant time effects were found regarding quality of life, as measured with the WHOQoL-BREF, indicating substantial improvements in 'perceived QoL' 'perceived health' and 'environment' among both groups at the 6-month follow-up moments. Yet, and not surprisingly, these time effects for physical health levelled off at the 90-day follow-up moment, suggesting a plateau effect in recovery. A similar trend was observed for psychological health scores, which improved significantly during the first 90 days and then levelled off. 'Psychological health' was significantly lower in female participants and persons in TCs, suggesting more severe and enduring psychological problems in this group. Similarly, the PROMIS-GH-10 demonstrated significant improvements in the study sample over time on physical and mental health among both groups, with a plateau effect for mental health. It turned out that 'age' had a negative impact on participants' perception of their physical health.

Overall, PREMAT scores [29, 41] at the 45-day follow-up were high, approaching mean scores of 4 (out of 5), with the highest scores observed for the items 'felt welcome', 'was held responsible for my behavior', and 'know that recovery is up to me', indicating the importance of a welcoming atmosphere but also an emphasis on personal responsibility and clarity during the first weeks of treatment. Items that were scored lowest by study participants were 'having enough privacy', 'enough one-to-one sessions' and 'been linked up with other services', suggesting that service users expect more privacy and individuals sessions and being offered support alternatives outside the treatment facility where they started. Not surprisingly, persons who dropped out from residential treatment early scored significantly lower on the PREMAT-NL and had significantly lower scores on the items 'know what the rules are', 'rules make sense', 'receiving enough space by others' and 'getting information where else they can go for help'. The latter item differences suggest that providing information about the rules and why these rules are installed, as well as psycho-education sessions and providing information on

other treatment and support options may make a difference between staying in treatment and dropping out. Also, getting enough (mental) space from others was considered more important by those who left treatment early.

Based on the lived experiences of a subsample of study participants (n=21) from the three treatment settings (outpatient treatment, residential psychiatric centres and therapeutic communities), we further explored individuals' treatment and recovery experiences over the 6 month study period during in-depth interviews. Using thematic analysis, we found that all participants underscored the importance of a comprehensive, patient-centered approach in SUD treatment that addresses the clinical, personal and social dimensions of recovery. Four themes appeared to be very central in the answers from respondents, irrespective of the treatment setting: (1) feeling connected, valued and respected; (2) understanding and managing substance use; (3) finding balance in life; and (4) directing your own care pathway. A sense of recognition and acceptance by both peers and service providers enhanced individuals' self-confidence and self-esteem, but also the ability to (re-)connect with others in treatment and the community (e.g. family, colleagues). Being in a safe environment, without access to substances and with professional support, enabled participants to become abstinent and to focus on future goals and perspectives. Most participants also expressed the need for a "stable, normal life", including decent housing, work, good health and satisfying activities. Finally, continued access to care and support was emphasized and deemed necessary for maintaining recovery.

VI. FEASIBILITY OF ROUTINE IMPLEMENTATION OF PROMS and PREMS

The feasibility study on the routine collection of PROMs and PREMs in a selected number of services showed that these measures are flexible tools that can serve a variety of purposes at different organizational levels and it is essential that the objectives of the data-collection are clearly defined. A bottom-up approach, taking into account common concerns and daily realities, and raising awareness about the usefulness and potential applications of PROMs and PREMs are crucial to promote implementation. Available good practices and implementation guidance can stimulate other organisations to consider the implementation of PROMs and PREMs. Practical, methodological and financial obstacles need to be addressed, like secure data collection infrastructure, implementation protocols, appropriate data-collection methods according to services' and service users' needs and routines and monitoring service users at risk of leaving the facility. To increase implementation willingness, it was suggested to introduce time-limited data collection periods and targeted PROM or PREM assessments rather than routine/daily assessment of a comprehensive set of PROMs. The PREMAT tool aligned best with clinical expectations and realities and was well received by professionals for its compactness, comprehensibility and completeness. In general, an important concern related to the generalizability of the data is how to include (more) service users who leave treatment prematurely as they are usually not included when applying convenience sampling. It was further emphasized that the use of PROMs and PREMs is just one element to improve quality of care and needs to be carefully monitored and adequately supported at all organisational levels [42-44]. Also, since the use of PROMs and PREMs is relatively new and since expectations and experiences differ between services, it is recommended to collaborate between services and organisations on this topic and exchange knowledge and experiences to adhere to a bottom-up approach in which organisations and service providers empower each other in implementing PROMs and PREMs.

VII. CONCLUDING OBSERVATIONS

In conclusion, the OMER-BE study filled an important gap in the AOD treatment sector in Belgium, since no comprehensive, cross-sectoral outcome study had been performed until recently. The study adressed the KCE recommendation to introduce the use of PROMs and PREMs in these type of services [20] and linked with recent recommendations and practices regarding routine outcome monitoring to improve treatment outcomes and adherence, as implemented, for example, in addiction treatment centres in the Netherlands [45]. Our findings illustrate that implementation of PROMs and PREMs is feasible, but requires substantial logistic support and monitoring (in this case 2.5 fulltime researchers and a dedicated data-collection system) and clear objectives, but may be hampered by practical and organisational concerns, as illustrated by limited participation of services in the French-speaking part of Belgium, slow recruitment and a disproportionate number of study participants in outpatient services and high attrition rates. Longitudinal findings demonstrate the effectiveness of residential treatment to initiate and maintain recovery and to contribute to the quality of life and physical and mental health of study participants. Patient-reported experiences are generally positive among those retained in treatment and in the study, but several questions remain around those not included or retained in the study. Qualitative interview data illustrate the role treatment can play in individuals' recovery trajectories, in particular in reconnecting, finding stability, managing substance use and opening realistic future perspectives. Finally, the feasibility study of routine implementation of PROMs and PREMs identified several barriers towards its implementation in daily clinical practice and various prerequisites and facilitators for regular use of these patient-reported measures to improve quality of care.

VIII. RECOMMENDATIONS STEMMING FROM THE OMER-BE STUDY

7.1 General recommendations

The implementation of PROMs and PREMs closely aligns with establishing recovery-oriented systems of care (ROSC) [46]. As highlighted by Day et al. [47], recovery is a long-term, multidimensional process that extends beyond single treatment episodes, requiring ongoing support structures that facilitate personal growth, social reintegration, and building and accessing recovery capital. A core principle of recovery-oriented support is the need for continuity of care. In that sense, international best practices show how ROSCs should extend beyond institutional boundaries and actively integrate peer-based recovery support services such as AA, employment and housing programs, and long-term recovery monitoring [47]. From that perspective, outcome monitoring should not only focus on clinical parameters (e.g. PROMs), but also assess broader domains such as housing stability, financial security, employment, and social participation as crucial determinants of sustained recovery [35]. Moreover, a proactive approach to monitoring individuals at risk of drop-out, particularly in outpatient settings, is essential to reduce early drop-out or disengagement and adjust interventions timely. Yet, collaboration between specialized addiction services and general support systems remains limited in Belgium [48, 49]. Without a comprehensive and person-centered approach to recovery (cf. ROSC), the implementation of PROMs and PREMs risks becoming an isolated administrative exercise rather than a meaningful tool for improving quality of care and empowering individuals in their recovery journey.

Moroever, the use of subjective indicators like PROMs and PREMs is part of a broader shift in the scientific and healthcare landscape, where scientific knowledge, professional expertise, and lived experience are increasingly recognized as equally valuable pillars of evidence. While traditional care

models have primarily relied on clinical and academic research, there is growing international recognition that the insights and experiences of service users are essential for more effective and person-centered support. The application of PROMs and PREMs aligns seamlessly with this shift, as they place the voices of service users at the center of care evaluation and improvement. This goes beyond merely collecting outcomes and experiences—it actively shapes support practices and informs policy development. In this sense, the implementation of PROMs and PREMs is not just a methodological innovation, but can contribute to a fundamental reorientation of care, where the expertise of individuals with lived experience is no longer considered supplementary but is recognized as an essential component of high-quality, recovery-oriented support [35, 50].

At clinical level, the OMER-BE study demonstrates how PROMs and PREMs hold significant potential for enhancing treatment practices, adapting elements based on service user experiences and stimulating shared decision-making. In routine recovery-supportive practices, PROMs and/or PREMs should not merely serve as data collection instruments but as dynamic tools that support person-centered care planning. Their value lies in allowing service providers to track treatment and recovery progress, facilitating structured conversations about personal recovery goals and next treatment steps. PROMs and PREMs can play a valuable role at key moments in the treatment and recovery process, such as intake assessments and transition points between treatment phases or types of support.

The ICHOM tool has proven to offer strong foundations for standardized outcome assessments, while the PREMAT-NL provides unique insights into treatment experiences. However, some modifications are needed to further enhance the practical applicability of these instruments. Since the PREMAT [41] was originally designed for residential settings, adjustments are necessary to ensure its relevance across different treatment modalities. PROMs should, in line with findings from recovery research, include measures that also focus on having meaningful activities and individuals' social integration/loneliness. A particular challenge identified in the OMER-BE study concerned the application of PROMs and PREMs in outpatient settings, which require more flexible, non-labor intensive approaches. A shortened version of the PREMAT-NL [29] —with fewer than 30 items—would make routine implementation more feasible, particularly in outpatient care. In addition, several practical considerations must be addressed to ensure accessibility and reliability of data collection. The digital divide presents a barrier for some service users, requiring alternative formats to ensure equal access. At the same time, digital solutions such as mobile-friendly surveys and remote data collection, should be leveraged to reach service users who engage less frequently with treatment services. In terms of timing of questionnaire administration, our study points to the importance of assessing outcomes at moments that align with service users' recovery trajectories. Inconsistencies in the time frames used across different questionnaires should be harmonized to improve the reliability and validity of longitudinal outcome monitoring. Extending the baseline assessment window beyond the applied three-week period and narrowing the focus of PROM assessments in outpatient settings may help to mitigate the low participation rates in these centres, as service providers prefer to use the first contacts/meetings with service users to build up a relationship of trust which is often deemed imcompatible with the use of (a comprehensive set of) standardized tools and instruments.

From an international perspective, alcohol and drug services in Belgium may – despite a historical backlog and lack of a monitoring culture – benefit from aligning outcome measurement practices with global initiatives such as the ICHOM Standard Set for Addictions [24]. The adoption of internationally

validated tools may not only enhance the robustness of data collection, but also facilitate cross-country comparisons that can inform better quality of services and and higher participation and retention rates in AOD treatment. Collaborative studies with countries that have more established PROM/PREM measurement systems—such as the Netherlands, the United Kingdom, and Australia—could provide valuable insights into optimizing implementation strategies and practices. The OMER-BE study further suggests that even time-limited routine outcome/experience measurements, when properly implemented, are a promising approach to improve the quality of AOD services and develop more person-centred recovery support.

Finally, the implementation of PROMs and PREMs needs to be framed within a broader culture of continuous learning and quality improvement, if we want these tools to fulfill their intended role [24]. Rather than being considered as administrative/governmental requirements, PROMs and PREMs should be approached as useful instruments for meaningful engagement between service providers and service users. Establishing a coordinated national framework for routine monitoring, integrating PROMs and PREMs into existing data systems, and ensuring that data collection is aligned with the realities of clinical practice are essential steps towards embedding these measures into the fabric and daily routines of AOD services. Ultimately, the OMER-BE study provides convincing evidence that systematic outcome measurement can support recovery, empower service users, drive improvements in care delivery and inform evidence-based policy making. To realize recovery-oriented systems of care in Belgium, better matching and integration of recovery support services is needed (including peer-based and informal support, but also recovery housing and employment/vocational support) and a coordinated, cross-sectoral strategy that integrates person-centered, knowledge-informed, and internationally aligned approaches for monitoring individuals' recovery progress.

For promoting the implementation of PROM and PREM assessment in AOD (and other) treatment services in Belgium, we have formulated several policy and practice recommendations at macro-, meso- and micro-level based on the OMER-BE study.

7.2. Macro-level recommendations (situated at the level of national and regional policies)

1. *Allocate dedicated resources for PROM and PREM implementation*

The OMER-BE study highlighted that implementing PROMs and PREMs in AOD treatment is a labor-intensive and resource-demanding process. To ensure the successful and sustainable integration of these tools, dedicated funding must be allocated to support essential components such as digital infrastructure and the development of standardized assessment protocols. For instance, investing in the necessary infrastructure to integrate PROMs and PREMs into existing systems such as the Treatment Demand Indicator (TDI) could ensure that outcome measurement becomes a routine part of care rather than an added administrative burden. Additionally, continuous professional development and training programs should be established to equip staff with the necessary skills to administer, interpret, and apply PROMs and PREMs effectively in clinical practice. Without adequate resources, PROM and PREM implementation risks being inconsistent, which might affect the reliability of outcome data and limit its potential to drive service improvements.

2. *Develop tailored infrastructure for seamless data collection*

A user-friendly and adaptable system for administering and storing PROM and PREM data needs to be developed to reduce the burden for both staff and service users. The OMER-BE study highlighted the dual role of technology: while digital tools can simplify implementation and improve data accuracy, they can also present challenges, such as usability concerns, leading some providers and users to prefer paper-based methods. Addressing these issues requires further refinement of digital infrastructure to balance usability with functionality. Digital solutions should be designed to integrate seamlessly with existing (organization-specific) systems to streamline workflows, minimize duplication and enhance data management efficiency. It must also offer secure storage, automated analysis, and real-time feedback mechanisms to support clinical decision-making. Additionally, strategies should be in place to bridge the digital gap, ensuring that technological solutions are inclusive and adaptable to the specific culture and operational realities of different treatment services. This includes providing alternative formats, such as paper-based versions, for individuals with limited digital skills or those who prefer non-digital options. By prioritizing user-friendliness and practicality, such infrastructure can facilitate routine outcome measurement without adding unnecessary complexity to service delivery.

3. *Establish a national framework for the (routine) implementation of PROMs and PREMs*

A comprehensive national policy framework should be developed to integrate the routine use of PROMs and PREMs into AOD treatment services. This framework must explicitly define its primary purpose: to enhance the quality of care by fostering a deeper understanding of service users' needs and evaluating the real-world impact of treatment. By embedding PROMs and PREMs into routine practice, this framework should serve not merely as a technical tool but as a driver of patient-centered, effective, and equitable care. A key objective should be to enhance the transparency and comparability of outcome data while maintaining a strong focus on improving service quality. To achieve this objective, this framework should balance standardization with flexibility, ensuring that PROMs and PREMs are both methodologically rigorous and practically applicable across diverse treatment settings. Furthermore, the framework should be designed to integrate seamlessly into existing routine practices, minimizing administrative burden on service providers. In that respect, based on the findings of the OMER-BE study, an implementation guide for the use of patient-reported measures in AOD services in Belgium needs to be developed, as well as providing training options and establishing self-sustaining learning networks of professionals. By embedding PROMs and PREMs into daily clinical workflows, a national framework can foster a culture of continuous quality improvement while equipping policymakers with robust data to enhance the effectiveness and accessibility of AOD treatment services [49].

7.3. Meso-level recommendations (situated at the level of organizations and services)

1. *Build capacity for routine use of PROMs and PREMs among staff*

The effective implementation of PROMs and PREMs in AOD treatment services relies on the skills, engagement, and support of both frontline workers and managers. The OMER-BE identified varying levels of motivation, confidence, and familiarity with these tools, highlighting the need for targeted capacity-building efforts. To address these gaps and to foster trust and cooperation among service providers, training programs should focus on the practical application of PROMs and PREMs, their role

in improving care quality, and strategies for integrating these tools into daily workflows. Providing ongoing practical support will be essential to ensure that staff feel confident and equipped to use these tools effectively. Fostering active participation of both service providers and service users in the development, adaptation, and implementation of PROMs and PREMs is essential beyond training and practical guidance. Ensuring that these tools are tailored to the realities of different treatment settings can enhance its practical relevance and increase staff involvement. Additionally, establishing a learning network among services and practitioners that are using these tools can facilitate knowledge exchange and problem-solving and stimulate continuous improvement and further advances.

2. *Use PROM and PREM data for continuous quality improvement and person-centred care*

Data obtained from PROM and PREM assessments should be actively leveraged to enhance the quality of care, support personalized treatment approaches, and strengthen accountability in AOD services. By systematically analyzing PROM and PREM data, treatment providers can monitor care quality, adjust interventions based on patient-reported needs and ensure that services act responsibly and evidence-driven. The OMER-BE study highlighted the potential of these tools to identify emerging trends, assess treatment effectiveness, and guide individualized and person-centred care planning. To fully realize these benefits, organizations should establish regular review processes that integrate outcome data into clinical decision-making and quality improvement initiatives. Embedding PROMs and PREMs into routine quality improvement efforts will not only enhance service effectiveness, but can also reinforce a culture of continuous learning and adaptation within AOD treatment settings.

3. *Enhance participant recruitment and retention strategies*

To ensure the validity and representativeness of findings, future efforts to implement routine outcome measurement of PROMs and PREMs should adopt tailored strategies to enhance participant recruitment and retention, especially in outpatient settings. The OMER-BE study identified significant challenges, including long waiting lists, low turnover rates, and infrequent contacts between service users and providers in outpatient facilities, which limited study participation and data collection. To address these barriers, recruitment timelines should be made more flexible, such as extending the baseline data collection window beyond three weeks, to accommodate the realities of outpatient care. Additionally, alternative engagement methods, including secure digital platforms, should be explored to reduce reliance on in-person interactions and facilitate smoother data collection. Leveraging online tools for remote survey completion, appointment reminders, and follow-ups can help maintain service user involvement while minimizing disruptions of their treatment schedules.

4. *Standardize outcome measurement tools across services*

Organizations should implement validated tools to ensure data quality and consistency in measuring service user outcomes and experiences across AOD services. The OMER-BE study demonstrated the feasibility and utility of an adapted tool based on the ICHOM Standard Set [24] and the PREMAT [41], confirming its value for the routine use in outcome measurement. However, while standardization is essential for enabling comparability across settings, the study also highlighted the need for flexibility and topical assessment. Outcome measurement tools must allow for the incorporation of additional assessment instruments or service-specific elements to ensure their relevance in different contexts. By adopting a structured, yet adaptable toolkit organizations can optimize the implementation of PROMs and PREMs in such a way that data collection is both reliable and useful for service

improvement. This toolkit should also be integrated into a broader, facility-wide quality improvement process that engages all staff members and extends beyond mere data collection.

7.4. Micro-level recommendations (situated at the level of clinical practice and interactions between service providers and service users)

1. *Integrate PROM and PREM assessments to enhance clinical practice and continuity of care*

Embedding PROMs and PREMs into routine care at key moments, such as intake assessments and transitions in the treatment process, provides clinicians with real-time insights into service user progress, enabling them to tailor treatment and address emerging needs effectively. This regular use of outcome measures aligns with patient-centered care principles and could support individuals' recovery process. Moreover, PROM and PREM data may play a critical role in ensuring continuity of care by identifying service users at risk of dropout or relapse. By linking outcome data to treatment transitions—such as the shift from residential to outpatient care—clinicians can anticipate potential challenges and offer timely, targeted interventions. This integrated approach ensures that service users receive consistent, effective support throughout their recovery journey, fostering long-term engagement and improved outcomes.

2. *Foster service user agency and shared decision-making*

The use of PROMs and PREMs offers a powerful opportunity to empower service users by involving them in the (co-)creation of their treatment trajectories. These tools provide a structured way to integrate service user feedback into care planning and progress evaluation, fostering a sense of ownership and motivating service users to remain actively engaged in their recovery journey. This aligns closely with the principles of recovery-supportive practiced, emphasizing service user agency, person-centered care, and shared decision-making. Such approach not only enhances the overall treatment experience, but also strengthens the foundations for sustained recovery and long-term well-being [47].

3. *Adapt tools to ensure accessibility for all service users*

The OMER-BE study underscores the need for PROMs and PREMs to be accessible to all service users, regardless of language, literacy, and cultural background. This requires the translation of tools into French and Dutch and simplifying their design to accommodate varying levels of health literacy. By ensuring inclusivity, service providers can obtain more accurate and representative data.

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