

Inpatients' experiences with interdisciplinary treatment for substance dependence:

Measurement, quality indicators and use of results

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Preface

This thesis and the project described originated in 2013. The Ministry of Health and Care Services formulated an aim in their “Oppdragsdokument” that the regional health authorities were to conduct a national user experience survey within interdisciplinary treatment for substance dependence (1). The Norwegian Directorate of Health commissioned the Norwegian Knowledge Centre for the Health Services (NOKC) to plan and carry out this survey in every hospital trust in Norway.

I had been employed as a researcher at the NOKC since 2011 and was given the opportunity to be the project leader for the first three surveys. The 2013-survey, and the following surveys in 2014, 2015 and 2017 were all conducted in a similar fashion, based on a development and pilot project the NOKC carried out in 2009 (2, 3). The survey in 2013 was the first national survey in this population, and the NOKC wanted to back what turned out to be near-yearly surveys with a research project. This research project was formulated as a PhD project, financed by the NOKC. In 2016, the NOKC was integrated with the Norwegian Institute of Public Health (NIPH), and the work with the national surveys continued as previously in the new organization.

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APPENDICES

Summary in English

Background: Substance dependence has a major impact on the patient's life and can cause major health problems. In Norway, patients can receive health care for their substance dependence in both public and private health-care institutions. Patient and user experiences are now recognized as being important for evaluating the quality of care, and patient-reported experience measures (PREMs) are demonstrably effective tools for evaluating quality of care and patient-centeredness. The increasing focus on the openness of results and outcomes from health services as well as the quality of care that patients receive has led to increased initiatives for assessing and reporting the quality of health care as well as monitoring quality-improvement initiatives. There are several ways to monitor quality in health care, and the development and application of quality indicators are often used to achieve this. Even though measurements and the reporting of patient experiences have become common, information about the use of patient-experience data in improving the quality of health care is scarce. There is also a dearth of knowledge about how to understand and use patient-experience data to increase the responsiveness of a health-care institution to the needs of its patients.

Aim: The overall aims of this thesis were to validate a questionnaire used in national surveys, to test the data material gathered via these surveys for use as quality indicators and to follow employees' reported use of these results in local quality-improvement work.

Method: A patient experience questionnaire previously developed was further adapted and used in four national cross-sectional surveys with patients receiving residential treatment for substance dependence. All patients, 16 years old or older, who were receiving residential treatment, were invited to participate. Both public and private residential institutions with a contract with the regional health authorities were included, and the data collection was carried out while the patients were still at the institutions. One week prior to each of the patient surveys, a selected group of employees were surveyed digitally, reporting on their attitudes towards and use of results from patient experience surveys. The psychometric evaluation of the patient instrument included assessment of internal validity, acceptability, and internal consistency. Quality indicators and a case-mix model were developed and evaluated through multilevel regression analyses, while the employee data were examined through chi-square tests and one-way analysis of variance. Free-text comments were analysed utilizing content analysis.

Results: The exploratory factor analyses with data from the 2013 patient-experience survey resulted in three scales: “treatment and personnel” with 12 items, “milieu” and “outcome” with five items each. The item-total correlations of the scales were all ≥ 0.4 . Cronbach’s α was 0.75 for “milieu” and 0.91 for the other two scales. The test–retest reliability parameter was greater than 0.8 for all scales ($n=187$), indicating good-to-excellent stability. Seventeen of the 18 associations were statistically significant ($p<0.05$) according to the hypotheses.

The intraclass correlation coefficient for the patient-reported experience scales was 2.3% for the “treatment and personnel” scale, 8.1% for “milieu” and 4.8% for “outcome”. Multivariate multilevel regression analyses showed that alcohol reported as the most frequently used substance, sex and age were significantly associated with two of the three scales. The length of stay, pressure to be admitted for treatment, and self-perceived health were significantly associated with all three scales. Explained variance at the individual level was approximately 7% for all three scales.

Around 400 employees were recruited in each of the four survey years, and the response rate varied from 61% to 79%. The employees reported generally positive attitudes towards patient-experience surveys, and 40–50% of them had implemented quality initiatives based on the results of the patient surveys. The mean score for the question about usefulness was higher than 3 (on a Likert scale from 1 to 5 points) for all four surveys. Many employees provided details about the changes that had been made in free-text comments. The results from the patient-experience surveys demonstrated positive changes over time.

Conclusion: The analyses of survey data demonstrated the good psychometric properties of the patient questionnaire, meaning that the PEQ-ITSD can be recommended for use in future PREMs applications in Norway and also other countries in which health care is organized in a similar manner. When adjusted for a specific set of variables, the three scales comprising the PEQ-ITSD functioned well as patient-experience-based quality indicators, using both data at the hospital-trust level and a merged data set. The analyses also showed that the indicators can be used to discriminate between different health-care providers and provide evidence for using the patient-reported indicators as national quality indicators. Patient experiences improved slightly during the four survey years, which could be interpreted as a result of employees’ active use of the patient survey results in quality improvement, and their generally positive attitudes towards patient experience survey.

Summary in Norwegian

Bakgrunn: Rusavhengighet har stor innvirkning på pasienters liv og kan forårsake store helseproblemer. I Norge kan pasienter få helsehjelp for sin rusavhengighet både i offentlige og private helseinstitusjoner. Pasient- og brukererfaringer er anerkjent som viktige i evalueringen av kvaliteten på helsetjenesten, og det er vist at pasientrapporterte erfaringer effektivt måler kvalitet og grad av brukerorientering. Det økende fokuset på åpenhet om resultater og utfall i helsetjenestene, samt kvaliteten på tjenestene pasientene mottar, har ført til en økning i tiltak for å vurdere og rapportere kvaliteten, samt overvåke kvalitetsforbedringsinitiativer. Det er flere måter å overvåke kvaliteten i helsetjenesten på, og kvalitetsindikatorer brukes ofte til dette formålet. Selv om målinger og rapportering av pasienterfaringer har blitt vanlige, er det fortsatt lite informasjon om bruk av pasienterfaringsdata for å forbedre kvaliteten på helsevesenet. Det er også fortsatt lite kunnskap om hvordan man kan forstå og bruke brukererfaringsdata til å øke helseinstitusjonens lydhørhet til pasientens behov.

Formål: Det overordnede målet med oppgaven var å validere et spørreskjema brukt i nasjonale undersøkelser, å teste det innsamlede datamaterialet til bruk som kvalitetsindikatorer og å følge ansattes rapporterte bruk av resultatene i lokalt kvalitetsarbeid.

Method: Et tidligere utviklet spørreskjema for pasienter ble videre tilpasset og brukt i fire nasjonale tverrsnittundersøkelser blant pasienter som fikk behandling for rusavhengighet. Alle pasienter, 16 år og eldre, som fikk døgnbehandling i spesialisthelsetjenesten, ble invitert til å delta. Både offentlige og private døgninstitusjoner med kontrakt med de regionale helseforetakene ble inkludert, og datainnsamlingen ble gjennomført mens pasientene fremdeles bodde på institusjonene. En uke før hver av pasientundersøkelsene ble en rekruttert gruppe medarbeidere invitert digitalt til å svare på spørreskjema om holdning til og bruk av resultater fra pasienterfaringsundersøkelser. Den psykometriske evalueringen av pasientinstrumentet inkluderte vurdering av intern validitet, akseptabilitet og intern konsistens. Kvalitetsindikatorer og case-mix-modell ble utviklet og evaluert gjennom flernivå regresjonsanalyser, mens ansattedataene ble undersøkt gjennom kjikvadrat-tester og enveis variansanalyse. Fritekstkommentarer ble analysert ved bruk av innholdsanalyse.

Resultater: De eksplorerende faktoranalysene med data fra pasienterfaringsundersøkelsen fra 2013 resulterte i tre skalaer: “behandling og personell” med 12 spørsmål, “miljø” og

“utbytte” med fem spørsmål hver. Item-total-korrelasjonene for skalaene var alle 0.4 eller høyere. Cronbachs α var 0.75 for "miljø" og 0.91 for de to øvrige. Test-retest-reliabiliteten var høyere enn 0.8 på alle skalaene ($n = 187$), noe som indikerer god til utmerket reliabilitet. 17 av de 18 assosiasjonene mellom enkeltvariabler og skalaene var statistisk signifikante ($p < 0.05$).

Intraklassekorrelasjonskoeffisienten for de pasientrapporterte erfarings skalaene varierte fra 2.3% for “behandling og personell” til 8.1% for “miljø”. Multivariate flernivå regresjonsanalyser viste at alkohol rapportert som det mest brukte rusmiddelet, kjønn og alder var signifikant assosiert med to av de tre skalaene. Lengden på oppholdet, press for å bli innlagt for behandling og selvrapportert helse var signifikant assosiert med alle tre skalaene. Forklart varians på individnivå var omtrent 7% for alle tre skalaene.

Rundt 400 ansatte ble rekruttert i hvert av de fire undersøkelsesårene, og svarprosenten varierte fra 61% til 79%. De ansatte rapporterte generelt om positive holdninger til pasienterfaringsundersøkelser, og 40–50% av dem hadde gjennomført kvalitetstiltak basert på resultatene av pasientundersøkelsene. Gjennomsnittlig skåre for spørsmålet om nytte var høyere enn 3 (på en Likert-skala fra 1 til 5 poeng) for alle fire undersøkelsene. Mange ansatte ga detaljerte beskrivelser om endringene som ble gjort i fritekstkommentarer. Resultatene fra pasienterfaringsundersøkelsene viste positive endringer over tid.

Konklusjon: Analysene av pasienterfaringsdataene viste gode psykometriske egenskaper for pasientskjemaet, og PEQ-ITSD anbefales for bruk i fremtidige pasienterfaringsundersøkelser i Norge og andre land med lignende organisering av helsetjenesten. Justert for et spesifikt sett med variabler, fungerte de tre skalaene som utgjør PEQ-ITSD godt som pasienterfaringsbaserte kvalitetsindikatorer, gitt data på helseforetaksnivå og et sammenslått datasett. Analysene viste også at indikatorene kan brukes til å skille mellom ulike helsetjenestetilbud og understøtter bruk av pasientrapporterte indikatorer som nasjonale kvalitetsindikatorer. I løpet av de fire undersøkelsesårene ble pasienterfaringene litt forbedret, noe som kan tolkes som et resultat av ansattes aktive bruk av resultater fra pasientundersøkelsen i kvalitetsforbedring, og deres generelt positive holdninger til pasienterfaringsundersøkelsene.

Abbreviations and terms

ANOVA	Analysis of variance, the attribution of variation in a variable to variations in one or more explanatory variables
Case-mix	A term used for the characteristic of a group of patients such as age, sex, and health status. Different institutions may have different case-mix for patients otherwise similar
EFA	Exploratory factor analysis
Factors/indicators/ scales/scale scores	Factors revealed in the EFAs are used as quality indicators and treated as scales. Thus, the different terms are used throughout the thesis
ICC	Intraclass correlation coefficient
Instrument	A form intended to collect data that measures topics of interest, using one or multiple measures or subscales. In this thesis, it refers to the PEQ-ITSD
NIPH	Norwegian Institute of Public Health
NOKC	Norwegian Knowledge Centre for the Health Services
OLS	Ordinary least squares
PEQ-ITSD	Patient Experiences Questionnaire for Interdisciplinary Treatment for Substance Dependence
PREMs	Patient-reported experience measures
PROMs	Patient-reported outcome measures
Questionnaire	A form used to collect data for analysis. In this thesis, it refers to the whole survey tool or a general description of a form used to collect self-reported data
Substance dependence	Being used instead of “substance abuse”, which is commonly used in international literature. Substance dependence was chosen after discussions with colleagues working on the national surveys and with employees in the Norwegian Directorate of Health, who has interdisciplinary treatment as one of their professional fields
User experience	In some parts of the health services, the term “user” is preferred over “patient”. Both “user” and “patient” can in this thesis be viewed as interchangeable and referring to people who are receiving health care

List of papers

- I. Haugum M, Iversen HH, Bjertnaes O, Lindahl AK. Patient experiences questionnaire for interdisciplinary treatment for substance dependence (PEQ-ITSD): reliability and validity following a national survey in Norway. *BMC psychiatry*. 2017;17(1):73.
- II. Haugum M, Iversen HH, Helgeland J, Lindahl AK, Bjertnaes O. Patient experiences with interdisciplinary treatment for substance dependence: an assessment of quality indicators based on two national surveys in Norway. *Patient preference and adherence*. 2019;13:453-64.
- III. Haugum M, Iversen HH, Bjertnaes O. National surveys of patient experiences with addiction services: do employee use the results in quality initiatives and are results improving over time? (resubmitted *BMC Health Services Research*)

The papers are referred to by their Roman numeral throughout the thesis.

1 INTRODUCTION

Substance dependence has a major impact on the patient's life and can cause major health problems. The World Health Organization has listed harmful alcohol use as one of the main risk factors for developing non-communicable diseases, and hence that it contributes to a substantial portion of the global burden of disease (4). Approximately 33,000 adult patients received interdisciplinary treatment for substance dependence in Norway in 2020 (5), and this number continues to increase (6–9).

1.1 Interdisciplinary treatment for substance dependence in Norway

In 2004, the Norwegian government implemented a reform that aimed to strengthen the health care and ensure a holistic treatment for substance dependence (10). Through this reform, patients struggling with alcohol and/or drug abuse were assigned the same rights for specialized treatment within the health services as all other patients (11). The new policies affecting these patients were designed to ensure the availability of high-quality prevention, treatment, rehabilitation and harm-reduction services. Thus, patients receiving interdisciplinary treatment for substance dependence now have the right to an individual plan, authorized by the Social Services Act, whereby those with long-term and complex needs for services are ensured a comprehensive, coordinated and individually adapted service offering. The individual plan covers relevant services in accordance with the Social Services Act, the Specialist Health Services Act, the Municipal Health Services Act and the Mental Health Care Act (10).

Part of this reform shifted the responsibility for treatment for substance dependence from the county municipality to the regional hospital trusts, so that as for somatic and mental health care, treatment for substance dependence became part of the specialist health services (12). The triad of social, psychological and medical competences became the focus, with the aim of ensuring these competencies when meeting and evaluating the patient (13). In the years after implementation of this reform, interdisciplinary treatment for substance dependence has been targeted by several governmental and nationwide initiatives (14). For example, “Pakkeforløp for psykisk helse og rus” aims to increase user involvement and user satisfaction via a coordinated clinical pathway (thus avoiding unnecessary waiting before an examination, treatment or follow-up) and by providing equal treatment regardless of where

the patient lives, better care for somatic health and good living habits (15). In Norway, users and patients have a legal right to be involved and participate in the planning, implementation and evaluation of their treatment, and the health services have a duty to ensure that involvement.

1.1.1 Residential treatment for substance dependence in Norway

In Norway, patients can receive health care for their substance dependence in both public and private health-care institutions. Some private health-care institutions have a contract with the regional health authorities. Those without a contract are not subject to the same mandatory reporting to the health authorities, and are therefore seldom included in the official statistics reporting on interdisciplinary treatment for substance dependence.

Public hospitals account for approximately 40% of the total hospital beds in Norway; the rest are covered by the private institutions with contracts with the regional health authorities. The number of hospital beds increased to 1752 between 2008 and 2011, and remained at that level until 2013 (16). A further increase in hospital beds was reported between 2013 and 2015, followed by a small decrease in the most previous years (17). The number of patients receiving health care for substance dependence has increased in the recent years, for both outpatient and residential treatment. Between 2015 and 2019 there was a 2% increase in the number of bed-days, an 8% increase in institutionalization and a 15% increase in outpatient treatment (17). There are geographical differences in the number of beds nationwide, with regional health authorities aiming to reach target figures provided by the government. These target figures also vary geographically, mirroring differences in population size across the different regions of Norway (17).

Employees working in the residential treatment sector come from various backgrounds. Nurses, social workers and psychologists account for many of the person-years, but medical doctors, psychiatrists, child-care workers and social educators are also frequently employed. In addition, there are many employees who come from other backgrounds, such as administrative personnel and people without formal health education (16), as well as around 300 consultants/employees with personal experience with dependence, working in the field of either substance dependence, mental health or both (18). The reform of 2004 also aimed to ensure that more employees with higher education were employed in the substance-

dependence sector under the assumption that a focus on higher education would ultimately increase the quality of health care (19).

In 2019, 15,522 adult patients received residential treatment for substance dependence, representing a small increase from 2015. Lengths of stay vary according to geographical region and between public and private institutions, and are longer in private hospitals than in their public counterparts; between 2016 and 2019, the length of stay in public hospitals decreased (from 12 to 10 days), while that for private institutions increased (from 22 to 26 days) (17).

Patients receiving or seeking help for substance dependence are not a homogeneous group. There are large variations among patients in various factors, including the extent and severity of the dependence, how the dependence has influenced their lives, and how they believe they can best live with their dependence. Moreover, some patients have psychiatric problems that require treatment and/or social problems such as housing, employment or financial issues that need to be addressed (13, 20–22). In addition, since substance dependence is generally more prevalent among males than females, the sex-related differences (both biological and how dependence develops) have necessitated the recommendation of sex-specific treatments (23).

There are more than 100 public hospitals or private institutions with a contract with the regional health authorities in Norway where patients can receive residential interdisciplinary treatment for substance dependence. Several therapeutic approaches are recommended for the treatment of substance dependence, with the national professional guideline provided by The Norwegian Directorate of Health listing 13 different approaches (23). This range of approaches is reflected in how the residential institutions treat their patients. For example, in some institutions the residents are considered “students” rather than “patients”; some implement particular programs, (e.g., the 12-step program), while others focus more on behavioural therapy and/or motivational interviews; some provide a philosophy-neutral treatment, while others are based on a particular religion without necessarily demanding that patients follow that religion (24). However, information regarding the particular treatment provided at individual institutions is not readily accessible.

The variations between both patients, treatments and institutions are inevitable and necessary; however, they make it difficult to compare treatment outcomes. There remain certain gaps in the knowledge, such as around how patients respond to treatment, whether the treatment led

to better long-term health, life or social functioning, and how robust the treatment effect is once patients are no longer in the care of the institutions (24).

1.2 User experiences with health care

Patient and user experiences are now recognized as being important for evaluating the quality of care (25). Patient-reported experience measures (PREMs) are demonstrably effective tools for evaluating quality of care and patient-centeredness (26–33). One definition of patient experiences is: “the sum of all interactions, shaped by the organization’s culture, that influence patient perceptions, across the continuum of care” (34). Some of the importance assigned to patient experiences and satisfaction are due to their links with patient safety and clinical effectiveness, as well as the desire to provide patient-centred care (35, 36). Several health systems measure and report patient experiences, and one can often find some or all of Picker’s eight domains cited when talking about person-centered care: (i) accessibility; (ii) effective treatment and trusted professionals; (iii) continuity of care and transitions; (iv) involvement in decisions and respect for preferences, needs and values; (v) comprehensible information and support for self-care; (vi) involvement of and support for family and friends; (vii) emotional support, empathy and respect; (viii) attention for physical and environmental needs (37, 38).

The terms “patient experiences” and “patient satisfaction” are often used interchangeably, but they are not the same. When measuring patient experiences, one asks if and how something specific happened when in contact with one specific health service, thus ensuring that data are easier to interpret and use for both health-care providers and patients (39, 40). On the other hand, patient satisfaction, is generally more subjective (39, 40) and relates to whether the patient’s expectations have been met, providing a judgmental description of the events (41, 42). However, both patient experiences and satisfaction are important when evaluating how they perceive the quality of health care, as well as the effects these concepts have on compliance and use of health services and health outcomes in the longer term.

There may be no perfect method for gathering patient-experience data, and it will often be guided by the purpose of the study. However, it is becoming increasingly common to use patient-experience data in public reporting on how different health-care providers are experienced, to rank or compare health-care providers and to motivate for and assess quality-improvement efforts (35, 43). Moreover, numerous countries are now using regional or

national surveys to assess patients' experiences, thus being able to generalize outcomes and to provide the robust results needed for the aforementioned public reporting (44). In a survey, standardized questionnaires can be used to capture large samples which is an important aspect if the patient perspective needs to be acknowledged and highlighted in the same way as other, more clinical or administrative data (45).

The Consumer Assessments of Healthcare Providers and Systems (CAHPS®) have been used for several years in the USA, and are regarded as the national standard for collecting data and reporting results about patient experiences (35). England's NHS (National Health Service) has carried out national surveys of hospital inpatients since 2002, using mainly self-completed postal questionnaires (28). In Norway, several patient populations are invited to participate in national surveys every year to assess the health care they have received. The Norwegian Institute of Public Health (NIPH) is responsible for carrying out user-experience surveys in Norway, the aim of which is to systematically measure user experiences of health care as a basis for (i) quality improvement, (ii) health-care management, (iii) patient choice and (iv) public accountability. The questionnaires are population- and/or diagnosis-specific, and are developed and distributed by the department within the NIPH with the national responsibility for user experience quality with health care. Given the potential range of areas that patients in interdisciplinary treatment consider important, their treatment should provide broad services targeting these issues (46–48), and patient involvement and influence are therefore considered essential (49–51). Furthermore, several studies have found that positive patient experiences and/or high satisfaction scores are correlated with improved outcomes across several types of subpopulations or treatment models (52–55).

1.3 User experiences as quality indicators

The increasing focus on the openness of results and outcomes from health services as well as the quality of care that patients receive has led to increased initiatives for assessing and reporting the quality of health care as well as monitoring quality-improvement initiatives (35, 56). There are several ways to monitor quality in health care, and the development and application of quality indicators are often used to achieve this. For such indicators to be of value, they must be relevant, scientifically sound, applicable and feasible (57, 58).

Systematic measurement and feedback is useful for monitoring and guiding improvements implemented by health-care providers, as well as for holding providers accountable for their

results through public reporting (59). Quality indicators are tools that measure system performance and health-care quality, and demonstrate the extent to which improvement efforts have led to changes (60). Quality has mostly been measured in terms of service and system performance without incorporating the perspectives, needs or values of the patients themselves. Health-care quality indicators from and/or incorporating patient perspectives are lacking, and have not been routinely integrated into evaluations of the performance of health systems; rather, such measurements have traditionally relied on routinely collected administrative and clinical data to monitor procedures, drug and treatment interventions, and outcomes (61–63). User experiences as quality indicators are an important supplement to other types of indicators (35, 64, 65), and positive patient experiences have been linked to improved patient health status while negative patient experiences have been shown to adversely affect health outcomes (66–68). PREMs and patient-reported outcome measures (PROMs) are increasingly used for benchmarking purposes to ensure that several aspects of the quality of health care are assessed, and to allow comparisons between health-care providers or even health systems (69).

Donabedian's classical approach to measuring the quality of health care includes patient satisfaction as an outcome along with changes in health, knowledge and behaviour (70). The model describes a causal link between the three components of structure, process and outcome, and while patient satisfaction is seen as part of the outcome, the other two components can be measured by PREMs (70). However, patient reports of the different quality components might all be classified as health-care outcomes since they are based on retrospective evaluations of the health services they have received. The national patient-experience surveys in Norway measure all three aspects of quality.

1.3.1 Quality indicators in interdisciplinary treatment for substance dependence

As with other fields of health care, patient satisfaction and experiences are important aspects when assessing the quality of health care in the treatment of substance dependence (71). In Norway there have been few quality indicators reported in interdisciplinary treatment for substance dependence, and they have focused mainly on whether various deadlines have been met, including waiting times (72). Given the political focus on these health services and the plans and strategies targeting interdisciplinary treatment for substance dependence, more

national quality indicators are now being reported or planned. When the NIPH was commissioned to conduct the national surveys upon which this thesis is based, one of the longer term goals was to test the data material for potential usage as quality indicators. Furthermore, a national quality registry has since been developed by Helse Stavanger HF that aims specifically to look at “treatment of harmful use or dependence of drugs” (73). The identification of quality indicators of interdisciplinary treatment for substance dependence is thus both a political and professional goal, and is currently the focus of several initiatives in Norway.

1.4 Use of results for quality improvement

One of the four aims of the national patient-experience surveys in Norway is quality improvement. The only way of determining whether interventions or changes are working is if the outcomes are measured in a valid and reliable manner. Nevertheless, from both a local and national perspective, if the goal is quality improvement then using a validated and reliable questionnaire is futile if the measurements are not followed by action or learning (45).

Even though measurements and the reporting of patient experiences have become common in many countries, information about the use of patient-experience data in improving the quality of health care is scarce (74–77). There is also a dearth of knowledge about how to understand and use patient-experience data to increase the responsiveness of a health-care institution to the needs of its patients (28, 75).

When the NIPH disseminates the findings from the patient-experience surveys, their reports are made for, and presented to, all levels of health care. Improvements in patient experiences could therefore be expected if providers use this information to implement quality initiatives (78). Although the findings of some studies suggest that patient-experience data can contribute to practice change (76), there have been few such studies. One survey that was conducted among employees in Norwegian paediatric departments showed that the employees reported implementing improvement initiatives to address problems identified in a national survey of parents, and that such surveys can be actively utilized in quality-improvement interventions (79). However, there is weak evidence for changes in patient experiences and the employees’ use of results.

1.5 Brief rationale for this thesis

Evaluating patient experiences is an important way of assessing the quality of health care, including for inpatients receiving interdisciplinary treatment for substance dependence. However, these patients are not always included when assessing the views of patient populations (71). To facilitate a national assessment, a questionnaire was developed and tested in Norway for measuring patient experiences in this specific population: the Patient Experiences Questionnaire for Interdisciplinary Treatment for Substance Dependence (PEQ-ITSD). The current version of that instrument has been used in several national surveys (2013, 2014, 2015 and 2017), which makes it important to test the instrument and ensure its validity. Given the paucity of literature focusing on reporting of patient experiences with substance dependence, one of the aims of the present work was to determine the possibility of developing national quality indicators from these data for this patient group in Norway. However, despite the results being distributed both online and through correspondence with health-care providers, there is little information regarding whether or how the results are being used in quality-improvement work. Therefore, a survey among health-care employees could help to uncover their attitudes towards and use of these data to improve or ensure the quality of care that their patients receive.

2 AIMS OF THE THESIS

The overall aims of this thesis were to validate the PEQ-ITSD instrument used in national surveys, to test the data material gathered via these surveys for use as quality indicators and to follow employees' reported use of these data in local quality-improvement work. The overall aim was investigated in three papers as described below.

Paper I

The aim of Paper I was to test the validity and reliability of a new questionnaire, the PEQ-ITSD, following the national survey in Norway in 2013.

Paper II

The aim of Paper II was to establish whether inpatient experiences can be used as national quality indicators of interdisciplinary treatment of substance dependence. The objectives were twofold:

- i) To use the data harvested from the national surveys to develop a feasible case-mix adjustment model.
- ii) To establish whether the quality indicator scores varied across health-care providers, thus testing the ability of the indicators to discriminate between levels of patient-reported quality.

Paper III

The aims of Paper III were as follows:

- i) To determine the attitudes of employees towards the national patient-experience surveys and their use of the results thereof when providing interdisciplinary treatment for substance dependence, and
- ii) To identify changes in patient experiences at the national level between 2013 and 2017.

3 METHODS

3.1 Overall study design

The NIPH has an established and well-documented approach to developing and psychometrically testing patient-experience questionnaires (80–84). This methodology was also applied in the studies described in Papers I–III of this thesis, and was followed to ensure the validity and reliability of the questionnaire, as well as other important aspects associated with measuring patient-reported quality of health care. An overview of the thesis and the various components is presented in Figure 1. Paper I describes the development and psychometric testing of the PEQ-ITSD, while Paper II reports on tests of the feasibility and application of patient survey data as quality indicators. Paper III describes the findings of surveys in which employees were asked to report whether or not they used the patient survey results in local quality-improvement work. This last paper reports both the employees' replies and explores how patient experiences have developed over the years, to see if any changes can be identified since the application of the PEQ-ITSD.

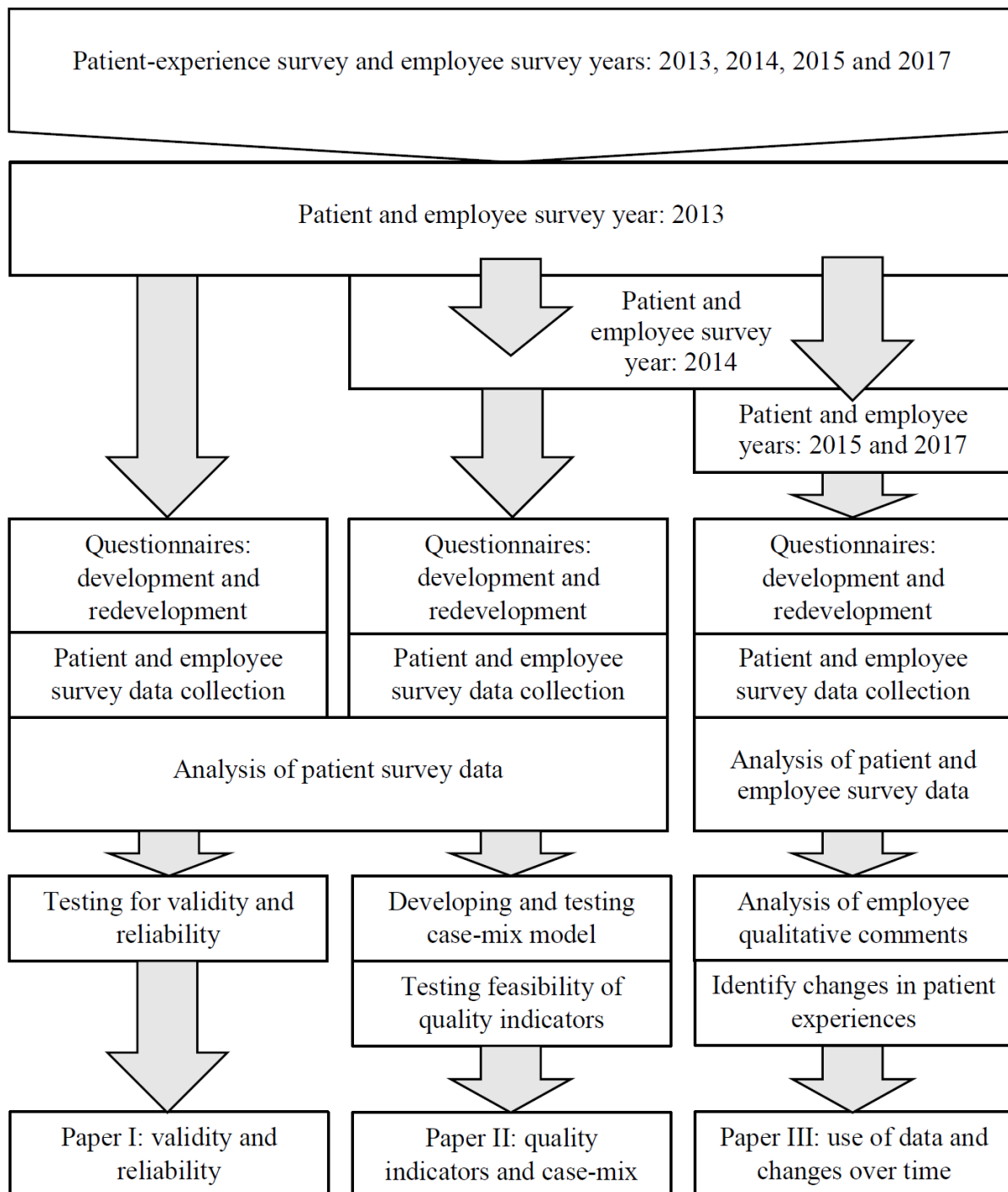


Figure 1: Overview of the PhD project that provided the data for Papers I–III.

3.2 Questionnaire development and further developments

The foundation of this PhD project can be found in the model used by the NIPH to develop, test and validate questionnaires used in health-services research. This model is described in detail in the following pages.

The PEQ-ITSD followed every step in this model; however, some of the steps of questionnaire development and testing were conducted and concluded before this PhD project commenced. Nevertheless, the full procedure is described below given its relevance for the entire project and the data collected using the questionnaire. The questionnaire used for collecting data among employees deviated somewhat from the NIPH model. The development method for the two questionnaires are therefore described separately.

3.2.1 Patient questionnaire

Figure 2 presents the steps and procedures taken by the NIPH to develop questionnaires for new populations. This model has been used for several years, and has been thoroughly documented (80–84).

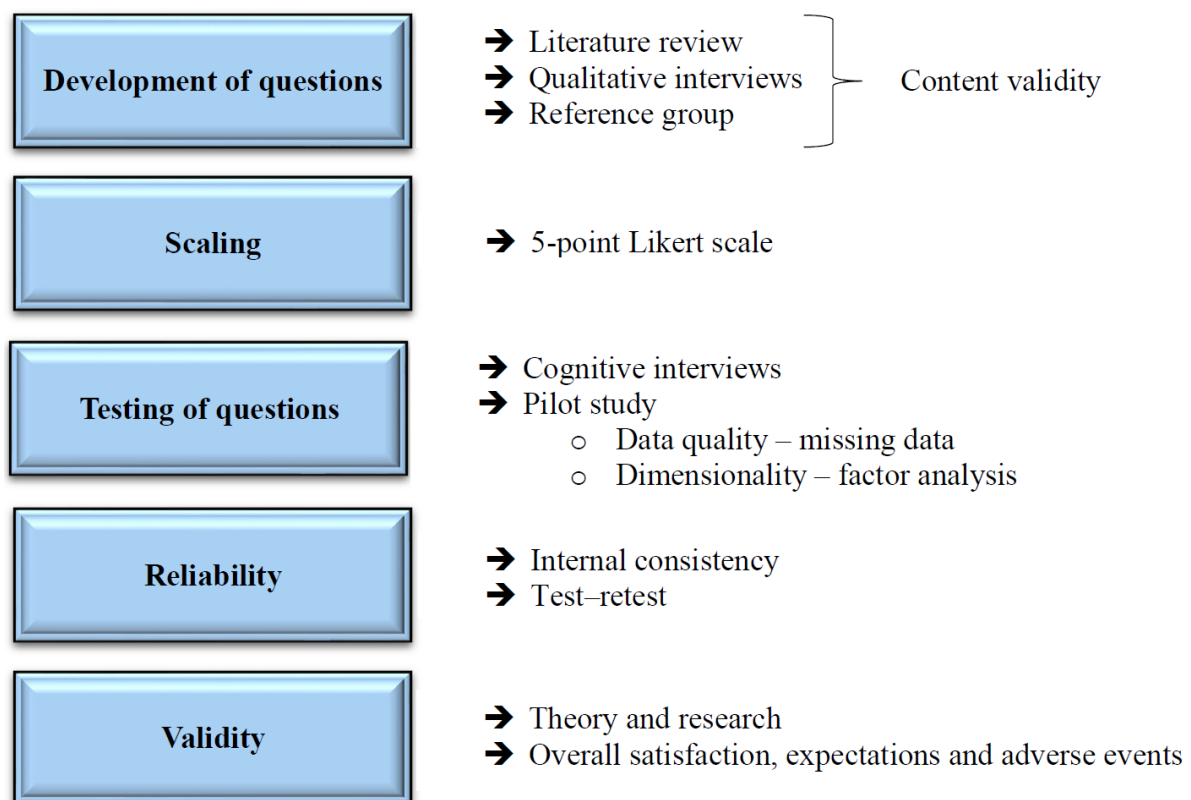


Figure 2: Model of questionnaire development and validation.

The original literature review to identify questionnaires for this patient population was conducted in 2006 (85). Several questionnaires were identified, but none were tested or considered relevant for large-scale use in the heterogeneous Norwegian setting, whereby the population comprised patients in treatment for several types of substance dependence. Nevertheless, the questionnaires identified in that review were utilized together with

questionnaires already in use locally in Norway to ascertain relevant topics or questions. The literature review was first updated late in 2007 (2) and again more recently in 2015, but no new directly relevant questionnaires were found.

The next steps in the development process were conducted between 2007 and 2011 (2, 86). A reference group including interest groups, researchers and clinicians/therapists met twice to discuss relevant topics for the questionnaire and give advice on the content. The purpose of including this group of experts was to collect their views and input from important stakeholders with knowledge of the relevant field and population. Next, 13 individual semistructured, qualitative, face-to-face interviews were conducted with patients to explore what they considered to be important to them as patients receiving treatment. The patients were seven females and six males, aged between 18 and 63 years. Five of the patients had experiences mainly with treatment for alcohol dependence, while the remaining eight had experiences with treatment for dependence on illicit drugs; some had several years of experience in multiple institutions, while others had shorter experiences with just one institution. The results from the interviews were analysed using conventional content analysis (87, 88) and were found to be highly consistent with those from the literature review and with the input from the reference group (2, 86).

After collecting all of the information from the patient interviews and reference group, the next step was to construct the questionnaire. The questions in the questionnaire focused on whether certain properties or behaviours were present at the institution and relied on factual descriptions rather than expectations and evaluations of how these were met (39–42). A preliminary draft of the questionnaire was thereafter tested in cognitive interviews, including 15 patients at 3 different institutions. The goal of these cognitive interviews was to explore how the patients evaluated the content, structure and format of the questionnaire (89). The results indicated that the patients found the questions relevant and easy to understand. Some minor changes to the questionnaire were made, such as to the wording of some questions, the placement of others and the inclusion of some new questions (2). Together these phases constituted the construction of the final questionnaire that was used in a pilot study.

A pilot study provides an opportunity to test the questionnaire in a similar population to that used in its development, and to detect any weaknesses. The use of a smaller pilot sample makes it possible to correct these weaknesses or mistakes before employing a large and costly

survey (90). The pilot study for the developed questionnaire was conducted at 14 institutions. The data were collected while the patients were living at the institutions, using two data-collection methods: (i) the patients received and replied to the questionnaire close to their date of discharge, and (ii) all patients living at the institutions received and replied to the questionnaire on the same day (cross sectional approach). Some of these patients also participated in a retest a few days later. A comparison between the two groups showed that the first group had stayed at the institution for a longer time, and hence had a longer experience with the institution, and that this group expressed somewhat more positive experiences. However, the second data-collection method reached all patients, including those with an unplanned discharge, and imposed a lighter workload on the employees.

The data collected from the pilot study were then analysed to explore missing data, such as non-response or portion replies of “not applicable”. Exploratory factor analysis (EFA) was conducted to determine the factor structure and dimensionality, and test–retest analyses were conducted to evaluate the reliability of the scales. Only minor changes were made to the questionnaire after the pilot study (2).

The final questionnaire included 45 questions designed to measure patient-experiences with their treatment and the institution. The questionnaire also allowed the writing of free-text comments to elaborate further on their experiences with the institution, or any comments pertaining to the questionnaire itself. In 2013, when planning began for the first national survey into interdisciplinary treatment for substance dependence, this questionnaire was expanded with six questions: three questions modified from the Patient Enablement Instrument (91), and three questions asking the patients about any help they received from the municipality. Thus, the 2013-questionnaire ultimately comprised 51 closed-ended questions and 2 open-ended questions: one asking patients to write more about their experiences at the institution, and another focused on the experiences with help and/or care from the municipality (84). The 2013-questionnaire is provided in Appendix 1. Over the survey-years, other questions have been added to address political initiatives (e.g. “pakkeforløp” implemented by the Norwegian Directorate of Health), increasing the number of closed-ended questions in the 2017 version of the questionnaire to 58.

The topics covered in the questionnaire were: (i) reception and waiting time, (ii) the therapists / the personnel, (iii) the treatment, (iv) the milieu and activity provision, (v)

preparations for the time after discharge, (vi) other assessments, (vii) previous admissions, (viii) help from the municipality, and (ix) background information. Most questions were scored on the following five-point Likert response scale: 1 = not at all, 2 = to a small extent, 3 = to some extent, 4 = to a large extent and 5 = to a very large extent. Most of the questions also included the option of “not applicable” or “don’t know”; these alternatives were added to discriminate between patients missing or skipping questions due to them not being relevant for the patient. This five-point Likert scale has been used as standard in the NIPH’s patient-experience surveys, following the finding that this scale outperformed the previously used ten-point scale (92).

3.2.2 Employee questionnaire

The questionnaire used in the four employee surveys was developed and used in a survey among staff at a French university teaching hospital (93). The hospital had been conducting patient-satisfaction surveys systematically for several years, and the researchers wanted to assess the opinions of the staff about the patient surveys as well as the use of the findings from those patient surveys in quality-improvement work. The procedure for developing the questionnaire shares many traits with the model used by the NIPH described above. The researchers conducted semistructured interviews that underwent content analysis to identify important themes that should be covered by the questionnaire. The questionnaire comprised 17 closed-ended and 4 open-ended questions. Factor analysis used to assess construct validity yielded two factors; the internal consistency of those two factors had a Cronbach’s α of >0.70 (93).

In 2007, the NIPH set out to conduct a similar study among employees at specialized paediatric departments in Norway, following a national parent-experience survey in 2005 (79, 94). The Norwegian questionnaire relied heavily on the questionnaire developed by Boyer et al. for use at a French university teaching hospital (93), with some Norway-centric modifications (i.e. the Norwegian health services and the aims of the NIPH). The focus of the questionnaire was the employees’ attitudes towards user involvement and user experience surveys and their use of the results from the national parent survey, as well as on whether the parent survey was deemed useful. The questionnaire comprised 18 closed-ended and 6 open-ended questions (79).

Before the first national patient-experience survey on residential treatment for substance dependence in 2013, the NIPH modified the employee questionnaire so that it would be relevant in this new setting, see Appendix 2 for the 2013-version. Some wording was changed to accommodate the specific part of the health services, and some changes were made in the background variables. The questionnaire used in 2013 comprised seven questions regarding the employees' attitudes towards patient involvement and patient experience surveys, and a question on whether their institution had carried out any local (i.e. own) patient-experience surveys. In addition, six background questions asked about sex, age, number of years employed at the institution, the type of work in which they participated, if they had a leadership position and their professional background (Paper III).

Before the second national patient-experience survey, conducted in 2014, the employee questionnaire was expanded with questions regarding if and how the employees had used the results from the patient survey the previous year in their quality-improvement work, and if they found the patient survey useful in that regard. A large portion of the questionnaire was scored on a five-point Likert scale ranging from "not at all" to "to a very large extent", and the remaining questions were predominantly scored on a categorical response scale. The questionnaire also contained five open-ended questions asking the employees to describe any behavioural changes among the staff or quality initiatives implemented after seeing the results of the patient surveys, barriers to using the patient survey results, any comments on how the NIPH presented these results, and any suggestions on topics they felt either the patient or employee questionnaire lacked or other issues regarding either survey. This expanded questionnaire, which comprised 27 items, was used in the last three employee surveys: 2014, 2015 and 2017 (Paper III). The three latest versions of the employee questionnaire are provided in Appendices 3–5.

3.3 Data collection

3.3.1 Patient survey

The first patient survey among patients receiving residential treatment for substance dependence was commissioned in 2013. The population of interest was all patients aged at least 16 years who were receiving residential treatment for substance dependence. Both public residential institutions and private residential institutions with a contract with the regional health authorities were included. Detoxification units and patients treated for

gambling addiction were excluded. All four patient surveys were commissioned by the Norwegian Directorate of Health, and participation was mandatory for the included institutions.

The national patient-experience surveys carried out by the NIPH usually invite patients to participate in a survey after their discharge or consultation. However, a previous Norwegian survey of psychiatric inpatients and sub-groups (including patients with substance dependence) showed that the response rate to such a mailed-to-home survey was very low, which jeopardized both the validity and the usefulness of the findings (95). Therefore, the method for data collection in this population was changed from post-discharge to on-site and while the patients were still in treatment. On-site data collection was employed for all four patient-experience surveys among patients in residential treatment for substance dependence, and were thus conducted as cross-sectional surveys. The NIPH decided which week the institutions were to collect the data, but the institutions themselves decided on which day in the given week. All patients were asked to complete the surveys on the same day to avoid discussions between patients and potential coordination of responses (cross-contamination). This method has also been used in a national survey among psychiatric inpatients (83).

Before implementation of the survey in 2013 there was little oversight of the different institutions in Norway providing residential treatment for substance dependence. The NIPH (then as the Norwegian Knowledge Centre for the Health Services, NOKC) reached out to the four regional health authorities to request the contact information of hospital trustees. These trustees were then asked by the NIPH to provide a full list of the residential institutions that operated either directly under the hospital trust, or private institutions from which the hospital trust purchased residential treatment. Contact information to persons at each of these institutions was also provided. In this way the NIPH was able to establish direct contact with each of the institutions included in the national survey during the months prior to survey data collection. The institutions named two employees: one who would be the local project leader, and a substitute. Since the project leader was to be in charge of the data collection, it was important to have close contact and to enable rapid exchange of information.

Prior to the first patient survey, the NIPH arranged telephone conferences with the local project leaders. The questions and discussions raised in these conferences and in other communications such as e-mail or telephone were used to shape the information given to the

institutions by the NIPH. The NIPH usually sends out flyers or posters with information regarding patient-experience surveys prior to their application; however, for the present population this was not done in order to avoid too much discussion by and possible influence on the patients before they received the questionnaires.

In the weeks leading up to each of the four surveys, the NIPH sent all the necessary material to each of the institutions. Paper questionnaires were prepacked in envelopes, one for each patient (with some additional copies). The envelopes also included an information letter explaining the purpose of the survey, and an envelope that the patients could use to return the completed questionnaire. The project leaders at the institutions were responsible for handing out the questionnaire, ensuring that the participating patients could complete them alone in quiet conditions to prevent them from discussing the responses with anyone, before collecting the sealed return envelope from those patients who chose to participate. Employees were allowed to help patients who had trouble reading or understanding the questionnaire, but they were instructed not to influence the responses given by the patients.

The surveys were conducted as anonymous quality-assurance projects. No register of participating patients was established and no patient background information was collected other than that requested on the questionnaire itself. Table 1 shows the information the local project leaders provided to the NIPH to enable calculation of the response rate, such as the number of patients staying at the institution on the given survey-day, how many received the envelope containing the questionnaire, how many were not present, how many did not wish to participate, and how many were excluded due to ethical considerations.

In 2013, one out of every fourth envelopes handed out also contained a retest questionnaire, which was identical to the first questionnaire. Patients receiving these were asked to respond to the retest at least 2 days after the main survey. The number of retests handed out was sufficient to ensure that a large enough number of patients received one, and that at least some patients at each institution received one. In addition, this method ensured some level of randomization, given that the NIPH had no control over which envelopes were provided to which patient within each institution.

Table 1: Response rates for the patient surveys by year.

Year	2013	2014	2015	2017
Number of institutions	98	101	110	110
Gross sample	1245	1279	1472	1449
Not present at institution	163	143	119	130
Excluded due to ethical considerations	12	23	33	25
Excluded	175	166	152	155
Corrected sample	1070	1113	1320	1294
Respondent	978	1017	1184	1172
Response rate	91.4%	91.4%	89.7%	90.6%

3.3.2 Employee survey

Prior to each of the four patient-experience surveys, the NIPH asked the local project leaders to recruit employees and leaders at their institution to participate in a survey asking about their attitude towards and use of patient-experience surveys. Convenience sampling was employed to ensure a broad range of views, experiences and opportunities to influence the institution, with the aim of recruiting (i) department managers, (ii) institution managers, (iii) quality advisors and (iv) one or two employees working specifically with quality assurance and improvement. In addition, the local project managers themselves were asked to participate. In general, between two and five employees were recruited at each institution, although some institutions did not recruit anyone and others recruited more than five. Table 2 shows the number of participants and the calculated response rate.

Table 2: Response rates for the employee surveys by year.

Year	2013	2014	2015	2017
Number of institutions	98	101	110	110
Sample	384	403	432	416
Respondents	304	244	266	279
Response rate	79.2%	60.6%	61.6%	67.1%

One week before the scheduled patient survey, each participating employee or manager received an e-mail containing a link to an online questionnaire. The online survey was conducted through Easyresearch/Questback (<https://www.questback.com/no/>) and later through TSD (Tjeneste for Sensitive Data) from the University of Oslo (<https://www.uio.no/tjenester/it/adm-app/nettskjema/>). Non-respondents received up to two reminders during that week.

3.4 Analysis of survey data

All quantitative data described in the following were analyzed using IBM SPSS Statistics for Windows, versions 23.0 to 26.0 (IBM, Armonk, NY, USA). The exception being the actual case-mix adjustment of the quality indicators described in Paper II, where R statistics, version 3.5.1 (and earlier) were used (available at <http://www.r-project.org>). Qualitative free-text comments made by both patients and employees were analysed using content analysis. Descriptive statistics are presented in all three papers as frequencies, percentages and mean values.

3.4.1 Paper I

Missing item and variability

The first step in the analysis of data from the first patient-experience survey in 2013 involved exploring the rate of missing values and utilization of the response scale of each item. The ceiling effect was examined by evaluating the portion of responses in the most positive response category. If the ceiling effect was smaller than 50%, the item was judged as being of adequate quality (96, 97). Missing items were assessed using missing-value analysis. The NIPH generally uses a cut-off of 10% for missing items (i.e. “not applicable” responses and skipped items). However, since the PEQ-ITSD instrument contained some questions already known to be less relevant for some of the patients (e.g. questions about certain treatments, such as medication), the cut-off for missing items was increased to 20% for this population.

Exploratory factor analyses

EFAs are used to interpret correlations in a given data set, and can reveal whether the responses to questions or items entered in a questionnaire are influenced by the same underlying dimension or factor (98). Items excluded from the EFAs were (i) items with >20% missing responses, (ii) background information, (iii) items focusing on other services than the residential institution and (iv) one item regarding incorrect treatment, so that some theoretical considerations also weighed in when analysing and constructing the subscales. All other items were entered into the EFAs. Given the nature of patient experiences, some correlation between the factors may be expected and so principal-axis factoring and oblique (promax) rotation were used (98, 99). Listwise deletion of cases was applied (100).

Two factor analyses were conducted: one with the items concerning structure and process (e.g. relationship and contact with clinicians/personnel) and another with the outcome-items

(e.g. effect of treatment at the time of measurement). The reason for conducting two analyses was to avoid contamination between the different types of items. Items with factor loadings below 0.4 and cross-loadings exceeding 0.3 were excluded, to ensure the best fit of the factor structure. The criterion for rotation was set to eigenvalues greater than 1.

Reliability

Cronbach's α and item-total correlation are commonly used to assess the internal consistency of subscales. All items in each subscale should contribute to the α ; hence, Cronbach's α is an assessment of the correlation between all items of the subscale. A common cut-off for α is ≥ 0.7 (100, 101). Item-total correlation is the correlation between each item and the total score of the remaining items of the subscale. As with the α , the criterion for inter-item correlation has become stricter over the years, with the coefficient increasing from 0.2 (102) to 0.5 (100). The most commonly used coefficient criterion for assessing internal consistency is 0.4 (103–106).

The intraclass correlation coefficient (ICC) was calculated to explore the test-retest reliability. Reliability was tested by correlating each subscale score from the patient survey with the corresponding subscale scores from the retest. The ICC was calculated with a two-way mixed-effects model and absolute agreement. The criteria were as follows: <0.5 , poor; $0.5–0.75$, moderate; $0.75–0.90$, good; and >0.90 , excellent (107).

Construct validity

Construct validity indicates whether a questionnaire or parameter measures a specific underlying construct (102). This can be based on theoretical knowledge or by testing if the scale scores are associated with other known measures in a way that could be expected. This association is often tested through correlations that show both the strength and the direction of association between the two variables under scrutiny. The association between the subscales determined using EFA was tested using an independent-samples *t*-test for one categorical variable, while Pearson's *r* was used to test the continuous variables. When testing the construct validity, hypotheses were formulated based on how the scale scores were expected to behave when correlated with other measures.

Based on experience from national patient-experience surveys in other populations and advice obtained from experts in the field, we hypothesized that patients reporting alcohol dependence would display more positive experiences compared with those with other types

of dependency (108, 109). In addition, it was hypothesized that waiting time (110, 111) and the pressure to receive treatment would be negatively correlated with the scale scores (83). Age is often found to be associated with patient experiences or satisfaction, and it was expected that age would be positively correlated with the scale scores in the present study (42, 108, 109, 112–114). Finally, we hypothesized that the two items measuring self-perceived physical and psychological health would be correlated (i.e. that patients reporting better self-perceived health would report better experiences) (42, 109).

3.4.2 Paper II

Determining level of health care for reporting quality indicators

Given the relatively small sample at each institution (many with ten or fewer beds), it was decided that a merged data set based on the surveys from both 2013 and 2014 should be used to enable the reporting of quality indicators. In Paper II, the 5-point scale used in the questionnaire was linearly converted to a scale from 0 to 100, whereby a higher score indicated a better outcome. To obtain a scale score, a respondent had to answer at least half of the questions for that scale. Since several of the participating institutions could be grouped into hospital trusts or private organizations with underlying departments/institutions (termed “hospital trust” henceforth), as well as in regional hospital trusts, it was possible to explore and inspect the properties of these scales at several levels of health care. Grouping the institutions in this way allowed assessment of the standard error of the scale scores, thereby revealing the health-care level at which the statistical uncertainty was too large. The criterion employed in other national patient-experience surveys performed in Norway was used, and thus scale scores were computed only where the standard error was lower than 6. This criterion meant that the hospital-trust level (i.e. public hospital trusts or private organizations with more than one underlying unit [institution]) was chosen to represent the provider level in the present study.

Weighting the data

Given that different patient groups may have different probabilities of responding to surveys, the results of national surveys reported by the NIPH are usually weighted to address non-response. If data are not weighted there is an increased risk of some groups being underrepresented. Weighted results are more representative for the entire patient population,

and not only those who chose to respond to the survey; hence, a common approach is to weight the data based on the probability of different groups responding (115).

The NIPH had no information on non-respondents since the four cross-sectional patient-experience surveys were conducted anonymously. The results were therefore weighted based on the self-reported length of stay at the institution to compensate for the probability of being sampled increasing with the duration of the stay.

Multilevel analyses

When measuring patient experiences, it is useful—and sometimes a main aim—to be able to compare between health-care providers. Health-care providers are not compared directly in the Norwegian program for patient-experience surveys, with instead each provider being compared with the mean of all providers on a given scale. However, health-care providers may provide different services to patient groups and the composition of the patient groups may change over time. Moreover, patients with different socio-demographic backgrounds or health characteristics may describe the quality of health care differently, making it necessary to develop and apply appropriate case-mix adjustments to ensure that comparisons are valid (109, 116, 117). Case-mix adjustments use statistical methods to predict what each health-care provider's score would be for a standard patient group, thereby removing predictable effects of differences in patient characteristics from the comparisons (118). Making such case-mix adjustments increases the accuracy of the results when making comparisons between health-care providers (117).

Associations between independent variables (i.e. background information from the questionnaire) and the scales were assessed by first performing bivariate multilevel analyses. The NIPH usually starts with bivariate linear regression (ordinary least squares [OLS]), but due to the nested nature of the data for this population, multilevel analyses were considered more suitable in order to compensate for the violation of the prerequisite for OLS that data are statistically independent (119). The most frequently used cut-off for determining the necessity for multilevel modelling is $ICC > 0.01$ (120), while the design effect, which in this case was calculated based on the mean number of responses across the hospital trusts and the ICC for each of the scales, should be > 2 (121).

The analyses only included institutions for which there were respondents from both survey years. After reviewing the scientific literature and concluding that there was a scarcity of

similar studies, we adopted an exploratory approach when testing the data material for developing the case-mix model. This approach was based on (i) scientifically published literature, (ii) the effect of background variables on the scales, (iii) the distribution of the background variables across the institutions and (iv) advice from external experts. The new variable of mixed use was also computed, which is the sum of how many substances each respondent reported to be using prior to admission, with values ranging from 1 to 6. This variable was computed to act as a proxy for the severity of dependence, which was suggested in several of the aforementioned sources as a possible adjuster.

Variables that were significantly associated with at least one of the scales in the bivariate models were entered into a multivariate model, while mixed use and survey year were entered into the multivariate model regardless of the results from the bivariate analyses in order to control for the effects of severity of dependence and time. The hospital trusts were entered as random intercepts into the null-model, which was used to calculate the proportion of the variance explained at the hospital-trust level based on the ICC. The full model included hospital trusts as random intercepts and all patient variables that were statistically significant ($p < 0.05$) on at least one of the scales in bivariate models as fixed effects. The variance explained by the full model was calculated as described by Snijders and Bosker (119).

Based on the findings from the multilevel analyses, adjusted scores were calculated for the hospital trusts on the three scales which constitute the PEQ-ITSD. Patient characteristics that were statistically significant on at least two of the three scales in the multivariate analysis were included in the case-mix model.

3.4.3 Paper III

In addition to the analyses described below, we conducted an EFA for the attitude questions in the employee questionnaire and tested the internal consistency of the scale (see the descriptions in Section 3.4.1).

One-way analysis of variance

One-way analysis of variance (ANOVA) allows for comparisons between groups on continuous variables to test whether the group means are statistically different from each other (99). Bonferroni's *post-hoc* test was applied to identify between-groups differences that were statistically significant. This *post-hoc* test modifies the significance level to account for more than one comparison being made.

Chi-square test

Chi-square tests were applied to test for group differences in categorical variables between the survey years (122).

Content analysis

Content analysis was applied to the responses to the open-ended questions in the employee questionnaire. Two researchers read each comment independently and categorized them into major topics. When new themes emerged, the categories were revised and the new theme checked for its fit with the other categories, thereby either becoming a new category or being integrated into and expanding an existing category. Content analysis of each topic was conducted to identify the most important themes (123). A consensus on the content of the comments was reached through discussions between the two researchers. Most of the questions in the employee questionnaire focused on the topics from the patient questionnaires, and it became clear that these topics could also be used to structure the responses from the employees.

3.5 Ethical considerations

3.5.1 Patient surveys

The national patient-experience data were collected anonymously, with no patient registration. The project was run as an anonymous quality assurance project and as a part of the national program. The Regional Committee for Medical and Health Research Ethics does not require research approval for quality assurance projects. The Norwegian Social Science Data Services states that if the information used is obtained anonymously, the project is not subject to notification. The data collection and the projects were concluded before implementation of the General Data Protection Regulation in Norway, and so no ethics approval was needed for the patient surveys. Patients were informed that their participation was voluntary and that they would remain anonymous. In accordance with all of the patient surveys in the national program, health professionals at the institutions could exclude individual patients for specific ethical reasons. Since no notification or ethics approval was needed, the NIPH obtained signed agreements with all of the participating institutions, describing the project and the responsibility of both the institutions and the NIPH for data collection, handling, analysis and reporting. Previously established guidelines concerning consent through a returned questionnaire were applied.

3.5.2 Employee surveys

The 2013, 2014 and 2015 surveys were approved by The Norwegian Social Science Data Services; the 2017 survey was approved by NIPH Data Protection Official.

4 SUMMARY OF RESULTS

4.1 Paper I

“Patient Experiences Questionnaire for Interdisciplinary Treatment for Substance Dependence (PEQ-ITSD): reliability and validity following a national survey in Norway”

In the 2013 survey, 978 patients from 98 institutions replied to the questionnaire. Few respondents left out items when responding, with the proportion of missing data ranging from 1.9% to 4.9%. The rate of responses in the “not applicable” category ranged from 0.3% to 29.6%. These two parameters together constitute the missing-item parameter. The following 5 of 33 items had a higher proportion of missing items than the cut-off for being entered into the EFAs (20.4%): #12c, benefit of treatment with medication; #18, help for psychological distress; #27 and #28, help with practical issues and further treatment after discharge; and #34, the personnel’s cooperation with patients’ next of kin. One item, “been subjected to malpractice”, had a higher response rate than the cut-off in the most favourable category (50%), with 51.4% of patients reporting “not at all”. All background variables and the following four items not focusing on experiences at the institution were excluded from the EFAs: #5 (“Did you have to wait to be admitted to the institution”), and #35 (“To what extent did you feel pressured/forced by others to be admitted?”), which were treated as background information; #11 (“Have you been patronized or insulted by the therapists/staff?”), where the response categories were too different to be added to the EFAs; and #36 (“Do you believe that you have been incorrectly treated in any way [according to your own judgement]?”) which were not entered into the EFAs due to a different focus compared with the other patient-experience questions.

Twenty-seven items were included in the EFAs. Separate factor analyses were conducted for the items related to structure and process and those related to outcome in order to avoid contamination between different aspects of the quality of care. Twenty items focused on structure and process and were entered into the first analysis. The following three items were excluded due to low factor loadings: #3 (“Were you informed of the institution’s rules and routines when you arrived?”), which had the lowest factor loading, and also cross-loaded with other factors; #23 (“Have the activities offered at the institution been satisfactory?”), due to low factor loading, and the presence of cross-loading; and #25 (“Have you been satisfied

with the possibility for privacy?”), due to low factor loading. The final factor solution comprised 17 items, which resulted in 2 factors that explained 51.8% of the variance.

Seven out of the original 27 items were related to outcome and relevant for inclusion in the second EFA. Three of these items were removed before running the analysis: #12c, due to high proportions of responses in the “not applicable” response category; and #12a and #12b, since both of these focused on specific treatments and hence were not as relevant as general outcome measures. Accordingly, five items were entered into the second EFA, which yielded one factor that explained 73.4% of the variance.

The EFAs identified three scales: “treatment and personnel” with 12 items, and “milieu” and “outcome” with five items each. The coefficients for item-total correlations of the scales were all ≥ 0.4 . Cronbach’s α was 0.75 for “milieu” and 0.91 for the other two scales. The test–retest reliability parameter was greater than 0.8 for all scales ($n=187$), indicating good-to-excellent stability. Seventeen of the 18 associations were statistically significant ($p<0.05$) according to the hypotheses.

4.1.1 Conclusions: Paper I

The PEQ-ITSD was developed using a thorough and well-established model, which ensured its content validity. Testing of the questionnaire showed that this instrument comprised three scales (“treatment and personnel”, “milieu” and “outcome”), which all showed good internal consistency and stability, as well as construct validity. The questionnaire showed good acceptability, with a high response rate and a low proportion of missing data.

4.2 Paper II

“Patient experiences with interdisciplinary treatment for substance dependence: an assessment of quality indicators based on two national surveys in Norway”

Paper II included data from the patient-experience surveys conducted in 2013 and 2014. In the 2014 survey, 1017 patients from 101 institutions completed the PEQ-ITSD. The merged data set therefore consisted of 1995 responses. The level of analysis was hospital trusts with more than one underlying institution. However, not all institutions could be categorized as hospital trusts, and so the analyses were performed with 1452 respondents from 21 hospital trusts (25–154 respondents per trust).

Multilevel bivariate regressions analyses revealed that 11 out of 16 variables were significantly associated with at least 1 of the 3 scales identified in Paper I (“treatment and personnel”, “milieu” and “outcome”; $p < 0.05$). The five variables that were not statistically significant were (i) “heroin/morphine” reported as the most frequently used drug prior to admission; (ii) “other” reported as the most frequently used drug prior to admission; (iii) mixed use; (iv) marital status and (v) education. The other variables and also mixed use and survey year were entered into the multilevel multivariate regression. Patients reporting alcohol as their most frequently used substance prior to admission, and female patients reported significantly better experiences on the “treatment and personnel” and “outcome” scales when other factors were controlled for. Respondents with longer stays at the institutions reported better experiences with “treatment and personnel” and “outcome”, but worse experiences on the “milieu” scale. Older patients reported better experiences on the “treatment and personnel” and “milieu” scales. Being pressured or forced by others to be admitted for treatment or having worse self-reported physical and/or mental health negatively influenced the scores on all three scales.

The ICC was 2.3% for the “treatment and personnel” scale, 8.1% for “milieu” and 4.8% for “outcome”. The design effect was >2 for all three scales. The proportion of the variance explained in the full model was 7.62% for “treatment and personnel”, 6.97% for “milieu” and 7.72% for “outcome”.

The weighted and case-mix-adjusted scale scores for the 21 hospital trusts were 54–66 on “treatment and personnel”, 62–87 on “milieu” and 59–77 on “outcome”. The mean national scale score was 61 for “treatment and personnel”, 75 for “milieu” and 68 for “outcome”. One hospital trust obtained a score that was significantly lower than the national mean for “treatment and personnel” ($p < 0.01$). For “milieu”, four hospital trusts scored lower than the national mean ($p < 0.01$ to $p < 0.001$), and two had higher scores ($p < 0.05$ to $p < 0.001$). Four hospital trusts varied significantly from the national mean on “outcome”, with two having higher scores and two having lower scores ($p < 0.05$ to $p < 0.001$).

4.2.1 Conclusions: Paper II

The following variables were suggested as case-mix adjustors when measuring patient experiences in similar populations: alcohol as the most frequently used substance, length of stay, pressure from others to be admitted for treatment, sex, age, and self-perceived physical

and mental health. Mixed use and time (e.g. survey year) should also be considered. The “outcome” scale was not adjusted for self-perceived physical and mental health, since changes in health can be viewed as an outcome of patients receiving treatment at the institutions.

The three scales comprising the PEQ-ITSD (“treatment and personnel”, “milieu” and “outcome”) functioned well as patient-experience-based quality indicators given that the scales were reported at the hospital-trust level, and so a merged data set covering 2 years was used and the proposed case-mix model was implemented. The variations in scale scores across health-care providers showed that the indicators can be used to discriminate between different providers, suggesting that scale scores can be improved through quality-improvement work.

4.3 Paper III

“National surveys of patient experiences with addiction services: do employees use the results in quality initiatives and are results improving over time?”

The EFA conducted with the five attitude questions in the employee-questionnaire revealed that the questions could be reported as a unidimensional scale, for which Cronbach’s α was 0.8 for all 4 years. The scale scores were higher than 80 for all survey years, but a slightly lower score was obtained in 2017. Although one-way ANOVA revealed a significant change over time in the attitude scale ($p < 0.05$), it was not supported after Bonferroni *post-hoc* correction. When testing the individual scale items, the score for item 5 was significantly lower in 2017 than in the two earlier surveys. The results were somewhat less positive for the item regarding whether the national patient-experience survey was useful for the institution, but the scores remained over 3.

The patient experience indicator with the best scores across the years was “milieu” (range, 75–77), followed by “outcome” (range, 68–70) and “treatment and personnel” (range, 60–63). The scores were the highest in 2017 for all three scales, and Bonferroni *post-hoc* correction revealed that the differences between the years were mostly attributable to the scores in 2017 being higher than those in 2013 or 2014.

The proportion of respondents reporting that their institution had implemented at least one improvement initiative after the patient survey performed during the previous year increased

from 40% in 2014 to around 50% for the later years. Most of the initiatives targeted preparations for the post-discharge time, the treatment, the milieu and activities, and the therapists or the personnel.

One of the open-ended questions asked employees to describe changes in their behaviour induced by the results from the patient-experience surveys. The number of responses to this question increased over time, at 48 (12%), 74 (28%) and 94 (34%) in 2014, 2015 and 2017, respectively. Content analysis showed that there were 50 (23%) comments on how employees had increased the user involvement in their work. Forty employees reported that they had tried to improve in the areas that had been identified as being worse than expected or desired from the patient-experience survey, or had targeted areas in which they knew they could improve. Other comments addressed the treatment; communication and information; the relationship between health personnel and patients; preparations for the post-discharge time; the milieu and activity provision; and providing more resources and positions, and organization in general.

The employees who responded that they had implemented improvement initiatives after the previous patient survey were asked to provide more details. This open-ended question was answered by 33–41% of the respondents across the survey years. Many of the initiatives focused on the organization of or the methods employed at the institution, and addressed routines. There were 81 comments describing different initiatives (27%) for ensuring that tasks were completed in a timely manner and in a better/more systematic order than previously. Routines for admitting new patients were highlighted in 58 (19%) comments. Sixty (20%) comments described initiatives targeted at preparing patients better for the post-discharge time. Other topics covered in these open-ended comments included a greater focus on activities for the patients, education and counselling for employees, patient involvement, working with friends or family, coordinating care, hiring more clinicians/personnel, and providing better information.

About half of the employees made comments in the open-ended question that was related to barriers to using the results from each patient-experience survey, with 40–50% implying that they experienced no barriers. The most common explanation of barriers was a lack of resources ($n = 50$) such as money, time, personnel and workload. Other employees ($n = 26$) found the patient-experience survey difficult to use due to the long time between

measurement and reporting, or had difficulty interpreting the results. Explanations for these difficulties were that the questions did not fit the patient group, the patients were no longer in the institution, or new patients not agreeing with the results or knowing what the previous patients meant in their responses. Twenty-one (5%) employees replied that there were few responses from their institution, making the results more uncertain. Other barriers included (i) many other things going on at the institution, such as changes or reorganization; (ii) lack of interest or priorities from the leaders; (iii) other initiatives or surveys already being implemented; and (iv) the results being primarily positive.

4.3.1 Conclusions: Paper III

The experiences of the patients improved slightly over time, with the best experiences being reported in the most recent survey for all indicators. Employees reported that they actively used the results from national patient-experience surveys when implementing quality-improvement initiatives. They also reported generally positive attitudes towards such surveys, but were somewhat less positive about the usefulness of the surveys for their own institutions. The most common quality-improvement initiatives involved targeting areas that had the worst findings in the patient-experience survey.

5 DISCUSSION

The overall aims of this thesis were to validate a questionnaire used in national surveys, the PEQ-ITSD, to test the data material through these surveys for use as quality indicators and to explore employees' reported use of these data in their local quality-improvement work. The following discussion elaborates on topics and methodological issues introduced in the papers of this thesis.

5.1 Methodological considerations

5.1.1 Overall study design

The work performed for this thesis involved further developing and testing an instrument for measuring patient experiences with interdisciplinary treatment for substance dependence. The patient-experience data were used to develop and test quality indicators. The employees working at residential institutions were also surveyed, which provide the opportunity to determine how employees viewed patient experiences, how results from the patient surveys were used in quality-improvement work and whether changes in patient experiences could be detected across the four survey years.

The main strengths of the work described in this thesis are the implementation of a systematic and comprehensive method of evaluating the patient questionnaire; the use of national data sets including all institutions in Norway; the large number of surveys conducted to ensure the collection of good-quality data; and that both the employees and patients were followed. In addition, the development of the original questionnaire followed an established and well-tested approach that included a review of the literature, discussions within a reference group, qualitative interviews, cognitive interviews and a pilot study. The surveys employed the same data collection method for all survey years, ensuring that changes in patient and employee scores were not due to methodological inconsistencies. The patient instrument demonstrated good psychometric properties and the patient data functioned well as patient-experience-based quality indicators. Patient experiences improved slightly over time, in line with the findings of the employee-surveys showing that the results from the patient-experience surveys were used in quality-improvement work.

5.1.2 Validity, reliability and bias

Internal validity concerns the degree to which the results are attributable to the independent variable and cannot explained by other factors (124). When measuring patient experiences, it is essential that the questionnaires used are valid and reliable. The rigorous development process employed here (as described in Section 3), including the literature review, qualitative interviews, reference group meetings, cognitive testing and the pilot study, ensured the content validity of the PEQ-ITSD. The questionnaire assessed aspects of treatment that were relevant to most patients receiving residential treatment. Some questions had a higher proportion of missing items (Paper I); however, those items were kept in the questionnaire because patient interviews and reference-group discussions had deemed them to be important to patients for whom they were relevant. Analysis of the qualitative interviews identified important topics and themes, and the quantitative analysis identified factors, or scales, suitable for measuring patient experiences in national surveys. Some findings of the qualitative and quantitative patient data overlapped, whereby all scales of the PEQ-ITSD could be identified in the qualitative data from both the early stages of development and the national surveys.

In the literature review performed prior to developing the PEQ-ITSD (85), some relevant questionnaires were retained (108, 110, 125–128). However, these questionnaires focused on narrower populations than that planned for inclusion in the present large-scale surveys in Norway. Administering a questionnaire developed for use in a specific setting directly in another setting can cause problems. Many of the items might be inappropriate or irrelevant in the new setting, which may present difficulties for the target population and threaten the validity of any findings (102). In addition, several of the questionnaires focused on patient satisfaction and lacked items relating to patient experiences with structures and processes of care. When the search was updated in 2007 (2) and 2015, no new relevant questionnaires were identified, indicating that research in a broader patient population that involved every patient receiving residential treatment for substance dependence was lacking. The findings of the current thesis contribute to filling that gap.

Respondents use several cognitive steps when responding to an item in a questionnaire, because information must first be retrieved and anything that is relevant must be selected from that information before providing a response. Replying to an item can therefore be

challenging. One way to mitigate this challenge is to generate items that are as unambiguous and simple as possible (102). To that end, great care was taken during the development and redevelopment of the patient questionnaire, modifying it to improve the comprehension and relevance for the patient population, and in the process increasing the validity, enabling more accurate scoring (129) and reducing the number of missing items (89). The overall low item non-response rate (Table 1) indicates that the items of the PEQ-ITSD were easy to read and understand, and were relevant for the included patient population.

Study designs using common methods (e.g. self-reported questionnaires) assessed using common sources (e.g. patients or employees) for independent and dependent variables in the same study can threaten validity due to common-method variance (130, 131). This type of bias is a problem whereby variations in responses are attributable to the method of measurement rather than the actual variation of the respondents' scoring that the questionnaire is attempting to measure. The results from a survey influenced by common-method bias are contaminated by "noise" stemming from the questionnaire, which may result in spurious method-specific variance with biased observed relationships. Construct validity was assessed here by testing hypothesized associations based on the correlations of factors with relevant background variables (Paper I), all of which were reported in the same questionnaire and thus carry a risk of common-sources bias. Using information from another data source will overcome this problem (131). Since the patient surveys were conducted anonymously, we were not able to collect data from Norwegian Patient Registry, for example, which could have reduced the risk of common-method bias in this study.

Response rates are often used as an indicator of data quality. A higher response rate suggests that the results are more trustworthy. However, an important aspect in surveys is not the response rate itself, but rather the degree of non-response bias (132). This can be assessed in two ways: (i) securing relevant variables in the sampling frame and analysing differences between respondents and non-respondents for these variables, or (ii) by interviewing non-respondents (133). Since the NIPH had no information about the non-respondents in either of the surveys, such non-response bias could not be assessed; however, the response rates for patients were so high ($\geq 90\%$) that non-response was not considered to be a substantial problem. The non-response rate was higher among the employees, but the lack of background information precluded such analyses. Therefore, whether or not non-responses introduced bias into the present study cannot be determined, and particularly so for the employee survey.

However, since responses were secured from most of the institutions, departments and hospital trusts, and from employees with differing education, background, and management statuses, we were confident that the views obtained from the employees represented a broad perspective. Furthermore, the employees were sampled using convenience sampling (i.e. the local project managers recruited employees based on specific criteria such that the results were not meant to be generalized); and the problem of non-response is therefore of less relevance (115). The rate of employee participation was bolstered by the NIPH informing them on multiple occasions about both the patient surveys and the purpose of the employee surveys, and by providing each non-responding employee with up to two reminders during the week leading up to the time when the patient surveys were due for completion.

Response bias may occur when the responses given on the questionnaire are not accurate (115). Self-administered questionnaires are at risk of response bias due to patients or employees selecting responses that do not truly reflect their opinions (102, 115). Response bias may have been present in the surveys described in this thesis. As with any survey of previous events, respondents were asked to recall events that had happened some time ago, which may introduce recall bias. All patients received the questionnaire on the same day, when some patients had been at the institution for several weeks, while others had been there for only a few days. Although the PEQ-ITSD predominantly includes items regarding instances that could occur on a more or less daily basis, the duration since some events (e.g. how the patients were received when they arrived at the institution) could influence the responses to some of the questions. Responses could therefore depend upon when the survey was conducted, and the responses could be somewhat affected by bias. However, given that the PEQ-ITSD focuses on experiences with specific behaviours or episodes in an institution in which the patients still reside, we believe that recall bias was of less importance in the present patient surveys.

The employee surveys were conducted 1 week before the patient surveys in each survey year, so at least 6 months would have passed since the results from the previous year's patient survey had been published. The time since publishing and the possibility that institutions could be working continuously on quality improvement based on several sources mean that some bias could have been introduced into the employees' replies. Some employees even mentioned this in their responses to open-ended questions, reporting that it was somewhat difficult to know whether the initiatives initiated at the institutions were due to the results

from the patient surveys, or when exactly the initiatives had started. Even so, many employees described that they often launched initiatives based on several sources, including the results from the patient surveys.

Social-desirability bias can also occur when conducting surveys. This type of bias arises when respondents present themselves in a favourable light when responding, rather than reporting their true feelings, experiences or opinions (102), thus threatening the internal validity of a study (134). For this reason, instead of asking employees about their own possible changes in behaviour towards the patients, we formulated the question so that each employee should evaluate whether the behaviour of “therapists/personnel” had changed (Paper III). However, the attitude questions in the employee survey could be subject to social-desirability bias, which should be considered when interpreting the results.

External validity

Since the patient surveys were mandatory at the institution level, we managed to measure all institutions with patients who were willing to participate on the day that the institution conducted the data collection. Because of this, and the high response rate for each year ($\geq 90\%$), the generalizability to the patient population as a whole was very good. The generalizability of the findings of the employee survey was less certain. However, generalizability was not the goal, as evidenced by the sampling method used, and one of the aims was to assess the reported use of the results at each institution. Furthermore, we also wanted to determine the attitudes of employees towards patient experience surveys. The relatively high response rate ($>60\%$ every year; Table 2) strengthens the possibility of the results being generalizable to all employees who meet the criteria for inclusion. Nevertheless, we had no background information about the respondents other than what they reported in the questionnaire, and no information at all about non-respondents. In addition, we do not know how the institutions differed in terms of employee status, or how many employees worked in quality improvement, increasing the possibility of reduced external validity and generalizability of the findings.

Quality indicators

The three scales tested in this study (“treatment and personnel”, “milieu” and “outcome”) are the first quality indicators based on patient experiences reported nationally in Norway for patients receiving residential treatment for substance dependence. The test–retest analysis of

the 2013 data showed good-to-excellent stability ($ICC > 0.8$), while the internal-consistency coefficient ranged from 0.75 to 0.91. These results mean that the rate of measurement error and statistical uncertainty were both low (102). The indicators were demonstrated to effectively discriminate between health-care providers, as indicated by the variation among the hospital trusts, suggesting that future studies could help to further improve quality (135).

Selecting and evaluating quality indicators is a comprehensive and challenging process. The OECD (Organisation for Economic Co-operation and Development) has named three criteria that should be met when selecting indicators: importance, scientific soundness and feasibility (136). Variations of these criteria have been used in some other studies evaluating quality indicators based on the perspectives of patients (137). The importance of a quality indicator can be addressed through the process of selecting the said indicator. The quality indicators in the present study were based on the PEQ-ITSD, which was developed using a thorough process, as described in this thesis. Each item (i.e. question) eligible for the indicators was based on findings in the scientific published literature, advice from expert groups, interviews with patients, through the researchers' experience from other patient population or from a combination of some or all of these elements. Together these features support the notion that the indicators were relevant to the patients, the clinicians and to persons working in or with the patient population. Furthermore, the national surveys were commissioned and funded by the Norwegian Directorate of Health, so that the indicators were important and relevant both professionally and politically. That the significance of quality indicators and measurement in this population is considered highly important and relevant is also supported by the agreements between the Norwegian Directorate of Health and the NIPH stating that the NIPH should assess the possibility of developing and reporting quality indicators and the commission being enacted several years in a row.

Scientific soundness requires validity, reliability and explicit evidence (136). According to Donabedian, there are three central components of quality: structure, process and outcome (70). "Structure" encompasses the physical setting and organizational characteristics in which health care is provided, while "process" comprises the methods by which health care is provided and is dependent on the structures that provide the resources and mechanisms to carry out care, therefore directly resulting in and impacting patient outcomes. "Outcome" considers the effects of care on the health status (70). The PEQ-ITSD contains questions concerning all three of these components, with "process" being the most covered. The

indicators “treatment and personnel” and “milieu” both contain items covering structure and process. The “outcome” indicator contains items regarding results and changes for the patients due to their stay at the residential institution.

The costs of measurement and data needs represent feasibility criteria (136). The patient surveys were conducted while the patients were living at the institutions, and the patients responded on a paper questionnaire. Since the surveys were conducted for all patients at each institution on the same day, there was no need to send nor indeed any possibility of sending reminders to non-respondents. The employee surveys were hosted on the Internet, whereby the employees received an e-mail with a link to the questionnaire. Both methods are relatively inexpensive (115), and the cost for each institution was very low given that the NIPH is responsible for planning and conducting the data collection.

5.2 Discussion of results and interpretation of findings

5.2.1 Measuring patient-reported quality using the PEQ-ITSD: Paper I

The PEQ-ITSD was developed using several important steps to ensure its validity and reliability. Including a literature review, meetings with reference groups, interviews with patients and pilot testing are all steps acknowledged as essential for developing a questionnaire with good measurement properties. Paper I presented the results from the validity and reliability testing, focusing on content validity, construct validity and reliability, which makes out several of the steps of the COSMIN (CONsensus-based Standards for the selection of health status Measurement INSTRument) checklist for assessing the quality of health-related patient-reported outcomes (138, 139).

The results from the literature review informed the project by identifying potentially important themes and questions to include in the PEQ-ITSD (2, 85). The scales identified through EFAs to some extent resembled two of the questionnaires identified through the literature review. The Treatment Outcome Profile (125) consists of three patient satisfaction subscales (treatment, staff and environment), while the Treatment Perceptions Questionnaire (110) has two subscales focusing on staff and the treatment program. The three identified scales of “treatment and personnel”, “milieu” and “outcomes” also correspond to the scales found in an on-site survey of psychiatric inpatients in Norway, a survey that is very similar to that used in the present study (83).

The scarcity of scientific published literature on patient experiences and validated questionnaires for a population such as the present Norwegian one (71, 85) rendered some of the evaluations and analyses more exploratory in nature. For example, the hypothesized associations constituting the testing of construct validity were based on the literature related to general patient satisfaction. The testing showed that several of the tested variables were significantly associated with the three scales of the PEQ-ITSD, but it is possible that other variables should also have been included in the testing. There is some information in the literature regarding assessments of patient experiences with treatment for substance dependence, and some published studies have focused on developing and validating relevant tools (84, 108, 110, 125–128, 140). However, several of these involved narrower populations than the present Norwegian one. Furthermore, a recent review in which 88 PREMs questionnaires were identified defined only 3 (including the PEQ-ITSD) as being specific to the condition of substance dependence (141), highlighting that this population remains underrepresented with respect to measuring treatment quality from the patient perspective.

The PEQ-ITSD was further validated using data from subsequent patient surveys. After each patient survey, researchers at the NIPH read and analysed all of the free-text comments made by the patients, and summarized the findings in their corresponding reports (142–144). Most of the topics raised and emphasized by the patients were recognizable from the patient questionnaire, further strengthening the validity of the questions, topics and scales constituting the PEQ-ITSD. Furthermore, the following sources of input among both patients and employees before and during the four survey years have been a highly valuable source of validation: the reference group, patient interviews, patients' free-text comments in the questionnaire, communication with employees before and during data collection, employees' responses to a questionnaire about the data collection in the patient survey, and employees' participation and their responses in the employee survey. All of these sources have been actively used during further development and implementation of subsequent surveys, as well as for informing the content of the PEQ-ITSD.

5.2.2 Predictors of quality of care and quality indicators: Paper II

The scales identified in Paper I were further examined in Paper II. In line with previous studies and the literature on quality indicators, one of the main aims was to develop a case-

mix model that could be used to adjust the patient results. This was done to examine whether the scales could be used and reported as national quality indicators.

The same case-mix model was suggested for all three scales or indicators, except for the “outcome” scale from which the two self-perceived health items were omitted. Self-perceived health might be expected to change due to the treatment received and can therefore be viewed as an outcome variable. Another variable that might have an impact on the “outcome” scale was length of stay, which was significantly associated with the three scales scores: a longer stay was positively associated with the “treatment and personnel” and “outcome” scales, but negatively associated with the “milieu” scale. This might have been due to patients who are generally more positive and have better experiences and outcomes receiving treatment for longer. Since the four surveys explored in this thesis were conducted in cross-sectional studies, it is important to consider that length of stay might exert a special effect on the “outcome” scale. This should be further explored using measurements made when patients are closer to discharge. It is possible that length of stay is only a relevant adjustor in cross-sectional studies. A case-mix adjustor should be specific to individual patients and outside the control of health-care providers (118). However, the length of stay can clearly be influenced by health-care providers. Still, in the present surveys, the aim was not to adjust for the actual length of stay of discharged patients, but to correct for the different institutions and hospital trusts having patients responding to the questionnaire regardless of how long they had been receiving treatment. Nevertheless, the suitability of length of stay should be re-evaluated whenever patient experiences are measured at or after discharge.

One clear limitation of the suggested case-mix model is that the only variables available were patient-reported responses. It is likely that other characteristics would be important to adjust for, such as patient administrative data and institution characteristics, and this should be considered in future surveys and measurements. The patient population was highly heterogeneous, and whether fair comparisons can be made, even with case-mix adjustments, should be discussed. The case-mix model should be considered as immature, and hence as a starting point for later development if and when other information than that from the questionnaires can be considered.

The discriminatory power of the scale scores assessed by calculating the proportion of the variance that was attributable to hospital trusts, and quantified by the ICC, showed that there

was a meaningful amount of variance at the hospital-trust level. The proportion of variability in the scale scores across hospital trusts was rather low. However, this is often the case in studies when the variability is assessed at several health-care levels, where most of the variability will usually be found at the department or patient level (145). Nevertheless, comparing the scale scores for the hospital trusts revealed that several of them varied significantly from the national mean, further supporting that the indicators are useful for discriminating between health-care providers. Local quality-improvement work thus has the potential to improve patient experiences, which are known to be associated with a higher overall quality of life. Patient quality of life, independent of other health conditions, could therefore be improved in the longer term (146). Furthermore, the duration of residential treatment and treatment satisfaction were found to be significant predictors of aftercare attendance, which was again associated with lower levels of substance use at 6-month follow-up (147).

5.2.3 Impact and relevance of patient-experience surveys according to employees: Paper III

If patient-experience data are to be used to improve the quality of health care, they must be reliable, valid and usable (45). While Papers I and II addressed the two first elements, the usability and usage of data were the main focus of Paper III.

Both the quantitative and qualitative employee data showed that the employees reported using data for quality improvement, and that the most commonly targeted areas were those with the worst results in the patient surveys, or those in which the employees knew they could improve the patient experiences. Some improvements in patient experiences were identified, especially in areas concerning preparation for the time after discharge.

The employees cited several barriers to using patient-experience survey data for quality improvement, which can be broken down into the categories of data-related, professional and organizational factors (78, 148). The NIPH has already started working on amending some of the data-related barriers. The timeliness of the reports and the small samples for each institution are some of the reasons why the NIPH is now continuously measuring patient experiences with interdisciplinary treatment for substance dependence, with patients being asked to participate closer to discharge. This will ensure a cumulated sample size, making it possible for more institutions to receive their own detailed results, instead of being

aggregated at a higher level in the health system. In addition, data interpretation should be easier, since the patients are in the same place in their clinical pathway, thus enabling the employees to use the data to an even bigger extent in the future.

A recent review suggested a framework for understanding and using patient-experience data to improve the quality of health care (149). One important point made by the authors is that a survey in itself will not improve health-care performance. Among other factors, the data must be understandable and disseminated broadly; this was ensured by how the NIPH conducted these surveys, published the results and followed up by continuously collecting feedback from employees. Furthermore, after publishing the results, some institutions contacted the NIPH for further data or help with interpreting the findings. The institutions must now work with improvement plans if they want to implement changes. Another aspect highlighted by the review, is how qualitative information can provide a more in-depth understanding of patient or employee experiences. The NIPH summarized and published the patients' free-text comments along with the quantitative data at the national level, adding more detail regarding how the patients think and feel about the institution or treatment. Such data can become very important when used as examples of how things could or should be done (149).

Patient experiences improved slightly over the four survey years in the present study, with the best results being achieved in the 2017 survey. However, the changes in patient experiences could only be explored at a national level due to the small samples for both patients and employees at the institution level. There is reason to believe that larger changes in patient experiences could have been detected if the samples were sufficiently large to allow analyses at the institution level. In addition, patient experiences should be measured both before and after implementing local improvement initiatives in order to improve the knowledge about what affects those experiences and thus establish the most effective interventions.

6 CONCLUSIONS

The work described in this thesis has validated, evaluated and tested a patient-experience questionnaire as well as data procured in four national surveys using the questionnaire for use as quality indicators. The employees in residential institutions for substance dependence were invited in all survey years to provide feedback on their use of the results and their attitudes towards patient-experience surveys. The patient questionnaire can be used to measure patient experiences in all institutions offering residential interdisciplinary treatment for substance dependence in Norway, across all types of misuse or treatments. Paper I describes the testing and validation of the patient-experience questionnaire. Paper II reports on analyses of the data from two national patient surveys to develop a case-mix adjustment model and tests of the ability of the quality indicators to discriminate between levels of patient-reported quality, thereby testing whether patient experiences in this population can be reported as national quality indicators. Paper III describes 4 years of results of patient-experience surveys and 4 years of results of employee surveys. The attitudes of employees towards patient-experience surveys and their reported use of the results from such surveys were explored, along with accompanying changes in patient experiences across the four survey years. The following findings were obtained:

- The analyses of survey data demonstrated the good psychometric properties of the patient questionnaire, meaning that the PEQ-ITSD can be recommended for use in future PREMs applications in Norway and also other countries in which health care is organized in a similar manner.
- When adjusted for a specific set of variables, the three scales comprising the PEQ-ITSD (“treatment and personnel”, “milieu” and “outcome”) functioned well as patient-experience-based quality indicators, using both data at the hospital-trust level and a merged data set. The analyses also showed that the indicators can be used to discriminate between different health-care providers and provide evidence for using the patient-reported indicators as national quality indicators.
- Patient experiences improved slightly during the four survey years, which could be interpreted as a result of employees’ active use of the patient survey results in quality improvement, and their generally positive attitudes towards patient-experience surveys.

7 IMPLICATIONS AND FUTURE RESEARCH

The results from this thesis contribute to the area of methods development and research in the increasingly important field of interdisciplinary treatment for substance dependence. The thesis makes a significant contribution to knowledge about patients' experiences and how the results of patient-experience surveys are relevant both as quality indicators and as information for quality-improvement work in the health services. There are a few questionnaires available for measuring patient experiences with treatment for substance dependence, but most target narrow subpopulations or focus on patient satisfaction. The PEQ-ITSD will help to fill this knowledge gap and expand the possibilities for measuring the quality of health care in a population that is not often asked to share their experiences.

The measurements in this population will continue through a new project run by the NIPH in which all patients are invited to reply to an electronic version of the PEQ-ITSD a few days before their discharge from residential care. This new project relies heavily upon the project described in this thesis with respect to the comprehensive network of contacts established through the survey-years, the questionnaire used and inviting patients to complete the questionnaire while they are still at their treatment institutions. However, one important aspect has been changed, namely the timing of the measurement: instead of asking every patient to complete the questionnaire on one day in a specific week like previously, patients are now asked to complete the questionnaire close to the time of discharge. This change is likely to increase the homogeneity of the patient population, thereby increasing the ICC and the likelihood of identifying differences at the institution level, and making it easier for employees to interpret and use the results. The new timing of measurements and given that the program will be running continuously until at least 2024 will provide the institutions with valuable data for quality-improvement work. It will also increase the number of respondents per institution, since the data will accumulate over time, thus obviating the need to present the indicators as a merged data set (i.e. from multiple survey years). Moreover, the quality indicators established and tested as described in Papers I and II may be tested for use at the institution level, instead of the hospital-trust level. The shift to continuous measurement using the PEQ-ITSD will ensure that these patients' voices are heard and considered important at both local and national levels.

The increase in possible responses and patients being at the same place in their clinical pathway when they complete the PEQ-ITSD together address much of the critiques raised by the employees both in the employee surveys and through their reporting to the NIPH after the patient surveys. These two points were often cited as important reasons for why data from patient surveys have either not been used or were reportedly difficult to use for local quality-improvement work.

In addition to being used in the continuous measurements by the NIPH, the PEQ-ITSD has been used in other settings and studies (22, 146), highlighting that the questionnaire is both needed and regarded as an important contribution to the field of patient-reported quality of health care. However, what constitutes quality from the patients' perspective is likely to change over time. It is therefore important to continuously re-evaluate the questionnaire and the quality indicators to ensure that the topics and questions are still relevant and considered important by patients. The shift in the data-collection method from a paper version of the questionnaire to an electronic format also warrants evaluation. The questionnaire can be considered quite extensive, and conversion to the digital format may have increased the response burden. Further research should explore whether the questions in the PEQ-ITSD are still considered important, and whether it could be shortened, for example by using item response theory to identify the best-performing items.

The quality indicators based on the PEQ-ITSD are the first of their kind in Norway. Previously, the only quality indicators for this patient population were a small number of indicators based on administrative and clinical data. Research is still needed to establish the indicators at the institution level, this is an important step towards measuring the quality of health care among this patient population. The continuous measurements will explore the possibility to move on from anonymous patient data, so that given the necessary permissions, patient administrative data can be collected from the Norwegian Patient Registry, and be merged with the patients' responses to the PEQ-ITSD. More research is needed into the case-mix model, and patient administrative data will help to explore the model further. Furthermore, patient administrative data can open up the possibility of following the patients over time: after treatment, progression into the services of the municipalities and then back to the institution if further admissions are needed. More research is needed to establish how patients perceive the health care they receive from the many service providers with which they have contact.

Future research on the indicators could consider the possibility of correlating some items from the questionnaire with other indicators for this population. For example, the PEQ-ITSD instrument includes a question on whether the patient had to wait long before they were admitted at the institution. This question could be correlated with the waiting time reported from the institution to the Norwegian Patient Registry in order to further validate the data obtained from the patient surveys. Moreover, if the patient-experience data are merged with data from the Norwegian Patient Registry, it may be possible to correlate findings from the continuous measurements of patients with data from the national quality registry (developed by Helse Stavanger HF), provided the two data sources are compatible. These correlations could then be assessed at both the individual and institution levels.

The new way of collecting data in this population, which ensures more responses from each institution, may make it possible to carry out the analyses that we initially wished to perform for Paper III: to explore the indicators at the institution level against the employees' reported use of results and implemented initiatives. This could provide valuable insight into what initiatives led to which changes in patient experiences, since data are obtained from patients before, during and after the implementation. The findings could be further investigated with the addition of free-text comments from both patients and employees, giving a detailed and comprehensive picture of the changes carried out and the resulting patient experiences.

Given a sufficiently large population, the patient data could be divided into subgroups for exploring any differences between the different patient groups receiving health care. It might be interesting to look closer into whether there are between-group differences that should be considered when reporting the results back to the institutions.

The NIPH measures user experiences based on four objectives: quality improvement, health care management, patient choice and public accountability. This thesis delivers on all of these aspects. The cross-sectional surveys were the first national surveys to be conducted in patients with substance dependence who receive residential treatment, and have contributed important and valuable data regarding how the quality of health care is perceived by this population. The systematic and high-quality measurements were based on widely accepted questionnaire development steps, data collection and data analyses. In addition to gathering data on patient experiences, the study reported on in this thesis measured the use of those

patient-experience data for the quality improvement of health care and the perceived usefulness by the employees who provided the health care that the patients evaluated.

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9 PAPER I–III

RESEARCH ARTICLE

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Patient experiences questionnaire for interdisciplinary treatment for substance dependence (PEQ-ITSD): reliability and validity following a national survey in Norway

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Abstract

Background: Patient experiences are an important aspect of health care quality, but there is a lack of validated instruments for their measurement in the substance dependence literature. A new questionnaire to measure inpatients' experiences of interdisciplinary treatment for substance dependence has been developed in Norway. The aim of this study was to psychometrically test the new questionnaire, using data from a national survey in 2013.

Methods: The questionnaire was developed based on a literature review, qualitative interviews with patients, expert group discussions and pretesting. Data were collected in a national survey covering all residential facilities with inpatients in treatment for substance dependence in 2013. Data quality and psychometric properties were assessed, including ceiling effects, item missing, exploratory factor analysis, and tests of internal consistency reliability, test-retest reliability and construct validity.

Results: The sample included 978 inpatients present at 98 residential institutions. After correcting for excluded patients ($n = 175$), the response rate was 91.4%. 28 out of 33 items had less than 20.5% of missing data or replies in the "not applicable" category. All but one item met the ceiling effect criterion of less than 50.0% of the responses in the most favorable category. Exploratory factor analysis resulted in three scales: "treatment and personnel", "milieu" and "outcome". All scales showed satisfactory internal consistency reliability (Cronbach's alpha ranged from 0.75-0.91) and test-retest reliability (ICC ranged from 0.82-0.85). 17 of 18 significant associations between single variables and the scales supported construct validity of the PEQ-ITSD.

Conclusion: The content validity of the PEQ-ITSD was secured by a literature review, consultations with an expert group and qualitative interviews with patients. The PEQ-ITSD was used in a national survey in Norway in 2013 and psychometric testing showed that the instrument had satisfactory internal consistency reliability and construct validity.

Keywords: Questionnaire, Patient satisfaction, Interdisciplinary treatment substance dependence, Substance use disorders, Validity, Reliability, Survey

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Background

Patient-reported quality is an important component of health care quality, and the routine collection of patients' experiences as part of quality measurements in health care has become widespread. Various populations are asked to give their feedback about health care services, providing patient-based information about the functioning of specific health care services and the health care system. Patient experiences have been linked to patient safety and clinical effectiveness, giving a clear clinical rationale for focus on such experiences [1].

Studies have shown that patient experiences are related to patient satisfaction [2]. One issue with satisfaction surveys is that they often report high satisfaction [3–6], challenging the usefulness of satisfaction surveys in quality improvement work, and calling for a more nuanced and multi-faceted approach [7]. Asking patients about their experiences of the health care delivery system has been identified as a useful method for establishing trends over time and comparisons among providers [2].

Several countries have national programs for monitoring and reporting on health care quality using patient experience surveys [8]. These national efforts create a need for standardized instruments of high quality, specialized for use in different settings [9]. Reliable and valid data about users' or patients' experiences requires a measurement tool developed and tested according to rigorous and comprehensive methods. Such development and testing of survey tools is challenging and a task that requires the consideration of many psychometric questions, like what questionnaire development steps are needed, establishing criteria for the psychometric testing and cut-off values for the relevant statistical tests [10]. The results from the development and the psychometric testing of the measurement tool should be documented and appraised to ensure the tool's properties. Within the patient satisfaction field, a systematic review revealed that such documentation and objective appraisal are not always carried out, with less than half of the included studies reporting some validity or reliability data [11]. Such lack of evidence casts doubt on the credibility of the results derived from the use of these instruments.

The Norwegian Institute of Public Health (NIPH) has the responsibility for carrying out national patient experience surveys in Norway. Usually, the population of interest is drawn at random from each service provider and potential participants are invited by means of a mailed questionnaire and invitation letter. The purpose of the program is to systematically measure user experiences of health care, as a basis for quality improvement, health care management, patient choice and public accountability. To serve this purpose, survey tools for different populations in health care have already been

developed and tested in Norway [12–22]. In 2013, the Ministry of Health decided that a national patient experience survey of interdisciplinary treatment for substance dependence should be conducted. The instrument bank in Norway lacked a validated questionnaire for this patient group, but a development and validation project was already in progress and was connected to the national survey that the Ministry had decided on.

In the field of interdisciplinary treatment for substance dependence, some validated questionnaires have been identified in the international literature, one of which is a quality-of-life instrument [23–28]. However, these are used within differentiated treatments and among people who use specific substances. Furthermore, several of these are satisfaction measurements, and not targeted at gathering information about patient experiences. Hence, there is a paucity of surveys in substance dependence treatment that can reliably and validly measure inpatients' experiences across treatments and types of substance use.

Within this field, research has shown that enhancing patient satisfaction may improve treatment outcomes [29–31]. A critical review within the field of addiction treatment, by Trujols et al. published in [7], summarizes important aspects of the evaluation of treatment. These aspects include patients' views on treatment, patients' opinions about medication, relations with therapists and influence on treatment, perception of needs and satisfaction with treatment, as well as indicators of user-perceived quality. However, these perspectives are not always in focus when evaluating the services [7].

The lack of a validated questionnaire for the measurement of patient experiences with interdisciplinary treatment for substance dependence led the Norwegian Knowledge Centre for the Health Services (now NIPH) to develop a new questionnaire for this patient group. The development of the questionnaire followed the standard methodology of our national program [12–22], including a literature review, cognitive interviews with patients and expert consultations. The questionnaire was included in the national survey in 2013 that the Ministry of Health decided on. The aim of this study was to test the construct validity and internal consistency reliability of a new questionnaire following the national survey in Norway in 2013. The survey included all 98 residential treatment institutions for substance dependence in Norway.

Methods

Questionnaire development

The Patient Experiences Questionnaire for Interdisciplinary Treatment for Substance Dependence (PEQ-ITSD) was developed through a thorough process that

included several recognized steps [12–22]. Firstly, a comprehensive literature review was conducted to search for valid and reliable questionnaires that could be used in the Norwegian context. The review concluded that there were no existing questionnaires ready and relevant for large-scale use in a Norwegian setting [32]. Questionnaires, both from the review and Norwegian questionnaires that had been used locally, were considered in terms of identifying important and relevant topics for the new questionnaire. Secondly, an expert group were consulted several times to discuss the content of the new questionnaire, as well as procedures for data collection. The expert group consisted of seven persons, including clinicians/therapists, researchers associated with treatment institutions and representatives from interest groups. Thirdly, qualitative interviews were conducted with 13 patients with various types of substance dependencies, with a focus on what they found to be important while in treatment. Fourthly, the resulting questionnaire was cognitively tested with patients ($n = 15$), and lastly, a pilot survey was conducted with 14 institutions ($n = 329$). The first version of the questionnaire included 45 questions [33].

Before the national survey, the questionnaire was expanded with three modified items from the Patient Enablement Instrument [34], and three questions about help from the municipality [35]. The former was included to obtain feedback from patients regarding outcomes of treatment, using the same approach as a newly published patient experience questionnaire for psychiatric inpatients [16]. The latter was included because of the importance of continuity of care and primary health care services in Norway for this patient group as well [36]. The questionnaire included in the national survey consisted of 51 closed-ended questions, most scored on a scale from 1 “not at all” to 5 “to a very large extent”. The topics covered in the questionnaire included “reception and waiting time”, “the therapists/the personnel”, “the treatment”, “the milieu and activity provision”, “preparations for the time after discharge”, “other assessments” and “previous admissions in substance dependence institutions”. The questionnaire also included questions about the respondents’ background. In addition to the closed-ended questions, there were two open-ended questions. One asked the respondents to write more about their experiences at the institution, and the other asked the respondents to write about their experiences of the help and care they had received from their municipality.

Data collection

Data were collected through a national survey in 2013. The survey was commissioned by the Norwegian Directorate of Health and was mandatory for all relevant

institutions. The included institutions were all public residential institutions and private residential institutions with a contract with the regional health authorities. Detoxification institutions were excluded. All patients aged 16 years and older were invited to fill out the questionnaire.

The survey was developed as part of the national program, but the very low rate of response to mailed post-discharge surveys of psychiatric inpatients and sub-groups of patients with substance dependence in these surveys restricts their validity and usefulness [37]. Consequently, this prompted a change to data collection, from post-discharge to on-site. In contrast to the NIPH’s standard data collection method, which is to send a postal questionnaire a few weeks after discharge to the patient’s home, all institutions carried out the survey on-site by distributing questionnaires to patients while in treatment. This data collection approach is also used for psychiatric inpatients [16].

Questionnaires were sent to participating institutions, where the institutions’ personnel were responsible for distributing and collecting the questionnaires. Each patient received an envelope containing an information sheet, the questionnaire and a reply envelope. Every fourth envelope also contained a retest-questionnaire and an additional reply envelope. The retest was to be carried out approximately two days after the original survey. The institutions were to ensure that the patients completed the questionnaire by themselves, without discussing the questions or their answers with other patients, health personnel or staff. If needed, the patients could receive help in reading and/or understanding the questions, without being influenced on how to respond.

After the survey, the institutions reported to the NIPH on the number of eligible patients, number of patients who participated, number of patients who declined participation and number of excluded patients. Based on this information, the NIPH calculated adjusted gross sample and response rates. No information about the patients was gathered other than background questions in the questionnaires, and hence the NIPH was able to create an anonymous dataset based on the information in the completed questionnaires.

Statistical analysis

Ceiling effect and item missing were assessed. Ceiling effect is commonly understood as the percentage of respondents answering in the most positive response category. A large ceiling effect can indicate measurement problems in respect of differentiating between care providers or points in time. The cut-off for the ceiling effect was set to 50%, i.e., an item was judged as of adequate quality if the ceiling effect was smaller than 50% [38, 39].

Exploratory factor analyses were conducted to assess the underlying dimensions of the questionnaire. Items with more than 20% missing responses were excluded. All other questions, except questions regarding background information and items about experiences with other services than residential institutions, were entered into exploratory factor analyses. As some correlation between the factors may be expected, principal axis factoring and oblique rotation with Promax was applied. Two separate factor analyses were conducted: The first factor analysis was conducted with items concerning structure and process. In the second analysis, all items related to outcome (as reported at the time of the measurement) were entered. Items with factor loading smaller than 0.4 were excluded, and the criterion for rotation was set to eigenvalues greater than 1.

The internal consistency of the resulting scales was assessed with the calculation of Cronbach's α and item-total correlation. Item-total correlation measures the correlation of each item with the total score of the remaining items of the scale. Cronbach's α is an assessment of the correlation between all items in the given scale. The cut-off for the α was set to the commonly used criterion of 0.7 or higher [40]. The criterion for item-total correlation is less established, and 0.2 [10], 0.4 [15, 41–43] and 0.5 [44] have all been used.

Test-retest reliability was assessed through calculation of the intraclass correlation coefficient (ICC). The ICC was used to test the reliability of the scores by correlating test and retest scores for each scale. A correlation of 0.7 or greater was considered satisfactory.

Construct validity relates to the degree to which the measurement actually measures a specific underlying construct [10]. This can be tested through assessing the association of the measurement's scales with other variables known to influence the construct of interest. A systematic review found that some variables were relevant across populations: age and health status [2]. Based on a literature search, previous work and experts' advice, it was hypothesized that the scale scores would correlate with type of misuse [26, 45], more specifically that patients with alcohol dependence would report better experiences. Shorter waiting time before treatment [24, 46] and less extent of forced treatment [16] were also hypothesized to influence the scale scores positively. Age [2, 26, 45, 47–49] was expected to positively correlate with scale scores. Furthermore, it was hypothesized that patients reporting better self-perceived physical and psychological health would report better experiences [2, 45]. Independent samples *t*-test was conducted for type of misuse, while Pearson's *r* was used to assess correlations for all other variables.

All analyses were conducted using SPSS version 23.0.

Results

On the day of the survey, the 98 participating institutions had a total of 1245 admitted patients. 12 patients were excluded due to ethical considerations and 163 were not present at the institution when the survey was conducted. Hence, the corrected sample was 1070 eligible patients. 978 patients filled out and returned the questionnaire, resulting in a response rate of 91.4%.

Two thirds of the sample were male with a mean age of 36.5 years (Table 1). 80.3% were single, and 11.9% had university or college education. The respondents' mean age when they developed a substance dependence was 20.3 years. 62.4% and 54.6% reported their physical and mental health as excellent, very good or good, respectively. 32.5% had no previous admissions to residential treatment, and 53.7% had been at the institution less than 3 months. The most frequently used substances prior to admission were cocaine/amphetamine (47.1%) and alcohol (46.4%). 58.9% reported two or more substances as the most frequently used substance.

The levels of missing data ranged from 1.9% to 4.9% (Table 2), while the responses in the "not applicable" category ranged from 0.3% to 29.6%. Five out of the 33 items had more than 20.4% item-missing (missing data + not applicable). The five items were #12c: benefit of treatment with medication; #18: help for psychological distress; #27 and #28: help with practical issues and further treatment after discharge; and #34: the personnel's cooperation with patients' next of kin.

All items, with one exception, met the criterion of less than 50.0% responses in the most favorable category. The exception was item #36 regarding malpractice, where 51.4% of the respondents answered "not at all".

A total of 27 items were included in the two factor analyses. Twenty items addressing structure and process were entered in the first factor analysis. Three items were excluded from the analysis, one at a time, due to low factor loadings. Hence, 17 items were entered in the final analysis, resulting in two factors that explained 51.8% of the variance (Table 3). Initially, seven items concerning outcomes were entered in the second factor analysis. Two items were removed due to the wording of the questions, asking for assessments of specific treatment initiatives. Hence, five general outcome items were entered in the second factor analysis, resulting in one factor which explained 73.4% of the variance. Cronbach's α for the three scales ranged from 0.75 (factor 2 – "milieu") to 0.91 (factor 1 – "treatment and personnel" and factor 3 – "outcome"), all of which were above the 0.7 criterion. The scales showed good test-retest reliability; all factors had a reliability greater than 0.8.

The associations between the scale scores and the tested variables were statistically significant in 17 out of 18 tests (Table 4). Independent Samples *T*-Test showed

Table 1 Sample characteristics (n = 978)

	number	percent
Gender		
Male	628	67.2
Female	306	32.8
Age	927	36.5 (mean)
Marital status		
Married/cohabiting	183	19.7
Single	744	80.3
Education		
Primary school	383	41.3
Secondary school	434	46.8
University or college	110	11.9
Age when substance dependence developed	919	20.3 (mean)
Self-perceived physical health		
Excellent	60	6.4
Very good	192	20.6
Good	330	35.4
Quite good	225	24.1
Poor	125	13.4
Self-perceived mental health		
Excellent	47	5.0
Very good	145	15.6
Good	317	34.0
Quite good	260	27.9
Poor	163	17.5
Most frequently used drug/substance prior to this admission		
Alcohol	454	46.4
Medication	428	43.8
Cannabis	427	43.7
Cocaine/amphetamine	461	47.1
Heroin/morphine	256	26.2
Other	124	12.7
Length of stay at this institution		
0-2 weeks	144	14.8
3-11 weeks	377	38.9
3-6 months	257	26.5
7-12 months	147	15.2
More than 12 months	45	4.6
Previous admissions		
No	304	32.5
Yes, once	243	26.0
Yes, twice	167	17.9
Yes, 3-5 times	136	14.6
Yes, more than 5 times	84	9.0

that patients reporting alcohol as their single used substance before treatment entry scored significantly higher on all three scales compared to patients who reported other types of substance dependencies. When comparing age and reported type of substance dependence, we found that those reporting only alcohol as their type of misuse are generally older (mean age 50 for alcohol, mean age 33 for other). Further testing showed that, for “treatment and personnel” and “outcome”, the effect of age disappears when controlling for alcohol use. However, since the effect of age was statistically significant for “milieu” when controlling for alcohol, both variables were kept in the model for construct validity testing.

Discussion

The data for this study was collected as part of the national patient experience program in Norway. It was the first national survey of patient experiences of interdisciplinary treatment for substance dependence. The PEQ-ITSD was designed for use among inpatients, and focuses on topics patients have reported to be important. The questionnaire was developed after a thorough review of the literature, meetings in an expert group, interviews with patients and results from a pilot survey. The testing and evaluation of the PEQ-ITSD showed that the questionnaire comprised three scales with excellent internal consistency reliability, test-retest reliability and construct validity. Furthermore, the questionnaire showed good acceptability given the high response rate and low proportion of item missing.

The questionnaire comprises three scales, resulting from two factor analyses. These three scales correspond to the scales found in the on-site survey of psychiatric inpatients in Norway, a survey conducted by the same methods as the current study [16]. It is somewhat difficult to compare the PEQ-ITSD with other instruments of interest, given the variation in the populations surveyed and the aim of the instruments. However, some parallels are found between the PEQ-ITSD's three scales and other instruments used in similar populations. The scales resemble to some extent both the Treatment Outcome Profile (TOP) [23] and the Treatment Perceptions Questionnaire (TPQ) [24], emphasizing the importance to the patients of the areas and topics constituting the PEQ-ITSD. The user satisfaction scale of TOP consists of three subscales; satisfaction with treatment; satisfaction with staff; satisfaction with environment, each consisting of three items. The two scales constituting the TPQ focus on perceptions of staff and treatment program. However, the TOP was primarily developed for use among patients in psychiatric care, and only secondarily tested for use among patients in treatment for substance dependence, while the testing of levels of validity and reliability was insufficient for both instruments.

Table 2 Item descriptives

		n	Missing (%)	Not applicable (%)	Mean ^a	Ceiling (%)
3	Were you informed of the institution's rules and routines when you arrived?	950	2.9	-	3.59	17.5
4	Were you welcomed in a satisfactory manner when admitted to the institution?	950	2.9	-	3.98	30.5
6	Have you had enough time for talk and contact with clinicians/personnel?	947	2.4	0.8	3.51	18.4
7	Do you perceive that the clinicians/personnel have understood your situation?	950	2.5	0.4	3.65	19.9
8	Have you had confidence in the clinicians'/personnel's professional competence?	943	2.7	0.9	3.68	23.2
9	Has one of the clinicians/personnel had primary responsibility for you?	927	3.3	1.9	3.75	28.7
10	To what extent have you been met with courtesy and respect?	945	3.1	0.3	4.16	39.4
12a	What benefit have you had from treatment in groups at the institution? ^b	861	3.3	8.7	3.33	15.8
12b	What benefit have you had from talking to a therapist at the institution? ^b	910	3.0	4.0	3.56	21.5
12c	What benefit have you had from treatment by medication at the institution? ^b	641	4.9	29.6	3.16	17.0
13	All in all, what benefit have you gained from the treatment at the institution? ^b	913	4.2	2.5	3.85	30.8
14	Has the information you have received regarding the treatment been satisfactory?	930	3.1	1.8	3.44	13.8
15	Have you had influence on your treatment?	926	3.1	2.2	3.53	17.0
16	Do you perceive that the treatment has been adjusted to your needs?	934	2.9	1.6	3.46	16.0
17	Have you received help for physical ailments or illness?	782	3.1	17.0	3.20	12.5
18	Have you received help for psychological distress?	763	3.8	18.2	3.09	12.8
19	Has your access to psychologists been satisfactory?	843	2.7	11.1	3.13	15.8
20	Has your access to medical doctors been satisfactory?	918	2.8	3.4	3.33	15.5
21	Have you felt safe at the institution?	959	1.9	-	4.17	38.5
22	Has the institution arranged for contact with other patients in a satisfactory manner?	955	2.4	-	3.78	23.6
23	Have the activities offered at the institution been satisfactory?	958	2.0	-	3.42	16.9
24	Have the meals at the institution been satisfactory?	958	2.0	-	3.92	38.0
25	Have you been satisfied with the possibility for privacy?	950	2.9	-	3.43	19.7
26	Do you perceive that the clinicians/personnel have prepared you for the time after discharge?	816	2.8	13.8	2.97	8.8
27	Do you perceive that the clinicians/personnel have helped you with practical issues for the time after discharge (e.g. housing, finances, work/school)?	727	3.0	22.7	2.81	9.4
28	Do you perceive that the clinicians/personnel have arranged for further treatment for the time after discharge?	748	3.3	20.2	2.89	9.6
29	Do you perceive that the clinicians/personnel have helped you so you can achieve a meaningful life after discharge?	784	3.1	16.8	3.12	13.0
30	All in all, is the help and treatment you receive at the institution satisfactory?	929	2.0	3.0	3.76	23.8
31	Do the help and treatment you receive at the institution improve your ability to understand your dependency problem?	927	2.0	3.2	3.64	23.6
32	Do the help and treatment you receive at the institution improve your ability to cope with your dependency problem?	902	2.0	5.7	3.61	20.7

Table 2 Item descriptives (*Continued*)

33	Do the help and treatment you receive at the institution give you faith that your life will improve after discharge?	914	2.2	4.3	3.74	26.0
34	Do you perceive that the clinicians/personnel have cooperated well with your next-of-kin?	714	2.1	24.8	2.71	9.4
36	Do you believe that you have been subjected to malpractice (based on your own opinion)? ^c	910	2.4	4.6	1.84	51.4

^a All items were scored on a 5-point response scale ranging from 1 ("not at all") to 5 ("to a very large extent")

^b Items with 5-point response scale ranging from 1 ("no benefit") to 5 ("very large benefit")

^c Items with reversed response scale, i.e. the lower the mean, the better the result

Accordingly, and given that the population in question consisted of all patients undergoing treatment for different types of misuse, it was necessary to develop a new questionnaire for use with a heterogeneous population in residential treatment for substance dependence.

The rationale for conducting two analyses was to avoid contamination between the outcome items and those concerning structure and process. The three scales may enable the institutions to identify areas where the quality, as seen by the patients, should be improved. The scales, along with feasible case mix adjustments, contribute to more valid comparisons across both institutions and time.

Through the search for relevant literature, it was discovered that there were a general lack of literature addressing issues of psychometric properties in questionnaires used in surveys of patients in substance dependence treatment. This is also supported by an overview of user satisfaction surveys in addiction services [7]. Furthermore, there is a general lack of validated patient experience instruments within this field [7, 32]. Due to the insufficient literature, the hypotheses for the construct validity testing were based on what was identified through the literature review of patient experiences of treatment for substance dependence, on the general literature on patient experiences, and on advice from experts from whom advice was sought. Six independent variables were suggested. Since little is known about what variables are most important in the given population, all six variables were entered in the validity testing for a more exploratory approach.

Most hypothesized associations were statistically significant. Several studies have found that age is associated with satisfaction or experiences [2, 26, 45, 47–49]. The patients' age was associated with the "treatment and personnel" and "milieu" scales. However, it was not significantly associated with "outcome". The age effect is mostly evident through older patients being less critical than younger patients. In the current data, the patients are, on average, younger than other populations, e.g. somatic inpatients. The mean age in the population replying to the PEQ-ITSD was 36.5 years. As previously described, both alcohol use and age were associated with the scale scores. However, testing showed that patients

reporting only alcohol as their dependence are older than patients reporting other types of dependencies, and that the effect of age disappears when controlling for alcohol use for two of the three scales. All significant correlations showed associations according to the hypotheses.

The patient experience surveys conducted by the NIPH are usually carried out as postal surveys. Patients are sent a postal invitation to answer a questionnaire after their hospital visit or doctor's appointment. However, due to expert advice and previous experience with low response rates among patients within psychiatric care, an on-site data collection method was chosen for the population at hand. In addition, previous research has concluded that personal contact in recruitment and data collection may increase the response rate [50, 51]. There are some concerns regarding the possible differences in responses that are elicited from postal surveys versus on-site data collection. Even though on-site data collection might increase the response rate and therefore increase the representativeness of the data, on-site data collection often results in more favourable responses compared to mailed surveys [52–54].

When deciding to collect the data on site, there are at least two possibilities: at discharge or as a cross-sectional study. One strength of the design that asks for participation at discharge is that the patients have been through their entire treatment, and therefore may be better able to answer all questions. In addition, the patients who have completed their treatment may have other experiences than those who have been in treatment for a shorter amount of time. A limitation of the same design is that the patients who drop out of treatment will not be reached. Furthermore, for institutions where patients are supposed to stay for a longer period of time, the inclusion period for obtaining a large enough sample can be very long, adding to the challenges of anonymity and outdated data. In the work on developing the questionnaire, both approaches were tested. It was found that the two approaches elicited somewhat different evaluations of the treatment and the institutions, but that a cross-sectional study was well suited to including all patients, and minimizing the work load on the

Table 3 Factor loadings and reliability statistics

	Factor loadings	Corrected item-total correlation	Cronbach's alpha	Test-retest reliability
<i>Treatment and personnel</i>			0.91	0.85
26	Do you perceive that the clinicians/personnel have prepared you for the time after discharge?	0.83	0.68	
29	Do you perceive that the clinicians/personnel have helped you so you can achieve a meaningful life after discharge?	0.76	0.68	
6	Have you had enough time for talk and contact with clinicians/personnel?	0.73	0.70	
17	Have you received help for physical ailments or illness?	0.64	0.56	
16	Do you perceive that the treatment has been adjusted to your needs?	0.64	0.72	
14	Has the information you have received regarding the treatment been satisfactory?	0.62	0.74	
7	Do you perceive that the clinicians/personnel have understood your situation?	0.59	0.73	
15	Have you had influence on your treatment?	0.59	0.61	
19	Has your access to psychologists been satisfactory?	0.56	0.53	
20	Has your access to medical doctors been satisfactory?	0.54	0.55	
9	Has one of the clinicians/personnel had primary responsibility for you?	0.52	0.51	
8	Have you had confidence in the clinicians'/personnel's professional competence?	0.50	0.69	
<i>Milieu</i>			0.75	0.84
21	Have you felt safe at the institution?	0.79	0.60	
4	Were you welcomed in a satisfactory manner when admitted to the institution?	0.69	0.57	
10	To what extent have you been met with courtesy and respect?	0.63	0.59	
22	Has the institution arranged for contact with other patients in a satisfactory manner?	0.54	0.51	
24	Have the meals at the institution been satisfactory?	0.48	0.39	
<i>Outcome^a</i>			0.91	0.82
32	Do the help and treatment you receive at the institution improve your ability to cope with your dependency problem?	0.87	0.82	
30	All in all, is the help and treatment you receive at the institution satisfactory?	0.83	0.78	
33	Do the help and treatment you receive at the institution give you faith that your life will improve after discharge?	0.81	0.76	
31	Do the help and treatment you receive at the institution improve your ability to understand your dependency problem?	0.81	0.76	
13	All in all, what benefit have you gained from the treatment at the institution?	0.77	0.73	

^aSeparate factor analysis for "Outcome"

employees, while tolerating the somewhat worse evaluations [33].

The PEQ-ITSD's three scales will be further tested for feasibility for use as external quality indicators. However, even though the scales have good psychometric properties and present a more robust result than single items, some important items were excluded after the psychometric testing. The items in the questionnaire have all been reported as important to

the patients, and the questionnaire should therefore not be reduced to merely the items comprising the three scales.

The psychometric testing of the PEQ-ITSD has shown that the data collected are of satisfactory quality, and that the questionnaire shows excellent psychometric properties. The instrument has been developed and tested for a population seldom previously invited to participate in similar surveys.

Table 4 Associations between scales and background variables about the patients

	Treatment and personnel	p	Milieu	p	Outcome	p
Type of misuse		<0.001		<0.001		<0.001
Alcohol only	66.14		80.34		72.76	
Other	58.77		73.72		66.56	
Waiting time before given an offer from the institution	-0.162	<0.001	-0.100	0.002	-0.139	<0.001
Pressured/forced by others to admit to treatment	-0.143	<0.001	-0.190	<0.001	-0.151	<0.001
Age	0.130	<0.001	0.196	<0.001	0.062	0.065
Self-perceived physical health	-0.157	<0.001	-0.066	0.044	-0.138	<0.001
Self-perceived psychological health	-0.184	<0.001	-0.167	<0.001	-0.201	<0.001

Independent-Samples *T*-Test for type of misuse, Pearson's *r* for continuous variables

Limitations

While the PEQ-ITSD has been developed and tested through rigorous methods as part of the national program in Norway, there are some limitations to both the questionnaire and this study. Every residential treatment facility, both public and private, was included. This means that the included institutions vary considerably regarding e.g. size of the patient population, type of substance dependence, and method of treatment. Many of the participating institutions are quite small and thus have few responders.

Another limitation of the design is that the data are collected anonymously. That is, no information about the respondents is gathered, other than what the respondents themselves report in the questionnaires. This design means that there is no available information about those who chose not to participate in the survey, and hence no knowledge of whether the respondents differ from the non-respondents in any systematic way. In other words, it is unknown whether the data are influenced by non-response bias, which may pose a threat to the generalizability of the results. However, the national survey of 2013 had a response rate of 91.4%, leading to the conclusion that non-response bias constitutes a minor issue in this population.

The described questionnaire has been developed and tested for use with inpatients on-site, and the generalizability to other populations, such as detoxification patients, out-patient clinics or discharged patients, is unknown.

Conclusions

The PEQ-ITSD has shown excellent measurement properties, such as internal consistency reliability, test-retest reliability and construct validity. The questionnaire comprises important themes elicited from patients and experts. The PEQ-ITSD can be used to measure inpatients' experiences of interdisciplinary treatment for substance dependence; however more research and testing are

needed to assess its feasibility for use in producing quality indicators.

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Availability of data and material

The datasets generated and analysed during the current study are not publicly available due to this being one part of an ongoing PhD-project at the National Institute of Public Health and the University of Oslo. The datasets are planned to be used in further analyses and publications, but are available from the corresponding author on reasonable request.

Authors' contribution

MH planned the paper together with HHI, OB and AKL. MH performed the statistical analyses with HHI, and drafted the manuscript. HHI participated in the planning process, statistical analyses, critically revised the manuscript draft and approved the final version of the manuscript. OB and AKL participated in the planning process, critically revised the manuscript draft and approved the final version of the manuscript. MH was the project manager for the national survey. All authors read and approved the final manuscript.

Competing interests

The authors declare that they have no competing interests.

Consent for publication

Not applicable.

Ethics approval and consent to participate

Data were collected anonymously, with no registration of the patients being surveyed. The project was run as part of the national program and was an anonymous quality assurance project. According to the Norwegian Regional Committees for Medical and Health Research Ethics, research approval is not required for quality assurance projects. The Norwegian Social Science Data Services states if the information used are anonymous, the project is not subject to notification (http://www.nsd.uib.no/personvern/en/notification_duty/meldeskjema?eng). Hence, no ethics approval was needed in this project. Patients were informed that participation was voluntary and that they would remain anonymous. In accordance with all the patient

surveys in the national program, health professionals at the institutions could exclude individual patients for special ethical considerations. Since no notification or ethics approval was needed, the NIPH obtained signed agreements with all the participating institutions, describing the project and both the institutions' and NIPH's responsibility in data collecting, handling, analysing and reporting. Previously established guidelines concerning consent through a returned questionnaire were applied.

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Patient experiences with interdisciplinary treatment for substance dependence: an assessment of quality indicators based on two national surveys in Norway

This article was published in the following Dove Press journal:
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Purpose: The quality of health care is often measured using quality indicators, which can be utilized to compare the performance of health-care providers. Conducting comparisons in a meaningful and fair way requires the quality indicators to be adjusted for patient characteristics and other individual-level factors. The aims of the study were to develop and test a case-mix adjustment model for quality indicators based on patient-experience surveys among inpatients receiving interdisciplinary treatment for substance dependence, and to establish whether the quality indicators discriminate between health care providers.

Patients and methods: Data were collected through two national surveys involving inpatients receiving residential treatment in Norway in 2013 and 2014. The same questionnaire was used in both surveys, and comprised three patient-experience scales. The scales are reported as national quality indicators, and associations between the scales and patient characteristics were tested through multilevel modeling to establish a case-mix model. The intraclass correlation coefficient was computed to assess the amount of variation at the hospital-trust level.

Results: The intraclass correlation coefficient for the patient-reported experience scales varied from 2.3% for “treatment and personnel” to 8.1% for “milieu”. Multivariate multilevel regression analyses showed that alcohol reported as the most frequently used substance, gender and age were significantly associated with two of the three scales. The length of stay at the institution, pressure to be admitted for treatment, and self-perceived health were significantly related to all three scales. Explained variance at the individual level was approximately 7% for all three scales.

Conclusion: This study identified several important case-mix variables for the patient-based quality indicators and systematic variations at the hospital-trust level. Future research should assess the association between patient-based quality indicators and other quality indicators, and the predictive validity of patient-experience indicators based on on-site measurements.

Keywords: quality of health care, health care quality indicator, case-mix adjustment, patient satisfaction, survey

Introduction

The systematic measurement and reporting of quality indicators in health care have become common in several countries during the last few decades.^{1,2} The reasons for the increased focus on health care performance are often linked, and include both the increasing expense and the variations in the quality of health care.³ Patient-reported experiences (also called user experiences) constitute parts of the frameworks for quality indicator projects for the Nordic Council, the OECD, and the WHO.^{2,4,5} The quality

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indicators used in Norway are meant to reflect aspects of the quality of health care, as a means to inform policy-makers, health care leaders, health personnel, and patients about health care performance.⁶ The Norwegian quality indicator system consists of several indicators of the quality of health care within different areas, using both patient administrative data and patient-reported experiences.⁷

Patient-experience surveys elicit a view of the quality of health care that cannot be provided by other clinical or administrative assessments. When measuring patient experiences on a national or other large scale, it is useful to be able to compare between health care providers or hospital trusts. While such comparisons may be informative when choosing a provider or allocating resources, patient characteristics not related to the quality of health care may influence how certain patient groups evaluate this quality. This makes it necessary to develop and apply appropriate case-mix adjustments to ensure that such comparisons are valid.^{8–10} In addition, different patient groups have different probabilities of responding to the surveys, which results in some groups being underrepresented in the resulting sample. A common approach to compensate for nonresponse is to weight data to reduce bias related to certain groups being underrepresented.¹¹ Weighted results are meant to be more representative for the complete patient population; that is, not only to those who actually replied to the survey. The aim of making case-mix adjustments is to increase the accuracy of the results when comparing different health care providers.¹⁰

There is no apparent consensus on how to develop or use quality indicators, with the approach often being determined by the objective of performing particular measurements.⁶ However, one step-by-step guide provided by the Agency for Healthcare Research and Quality suggests that the performance of such quality indicators should be judged according to: face validity, precision, minimum bias, construct validity, fostering real quality improvement, and application,¹² each of these factors being related to data quality, validity, reliability, applicability, and feasibility.⁶

In 2013, the Norwegian Directorate of Health commissioned a national patient-experience survey involving inpatients receiving interdisciplinary treatment for substance dependence.¹³ In Norway, the regional hospital trusts are decreed by law to offer interdisciplinary treatment for substance dependence. This is a service for patients with substance dependence that include both medical, psychological and social work professionals, and the treatment focuses on both patients' health problems and social situations. The

service includes residential, day, polyclinic and ambulatory services.¹⁴ In the agreement between that directorate and the Norwegian Institute of Public Health (NIPH), the directorate underlined that it wanted to test the possibility of developing quality indicators based on the national survey. The NIPH is responsible for conducting national patient-experience surveys, and has a long history of conducting national surveys and reporting corresponding quality indicators based on patient experiences. However, after testing the data material from this population as quality indicators, the NIPH concluded that the number of respondents at each institution was too small for reporting proper indicators. It was therefore decided to expand the sample with another national survey of the same population, which was conducted 1 year later.¹⁵

The NIPH usually samples 400 respondents from each participating unit (eg, hospital) when measuring the experiences that patients have with health care. However, the institutions offering interdisciplinary treatment for substance dependence in Norway are substantially smaller than this, which necessitated some adjustments to the usual methods employed when conducting patient-experience surveys and reporting the results from these surveys. There is a growing body of literature when it comes to assessing patient experiences and patient reported outcomes with different types of treatment for substance dependence. Some of these efforts focus on developing and validating relevant tools.^{16–23} Within the literature, some evidence can be found regarding patient characteristics that should be considered for case-mix adjustments.^{24–26} However, several of these studies are conducted in more narrow populations than the Norwegian one, which are including all patients treated for substance dependence, hence suggesting that a more-explorative approach was needed in the current setting.

The aim of this study was to establish whether the experiences of inpatients can be used as a basis for national quality indicators of interdisciplinary treatment for substance dependence. The objective was twofold: (i) to use the data material from the national surveys to develop a feasible case-mix adjustment model, and (ii) to establish whether the quality indicator scores vary across health care providers, hence testing the ability of the indicators to discriminate between levels of patient-reported quality.

Material and methods

Sample and data collection

All public and private residential institutions with a contract with regional health authorities were included in the national

surveys. The included institutions represented a range of treatments, dependencies, programs, number of patients and length of stay, while detoxifications institutions were excluded. The surveys were conducted as national measurements, and it was mandatory for the institutions to participate. The NIPH established contact with each of the institutions through the four regional health authorities, which provided contact information to their underlying hospital trusts, which again provided information on the leaders at all the institutions working with interdisciplinary treatment for substance dependence. The NIPH could from there establish contact with health personnel at each institution, and together with them plan and conduct the surveys. All patients staying at the institutions, aged 16 years and older, were invited to participate. Individual patients could be excluded based on ethical considerations by personnel at each institution.

In 2013, 1,245 patients were staying at the residential institutions during the data collection. Twelve of the patients were excluded due to ethical considerations, while 163 patients were not available for participation (due to, eg, doctor's visit, leave from the institution). Hence, 1,070 inpatients from 98 institutions were eligible for inclusion in 2013. In 2014, 23 patients of 1,279 were excluded due to ethical considerations, while 143 patients were not available, leaving 1,113 patients eligible for participation.

The data were collected using a cross-sectional design on a single day decided by the institutions during a single designated week decided by the NIPH. The health personnel at each institution were responsible for handing out and collecting the answered questionnaires, making this an on-site survey. The questionnaires were distributed to the institutions in prepacked envelopes containing an information sheet, the questionnaire, and a return envelope before the day of data collection. The health personnel was instructed to give one envelope to each consenting patient. Patients were informed that participation was voluntary, and that no one would know their answers to the questions. Pre-established practice with treating a filled-out and returned questionnaire as consent to participate was employed. The surveys were conducted anonymously, and carried out as a quality assurance project. No demographic information other than the background items in the questionnaire was collected. The participating institutions did not provide information to the NIPH about their respondents, other than the number of eligible patients and the reasons for

ineligibility. One of the consequences of this procedure is a lack of information regarding nonrespondents.

Measures

The questionnaire used in the survey was the Patient Experiences Questionnaire for Interdisciplinary Treatment for Substance Dependence (PEQ-ITSD), which consists of 51 closed-ended questions. The data quality, validity, and reliability of the PEQ-ITSD have been comprehensively described, tested, and reported on previously.¹⁷ Most of the questionnaire items are scored on a 5-point scale, ranging from "not at all" to "to a very large extent." The questionnaire-scale was linearly converted to a scale from 0 to 100, where a higher score indicated a better outcome. To obtain a scale score, a respondent had to answer at least half of the questions constituting each scale.

Identical versions of the questionnaire were used in the surveys performed in 2013 and 2014. The questionnaire comprises three scales: "treatment and personnel," "milieu," and "outcome", which were derived from exploratory factor analyses, and has shown good internal consistency reliability, test-retest reliability and construct validity. The variation in the three scale scores and the regression models' variance constitute the main outcomes in the following analyses. The "treatment and personnel" scale consists of 12 items concerning topics such as the relationships of patients to personnel, their access to personnel, and patient centeredness. The "milieu" scale consists of five items relating to the safety experienced by patients at the institution, how they were received when they arrived, and their opinion of the meals quality. The "outcome" scale also consists of five items, which asks the patients whether they consider that the time spent at the institution has helped them as it should and has prepared them adequately for their life after discharge.

The demographic variables collected through the respondents' replies to the questionnaire, ie, the variables tested as relevant case-mix adjustors, were: gender, marital status, education, self-perceived physical and mental health, most frequently used drug or substance prior to this admission, length of stay at this institution, number of previous admissions, age, and age when they developed the substance dependence. In addition to the mentioned variables, a new variable, mixed use, was computed. This variable corresponds to the number of substances that each respondent reported using most frequently before admission, with a possible value from 1 to 6. This variable acted as a proxy for the severity of dependence.

Given the smallness of the sample at each institution, the scales were inspected at several levels of health care. The participating institutions could be grouped into hospital trusts or private organizations as well as in regional hospital trusts. Grouping the institutions in this way allowed us to assess the standard error of the scale scores, and thereby determine the health care level at which the statistical uncertainty was too large. We used the criterion employed in other national patient-experience surveys performed in Norway, which is to compute scale scores only where the standard error is lower than 6. This criterion leads to that the hospital trust level was chosen to represent the provider level in this study, meaning public hospital trusts or private organizations with more than one underlying unit (institution).

Results of national surveys reported by the NIPH are usually weighted to address nonresponse. However, the present survey did not include this information. The results were weighted based on self-reported length of stay at the institution in order to compensate for the larger probability of being sampled when having stayed longer at the institution.

Analysis

Due to the nested nature of the data (ie, the respondents were nested within the hospital trusts), and violation of the prerequisite that the data are statistically independent, multilevel modeling was used in all regression analyses.²⁷ For multilevel modeling to be necessary, it is often stated that the ICC should be larger than 0.01,²⁸ and that the design effect should be larger than 2.²⁹ In line with these recommendations, we calculated both the ICC and design effect.

Associations between independent variables and the scales were assessed with a merged data set containing data from 2013 to 2014. The analyses only included institutions that had respondents from both survey years. The tested variables and the resulting model were based on (i) the scientific literature, (ii) the effect of background variables on the scales, (iii) the distribution of the background variables across the institutions, and (iv) suggestions from external experts that we sought advice from.

The multilevel analyses assessed the amount of variation at the hospital-trust level. In the null model, the hospital trusts were entered as random intercepts. This model was used to calculate the proportion of the variance explained at the hospital-trust level based on the ICC. The design effect was calculated based on the mean number of responses across the hospital trusts and the ICC for each of

the scales. The full model included hospital trusts as random intercepts and all patient variables that were statistically significant on a 0.05-level with at least one of the scales in bivariate models as fixed effects. Mixed use and survey year were entered into the multivariate model regardless of results from the bivariate analyses. The variance explained by the full model was calculated as described by Snijders and Bosker.²⁷ Based on findings from the multilevel analysis, we calculated adjusted scores for all hospital trusts on the three scales. Variables that were statistically significant on a 0.05-level on at least two of the scales in the multivariate analysis were included in the case-mix model.

The statistical analyses were conducted using SPSS (version 24.0; SPSS Inc., Chicago, IL, USA) and R software.³⁰

Results

In total, 978 inpatients in 2013 and 1,017 inpatients in 2014 responded to the national survey, giving a total merged data set of 1,995 respondents. The response rate for both years was 91%. The analyses were applied to 1,452 respondents from 21 hospital trusts, whose sample sizes ranged from 25 to 154. Table 1 shows that the mean age in the merged sample at the hospital-trust level was 36 years, and 69% of the respondents were male. Most (82%) of the respondents reported being single and 89% had finished primary school. The mean age when the respondents had developed substance dependence was 20 years, and the most frequently used substances prior to the current admission were alcohol, cocaine/amphetamine and cannabis, closely followed by medication. Sixty-four percent of the respondents reported their physical health to be good, very good or excellent, with 56% reporting this for the question about mental health. About half of the respondents had been at the institution for <3 months, and 68% had one or more previous admissions to a residential institution.

The multilevel bivariate regression models showed that all but five variables of 16 had a significant association with at least one of the scales (results not shown). The five variables were (i) heroin/morphine as the most frequently used drug prior to admission, (ii) other as the most frequently used drug prior to admission, (iii) mixed use, (iv) marital status, and (v) education. All of the other background variables were associated with at least one of the scales at the 0.05 level. Table 2 shows the multilevel multivariate regression model and that patients reporting alcohol as their most frequently used substance before admission had significantly better experiences on the

Table 1 Sample descriptives at the hospital trust level in 2013, 2014, and both years combined

	2013		2014		2013+2014	
	n	%	n	%	n	%
Gender						
Male	450	66.0	489	71.0	939	68.5
Female	232	34.0	200	29.0	432	31.5
Marital status						
Married/cohabiting	132	19.5	116	17.0	248	18.2
Single	545	80.5	566	83.0	1,111	81.8
Education						
Primary school	282	41.7	271	40.1	553	40.9
Secondary school	321	47.4	334	49.5	655	48.4
University or college	74	10.9	70	10.4	144	10.7
Self-perceived physical health						
Excellent	45	6.6	54	7.8	99	7.2
Very good	141	20.7	146	21.2	287	20.9
Good	241	35.4	248	36.0	489	35.7
Quite good	162	23.8	171	24.8	333	24.3
Poor	92	13.5	70	10.2	162	11.8
Self-perceived mental health						
Excellent	32	4.7	40	5.8	72	5.3
Very good	107	15.7	124	18.1	231	16.9
Good	228	33.5	229	33.4	457	33.5
Quite good	190	27.9	190	27.7	380	27.8
Poor	123	18.1	103	15.0	226	16.5
Most frequently used drug/substance prior to this admission						
Alcohol	321	44.8	337	45.9	658	45.3
Medication	330	46.0	304	41.4	634	43.7
Cannabis	323	45.0	332	45.2	655	45.1
Cocaine/amphetamine	348	48.5	367	49.9	715	49.2
Heroin/morphine	200	27.9	213	29.0	413	28.4
Other	95	13.2	83	11.3	178	12.3
Length of stay at this institution						
0–2 weeks	95	13.3	96	13.2	191	13.3
3–11 weeks	264	37.1	284	39.0	548	38.1
3–6 months	203	28.5	219	30.1	422	29.3
7–12 months	107	15.0	99	13.6	206	14.3
>12 months	43	6.0	30	4.1	73	5.1
Previous admissions						
No	211	30.9	229	33.4	440	32.2
Yes, once	180	26.4	174	25.4	354	25.9
Yes, twice	130	19.1	113	16.5	243	17.8
Yes, 3–5 times	97	14.2	117	17.1	214	15.6
Yes, >5 times	64	9.4	53	7.7	117	8.6
	n	years	n	years	n	years
Age	678	35.9 (mean)	667	36.1 (mean)	1,345	36.0 (mean)
Age when substance dependence developed	669	19.6 (mean)	673	19.8 (mean)	1,342	19.7 (mean)

Table 2 Results from multilevel regression models of the associations between independent variables and scale scores

Variable	Treatment and personnel		Milieu		Outcome	
	Estimate	P	Estimate	P	Estimate	P
Most frequently used drug/substance prior to this admission						
Alcohol	3.764	0.006	2.014	0.086	3.638	0.020
Medication	1.052	0.512	-0.747	0.586	1.724	0.345
Cannabis	-1.904	0.211	-1.503	0.248	-3.201	0.065
Cocaine/amphetamine	2.581	0.081	2.842	0.024	2.025	0.230
Mixed use ^a	-0.463	0.626	0.638	0.432	0.203	0.851
Length of stay at this institution ^b	2.249	0.000	-1.490	0.001	2.434	0.000
Pressured/forced by others to be admitted for treatment	-0.919	0.025	-1.062	0.002	-1.651	0.000
Gender						
Male	-	-	-	-	-	-
Female	2.623	0.020	0.117	0.903	3.730	0.004
Age	0.177	0.003	0.251	0.000	0.055	0.420
Age when substance dependence developed	0.044	0.537	-0.024	0.687	0.139	0.083
Self-perceived physical health ^b	-1.830	0.000	-1.347	0.002	-1.592	0.007
Self-perceived mental health ^b	-1.869	0.000	-1.596	0.000	-2.837	0.000
Year						
2013	-	-	-	-	-	-
2014	-0.352	0.726	0.072	0.933	0.169	0.882

Notes: ^aSum of the respondent replies to which substance was most frequently used before admission, and indicates how many substances each respondent reported to have used (range =1–6); ^bnumerical variables.

Table 3 Summary statistics on model variance

Scale	Var(U_{0j}) ^a	Var(R_{ij}) ^b	Total variance explained (%) ^c	ICC ^d	Design effect
Treatment and personnel	7.55	298.01	7.62	0.023	2.34
Milieu	23.29	218.99	6.97	0.081	5.69
Outcome	20.69	382.26	7.72	0.048	3.90

Notes: ^aHospital-trust-level variance. ^bPatient-level residual variance. ^cTotal variance explained calculated only for the individual level. ^dICC calculated from the multilevel regression null models with hospital trusts as random intercepts.

“treatment and personnel” and “outcome” scales when other factors were controlled for. Respondents with longer stays at the institutions reported better experiences with “treatment and personnel” and “outcome,” but worse experiences on the “milieu” scale. Being pressured or forced by others to be admitted for treatment had a negative impact on all three scales. Females had significantly better experiences than males regarding “treatment and personnel” and “outcome,” while older patients reported better experiences on the “treatment and personnel” and “milieu” scales. Patients reporting worse health (both physical and mental) reported worse experiences on all three scales.

Table 3 shows that the ICC varied from 2.3% for “treatment and personnel” to 8.1% for “milieu”, which indicate meaningful variance in the scale scores at the hospital-trust level, and the need for multilevel modeling.

The design effect was larger than 2 for all three scales. The proportion of the explained variance in the full model was 7.62% for “treatment and personnel,” 6.97% for “milieu,” and 7.72% for “outcome.”

Figure 1 displays the variation in results from the 21 participating hospital trusts, comprising hospital trusts or private organization with underlying departments/institutions. Each line represents one scale, while the results for each hospital trust appearing as points on the lines in the same order for all three scale scores. The scale scores for “treatment and personnel” varied from 54 to 66, while those for “milieu” varied from 62 to 87 and, those for “outcome” varied from 59 to 77. The mean national scale scores for the merged material were 61 for “treatment and personnel,” 75 for “milieu,” and 68 for “outcome.” One hospital trust obtained a score that was significantly lower than the national mean for “treatment and personnel”

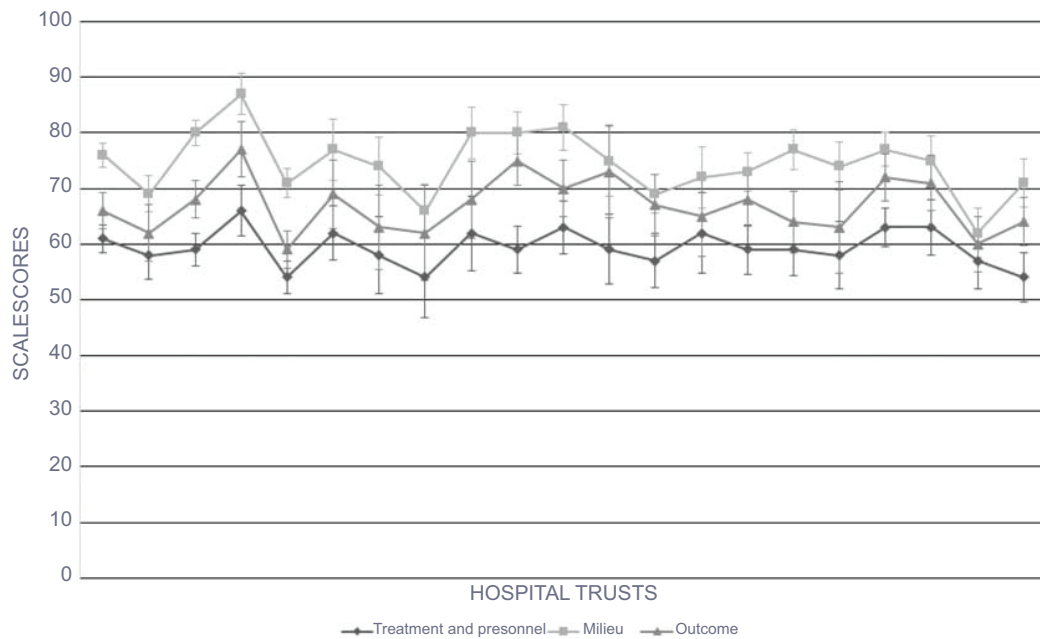


Figure 1 Variations in mean scale scores with 95% confidence intervals across hospital trusts.^a

Note: ^aSomewhat fewer respondents compared to other results due to the R analyses eliminating cases with missing data on one or more variables in the case-mix adjustment model.

($P < 0.01$). For “milieu,” four hospital trusts scored lower than the national mean ($P < 0.01$ to $P < 0.001$) and two had higher scores ($P < 0.05$ to $P < 0.001$). Four hospital trusts varied significantly from the national mean for “outcome,” with two in each direction ($P < 0.05$ to $P < 0.001$).

Discussion

This study explored the effects of patient characteristics on different aspects of the experiences of patients receiving residential treatment for substance dependence, with the aim of developing a feasible case-mix model to enable fairer comparisons between health care providers. The results showed that there is a need to adjust for several of the available variables, such as length of stay at the institution, pressure from others to be admitted for treatment, and self-perceived physical and mental health. Furthermore, alcohol reported as the most frequently used substance, being female, and increasing age were positively associated with two of the three scales. The results also showed that the indicators can be used to discriminate between health care providers.

The multilevel models showed that the scale scores should be adjusted for self-perceived physical and mental health. For both the “treatment and personnel” and “milieu” scales, comprising items related to aspects related to the residential institution only, self-perceived health

should function well as a case-mix variable. However, for the “outcome” scale, which measures the experiences of patients with aspects related to the treatment results, self-perceived health was omitted from the case-mix adjustment, even though the two variables were significantly associated with the scale. The reason for omitting self-perceived health is that both of these variables can be viewed as outcome variables, since the health of the patients might be expected to change due to them receiving treatment at the institutions.

In addition to the previously mentioned variables, the full case-mix model also included the computed variable of mixed use. Professionals in the field of substance-dependence treatment were approached for advice on the variables they thought should be included in the testing—their suggestions were age, marital status, gender, and mixed use. Mixed use was not significantly associated with any of the three scales, but the variable was kept in the model to compensate for the “outcome” scale not being adjusted for self-perceived health, and also functioning as a proxy for severity.

Age and self-perceived health have been found to be significantly associated with patient experiences and/or satisfaction in several populations, with patients who rate their health more positively and/or are older reporting satisfaction or better experiences.^{31–33} This is consistent with the findings of the present study. Other variables that

have been demonstrated (although more inconsistently) to be associated with the experiences of patients include education, marital status, income, and gender,^{31–33} but only gender was found to be significantly associated with the scale scores in the current study.

In line with the above-mentioned findings in other populations as well as those in the current study, a study conducted in the USA found that both self-perceived physical health and mental health were the strongest predictors of survey scores for patients receiving behavioral health care, such as treatment for mental illness or treatment for alcohol or drug use.⁹ Other variables reported as significant were education, age, and race/ethnicity, along with whether or not the patients were treated for alcohol or drug use. Education was not significantly associated with the scale scores in the current study; however, in the Norwegian sample, few respondents reported having a university- or college-level education, and the potential effect of differences in education level could be weaker. The PEQ-ITSD currently does not include questions on race or ethnicity, so these variables were not tested in the current study.

The length of stay at the institution was significantly associated with all of the scale scores: a longer stay was associated with more-positive evaluations on both the “treatment and personnel” and “outcome” scales, but with more negative evaluations on the “milieu” scale. This might be due to patients who have stayed in an institution for a longer time becoming more familiar with the personnel and the institution as a whole, forming relationships and trust, and being able to experience some benefits from their treatment that patients with shorter stays have not yet experienced. However, patients with longer stays may also become more tired of the institution and other patients, hence affecting the “milieu” score negatively. Another possible explanation is that patients who generally are more positive and have better experiences and outcomes stay longer in treatment.

Even though length of stay has been demonstrated to be a predictor of the results in these surveys, its suitability as a case-mix adjustor has been discussed. Ideally, a case-mix adjustor should be specific to individual patients and also outside the control of health care providers.³¹ The length of stay can clearly be influenced by health care providers, and a shorter length of stay in hospitals has been shown to negatively affect the quality of health care.³⁴ However, the point in our study is not to adjust for the actual length of stay for discharged patients, but to correct for the fact that institutions and hospital trusts at the time of measurement had different patient-mix concerning length of stay. The time of

measurement (a single day in a specific week) was decided by the external research organization, and so was outside the control of the different health care providers. Thus, differences in the length of stay at the time of measurement might be considered a valid and important case-mix adjustor in our study.

To be pressured or forced by others to be admitted for treatment had a negative impact on the scores on all the scales. The question did not distinguish who applied the pressure/force and may, therefore, be given a high score by all patients regardless of the legal status on their admission (voluntary vs involuntary) or the reason for seeking treatment. Previous research has shown that patients receiving psychiatric residential treatment who report higher levels of coercion (both perceived and documented) either at admission or during treatment report lower satisfaction or worse experiences with treatment.^{35,36}

The present results also indicated that respondents reporting alcohol as their previously most-used substance reported more positive experiences which therefore influenced the scores. Our external experts described this as a possible effect of age, in that people with alcohol dependence are generally older than people with other types of dependence. However, the current study identified each of alcohol dependence and age as predictors for scale scores when controlling for the other.

The data materials in national surveys are usually weighted to minimize the potential bias of nonresponses. As stated above, no information were collected concerning the background of patients or administrative information other than what the respondents replied in the questionnaire. This prevented the standard weighting procedure, where information on nonrespondents is compared to that on respondents in order to weight respondents to make them more representative of the total population. However, the high response rate of 91% strengthens the generalizability of the findings and reduces the need to implement weighting procedures based on responses.

The surveys were conducted as cross-sectional studies, and the results are therefore a description of the current status of the residential institutions. This means that some patients would have already been at the institutions for several weeks or even months, while others had arrived more recently. This way of recruiting patients and collecting data leads to a skewness in the possibility of being sampled to the surveys, since patients who have stayed for a longer time will have a higher probability of being sampled, and so those responding to the survey may have a longer stay on average. The data materials from these surveys are therefore

weighted based on the length of stay, with patients with longer stays having smaller weights.

Implications

When measuring quality and reporting quality indicators based on patient experiences in similar populations as the one surveyed in this study, the following variables are suggested case-mix adjustors: alcohol as the most frequently used substance, length of stay, pressure from others to be admitted for treatment, gender, age, and self-perceived physical and mental health. We also recommend adjusting for mixed use. Given several measuring points, one should also consider adjusting for this. Case-mix adjustments based on these suggestions should be considered when comparing between health care providers and to enhance the clinical legitimacy. Information on nonrespondents should be considered collected as a means to weight the results for response, especially in studies where the response rate is relatively low.

One of the main objectives of case-mix adjustments is to ensure fairer comparisons between health care providers based on survey scores. This is achieved by predicting how health care providers would score or rate if the populations were more standardized.³¹ Case-mix adjustments usually have a relatively small impact;⁹ and the need for such adjustments has been discussed.³⁸ However, some still argue that even small adjustments show that the appropriate measures have been taken to ensure valid comparisons, and to reduce the probability of health care providers attracting “easier” populations to improve their scores, such as patients who are older or in better health.^{9,38}

Quality indicators are often reported based on patient administrative data and/or registries. However, patient experiences and satisfaction have become an acknowledged and important way to measure aspects of the quality of health care, including in treatment for substance dependence.³⁷ The three scales tested in this study are the first quality indicators based on patient experiences reported nationally in Norway for this population, and they have been shown to effectively discriminate between health care providers, as indicated by the relatively large variations among the hospital trusts. In addition, it appears that the scale scores are somewhat correlated for each hospital (Figure 1). Furthermore, the scales can be used as quality indicators given their relevance to patients, and they have been demonstrated to be valid and reliable.¹⁷ The scales provide an important tool for use when measuring and discussing the quality of interdisciplinary treatment for substance dependence in Norway, and the current study has

shown how the survey scores should be adjusted based on patient characteristics in order to ensure valid and fair comparisons between hospital trusts.

Limitations

One of the limitations of this study was that the only available case-mix variables were patient-reported responses to the questionnaire. It is probable that other patient characteristics can impact the experiences of inpatients, and therefore should have been included in the analyses. Although this limitation is quite common when attempting to measure quality,³⁹ it is a topic that needs further exploration and which presupposes the availability of other background variables. Further developments of these measures in the given patient population should consider the availability of possibly important independent variables, such as patient administrative data and institution characteristics, eg, treatment programs or planned treatment duration.⁴⁰

Another limitation was the lack of information on the health of respondents at admission. This made it impossible to know whether the self-reported health answered in the questionnaire had changed from admission and, if it had, in what direction. A possible solution is to include transition questions that either ask the respondents about their health status prior to admission, or ask them to compare their current health status with that prior to admission. Changes in health might be interpreted as an outcome in itself, but could also be used to validate the patient-reported experience scales, especially the outcome scale.

The cut-off for reporting quality indicator scores was set at the level of hospital trusts with more than one underlying unit, and with merged data from two identical surveys. The rationale for this approach was to ensure a sufficient number of respondents per unit. Since not all residential institutions in Norway are organized together under hospital trusts or are part of a larger private organization, some institutions do not receive results on the indicators and so were excluded from the present analyses. This means that even though they have a relatively large patient population, some institutions will not receive case-mix-adjusted indicator scores. A solution could be to merge even more data sets (covering more survey years), but the results from several years might be difficult to use and interpret, and was deemed unnecessary in the present study.

The present surveys were conducted as two cross-sectional surveys performed in consecutive years. The included patients might, therefore, have been at the institutions for very different durations, which is why the data were both weighted and adjusted for the length of stay.

Another approach would have been to collect data at discharge. Such an approach has been discussed previously, and deemed a more-time-consuming method for data collection, since many institutions are small and their patient flows are therefore relatively low; in addition, it could mean losing patients that drop out of treatment.¹⁷ We are currently working on how to collect the experiences of patients at discharge in a fashion that is feasible for all involved. Furthermore, assessing the predictive validity of on-site patient-based indicators will be important for future research, preferably using a longitudinal design.

Conclusion

This study found that the three scales comprising the PEQ-ITSD function well as patient-experience-based quality indicators at the hospital-trust level, given that data from 2 years were merged and implementation of the proposed case-mix model. The variations in scale scores across health care providers show that the indicators can be used to discriminate between different providers, suggesting the possibility of improving scale scores through improvement work. Future research should assess the associations between patient-based quality indicators and other quality indicators, and the predictive validity of patient-experience indicators based on on-site measurements.

Ethics approval and informed consent

Data were collected anonymously, with no registration of the patients being surveyed. The project was run as part of the national program and was an anonymous quality assurance project. According to the Norwegian Regional Committees for Medical and Health Research Ethics, research approval is not required for quality assurance projects. The Norwegian Social Science Data Services states if the information used are anonymous, the project is not subject to notification (http://www.nsd.uib.no/per/sonvern/en/notification_duty/meldeskjema?eng). Hence, no ethics approval was needed in this project. Patients were informed that participation was voluntary and that they would remain anonymous. In accordance with all the patient surveys in the national program, health professionals at the institutions could exclude individual patients for special ethical considerations. Since no notification or ethics approval was needed, the NIPH obtained signed agreements with all the participating

institutions, describing the project and both the institutions' and NIPH's responsibility in data collecting, handling, analyzing and reporting. Previously established guidelines concerning consent through a returned questionnaire were applied.

Data availability

The datasets generated and analyzed during the current study are not publicly available due to this being one part of an ongoing PhD-project at the NIPH and the University of Oslo. Request for permission to use the data must be directed to the NIPH.

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Author contributions

All authors made substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; took part in drafting the article or revising it critically for important intellectual content; gave final approval of the version to be published; and agree to be accountable for all aspects of the work.

Disclosure

The authors report no conflicts of interest with this work.

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Appendix 1. Patient questionnaire, 2013



PasOpp Rus

Høst 2013

Hva er dine erfaringer med døgnopphold i rusinstitusjon?

Hensikten med denne undersøkelsen er å gjøre tilbudet bedre for pasienter innen rusbehandling i spesialisthelsetjenesten. Vi vil gjerne høre om dine erfaringer fra den institusjonen du nå er innlagt ved.



Om utfyllingen: Sett kryss midt i rutene. Slik: ☒ Ikke slik: ☒



Litt om din bakgrunn

- | | | | | | | | |
|----|--|-------------------------------------|--|--|--|--|--|
| 1. | Hvilket rusmiddel brukte du mest før denne innleggelsen?
<i>Du kan sette flere kryss.</i> | Alkohol
<input type="checkbox"/> | Medikamenter
<input type="checkbox"/> | Cannabis
<input type="checkbox"/> | Kokain/
amfetamin
<input type="checkbox"/> | Heroin/
morfinstoffer
<input type="checkbox"/> | Annet
<input type="checkbox"/> |
| 2. | Hvor lenge har du vært innlagt ved denne institusjonen? | | 0-2
uker
<input type="checkbox"/> | 3-11
uker
<input type="checkbox"/> | 3-6
måneder
<input type="checkbox"/> | 7-12
måneder
<input type="checkbox"/> | Over 12
måneder
<input type="checkbox"/> |



Mottakelse og ventetid

- | | | | | | | |
|----|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | | Ikke i det hele tatt | I liten grad | I noen grad | I stor grad | I svært stor grad |
| 3. | Fikk du informasjon om institusjonens regler og rutiner da du kom? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. | Var måten du ble tatt imot på ved institusjonen tilfredsstillende? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | | | | | | |
| | | Nei | Ja, men ikke lenge | Ja, ganske lenge | Ja, altfor lenge | |
| 5. | Måtte du vente for å få tilbud ved institusjonen? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Behandlerne/personalet

Tenk på behandlerne og personalet ved institusjonen når du svarer på spørsmålene nedenfor.

- | | | | | | | | |
|-----|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | | Ikke i det hele tatt | I liten grad | I noen grad | I stor grad | I svært stor grad | Ikke aktuelt |
| 6. | Har du fått nok tid til samtaler og kontakt med behandlerne/personalet? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. | Opplever du at behandlerne/personalet har forstått din situasjon? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. | Har du hatt tillit til behandlerne/personalets faglige dyktighet? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. | Har en fra behandlerne/personalet hatt hovedansvaret for deg? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | | | | | | | |
| 10. | I hvilken grad har du blitt møtt med høflighet og respekt? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | | | | | | | |
| 11. | Har du blitt behandlet nedlatende eller krenkende av behandlerne/personalet? | <input type="checkbox"/> | Ja, en gang | Ja, noen ganger | Ja, mange ganger | | |

Behandlingen

12. Hvilket utbytte har du hatt av følgende behandlingstilbud ved institusjonen: ⊥
Kryss av for Ikke aktuelt for de du ikke mottar.

	Ikke noe utbytte	Lite utbytte	En del utbytte	Stort utbytte	Svært stort utbytte	Ikke aktuelt
Behandling i grupper?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Samtaler med én behandler?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Behandling med medisiner?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

⊥

13. Alt i alt, hvilket utbytte har du hatt av behandlingen ved institusjonen?
- | | Ikke noe utbytte | Lite utbytte | En del utbytte | Stort utbytte | Svært stort utbytte | Ikke aktuelt |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

14. Har informasjonen du har fått om behandlingen din vært tilfredsstillende?
- | | Ikke i det hele tatt | I liten grad | I noen grad | I stor grad | I svært stor grad | Ikke aktuelt |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

15. Har du hatt innflytelse på behandlingen din?
- | | Ikke i det hele tatt | I liten grad | I noen grad | I stor grad | I svært stor grad | Ikke aktuelt |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

⊥

16. Opplever du at behandlingen har vært tilpasset dine behov?
- | | Ikke i det hele tatt | I liten grad | I noen grad | I stor grad | I svært stor grad | Ikke aktuelt |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

17. Har du fått hjelp med fysiske plager eller sykdom?
- | | Ikke i det hele tatt | I liten grad | I noen grad | I stor grad | I svært stor grad | Ikke aktuelt |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

18. Har du fått hjelp med psykiske plager?
- | | Ikke i det hele tatt | I liten grad | I noen grad | I stor grad | I svært stor grad | Ikke aktuelt |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

⊥

19. Har du hatt tilfredsstillende tilgang til psykolog?
- | | Ikke i det hele tatt | I liten grad | I noen grad | I stor grad | I svært stor grad | Ikke aktuelt |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

20. Har du hatt tilfredsstillende tilgang til lege?
- | | Ikke i det hele tatt | I liten grad | I noen grad | I stor grad | I svært stor grad | Ikke aktuelt |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Miljøet og aktivitetstilbudet

- | | Ikke i det hele tatt | I liten grad | I noen grad | I stor grad | I svært stor grad |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 21. Har du følt deg trygg ved institusjonen? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 22. Har institusjonen tilrettelagt for kontakt med andre pasienter på en tilfredsstillende måte? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 23. Har aktivitetstilbudet ved institusjonen vært tilfredsstillende? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 24. Har måltidene ved institusjonen vært tilfredsstillende? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 25. Har du vært tilfreds med muligheten for privatliv? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Forberedelse til tiden etter utskrivning

Spørsmålene nedenfor handler om forberedelse til tiden etter utskrivning.

- | | Ikke i det hele tatt | I liten grad | I noen grad | I stor grad | I svært stor grad | Ikke aktuelt |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 26. Opplever du at behandlerne/personalet har forberedt deg på tiden etter utskrivning? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 27. Opplever du at behandlerne/personalet har hjulpet deg med praktiske løsninger for tiden etter utskrivning (<i>f.eks. bolig, økonomi, arbeid/skole</i>)? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 28. Opplever du at behandlerne/personalet har tilrettelagt for videre behandling for tiden etter utskrivning? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 29. Opplever du at behandlerne/personalet har hjulpet deg slik at du kan få et meningsfullt liv etter utskrivning? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Andre vurderinger

	Ikke i det hele tatt	I liten grad	I noen grad	I stor grad	I svært stor grad	Ikke aktuelt
30. Alt i alt, er hjelpen og behandlingen du har fått ved institusjonen tilfredsstillende?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Gjør hjelpen og behandlingen du får ved institusjonen deg bedre i stand til å <u>forstå</u> rusproblemene dine?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Vet ikke <input type="checkbox"/>
32. Gjør hjelpen og behandlingen du får ved institusjonen deg bedre i stand til å <u>mestre</u> rusproblemene dine?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Vet ikke <input type="checkbox"/>
⊥						⊥
33. Gir hjelpen og behandlingen du får ved institusjonen deg tro på at du vil få et bedre liv etter utskrivning?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Vet ikke <input type="checkbox"/>

	Ikke i det hele tatt	I liten grad	I noen grad	I stor grad	I svært stor grad	Ikke aktuelt
34. Opplever du at behandlerne/ personalet har samarbeidet godt med dine pårørende?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. I hvilken grad følte du deg presset/ tvunget av andre til å legge deg inn?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Ikke aktuelt <input type="checkbox"/>
⊥						
36. Mener du at du på noen måte har blitt feilbehandlet (etter det du selv kan bedømme)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Ikke aktuelt <input type="checkbox"/>

⊥

Tidligere innleggelser ved rusinstitusjoner

Spørsmålene nedenfor handler om tidligere innleggelser ved rusinstitusjoner med unntak av rene avrusningsenheter.

37. Har du vært innlagt på en rusinstitusjon før denne innleggelsen?
- | | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Nei | Ja, én gang | Ja, 2 ganger | Ja, 3 - 5 ganger | Ja, mer enn 5 ganger | |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
38. Hvis du tidligere har vært innlagt, synes du oppfølgingen/ettervernet etter utskrivningen var tilfredsstillende? (Tenk på den siste innleggelsen hvis du har vært innlagt flere ganger.)
- | | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Ikke i det hele tatt | I liten grad | I noen grad | I stor grad | I svært stor grad | Ikke aktuelt |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
39. Hvis du tidligere har vært innlagt, var den siste innleggelsen ved denne institusjonen?
- | | | | | | |
|--------------------------|--------------------------|--|--|--|--------------------------|
| Ja | Nei | | | | Ikke aktuelt |
| <input type="checkbox"/> | <input type="checkbox"/> | | | | <input type="checkbox"/> |

Hjelp fra kommunen du bor i

40. Hvis du tidligere har fått hjelp fra kommunen du bor i, har hjelpen alt i alt vært tilfredsstillende?
- | | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|----------------------------------|
| Ikke i det hele tatt | I liten grad | I noen grad | I stor grad | I svært stor grad | Ikke aktuelt/har ikke fått hjelp |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
41. Hvis du tidligere har fått hjelp fra kommunen du bor i, hvem/hvilken instans har vært viktigst for deg? Du kan sette flere kryss.
- | | | | | | |
|--------------------------|--------------------------|-------------------------------|--------------------------|--------------------------|--------------------------|
| Rus-konsulent | Ansvars-gruppe | Oppfølgings-tjenester i bolig | Hel-døgns-tilbud | Fastlege | Annet |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
42. Hvis "annet" på spørsmål 41, hvilken instans?
-

Bakgrunnsopplysninger

43. Er du mann eller kvinne? Mann Kvinne
 ⊥
44. Hvilket år ble du født? Årstall
1 9
45. Er du gift/samboende? Ja Nei
46. Hvilken utdanning har du? Grunnskole Videregående skole Høgskole/ universitet
47. Hvor gammel var du da du fikk et rusproblem? Alder
-
48. Har du en individuell plan?
(Alle med behov for langvarige og koordinerte helse- og sosialtjenester har rett til en individuell plan.) Ja Nei Vet ikke ⊥
49. Hvis du har en individuell plan, er du tilfreds med denne planen? ⊥
Ikke i det hele tatt I liten grad I noen grad I stor grad I svært stor grad Ikke aktuelt
50. Hvordan vil du si din *fysiske* helse er? Utmerket Meget god God Nokså god Dårlig
51. Hvordan vil du si din *psykiske* helse er? Utmerket Meget god God Nokså god Dårlig

Appendix 2. Employee questionnaire, 2013



Bruk av pasienterfaringsdata i kvalitetsforbedrende arbeid

Bruk av resultater/2013

Nasjonalt kunnskapssenter for helsetjenesten gjennomfører årlig nasjonale bruker-erfaringsundersøkelser i norsk helsetjeneste. Høsten 2013 gjennomføres undersøkelser innen tverrfaglig spesialisert rusbehandling ved alle rusinstitusjoner i Norge.

Vi gjør nå en kartlegging blant ansatte ved rusinstitusjonene. Kartleggingen gjennomføres som en elektronisk spørreundersøkelse i 2013 og 2014. I den første delen av undersøkelsen spør vi om ansattes vurderinger av pasienterfaringsundersøkelser. I den andre delen ønsker vi også tilbakemeldinger på nytte og bruk av resultater fra

brugerundersøkelsen i 2013.

Det er frivillig å svare på undersøkelsen, men vi setter stor pris på om du bruker noen minutter til å svare. Tilbakemeldingene er svært verdifulle for oss og kan hjelpe oss og gjøre våre tjenester bedre og mer tilpasset mottakerne i norsk helsetjeneste i fremtiden.

Generelt om pasienterfaringer og pasienterfaringsundersøkelser

	Ikke i det hele tatt	I liten grad	I noen grad	I stor grad	I svært stor grad
1. Mener du det er viktig at pasienter tas med på råd i forbindelse med behandling?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Mener du det er viktig at pasienter involveres når kvaliteten på helsetjenester skal evalueres?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Alt i alt, mener du at pasienterfaringsundersøkelser er viktig?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Alt i alt, mener du at pasienterfaringsundersøkelser kan bidra til å forbedre helse-tjenesten?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Mener du at pasienterfaringsundersøkelser kan bidra til å bedre den medisinske kvaliteten i helsetjenesten?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. Hvilke tjenester mener du at pasientene er best i stand til å vurdere kvaliteten på?

	Ja	Nei, men har konkrete planer om å gjøre det	Nei, og har ingen planer om å gjøre det	Vet ikke
7. Har dere gjennomført lokale pasienterfaringsundersøkelser ved din institusjon?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Bakgrunnsinformasjon

8. Er du mann eller kvinne?

Mann

Kvinne

9. Hva er din alder?

Antall år

10. Hvor mange år har du jobbet ved institusjonen?

Antall år

11. Stillingsinnhold? *(Du kan sette flere kryss)*

(Med kvalitets- og fagutvikling mener vi ansvar for organiserte aktiviteter, ikke det individuelle ansvaret som alt helsepersonell er pålagt.)

Klinisk arbeid

Administrasjon

Kvalitetsutvikling/
Fagutvikling

Annet

12. Har du en stilling med lederansvar?

Nei

Ja, mellomleder

Ja, leder på høyere nivå

13. Hva er din faglige bakgrunn? (Du kan sette flere kryss)

Lege

Psykolog

Sykepleier

Vernepleier

Barnevernspedagog

Sosionom

Annet (spesifiser type utdanning og varighet)

Tusen takk for at du tok deg tid til å svare!

Appendix 3. Employee questionnaire, 2014

Bruk av pasienterfaringsdata i kvalitetsutvikling

Nasjonalt kunnskapssenter for helsetjenesten gjennomfører årlig nasjonale brukererfaringsundersøkelser i norsk helsetjeneste. Høsten 2013 ble undersøkelser innen tverrfaglig spesialisert rusbehandling gjennomført ved alle rusinstitusjoner i Norge. Undersøkelsene gjentas høsten 2014.

Vi gjør nå en kartlegging blant ansatte ved rusinstitusjonene. Kartleggingen gjennomføres som en elektronisk spørreundersøkelse. Høsten 2013 spurte vi om ansattes vurderinger av pasienterfaringsundersøkelser. Nå ønsker vi også tilbakemeldinger på nytte og bruk av resultater fra undersøkelsen blant pasientene i 2013. Det er frivillig å delta, men vi setter stor pris på om du bruker noen minutter på å svare.

Tilbakemeldingene dine er svært verdifulle for oss og kan hjelpe oss å gjøre våre tjenester bedre og mer tilpasset mottakerne i norsk helsetjeneste i fremtiden.

Generelt om pasienterfaringer og pasienterfaringsundersøkelser

1. Mener du det er viktig at pasienter tas med på råd i forbindelse med behandling?
2. Mener du det er viktig at pasienter involveres når kvaliteten på helsetjenester skal evalueres?
3. Alt i alt, mener du at pasienterfaringsundersøkelser er viktig?
4. Alt i alt, mener du at pasienterfaringsundersøkelser kan bidra til å forbedre helsetjenesten?
5. Mener du at pasienterfaringsundersøkelser kan bidra til å bedre den medisinske kvaliteten i helsetjenesten?

«Ikke i det hele tatt» til «I svært stor grad»

6. Har dere gjennomført lokale pasienterfaringsundersøkelser ved din institusjon/avdeling etter at undersøkelser ble gjennomført ved alle institusjonene i 2013?

«Ja» - «Nei, men har konkrete planer om å gjøre det» - «Nei, og har ingen planer om å gjøre det» - «Vet ikke»

Om undersøkelsen «Pasienterfaringer med døgnopphold innen tverrfaglig spesialisert rusbehandling» i 2013

7. Hvordan har du blitt informert om resultatene fra undersøkelsen i 2013 for din institusjon/avdeling? (Du kan sette flere kryss).

«På møter» - «Gjennom oppslag» - «Interne notater eller e-post» - Gjennom uformelle møter med kolleger» - «Annet» - «Har ikke blitt informert»

8. Har resultatene fra undersøkelsen blitt formelt diskutert hos dere (for eksempel på avdelings- eller ansattmøter)?

«Ja» - «Nei» - «Vet ikke»

9. Har resultatene fra undersøkelsen blitt uformelt diskutert hos dere?

«Ikke i det hele tatt» til «I svært stor grad»

10. Har resultatene fra undersøkelsen ledet til endring i behandlernes/ personalets atferd overfor pasientene ved din institusjon/avdeling?

«Ja» - «Nei» - «Vet ikke»

Hvis ja, på hvilken måte?

.....
.....
.....

Tiltak etter undersøkelsen

11. Har dere iverksatt tiltak for å rette på utfordringene som ble identifisert i undersøkelsen blant pasientene i 2013?

«Ja, ett tiltak» - «Ja, flere tiltak» - «Nei» - «Vet ikke»

12. Hvis dere har iverksatt tiltak for å rette på utfordringene som ble identifisert i undersøkelsen i 2013, beskriv tiltakene så utførlig som mulig:

.....
.....
.....
.....
.....
.....

13. I undersøkelsen i 2013 vurderte pasienten institusjonen på ulike områder. Er tiltaket/tiltakene du beskrev ovenfor rettet mot noen av disse områdene? (Du kan sette flere kryss).

«Mottagelse og ventetid»

«Behandlerne/personalet»

«Behandlingen»

«Miljøet og aktivitetstilbudet»

«Forberedelse til tiden etter utskrivning»

«Hjelp fra kommunen»

«Annet»

14. Hvorfor valgte dere dette tiltaket/tiltakene? (Du kan sette flere kryss).

«Forslag fra pasientene» - «Forslag fra ansatte» - «Forskningsbasert dokumentasjon» -
«Retningslinjer/veiledere/sentrale føringer» - «Annet» - «Vet ikke»

15. Mener du at tiltaket/tiltakene som er iverksatt har hatt ønsket effekt?

«Ikke i det hele tatt» til «I svært stor grad» - «Vet ikke»

Andre vurderinger

16. Er det noe du opplever har hindret bruken av resultatene fra undersøkelsen ved din institusjon/avdeling?

.....
.....
.....

17. Har du kjennskap til resultatrapporten fra undersøkelsen «Pasienterfaringer med døgnopphold innen tverrfaglig spesialisert rusbehandling» for din institusjon/avdeling?

«Ja» - «Nei» - «Vet ikke»

Hvis ja, har du forslag til endringer som kunne gjort rapporten bedre for deg?

.....
.....
.....

18. Alt i alt, opplever du at undersøkelsen «Pasienterfaringer med døgnopphold innen tverrfaglig spesialisert rusbehandling» har vært nyttig for din institusjon/avdeling?

«Ikke i det hele tatt» til «I svært stor grad»

Bakgrunnsinformasjon

19. Er du mann eller kvinne?

«Mann» «Kvinne»

20. Hva er din alder?

«Antall år»

21. Hvor mange år har du jobbet ved institusjonen?

«Antall år»

22. Stillingsinnhold? (Du kan sette flere kryss)

(Med kvalitets- og fagutvikling mener vi ansvar for organisert aktiviteter, ikke det individuelle ansvaret som alt helsepersonell er pålagt.)

«Klinisk arbeid» «Administrasjon» «Kvalitetsutvikling/Fagutvikling» «Annet»

23. Har du en stilling med lederansvar?

«Nei» «Ja, mellomleder» «Ja, leder på høyere nivå»

24. Hva er din faglige bakgrunn? (Du kan sette flere kryss)

«Lege» «Psykolog» «Sykepleier» «Vernepleier» «Barnevernspedagog» «Sosionom» «Annet (spesifiser type utdanning og varighet)»

25. Svarte du på skjemaet vi sendte ut i fjor høst om vurderinger av pasienterfaringsundersøkelser?

«Ja» - «Nei» - «Vet ikke/husker ikke»

26. Har din institusjon/avdeling deltatt i konkrete tiltak i forbindelse med den nasjonale pasientsikkerhetskampanjen/ pasientsikkerhetsprogrammet?

«Ja» - «Nei» - «Vet ikke»

Har du andre kommentarer til pasienterfaringsundersøkelsen i 2013 eller denne undersøkelsen kan du skrive mer om dette her

Appendix 4. Employee questionnaire, 2015

Bruk av pasienterfaringsdata i kvalitetsutvikling

Nasjonalt kunnskapssenter for helsetjenesten gjennomfører årlig nasjonale brukererfaringsundersøkelser i norsk helsetjeneste. Høsten 2013 og 2014 ble undersøkelser innen tverrfaglig spesialisert rusbehandling gjennomført ved alle rusinstitusjoner i Norge. Undersøkelsen gjentas høsten 2015.

Vi gjør nå en kartlegging blant ansatte ved rusinstitusjonene. Kartleggingen gjennomføres som en elektronisk spørreundersøkelse. Høsten 2013 spurte vi om ansattes vurderinger av pasienterfaringsundersøkelser. I 2014 spurte vi også om tilbakemeldinger på nytte og bruk av resultater fra undersøkelsen blant pasientene i 2013. Årets undersøkelse er en gjentakelse av den fra 2014. Det er frivillig å delta, men vi setter stor pris på om du bruker noen minutter på å svare.

Tilbakemeldingene dine er svært verdifulle for oss og kan hjelpe oss å gjøre våre tjenester bedre og mer tilpasset mottakerne i norsk helsetjeneste i fremtiden.

Generelt om pasienterfaringer og pasienterfaringsundersøkelser

1. Mener du det er viktig at pasienter tas med på råd i forbindelse med behandling?
2. Mener du det er viktig at pasienter involveres når kvaliteten på helsetjenester skal evalueres?
3. Alt i alt, mener du at pasienterfaringsundersøkelser er viktig?
4. Alt i alt, mener du at pasienterfaringsundersøkelser kan bidra til å forbedre helsetjenesten?
5. Mener du at pasienterfaringsundersøkelser kan bidra til å bedre den medisinske kvaliteten i helsetjenesten?

«Ikke i det hele tatt» til «I svært stor grad»

6. Har dere gjennomført lokale pasienterfaringsundersøkelser ved din institusjon/avdeling etter at den nasjonale undersøkelsen ble gjennomført ved alle institusjonene i 2014?

«Ja» - «Nei, men har konkrete planer om å gjøre det» - «Nei, og har ingen planer om å gjøre det» - «Vet ikke»

Om undersøkelsen «Pasienterfaringer med døgnopphold innen tverrfaglig spesialisert rusbehandling» i 2014

7. Hvordan har du blitt informert om resultatene fra undersøkelsen i 2014 for din institusjon/avdeling? (Du kan sette flere kryss).

«På møter» - «Gjennom oppslag» - «Interne notater eller e-post» - Gjennom uformelle møter med kolleger» - «Annet» - «Har ikke blitt informert»

8. Har resultatene fra undersøkelsen i 2014 blitt formelt diskutert hos dere (for eksempel på avdelings- eller ansattmøter)?

«Ja» - «Nei» - «Vet ikke»

9. Har resultatene fra undersøkelsen i 2014 blitt uformelt diskutert hos dere?

«Ikke i det hele tatt» til «I svært stor grad»

10. Har resultatene fra undersøkelsen i 2014 ledet til endring i behandlernes/ personalets atferd overfor pasientene ved din institusjon/avdeling?

«Ja» - «Nei» - «Vet ikke»

Hvis ja, på hvilken måte?

.....
.....
.....

Tiltak etter undersøkelsen

11. Har dere iverksatt tiltak for å rette på utfordringene som ble identifisert i undersøkelsen blant pasientene i 2014?

«Ja, ett tiltak» - «Ja, flere tiltak» - «Nei» - «Vet ikke»

12. Hvis dere har iverksatt tiltak for å rette på utfordringene som ble identifisert i undersøkelsen i 2014, beskriv tiltakene så utførlig som mulig:

.....
.....
.....
.....
.....
.....

13. I undersøkelsen i 2014 vurderte pasienten institusjonen på ulike områder. Er tiltaket/tiltakene du beskrev ovenfor rettet mot noen av disse områdene? (Du kan sette flere kryss).

«Mottagelse og ventetid»

«Behandlerne/personalet»

«Behandlingen»

«Miljøet og aktivitetstilbudet»

«Forberedelse til tiden etter utskrivning»

«Hjelp fra kommunen»

«Annet»

14. Hvorfor valgte dere dette tiltaket/tiltakene? (Du kan sette flere kryss).

«Forslag fra pasientene» - «Forslag fra ansatte» - «Forskningsbasert dokumentasjon» -
«Retningslinjer/veiledere/sentrale føringer» - «Annet» - «Vet ikke»

15. Mener du at tiltaket/tiltakene som er iverksatt har hatt ønsket effekt?

«Ikke i det hele tatt» til «I svært stor grad» - «Vet ikke»

Andre vurderinger

16. Er det noe du opplever har hindret bruken av resultatene fra undersøkelsen ved din institusjon/avdeling?

.....
.....
.....

17. Har du kjennskap til resultatrapporten fra undersøkelsen «Pasienterfaringer med døgnopphold innen tverrfaglig spesialisert rusbehandling» for din institusjon/avdeling?

«Ja» - «Nei» - «Vet ikke»

Hvis ja, har du forslag til endringer som kunne gjort rapporten bedre for deg?

.....
.....
.....

18. Alt i alt, opplever du at undersøkelsen «Pasienterfaringer med døgnopphold innen tverrfaglig spesialisert rusbehandling» har vært nyttig for din institusjon/avdeling?

«Ikke i det hele tatt» til «I svært stor grad»

Bakgrunnsinformasjon

19 Er du mann eller kvinne?

20 Hva er din alder?

21 Hvor mange år har du jobbet ved institusjonen?

22 Stillingsinnhold? (Du kan sette flere kryss)

«Klinisk arbeid» «Administrasjon» «Kvalitetsutvikling/fagutvikling» «Annet»

23 Har du stilling med lederansvar?

«Nei» «Ja, mellomleder» «Ja, leder på høyere nivå»

24 Hva er din faglige bakgrunn? (Du kan sette flere kryss)

«Lege» «Psykolog» «Sykepleier» «Vernepleier» «Barnevernspedagog» «Sosionom» «Annet (spesifiser type utdanning og varighet)»

25 Svarte du på skjemaet vi sendte ut i fjor høst om vurderinger av pasienterfaringsundersøkelser?

«Ja» - «Nei» - «Vet ikke/husker ikke»

26 Den nasjonale pasienterfaringsundersøkelsen har vært gjennomført årlig i perioden 2013 til og med 2015. Hvor ofte mener du denne undersøkelsen bør gjennomføres?

«Flere ganger i året» - «Årlig» - «Hvert andre år» «Sjeldnere»

Har du andre kommentarer til pasienterfaringsundersøkelsen i 2014 eller denne undersøkelsen kan du skrive mer om dette her

Appendix 5. Employee questionnaire, 2017

Bruk av pasienterfaringsdata i kvalitetsutvikling

Side 1

Obligatoriske felter er merket med denne stjernen *

Folkehelseinstituttet gjennomfører nasjonale brukererfaringsundersøkelser i norsk helsetjeneste. Våren 2017 gjennomfører vi for fjerde gang undersøkelser innen tverrfaglig spesialisert rusbehandling ved alle rusinstitusjoner i Norge.

Vi har i forbindelse med undersøkelsene gjort kartlegginger blant ansatte ved rusinstitusjonene. Kartleggingene gjennomføres som elektroniske spørreundersøkelser der vi spør om vurderinger av pasienterfaringsundersøkelser og nytte og bruk av resultatene.

Det er frivillig å delta, men tilbakemeldingene dine er svært viktige for oss og vi setter stor pris på om du bruker noen minutter på å svare.

Side 2

Obligatoriske felter er merket med denne stjernen *

Pasienterfaringer og pasienterfaringsundersøkelser

Mener du det er viktig at pasienter tas med på råd i forbindelse med behandling?

Ikke i det hele tatt

I liten grad

I noen grad

I stor grad

I svært stor grad

Mener du det er viktig at pasienter involveres når kvaliteten på helsetjenester skal evalueres?

Ikke i det hele tatt

I liten grad

I noen grad

I stor grad

I svært stor grad

Obligatoriske felter er merket med denne stjernen *

Pasienterfaringer og pasienterfaringsundersøkelser

Alt i alt, mener du at pasienterfaringsundersøkelser er viktig?

Ikke i det hele tatt

I liten grad

I noen grad

I stor grad

I svært stor grad

Alt i alt, mener du at pasienterfaringsundersøkelser kan bidra til å forbedre helsetjenesten?

Ikke i det hele tatt

I liten grad

I noen grad

I stor grad

I svært stor grad

Obligatoriske felter er merket med denne stjernen *

Pasienterfaringer og pasienterfaringsundersøkelser

Mener du at pasienterfaringsundersøkelser kan bidra til å bedre den medisinske kvaliteten i helsetjenesten?

Ikke i det hele tatt

I liten grad

I noen grad

I stor grad

I svært stor grad

Har dere gjennomført lokale pasienterfaringsundersøkelser ved din institusjon/avdeling etter at den nasjonale undersøkelsen ble gjennomført ved alle institusjonene i 2015?

Ja

Nei, men har konkrete planer om å gjøre det

Nei, og har ingen planer om å gjøre det

Vet ikke

Obligatoriske felter er merket med denne stjernen *

Om pasienterfaringsundersøkelsen i 2015

Spørsmålene under handler om undersøkelsen «Pasienterfaringer med døgnopphold innen tverrfaglig spesialisert rusbehandling» som ble gjennomført i 2015.

Hvordan har du blitt informert om resultatene fra undersøkelsen i 2015 for din institusjon/avdeling? *(Du kan sette flere kryss).*

- På møter
- Gjennom oppslag
- Interne notater eller e-post
- Gjennom uformelle møter med kolleger
- Annet
- Har ikke blitt informert

Har resultatene fra undersøkelsen i 2015 blitt formelt diskutert hos dere (for eksempel på avdelings- eller ansattmøter)?

- Ja
- Nei
- Vet ikke

Har resultatene fra undersøkelsen i 2015 blitt uformelt diskutert hos dere?

- Ikke i det hele tatt
- I liten grad
- I noen grad
- I stor grad
- I svært stor grad

Obligatoriske felter er merket med denne stjernen *

Om pasienterfaringsundersøkelsen i 2015

Spørsmålene under handler om undersøkelsen «Pasienterfaringer med døgnopphold innen tverrfaglig spesialisert rusbehandling» som ble gjennomført i 2015.

Har resultatene fra undersøkelsen i 2015 ledet til endring i behandlernes/ personalets atferd overfor pasientene ved din institusjon/avdeling?

- Ja
- Nei
- Vet ikke

Hvis ja, på hvilken måte?

Obligatoriske felter er merket med denne stjernen *

Tiltak etter undersøkelsen

Har dere iverksatt tiltak for å rette på utfordringene som ble identifisert i undersøkelsen blant pasientene i 2015? *

- Ja, ett tiltak
- Ja, flere tiltak
- Nei
- Vet ikke

Obligatoriske felter er merket med denne stjernen *



Dette elementet vises kun dersom alternativet «Ja, flere tiltak» eller «Ja, ett tiltak» er valgt i spørsmålet «Har dere iverksatt tiltak for å rette på utfordringene som ble identifisert i undersøkelsen blant pasientene i 2015?»

Tiltak etter undersøkelsen

Beskriv tiltakene dere har gjennomført for å rette på utfordringene som ble identifisert i undersøkelsen i 2015 så utførlig som mulig:



Dette elementet vises kun dersom alternativet «Ja, flere tiltak» eller «Ja, ett tiltak» er valgt i spørsmålet «Har dere iverksatt tiltak for å rette på utfordringene som ble identifisert i undersøkelsen blant pasientene i 2015?»

I undersøkelsen i 2015 vurderte pasienten institusjonen på ulike områder. Er tiltaket/tiltakene du beskrev ovenfor rettet mot noen av disse områdene? *(Du kan sette flere kryss).*



Dette elementet vises kun dersom alternativet «Ja, flere tiltak» eller «Ja, ett tiltak» er valgt i spørsmålet «Har dere iverksatt tiltak for å rette på utfordringene som ble identifisert i undersøkelsen blant pasientene i 2015?»

Mottagelse og ventetid

Behandlerne/personalet

Behandlingen


Miljøet og aktivitetstilbudet

Forberedelse til tiden etter utskrivning

Hjelp fra kommunen


Annet

Hvorfor valgte dere dette tiltaket/tiltakene? (Du kan sette flere kryss).

 Dette elementet vises kun dersom alternativet «Ja, flere tiltak» eller «Ja, ett tiltak» er valgt i spørsmålet «Har dere iverksatt tiltak for å rette på utfordringene som ble identifisert i undersøkelsen blant pasientene i 2015?»

- Forslag fra pasientene
- Forslag fra ansatte
- Forskningsbasert dokumentasjon
- Retningslinjer/veiledere/sentrale føringer
- Annet
- Vet ikke

Mener du at tiltaket/tiltakene som er iverksatt har hatt ønsket effekt?

 Dette elementet vises kun dersom alternativet «Ja, flere tiltak» eller «Ja, ett tiltak» er valgt i spørsmålet «Har dere iverksatt tiltak for å rette på utfordringene som ble identifisert i undersøkelsen blant pasientene i 2015?»

- Ikke i det hele tatt
- I liten grad
- I noen grad
- I stor grad
- I svært stor grad
- Vet ikke

Obligatoriske felter er merket med denne stjernen *

Andre vurderinger

Er det noe du opplever har hindret bruken av resultatene fra undersøkelsen i 2015 ved din institusjon/avdeling?

Har du kjennskap til resultatrapporten fra undersøkelsen «Pasienterfaringer med døgnopphold innen tverrfaglig spesialisert rusbehandling» for din institusjon/avdeling i 2015?

- Ja
- Nei
- Vet ikke

Hvis ja, har du forslag til endringer som kunne gjort rapporten bedre for deg?

Alt i alt, opplever du at undersøkelsen «Pasienterfaringer med døgnopphold innen tverrfaglig spesialisert rusbehandling» i 2015 har vært nyttig for din institusjon/avdeling?

- Ikke i det hele tatt
- I liten grad
- I noen grad
- I stor grad
- I svært stor grad

Obligatoriske felter er merket med denne stjernen *

Bakgrunnsinformasjon

Er du mann eller kvinne?

Mann

Kvinne

Hva er din alder?

Hvor mange år har du jobbet ved institusjonen?

Obligatoriske felter er merket med denne stjernen *

Bakgrunnsinformasjon

Stillingsinnhold? *(Du kan sette flere kryss).*

- Klinisk arbeid
- Administrasjon
- Kvalitetsutvikling/fagutvikling
- Annet

Har du stilling med lederansvar?

- Nei
- Ja, mellomleder
- Ja, leder på høyere nivå

Hva er din faglige bakgrunn? *(Du kan sette flere kryss).*

- Lege
- Psykolog
- Sykepleier
- Vernepleier
- Barnevernspedagog
- Sosionom
- Annet (spesifiser type utdanning og varighet under)

Hvis "annet", spesifiser type utdanning og varighet her:

Obligatoriske felter er merket med denne stjernen *

Bakgrunnsinformasjon

Svarte du på skjemaet vi sendte ut i høsten 2015 om vurderinger av pasienterfaringsundersøkelser?

- Ja
- Nei
- Vet ikke/husker ikke

Den nasjonale pasienterfaringsundersøkelsen har vært gjennomført jevnlig i perioden 2013-2017. Hvor ofte mener du denne undersøkelsen bør gjennomføres?

- Flere ganger i året
- Årlig
- Hvert andre år
- Sjeldnere

 Sideskift

Obligatoriske felter er merket med denne stjernen *

Andre kommentarer

Har du andre kommentarer til pasienterfaringsundersøkelsen i 2015 eller denne undersøkelsen kan du skrive mer om dette her: