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**Establishing Standards for Assessing Patient-reported Outcomes and Experiences of  
Mental Health Care in OECD Countries**

**Technical Report of the PaRIS Mental Health Working Group Pilot Data Collection**

Katherine de Bienassis\*, Emily Hewlett\*, Candan Kendir\*, Solvejg Kristensen\*\*, Jan Mainz\*\*\*, and Niek Klazinga\*

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Authorised for publication by Stefano Scarpetta, Director, Directorate for Employment, Labour and Social Affairs

(\*) OECD, Directorate for Employment, Labour and Social Affairs, Health Division

(\*\*) Psychiatry, North Denmark Region, Denmark

(\*\*\*) Psychiatry, North Denmark Region, Denmark, Danish Center for Health Services Research, Aalborg University, The Danish Health Data Authority

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# Establishing Standards for Assessing Patient-reported Outcomes and Experiences of Mental Health Care in OECD Countries

Technical Report of the PaRIS Mental Health Working Group Pilot Data  
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# Executive Summary

Patient-reported measures are a critical tool for improving policy and practice in mental health care. However, to date, the use of patient-reported measures in mental health care is limited to a small number of countries and settings, despite an increasing body of knowledge and expertise that can inform implementation. There is a pressing need, both within and across countries, to consistently and effectively measure the effects and impact of care for patients who use mental health care services. This report documents the effort to harmonize patient-reported indicators in mental health care by the OECD Patient-reported Indicator Surveys (PaRIS) Working Group on Mental Health, including guidance, indicator specifications, and pilot results.

Feedback from over 45 international experts was used to assess priority domains for the harmonization of patient-reported outcome and experience measures (PROMs and PREMs) in mental health. These domains were then aligned with other ongoing OECD initiatives, including the PaRIS survey for people living with chronic conditions, the health care quality and outcomes data collection guidelines, the OECD Well-being Framework, and the OECD's people-centred care framework.

The developed pilot data collection guidelines consist of four PREMs items aligned with the OECD's patient experience in ambulatory care indicators and the OECD's people-centred care framework. PROMs metrics included two OECD Well-being Items—metrics developed as part of the OECD's Guidelines on Measuring Subjective Well-Being, and the WHO-5 Questionnaire—a five-item outcome scale that is widely used in both mental health care and for population well-being metrics, dually included in the patient questionnaire for the PaRIS survey of patients living with chronic conditions.

The PaRIS pilot data collection on mental health includes 15 data sources from 12 countries, collected over the course of 2021. Analysis includes both mapped findings from existing data collections, as well as new data submitted in accordance with the developed guidelines. While the scope of included data varies from individual sites to national surveys, the results demonstrate increased adoption of national and subnational efforts to capture patient-reported information in mental health care systems.

Analysis of data collected through the PaRIS mental health pilot documents, in general, positive patient-reported experiences of mental health care. The results also suggest improvement in patient-reported outcomes for those receiving mental health care services in the settings which were able to submit data.

Key findings from the PaRIS mental health pilot data collection include the following:

- An average 85% of hospitalised patients and 88% of individuals receiving community mental health services reported being treated with courtesy and respect by their care providers among sites/countries that were able to submit data. Ensuring that people

receiving care for mental ill health are treated fairly and with respect is a minimum standard for health systems and care providers when delivering health services.

- Preliminary findings suggest that co-production in mental health care could be improved. 78% of hospitalised patients and 88% of individuals receiving community-based mental health services felt their care providers explained things in a way that was easy to understand. The share of mental health service users who felt satisfied with their involvement in their treatment decisions was 81% for hospitalised patients and 87% for individuals receiving community health services.
- Initial findings of the PaRIS mental health pilot data indicate improvement following treatment on patient-reported outcomes. Across sites that were able to submit data, there was an average improvement of over 2 points from admission to discharge on life satisfaction, and almost 2 point improvement on respondents saying that they felt the things they were doing in their life were worthwhile on a scale of 1 to 10.

The experience shows the potential for routine data collection of PROMs and PREMs for those receiving mental health care in inpatient and community settings—and the potential application of these initiatives for international benchmarking. While the results of the pilot data collection indicate real international progress measuring patient-reported outcomes and experiences—there remain significant gaps in the coverage of measures across countries. Further harmonisation and standardisation are needed to establish meaningful comparisons for international benchmarking and performance assessment purposes. A number of methodological, resourcing, and governance challenges remain and potentially hinder PROMs and PREMs from fully reaching their full potential of use in mental health care, and many countries still face limitations in bringing these measures to scale, as demonstrated by the limited available data for analysis. Policy support and appropriate resourcing are necessary to ensure the systematic uptake and reporting of patient-reported metrics in mental health care.

# Résumé

Les mesures rapportées par les patients sont un outil essentiel pour améliorer les politiques et les pratiques en matière de soins de santé mentale. Cependant, à ce jour, l'utilisation des mesures rapportées par les patients dans les soins de santé mentale est limitée à un petit nombre de pays et d'établissements, en dépit d'un ensemble croissant de connaissances et d'expertise qui peuvent guider la mise en œuvre. Il existe un besoin pressant, tant au sein des pays qu'entre eux, de mesurer de manière cohérente et efficace les effets et l'impact des soins pour les patients qui utilisent les services de soins de santé mentale. Ce rapport documente l'effort d'harmonisation des indicateurs rapportés par les patients dans les soins de santé mentale par le groupe de travail de l'OCDE sur les enquêtes liés aux indicateurs rapportés par les patients (OECD Patient-Reported Indicator Surveys - PaRIS) dans le domaine de la santé mentale, y compris les orientations, les spécifications des indicateurs et les résultats des projets pilotes.

Les commentaires de plus de 45 experts internationaux ont été utilisés pour évaluer les domaines prioritaires pour l'harmonisation des mesures de résultats et d'expérience rapportées par les patients (PROMs et PREMs) dans le domaine de la santé mentale. Ces domaines ont ensuite été alignés sur d'autres initiatives en cours à l'OCDE, notamment l'enquête PaRIS sur les personnes vivant avec des maladies chroniques, les lignes directrices pour la collecte de données sur la qualité et les résultats des soins de santé, le cadre de l'OCDE sur le bien-être et le cadre de l'OCDE sur les soins centrés sur la personne.

Les lignes directrices développées pour la collecte de données pilote consistent en quatre éléments PREMs alignés sur les indicateurs de l'OCDE sur l'expérience du patient dans les soins ambulatoires et sur le cadre de l'OCDE concernant les soins centrés sur la personne. Les mesures PROMs comprenaient deux éléments provenant des indicateurs de l'OCDE sur le bien-être : des mesures développées dans le cadre des lignes directrices de l'OCDE sur la mesure du bien-être subjectif, ainsi que le questionnaire WHO-5, une échelle de résultats en cinq points largement utilisée dans le domaine des soins de santé mentale et pour les mesures du bien-être de la population, tous deux inclus dans le questionnaire pour les patients dans le cadre de l'enquête PaRIS sur les patients vivant avec des maladies chroniques.

La collecte pilote de données PaRIS sur la santé mentale comprend 15 sources de données provenant de 12 pays, recueillies au cours de l'année 2021. L'analyse comprend à la fois les résultats cartographiés des collectes de données existantes, ainsi que les nouvelles données soumises conformément aux lignes directrices élaborées. Bien que l'étendue des données incluses aille de lieux individuels à des enquêtes nationales, les résultats démontrent une adoption accrue des efforts nationaux et infranationaux pour capturer les informations rapportées par les patients dans les systèmes de soins de santé mentale.

L'analyse des données recueillies dans le cadre du projet pilote PaRIS sur la santé mentale fait état, en général, d'expériences positives rapportées par les patients en matière de soins de santé mentale. Les données suggèrent également une amélioration des résultats, rapportés

par les patients, chez ceux qui reçoivent des services de soins de santé mentale dans les établissements qui ont pu soumettre des données.

Les principaux résultats de la collecte de données du projet pilote PaRIS sur la santé mentale sont les suivants :

- En moyenne, 85 % des patients hospitalisés et 88 % des personnes recevant des services communautaires de santé mentale ont déclaré avoir été traités avec courtoisie et respect par leurs prestataires de soins parmi les lieux/pays qui ont pu soumettre des données. S'assurer que les personnes recevant des soins pour des troubles mentaux sont traitées avec équité et respect est un critère minimal pour les systèmes de santé et les prestataires de soins lorsqu'ils fournissent des services de santé.
- Les résultats préliminaires suggèrent que la co-production dans les soins de santé mentale pourrait être améliorée. 78 % des patients hospitalisés et 88 % des personnes bénéficiaires de services communautaires de santé mentale ont estimé que leurs prestataires de soins leur ont expliqué les choses d'une manière facile à comprendre. La part des usagers des services de santé mentale qui se sentaient satisfaits de leur participation aux décisions relatives à leur traitement était de 81 % pour les patients hospitalisés et de 87 % pour les personnes recevant des services de santé communautaire.
- Les premiers résultats des données du projet pilote PaRIS sur la santé mentale indiquent une amélioration des résultats après traitement, tels que rapportés par les patients. Parmi les lieux qui ont pu soumettre des données, on a constaté sur une échelle de 1 à 10 une amélioration moyenne de plus de 2 points entre l'admission et la sortie du patient en ce qui concerne la satisfaction par rapport à la vie, et une amélioration de près de 2 points pour les personnes interrogées qui ont déclaré que les choses qu'elles faisaient dans leur vie avaient de la valeur.

L'expérience montre le potentiel de la collecte systématique de données PROMs et PREMs pour les personnes recevant des soins de santé mentale en milieu hospitalier et communautaire, et l'application potentielle de ces initiatives pour l'étalonnage international. Si les résultats de la collecte pilote de données indiquent un réel progrès international pour mesurer les résultats et les expériences rapportés par les patients, il reste des lacunes importantes dans la couverture des mesures entre les pays.

Une harmonisation et une normalisation plus poussées sont nécessaires pour établir des comparaisons significatives à des fins d'étalonnage international et d'évaluation des performances. Un certain nombre de défis méthodologiques, de problèmes de ressources et de gouvernance subsistent et empêchent potentiellement les PROMs et PREMs d'atteindre leur plein potentiel d'utilisation dans les soins de santé mentale, et de nombreux pays sont encore confrontés à des limitations dans la mise en place de ces mesures, comme le démontre la faible disponibilité des données pour l'analyse. Un soutien politique et des ressources appropriées sont nécessaires pour assurer la mise en place et la déclaration systématiques des mesures rapportées par les patients dans les soins de santé mentale.



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# Acronyms

ICHOM	International Consortium for Health Outcomes Measurement
OECD	Organisation for Economic Co-operation and Development
PaRIS	Patient-reported Indicator Surveys
PROM	Patient-reported outcome measure
PREM	Patient-reported experience measure
WHO-5	The World Health Organisation- Five Well-Being Index

# 1 Introduction

1. Mental health is a vital component of individual well-being as well as social and economic participation. However, many OECD countries consider that their mental health care is inadequate. Between one in six and one in five people, experience a mental health problem in any given year, and an estimated one in two people experience a mental health problem in their lifetime (OECD, 2019<sup>[1]</sup>). The most common mental health problems are anxiety disorder (5.1 % of the population), followed by depressive disorders (4.5 %), and drug and alcohol use disorders (2.9 %) (IHME, 2019<sup>[2]</sup>).
2. Since the start of the COVID-19 crisis, levels of mental distress have increased, with the prevalence of anxiety and depression even doubling in some countries (OECD, 2021<sup>[3]</sup>). Even before the pandemic, mental-ill lead to significant costs, driving economic costs equal to more than 4.2% of GDP, some of which are the direct costs of treatment, but also indirect costs related to lower employment rates and reduced productivity (OECD, 2021<sup>[4]</sup>).
3. Understanding of the impact that mental health care makes on service users' lives is still limited; there is a pressing need to measure the effects and impact of prevention and treatment approaches more consistently and effectively. Patient-reported measures are a critical tool for improving policy and practice in mental health care. Patient-reported metrics can shed light on the quality of care provided to individuals diagnosed with a mental condition (de Bienassis et al., 2021<sup>[5]</sup>). Patient-reported metrics are increasingly being used in mental health care to capture the service user's experience of health services and to provide the service user's perspective on his or her own health status, and assess how it may have changed over the course of treatment.
4. In an effort to address this measurement gap, the OECD has been working with patients, clinicians, academics and policymakers in a Working Group to foster mental health patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) collection that enable international comparisons. This work has been conducted under the umbrella of the Patient-reported indicator Surveys (PaRIS) project—which includes the creation of an international survey evaluating PROMs and PREMs for those with chronic health conditions, as well as the harmonisation of patient-reported indicators around specific conditions or procedures<sup>1</sup>. Specifically, the objective of the PaRIS Mental Health Working Group has been to develop minimum data set of PROMs/PREMs for pilot data collection and reporting, to develop suitable indicators and specifications, to advise on international collection of standardised PROMs/PREMs, advise on international benchmarking and reporting, and to share national and international experiences to advance use of PROMs/PREMs.
5. This report serves to document the processes and findings of the OECD's PaRIS Mental Health Working Group and its pilot data collection. In doing so, the report documents efforts to begin standardizing PROMs/PREMs in mental health care across OECD countries and the developed guidance and standards by the working group (including recommended

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<sup>1</sup> <https://www.oecd.org/health/paris/>

items and indicator specifications). Next, the report documents the first findings of the OECD effort to produce international comparisons on patient outcomes and their experiences with mental health services. Finally, this report documents areas related to mental health patient-reported indicator benchmarking that would benefit from further methodical work.

## Setting the scene: Unlocking the potential of PROMs and PREMs in mental health care

6. There has been a proliferation of patient-reported measures of quality of life, experience, and health status in mental health care over the last two decades (Fujisawa and Klazinga, 2018<sup>[6]</sup>). Some of these instruments are used not only for people living with mental illness but also for people with other conditions who are experiencing anxiety and depression or to survey the general population.

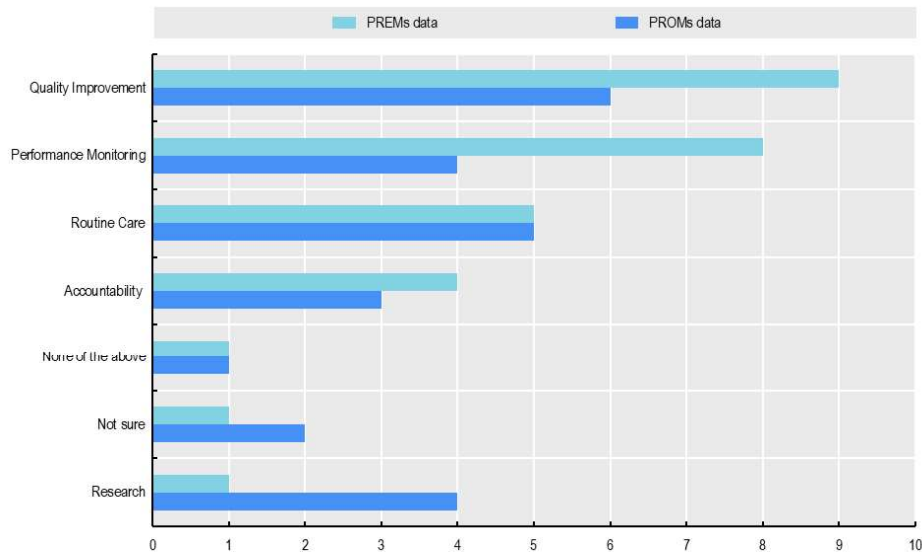
7. Among existing measures, there are a number of commonly used generic instruments, non-condition specific mental health PROM instruments, and condition specific instruments that are used by clinicians and researchers to gather information directly from patients. Some of the instruments used to measure PROMs can also be used as diagnostic tools to identify mental health-related symptoms, such as assessing the level of anxiety, distress, and stress. Examples of common PROMs and PREMs used in mental health care are presented in Table 1.1.

**Table 1.1. Examples of Common PROMs tools used in Mental Health Care Settings**

Generic Instruments to measure PROMs	Non-Condition Specific Mental Health PROM instruments	PROM instruments for specific mental health conditions
EQ-5D PROMIS-10 SF-36 The Veteran RAND 12-item Health Survey (VR-12)	Clinical Outcomes in Routine Evaluation (CORE) Health of the Nation Outcome Scales (HONOS) Hopkins Symptom Checklist (SCL) Kessler Psychological Distress Scale (K10 and K6) Manchester Short Assessment of Quality of Life (MANSA) Outcome Questionnaire (OQ-45) Recovering Quality of Life (ReQoL) The Symptom Checklist – 90 (SCL-90) World Health Organization Well-Being Index (WHO-5)	Beck Depression Inventory Becks Anxiety Inventory Brief Psychiatric Rating Scale (BPRS) Center for Epidemiologic Studies Depression Scale (CES-D) Depression Anxiety and Stress Scale (DASS) Hamilton Anxiety Rating Scale Severe Outcome Questionnaire (S-OQ) Patient Health Questionnaire (PHQ-9) The Generalized Anxiety Disorder questionnaire (GAD-7) The Hospital Anxiety and Depression Scale

Source: (de Bienassis et al., 2021<sup>[5]</sup>)

8. The use of patient-reported measures in mental health care is still nascent, but there is an increasing body of knowledge and expertise. Figure 1.1 shows the results of a 2018 snapshot survey among experts participating in the PaRIS mental health working group. These findings show that a significant number of countries (nine) reported using PREMs in quality improvement in relation to mental health care, and six reported using PROMs for this purpose. Other areas where PROMs and PREMs were reported to be used in mental health care across a number of countries included performance monitoring and routine care.

**Figure 1.1. Country uses of PROMs and PREMs data in relation to mental healthcare**

Note: N=11 country respondents

Source: 2018 PaRIS Mental Health Working Group Snapshot Survey

9. Broader use of patient-reported metrics is fundamental to improve quality of health services delivery, enhance service user outcomes and experiences, and increase the efficiency of health systems by focusing on outcomes that matter most to people. Moreover, there are opportunities for providers, systems, and countries to learn from each other, improve, and innovate in how they deliver mental health services.

### Challenges and opportunities for using PROMs and PREMs in mental health care

10. There are numerous challenges specific to the collection and use of PROMs and PREMs in mental health care. The proliferation of different tools, as described in the previous section, makes it difficult for policy makers and health care providers to select the appropriate tool and benchmark results with other organisations. Similarly, there has been a lack of consensus on other key aspects of data collection, such as cut-off points, time-points for data collection, and demographic and health care information that is collected with survey results.

11. A number of countries have national PREM programs for inpatient stays in general hospitals, but do not include psychiatric patients and/or psychiatric hospitals in the data collections. For example, in the US, the modified Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPs) survey for mental health care is currently not being used by Medicare to generate information on patient experience (AHRQ, 2019<sup>[7]</sup>). Similarly, France's national patient experience survey e-Satis is not implemented yet in psychiatric and mental health facilities and the Canadian Patient Experiences Survey on Inpatient Care (CPES-IC) excludes mental health and rehabilitation service users (CIHI, 2019<sup>[8]</sup>).

12. Another challenge is that PROMs in mental health are dually used as tools to measure changes in patient outcomes, as well as screening tools to inform mental health condition diagnosis. Similarly, there is a risk in using the same tool for various purposes across the micro-

, meso-, and macro-level—as one tool may not necessarily be fit for all purposes. Especially the balance between the use of PROMs and PREMs in mental health for internal quality improvement purposes and external accountability purposes, should be guarded—to potential for misaligned incentives between quality improvement and performance assessment. Finally, mechanisms and effectiveness (or lack thereof) of using mental health PROMs/PREMs for benchmarking and pay for performance mechanisms have yet to be fully explored. See Box 1.1 for examples of key questions for policy makers to consider before using PROMs and PREMs.

### Box 1.1. Examples of Key Questions to Consider Before Using PROMs and PREMs in Mental Health Care

- Are the instruments scientifically acceptable (i.e. are they reliable, valid, and psychometrically sound)?
- Is a generic or condition specific PROM/PREM (or both) most appropriate given the ultimate goal?
- Have service users been involved in all stages of identifying and choosing what measures are most meaningful to them (i.e. have service users been involved in the development and selection of tools)?
- Can PROMs/PREMs be integrated into existing systems of care (i.e. EHRs, time points for data collection/patient consultation)?
- Is the burden of data collection on patients and care providers acceptable given the added value of the information that will be generated?
- Will information generated lead to actionable results at the micro-, meso-, and macro-level? Can the same tool be useful across levels?

Source: (de Bienassis et al., 2021<sup>[9]</sup>)

13. The potential for mental health PROMs and PREMs, especially if they were used more widely, to help improve mental health policy and services makes these challenges worth grappling with. For example, research from Israel has found routine use of PROMs to evaluate Quality of Life (QoL) can predict psychiatric rehospitalisation (Shadmi et al., 2018<sup>[10]</sup>). Improved integration of PROMs and PREMs in mental health care can be an avenue to improve patient outcomes.

14. Some countries are finding that building robust patient-reported tools that meet patients' needs demands extensive patient involvement in the tool's development. There are already several nationally used mental health patient-reported tools that have been co-developed with mental health services users, including those in Australia, New Zealand, and Belgium (Flanders). More information on examples of national/regional PROMs/PREMs programs in mental health can be found in Box 1.2.



## Box 1.2. Examples of National/Regional PROMs/PREMs Programs in Mental Health

<b>Belgium (Flanders)</b>	The Flemish Mental Health Services survey consists of 37 PREM items and 8 demographic variables, and was co-created with patients. The survey includes domains related to safe care, patient rights, care coordination, and patient participation, among others. The survey is completed continuously by patients at discharge from psychiatric hospitals and psychiatric wards in general hospitals. The survey is also administered in conjunction with other mental health services delivered in settings including sheltered living, psychiatric care houses, ambulatory mental health services.
<b>Denmark</b>	In Denmark, clinical quality indicators inform clinicians, leaders, policy makers and politicians, patients and the public about the quality of care provided. The national Danish clinical registries (RKKP) are mandated by law and regulated by the national government. PRO-Psychiatry was initiated as of 2016 for patients diagnosed with unipolar depression and schizophrenia, and carries routine use of patient-reported outcomes (PRO) within hospital-based psychiatric care for clinical consultation. The PRO-data have a secondary use for monitoring the patient perceived quality of care at the aggregated patient level in the Danish Depression Database and the Danish Schizophrenia Register. Further the PRO-data are transferred to the individual patient's eHealth portal for self-management (Kristensen et al., 2018 <sup>[11]</sup> ). Since 2000, Danish National Surveys of Patient Experiences on somatic hospitals have been implemented. In addition, national surveys on patients and relatives' experiences with mental health have been implemented since 2002. The surveys are conducted as annual nationwide surveys among inpatients and outpatients in Danish hospitals investigating experiences related to: clinical services, patient safety, patient and staff member continuity, co-involvement and communication, information, course of treatment, discharge, inter-sectoral cooperation. Results are presented at unit, hospital, regional and national level, and they are available for the public on the official portal for the public Danish health care services, Sundhed.dk (Mainz, Kristensen and Bartels, 2015 <sup>[12]</sup> ).
<b>Israel</b>	In July 2011, the Ministry of Health and the Laszlo N. Tauber Family Foundation, a not-for profit organisation that supports research into services for persons with psychosocial and psychiatric disabilities, signed a contract with the University of Haifa to launch the National Outcome Rehabilitation Monitoring Implementation and Research Project (NORM-IRP). The goal was to provide updated information about the process and impact of psychiatric rehabilitation services in Israel and create an infrastructure to establish routine monitoring of PROMs and clinician ratings to inform policy and care. The project included the selection of assessment instruments, developing an assessment protocol, and agreeing appropriate data use and reporting guidelines. Three sources of information were integrated: 1) PROMs reported by users of psychiatric rehabilitation services; 2) Practitioners' assessment 3) Information from the Israeli National Psychiatric Hospitalization Registry, which records data regarding treatment and illness history as well as service utilisation and additional basic demographic information. The data were used to provide personal feedback to each service user and staff member on their ratings (Roe et al., 2016 <sup>[13]</sup> ), enable a comparison to previous years, and prepare reports for relevant agencies summarising the data collected from and about the users of their specific service (Roe et al., 2015 <sup>[14]</sup> ). Comprehensive reports were also prepared for policy makers, uploaded to the Ministry of Health website and findings relevant for the scientific community were published in journals (Shadmi et al., 2017 <sup>[15]</sup> ) (Shadmi et al., 2018 <sup>[10]</sup> ) (Rotstein et al., 2018 <sup>[16]</sup> ).
<b>Netherlands</b>	In the Netherlands the collection of PROMS and PREMS in mental health care settings has been routine since 2011. However, the organisation of data collection and reporting has changed over the past years. In 2006 the Netherlands introduced a regulated competition for health care in which insurers and providers have to negotiate on costs and quality of care. This also applied to a major part of mental health care (Nas C and van Geldrop A, 2013 <sup>[17]</sup> ). In 2010, the Dutch Health Inspectorate, health insurers, service user organisations, and mental health care providers agreed on ten performance indicators serving both treatment goals, including the Routine Outcome Measurement (ROM) which addresses 'effectiveness of treatment and support' (including PROMs), 'safety', 'Client satisfaction' (based on PREMs) and 'Efficiency'. From 2011 on, mental health services received a financial incentive for the submission of ROM data to the Mental Health Care Benchmark Foundation (SBG) who presented the outcomes in a national Benchmark used by the health insurers for their purchasing policy (Fort et al., 2014 <sup>[18]</sup> ). The national benchmark has since been discontinued, and in 2019 the Quality Institute for Mental Health Care (AKWA) was established with the role of advising mental health care providers on the development of systems for quality assurance including the use of PROMs and PREMs. They also facilitate learning and quality improvement with a data portal where providers can benchmark their services and identify points for improvement (AKWA GGZ, 2019 <sup>[19]</sup> ). For transparency purposes outpatient mental health and Addiction Care services in the Netherlands are obliged to provide aggregated data on PREMs from 2021 on. This data is published on a facility level on a public website for people to consult when they want to choose a service provider.
<b>New Zealand</b>	New Zealand completed a national survey in 2019 to collect PREMs for mental health and addiction using the Ngā Poutama survey for consumers. The survey was the first national experience survey of its kind in New Zealand to utilise a methodology where consumers, and separately family members, were asked to participate in the experience survey after discharge or transition from a mental health or addiction service. This complements an existing survey, which collects information on patient experience while a service user is actively receiving services. Both experience surveys include a number of domains, such as being treated

	with respect, being actively involved in care and support plans, feeling listened to, cultural and spiritual needs being met. New Zealand is also currently developing an outcomes framework for mental health and well-being. This framework is in development, with an emphasis on holistic well-being outcomes, to monitor and report on well-being outcomes at a population level (everyone in New Zealand) and at a service level (people who use mental health and addiction services).
<b>Norway</b>	Beginning in January 2020, the Norwegian Institute of Public Health began continuous electronic measurements of patient experiences with specialised mental health care and interdisciplinary treatment for substance dependence in Norway. The Ministry of Health and Care Services and the Norwegian Directorate of Health commissioned the measurements. The surveys include inpatients receiving specialised mental health care and interdisciplinary treatment for substance dependence. The initiative, which follows several cross-sectional national surveys, uses the Psychiatric Inpatient Patient Experience Questionnaire-On site (PIPEQ-OS) and the Patient Experiences Questionnaire for Interdisciplinary Treatment for Substance Dependence (PEQITSD) (2), both developed and validated to measure patient experiences on-site (Bjertnaes, Iversen and Kjollesdal, 2015 <sup>[20]</sup> ) (Haugum et al., 2017 <sup>[21]</sup> ). The questionnaires are part of the Norwegian program for the measurement of patient-reported experiences that was set up to provide external indicators at the institution level to support quality improvement, hospital management, free patient choice and public accountability.

Source: (de Bienassis et al., 2021<sup>[9]</sup>)

15. In recent years, more and more countries reported new efforts to evaluate patient-reported experiences and outcomes in mental health—or have the intention to do so. The next section of this report outlines the processes for determining recommended metrics and documents the project results and findings.

# 2 The PaRIS mental health pilot data collection

## Motivation and the PaRIS Mental Health Working Group

16. Given the health, social and economic impact of mental ill-health across all OECD countries, there is significant value to being able to assess the quality and outcomes of care in this area using internationally-comparable measures. Existing internationally comparable outcome and process indicators – while very useful in some circumstances – do not provide the entire picture of quality and performance. This information gap impedes efforts to improve care, practice and policy, and limits cross-country learning.

17. Since May 2018 the OECD has been working with patients, clinicians and policymakers in a Working Group to develop mental health PREM and PROM data collection that enable international comparisons and to share and learn from national experiences. The group met a total of 10 times between July 2018 and July 2021. The working group included representatives from 21 countries: Australia, Belgium, Canada, Chile, Costa Rica, Czech Republic, Denmark, Estonia, France, Germany, Ireland, Israel, Japan, Korea, Mexico, Netherlands, Norway, Portugal, Slovenia, Sweden, and the United Kingdom. The working group also included participants from the International Consortium for Health Outcomes Measurement (ICHOM) and the OECD Participants on the working group can be found in 3Annex E.

18. The first step of the process for developing PROM and PREM data collection standards in mental health for international benchmarking relates to the identification of key concepts of importance in regards to patient experience and outcomes. The group participated in two rounds of adapted Delphi surveys to identify priority domains for mental health PROMs and PREMs. These exercises identified three domains of both PROMs and PREMs which were noted to be of high importance across international respondents (see Figure 2.1).

**Figure 2.1. Priority Domains Agreed Upon by the OECD PaRIS Mental Health Working Group**



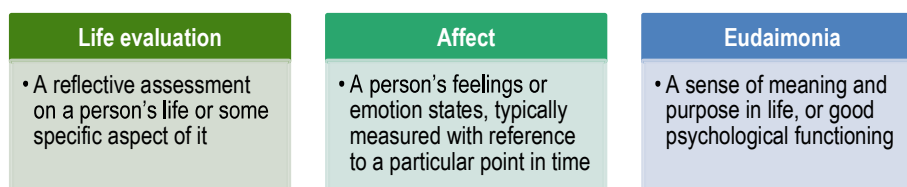
Source: (de Bienassis et al., 2021<sup>[9]</sup>)

19. Based on input from experts on the availability and use of existing measures, the Secretariat proposed to develop an initial set of indicators addressing all three areas of PREMs (respect and dignity, communication and relationship with the health care team, shared decision making) and the area of well-being in the area of PROMs (see 3Annex A for the developed data collection guidelines). The remaining areas of PROMs (relief of symptom burden, restoring social function, and recovery support) were decided to be addressed in a future pilot data collection.

### ***Patient-reported outcome measures related to well-being***

20. Restoring well-being was identified as a priority domain by the PaRIS working group members. Subjective well-being can be defined as “good mental states, including all of the various evaluations, positive and negative, that people make of their lives and the affective reactions of people to their experiences” (OECD, 2013<sup>[22]</sup>). It encompasses at least three different elements: life evaluation, affect, and eudaimonia (see Figure 2.2).

**Figure 2.2. Elements of measuring subjective well-being**



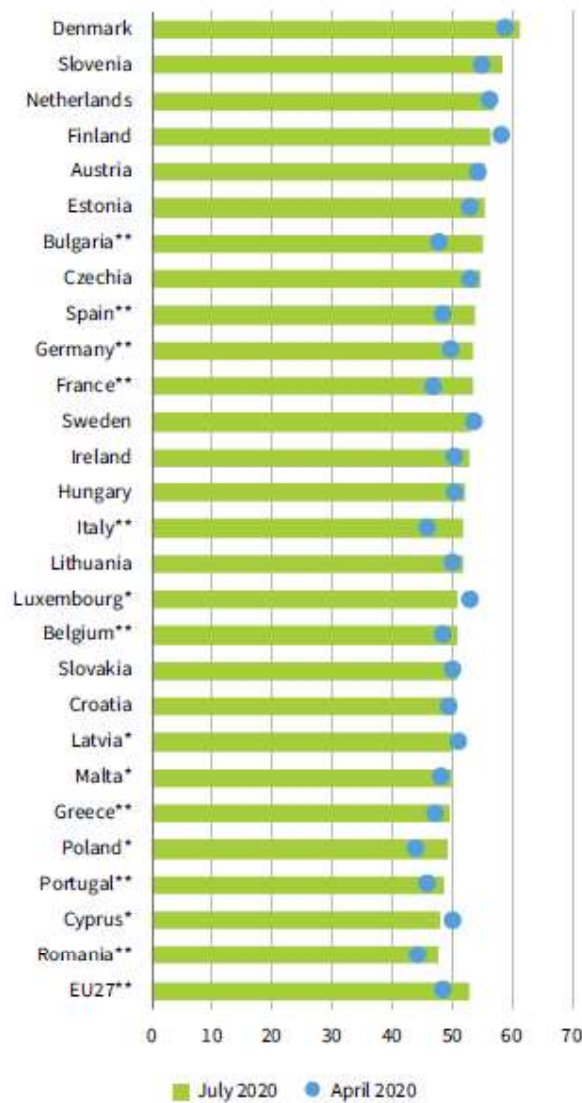
Source: OECD, 2013

21. In 2013, the OECD published Guidelines on Measuring Subjective Well-being, providing guidance on collecting information on people's evaluations and experiences of life (OECD, 2013<sup>[22]</sup>). The guidelines identify the best approaches for measuring, in a reliable and consistent way, the various dimensions of subjective well-being, and provide guidance for reporting on such measures. The guidelines also include a number of prototype survey modules on subjective well-being that national and international agencies can use in their surveys. Given that the OECD currently compiles national-level data on these three facets of subjective well-being, the working group was supportive of including two core items from this guidance into the pilot data collection on life evaluation and eudaimonia (see 3Annex A and 3Annex B).

22. The WHO-5 items were also suggested by the working group. The 5-item World Health Organization Well-Being Index (WHO-5) is a short and generic global rating scale measuring mostly affective aspects of subjective well-being. It is derived from the WHO-10, which is derived from a 28-item rating scale, used in a WHO multicentre study in 8 different European countries. Unlike the WHO-10 and the 28-item rating scale, the WHO-5 contains only positively phrased items. The WHO-5 items are (1): “I have felt cheerful and in good spirits”, (2) “I have felt calm and relaxed”, (3) “I have felt active and vigorous”, (4) “I woke up feeling fresh and rested”, (5) “My daily life has been filled with things that interest me”. The respondent rates these statements ranging from 5 (all the time) to 0 (none of the time), considering the last 14 days. The clinical validity of the questionnaire has been evaluated to be very high as the scale can be used irrespective of the presence of an illness and across care settings (Topp et al., 2015<sup>[23]</sup>). For example, the WHO-5 has been found to be a valid screening tool for depression in primary care (Primack, 2003<sup>[24]</sup>). When used for diagnostic purposes, a score lower than 50 on the WHO-5 suggests poor mental well-being and is a sign for further testing. A score equal or below 28 is indicative of depression (Löwe et al., 2004<sup>[25]</sup>).

23. The WHO-5 has been recommended as part of the International Consortium for Health Outcomes Measurement's (ICHO) core adult set of patient-reported outcome measures (Gangannagari et al., 2021<sup>[26]</sup>). The WHO-5 has also been used to measure population levels of mental well-being. In the context of COVID-19, Eurofound has used the WHO-5 scale to assess population mental well-being during different phases of the pandemic, finding that on average, mental well-being among EU respondents using the WHO-5 tool averaged 49 in April 2020, increasing to 53 in July 2020 (Eurofound, 2020<sup>[27]</sup>) (see Figure 2.3).

Figure 2.3. Population level WHO-5 mental well-being index (mean scores by country)



Note: \* Low reliability in July for Cyprus, Latvia, Luxembourg, Malta and Poland. \*\*Statistically significant change ( $p \leq 0.05$ ).

Source: (Eurofound, 2020<sup>[27]</sup>)

### **Patient-reported experience measures**

24. Since 2013, data for patient-reported experience indicators have been collected through the OECD's Health Care Quality and Outcomes project data collection, which takes place every two years. A number of other OECD countries also report data collected through national surveys and as of 2017, 22 countries report PREMs collected either through national or international surveys to the OECD (Fujisawa and Klazinga, 2017<sup>[28]</sup>). Several of these items have been mapped to the OECD's dimensions of the Framework for People-centered Health Systems: voice, choice, co-production, integration, and respectfulness (see Figure 2.4). Based on this, three items were recommended for inclusion. One additional item, not included in the OECD-Proposed Set of Questions on Patient Experiences with Ambulatory Care, on courtesy and respect, adapted from the Commonwealth Fund Questionnaire, was also recommended for inclusion (see 3Annex A and 3Annex B). As of 2020, the item on respect and dignity has since been added to the HCQO bi-annual data collection as well.

**Figure 2.4. Dimensions, domains and policy benchmarks for the OECD People-Centred Health Systems Framework**

Dimension	Policy benchmarks
Voice	Participation in decision-making bodies: Patients having a formal participation role in health policy
Choice	Choice of healthcare providers: Patient choice for primary, specialist and hospital care Access to healthcare: Unmet need due to affordability
Co-production	Patients given accessible information: Share of patients receiving easy-to-understand explanations by their doctor Patients are consulted about their care: Share of patients being informed or consulted about their care Share of individuals using digital tools for health: Proportion of patients using patient portals and apps Patients are engaged in their care: Share of individuals using the internet for seeking health information in the previous 3 months
Integration	Use of digital technology for integration of care: Computers used by primary care physician for common tasks Use of electronic clinical records: Share of primary care physician offices using Electronic Clinical Records Co-ordination of care: Share of patients not experiencing a problem with care co-ordination
Respectfulness	High personal attention: Share of patients who spent enough time with their regular doctor or any doctor during the consultation Fair treatment: Share of people agreeing that people are treated equally in their area Respectful treatment: Share of hospital patients treated by doctors and nurses with respect

Source: (OECD, 2021<sup>[29]</sup>)

### **The PaRIS Mental Health Pilot Data Collection**

#### **Characteristics of included data**

25. The OECD PaRIS Mental Health Pilot data collection included 15 data submissions from 12 countries. Data submissions were primarily provided by completion of the data submission form by sites or countries. In the cases of Ireland and New Zealand, the data were abstracted from publicly available reports (Ó Féich et al., 2019<sup>[30]</sup>; Health Quality & Safety Commission of New Zealand, 2020<sup>[31]</sup>). Data from Australia, Belgium (Flanders), Canada, Ireland, New Zealand, and the United Kingdom were provided by mapping findings from existing data collections onto the domains of interest. In these cases, the items and calculation methods may vary. The wording of included items can be found in 3Annex C.

26. Countries varied in terms of reporting on the recommended indicators (see Table 2.1). All countries that provided data were able to provide figures on the PREM domain of courtesy and respect—either in the inpatient setting, the community services setting, or both. A significant number of countries were also able to provide information on the PREM domains related to time spent with providers, providers explaining things in a way that was easy to understand, and involvement in treatment decisions.

**Table 2.1. PaRIS Mental health country data on recommended indicators, OECD pilot data collection 2020/2021**

	OECD Well-being core questions		WHO-5		PREM 1 (Courtesy and respect)		PREM 2 (Care providers spend enough time with you)		PREM 3 (Care providers explain things in a way that was easy to understand)		PREM 4 (Involvement in decisions about treatment)	
	Inpatient	Community	Inpatient	Community	Inpatient	Community	Inpatient	Community	Inpatient	Community	Inpatient	Community
Australia (Public)					X	X			X	X	X	X
Australia (Private)					X	X	X	X	X	X	X	X
Belgium (Flanders)					X	X					X	X
Belgium (Networks)		X		X		X		X		X		X
Canada					X				X		X	
France	X		X		X		X		X		X	
Japan	X	X	X	X	X	X	X	X	X	X	X	X
Korea	X		X		X	X	X	X	X	X	X	X
Ireland					X	X						
Netherlands									X		X	
Portugal	X	X	X	X	X	X	X	X	X	X	X	X
Slovenia						X		X		X		X
New Zealand					X	X			X			
United Kingdom						X		X				X

Source: PaRIS Mental Health Working Group Pilot Data Collection 2020/2021

27. A smaller number of countries were able to provide information on PROMs. Five countries were able to provide information on the OECD subjective well-being indicators either in the inpatient or community health care setting (Belgium, France, Japan, Korea, and Portugal,). The five of the same six countries were able to provide information using the WHO-5 tool. All sites that were able to provide data on mental health PROMs initiated new data collections in compliance with the OECD PaRIS project—no existing data were available from countries via ongoing data collection efforts.

Table 2.2. Characteristics of PaRIS Mental Health Pilot Data Submissions 2020/2021

Country	Inpatient vs. Community	Location/Sites	Dates	Total number of Participants	Source	Mapped from previously existing survey
Australia (Public Sector)	Inpatient and Community	86 sites in New South Wales, Victoria, Queensland	July 2018-June 2019	Inpatient: 18,465 Community: 12,817	Data submitted by country	Yes Australian Your Experience of Service (YES) Survey
Australia (Australian Private Hospitals Association)	Inpatient and Community	48 sites (NSW, ACT, VIC, QLD, SA, WA and TAS)	July 2018-June 2019	Inpatients: 34,538 (65.7% response rate) Ambulatory Care Patients: 14,027 (37.3% response rate)	Data submitted by country	Yes Patients Experiences of Care Survey for Overnight Inpatients; Patients Experiences of Care Survey for Day Program Patients
Belgium (Flanders)	Inpatient and Community	73 sites in Flanders <sup>2</sup>	August-October 2020	3,933	Data submitted by country	Yes Data from the Flemish Mental Health Services survey
Belgium (Networks)	Community	20 sites in Flanders, Wallonie, and Brussels	November 2020-March 2021	391	Data submitted by country	No
Canada	Inpatient	16 inpatient units in Whitby, Ontario	April 2019-October 2020	1,572 inpatients across units during the data collection period (34% response rate)	Data submitted by country	Yes
France	Inpatient	2 inpatient units, GHU Paris psychiatry & neurosciences	February 2021-June 2021	264 (79.55% response rate)	Data submitted by country	No
Ireland	Inpatient and Community	National online survey	November 2017 and April 2018	1,188 participants (response rate not applicable)	Mental Health Reform publication of the "My Voice Matters Survey"	Yes My Voice Matters Survey
Japan	Inpatient and Community	40 prefectures from 8 regions	May 2021	210 participants	Data submitted by country	No
Korea	Inpatient and Community	7 sites in Seoul	September 2020-January 2021	98 participants (99% response rate)	Data submitted by country	No
Netherlands	Inpatient	National Survey	January 2020-January 2021	1,990 participants (82% response rate)	Data submitted by country	Yes Consumer Quality Index (CQi) ambulante CCZ en VZ
New Zealand	Inpatient and Community	National survey (multiple formats)	2019	267 (3.3% response rate)	Health Quality and Safety Commission Report "Nga Poutama: Survey of mental health and addiction consumers, family & whanau experience"	Yes Ngā Poutama survey for consumers
Portugal	Inpatient and Community	Six sites	April-June 2021	119 respondents	Data submitted by country	No
Slovenia	Community	One adult community health centre covering 60,135 adult population	June-July 2021 (9-weeks trial)	92 participants	Data submitted by country	No
United Kingdom	Community	National Survey (Mail)	2020	55 NHS mental health trusts and social enterprises, 17,601 people who received treatment for a mental health condition between 1 September 2019 and 30 November 2019 (26% response rate).	Data submitted by country	Yes CQC Community Mental Health Survey 2020

Source: PaRIS Mental Health Working Group Pilot Data Collection 2020/2021

<sup>2</sup> Data were provided by the Flemish Institute for the Quality of Care, the official organization overseeing the development and measurement of quality indicators in Flanders (i.e. a region in Belgium) in collaboration with the Flemish Patients' Platform who developed the PREM survey. More information about publicly available PREMs on mental health care in Flanders can be found on the website of the Flemish Institute for the Quality of Care: [www.zorgkwalletit.be](http://www.zorgkwalletit.be).

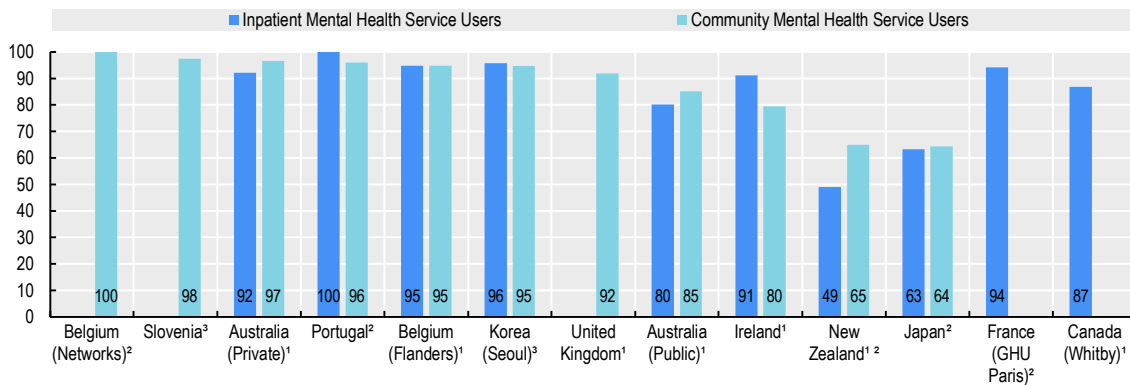


**Preliminary findings: Patient-reported experiences**

28. Preliminary findings from the data collection demonstrate high performance in general across PREMs. Courtesy and respect are essential components of people-centred health care. Ensuring that people are treated fairly and with respect, have their voices heard, and needs attended to, is a minimum standard for health systems and care providers when providing care (OECD, 2021<sup>[29]</sup>). This is particularly important for mental health care, where mental health service users may face marginalisation and stigmatization. To bring awareness to this issue, the WHO’s Mental Health Action Plan 2013-2023 has highlighted the particular importance of ensuring dignity for people affected by mental disorders (WHO, 2021<sup>[32]</sup>).

29. The item regarding treatment with courtesy and respect by care providers for people receiving care for mental health services saw an average of 85% for hospitalised patients and 88% for individuals receiving community health services. These figures are comparable to population level statistics from the Commonwealth Fund, where an average of 89% of respondents across eleven OECD countries reported feeling that both doctors and nurses treated them with respect during a recent hospital stay, ranging from just over three-quarters of patients in the United Kingdom to nearly 95% in France (OECD, 2021<sup>[29]</sup>).

**Figure 2.5. Share of inpatient and community mental health service users who were treated with courtesy and respect by care providers**

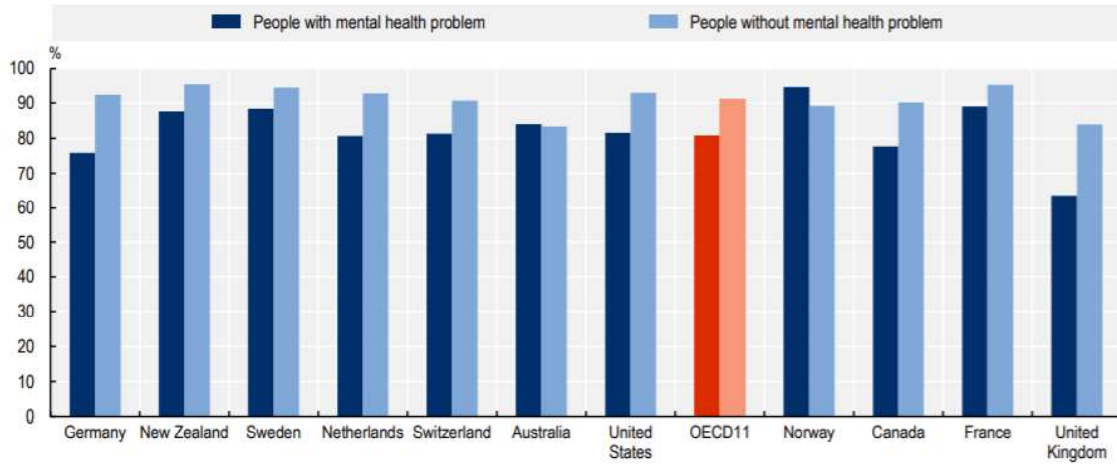


Note: 1. Mapped onto domain from existing survey effort. 2. Sample less than 500. 3. Sample less than 100. Data included from most recent available collection spanning 2017-2021.

Source: PaRIS Mental Health Pilot Data Collection 2020-2021

30. In 2020, responses to the Commonwealth Fund International Health Policy Survey in 11 countries showed that people who reported having a mental health problem were less likely to report being treated with courtesy and respect during a hospital stay than people without a mental health problem (includes hospital stays for any health condition, not only mental health care) (Commonwealth Fund, 2020<sup>[33]</sup>). On average, there was a 10 percentage point gap between people who did not report a mental health problem and reported being treated with courtesy and respect, and people with a mental health problem. In Germany, the Netherlands, the United States, and Canada the gap exceeded 10 percentage points, and in the United Kingdom it was 20.3 percentage points (see Figure 2.6).

Figure 2.6. Share of people who reported being treated with courtesy and respect by doctors and nurses during hospitalisation, 2020



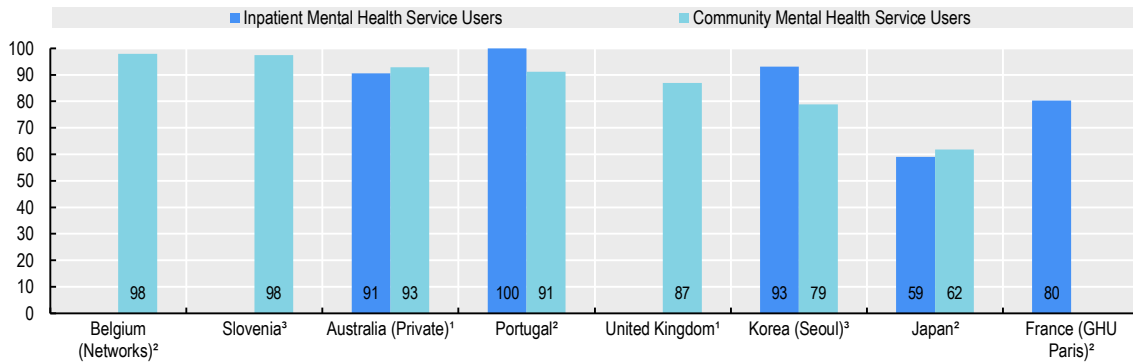
Note: People 'with mental health problems' includes adults who responded "yes" to "Have you ever been told by a doctor that you have depression, anxiety or other mental health problems", and their responses to other survey questions. Sample sizes and survey response rates differ between countries, and results may be based on small samples. It is not possible to distinguish between individuals who were suffering from a mental health problem at the time of the survey, and those who had experienced mental ill-health in the past but have since recovered, nor whether the hospitalisation was for a mental health problem. Cultural and linguistic differences in how the question was interpreted could also influence responses. Results have not been risk-adjusted for co-morbidities and socio-economic status. Source: OECD calculations based on the Commonwealth Fund International Health Policy Survey 2020 (Commonwealth Fund, 2020<sup>[33]</sup>), <https://www.commonwealthfund.org/series/international-health-policy-surveys>.

31. The time spent with care providers was considered as an indicator under the domain of respectfulness in alignment of the OECD Patient Centred Health Systems Framework, where it was included under the rationale that, "making sure the patient is heard, that the consultation is thorough, and their care is tailored accordingly, is foundational to delivering truly person-centred care." For sites that were able to report on the item regarding if they felt they had enough time with care providers, the average across data submissions was 85% for hospitalised patients and 87% for individuals receiving community health services (see Figure 2.7).

32. Both of these rates are higher than population reports in ambulatory care<sup>3</sup> across 18 OECD countries—where 82% of respondents reported being satisfied with the level of time spent with them by their regular physician in primary care, reporting that their regular doctor spent enough time with them during their consultation (see Figure 2.8).

<sup>3</sup> Not specific to mental health care

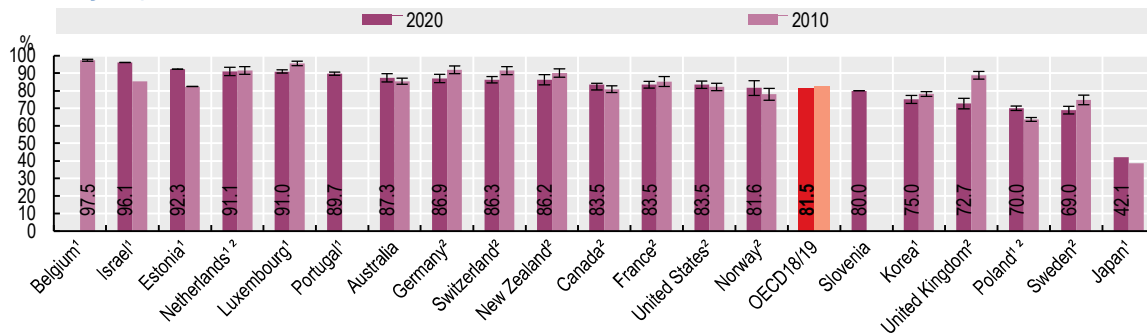
**Figure 2.7. Share of inpatient and community mental health service users who felt they had enough time with care providers**



Note: 1. Mapped onto domain from existing survey effort. 2. Sample less than 500. 3. Sample less than 100. Data included from most recent available collection spanning 2017-2021.

Source: PaRIS Mental Health Pilot Data Collection 2020-2021

**Figure 2.8 Doctor spending enough time with patient during consultation, 2010 and 2020 (or nearest year)**



Note: H line shows 95% confidence intervals. 1. National sources. 2. Data refer to patient experiences with regular doctor or regular practice.

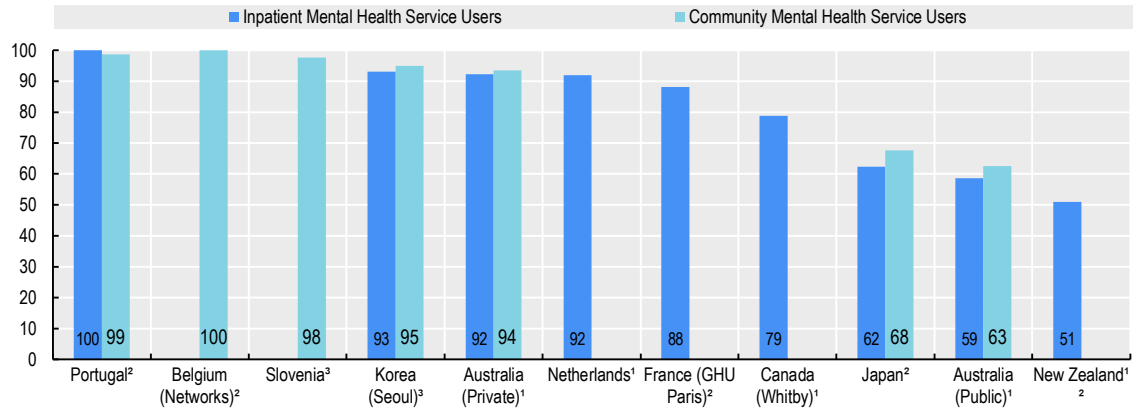
Source: Commonwealth Fund International Health Policy Survey 2010 and 2020 and other national sources, Health at a Glance 2021

33. A key aspect of people-centred care is that patients are consulted and given sufficient information in order to participate in the decision-making process and to make informed decisions. Previous work from the OECD, using data from the Commonwealth Fund International Health Policy Survey of Adults, has found that people who have been told by a doctor that they have depression, anxiety or other mental health problems are more likely to report receipt of conflicting information from health care professionals (OECD, 2019<sup>[1]</sup>). Clear and understandable communication is necessary to ensure that mental health service users understand what care they are receiving and why—ensuring that they have the appropriate information to be actively involved in the decision-making process.

34. For the share of mental health service users that felt their care providers explained things in a way that was easy to understand, the average across data submissions was 78% for hospitalised patients and 88% for individuals receiving community health services (see Figure 2.9). The average across participating sites and countries in the PaRIS mental health data collection is lower than population level data across 18 OECD countries where 91% of respondents found that their doctor provided easy-to-understand explanations when they needed medical services (Figure 2.10). None the less, data from five countries

found that over 90% of respondents using mental health services felt that their care providers explained things in a way that was easy to understand—including patients in both inpatient and community based settings.

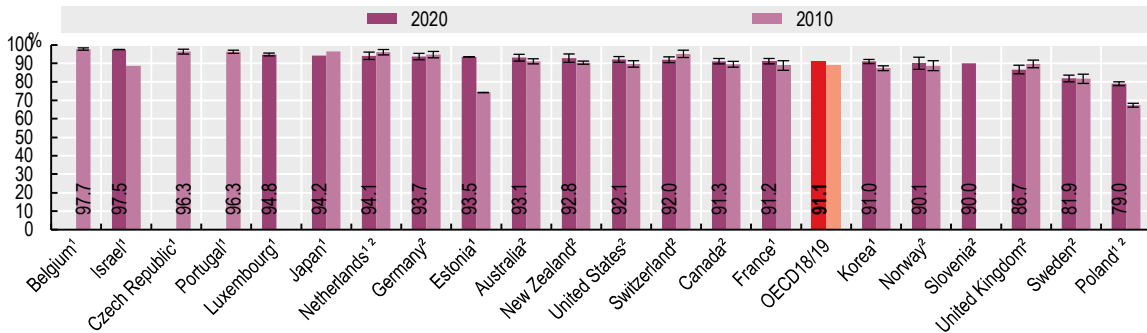
**Figure 2.9. Share of inpatient and community mental health service users who felt their care providers explained things in a way that was easy to understand**



Note: 1. Mapped onto domain from existing survey effort. 2. Sample less than 500. 3. Sample less than 100. Data included from most recent available collection spanning 2017-2021.

Source: PaRIS Mental Health Pilot Data Collection 2020-2021

**Figure 2.10 Doctor providing easy-to-understand explanations, 2010 and 2020 (or nearest year)**

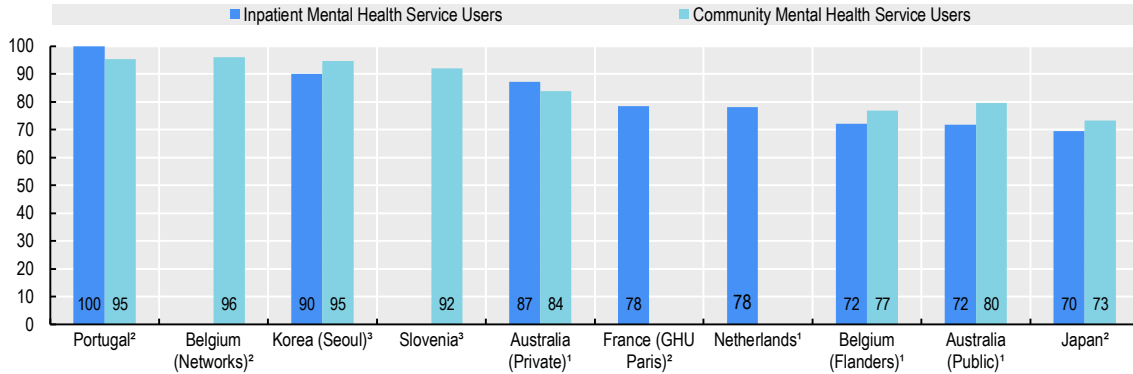


Note: H line shows 95% confidence intervals. 1. National sources. 2. Data refer to patient experiences with regular doctor or regular practice. Source: Commonwealth Fund International Health Policy Survey 2010 and 2020 and other national sources, Health at a Glance 2021.

35. Shared decision making—that patients are given an opportunity to be involved in decisions about their care, if they want to be—is a key principle of people-centred health care. Shared decision-making processes have been increasingly adopted in mental health services provision and there is a growing research body demonstrating that shared decision making is feasible and can be productive in the course of psychiatric treatment (Slade, 2017<sup>[34]</sup>). However, while the majority of OECD countries required, or strongly recommended, service users’ involvement in care design of care plans, in many countries this is required in principle but does not always happen, or depends on the care setting. For example in Japan medical practitioners are obliged to draw up an inpatient-care plan and deliver it to the patient or the family with adequate explanation of care, which addresses a certain level of involvement but not an active role in decision-making processes (OECD, 2021<sup>[4]</sup>).

36. Based on pilot data, the share of mental health service users who felt satisfied with their involvement in their treatment decisions, the average across data submissions was 81% for hospitalised patients and 87% for individuals receiving community health services (see Figure 2.11). This is on par with the 83% of population based survey respondents across OECD countries that reported that their doctor involved them as much as they wanted to be in decisions about their care and treatment (see Figure 2.12).

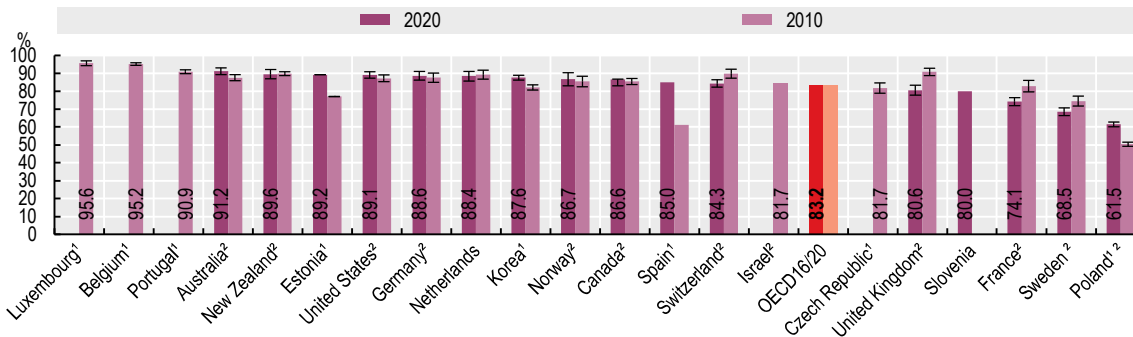
**Figure 2.11. Share of inpatient and community mental health service users who felt involved in their treatment decisions**



Note: 1. Mapped onto domain from existing survey effort. 2. Sample less than 500. 3. Sample less than 100. Data included from most recent available collection spanning 2017-2021.

Source: PaRIS Mental Health Pilot Data Collection 2020-2021

**Figure 2.12 Doctor involving patient in decisions about care and treatment, 2010 and 2020 (or nearest year)**



Note: H line shows 95% confidence intervals. 1. National sources. 2. Data refer to patient experiences with regular doctor or regular practice.

Source: Commonwealth Fund International Health Policy Survey 2010 and 2020 and other national sources, Health at a Glance 2021

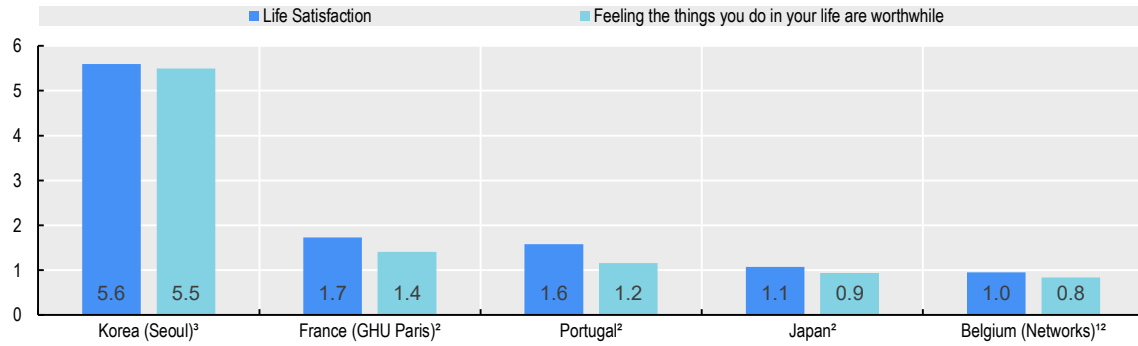
**Preliminary findings: Patient-reported outcomes**

Life satisfaction measures how people evaluate their life as a whole rather than their current feelings. Using the same item and response categories as documented in the methodology for the OECD Guidelines on Measuring Subjective Well-being, six sites/countries were able to calculate the change in life satisfaction following treatment for mental health conditions. Across sites that were able to submit data, there was an average improvement of over 2 points from admission to discharge on life satisfaction, and an almost 2 point improvement on respondents saying that they felt the things they were doing in their life were

worthwhile (see Figure 2.13). The scope of this change is considerable, for example, research from other contexts has found that people who are unemployed typically report a life satisfaction level around 1.0 scale points lower than those who are employed, on average, after controlling for individual characteristics (OECD, 2021<sup>[35]</sup>).

**Figure 2.13. Improvement in subjective well-being from admission to discharge for people receiving mental health services**

Change in average crude score (0-10) from admission to discharge (or following discharge) using OECD Subjective Well-being Items.



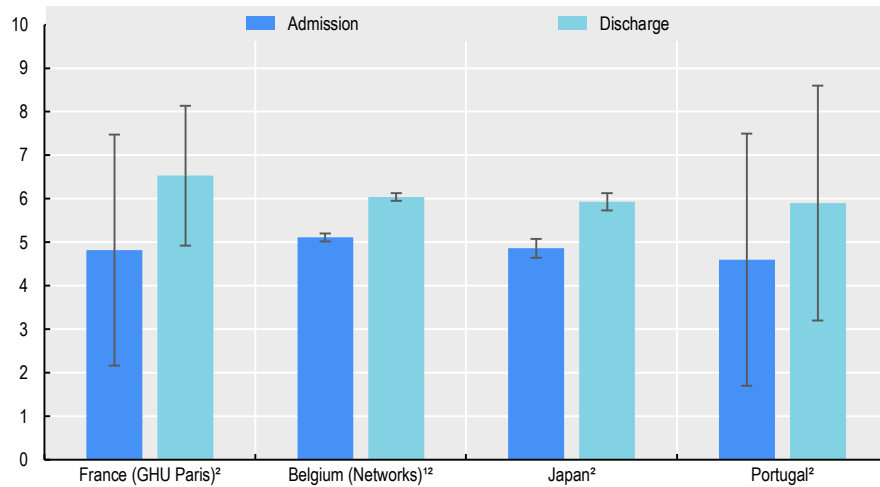
Note: 1. Community-based services. 2. Sample less than 500. 3. Sample less than 100. Data included from most recent available collection spanning 2017-2021.

Source: PaRIS Mental Health Pilot Data Collection 2020-2021

37. Crude data, including response averages at admission and discharge and standard errors, can be found in Figure 2.14 and Figure 2.15. On average, across sites and countries where information is available, the average life satisfaction at discharge was 6.1, compared to 4.8 at admission. For patients evaluating if things in life seemed worthwhile, the average score was 5.5 at admission and 6.5 at discharge. While sites reported improved outcomes on these indicators overall, findings from GHU in Paris and Portugal had overlapping confidence intervals due to small sample sizes.

**Figure 2.14. Subjective well-being at admission and discharge for people receiving mental health services, life satisfaction**

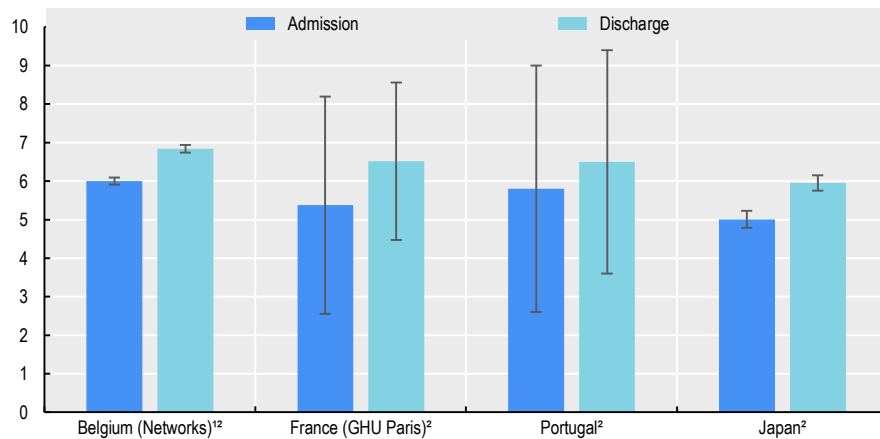
Average crude score (0-10) at admission and discharge (or following discharge) using OECD Subjective Well-being Items.



Note: 1. Community-based services. 2. Sample less than 500. Data included from most recent available collection spanning 2017-2021. Source: PaRIS Mental Health Pilot Data Collection 2020-2021

**Figure 2.15. Subjective well-being at admission and discharge for people receiving mental health services, feeling that things in life are worthwhile**

Average crude score (0-10) at admission and discharge (or following discharge) using OECD Subjective Well-being Items.

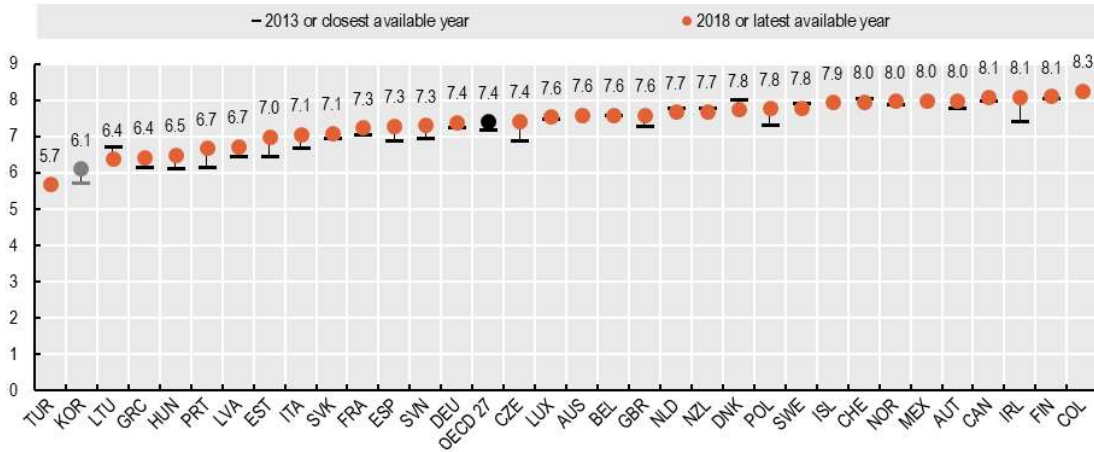


Note: 1. Community-based services. 2. Sample less than 500. Data included from most recent available collection spanning 2017-2021. Source: PaRIS Mental Health Pilot Data Collection 2020-2021

38. According to data from the OECD How's Life? report and database, figures for general satisfaction with life on a zero-to-ten scale, the average across 27 OECD countries at a population level was 7.4 in 2018 (see Figure 2.16). Population level results from Eurofound during COVID-19 found that the European

average score for life satisfaction was 6.3 in April 2020 and 6.7 in July in 2020 (Eurofound, 2020<sup>[27]</sup>). These figures can be compared to data from 2017, which found the European average core to be 6.8 (Eurofound, 2017<sup>[36]</sup>). While not all of the data included in the PaRIS mental health pilot were collected during the COVID pandemic, these figures help put the findings of mental health service users into context as compared to population level assessments.

**Figure 2.16. Average population level-life satisfaction score (using OECD Subjective Well-being), 40 countries**



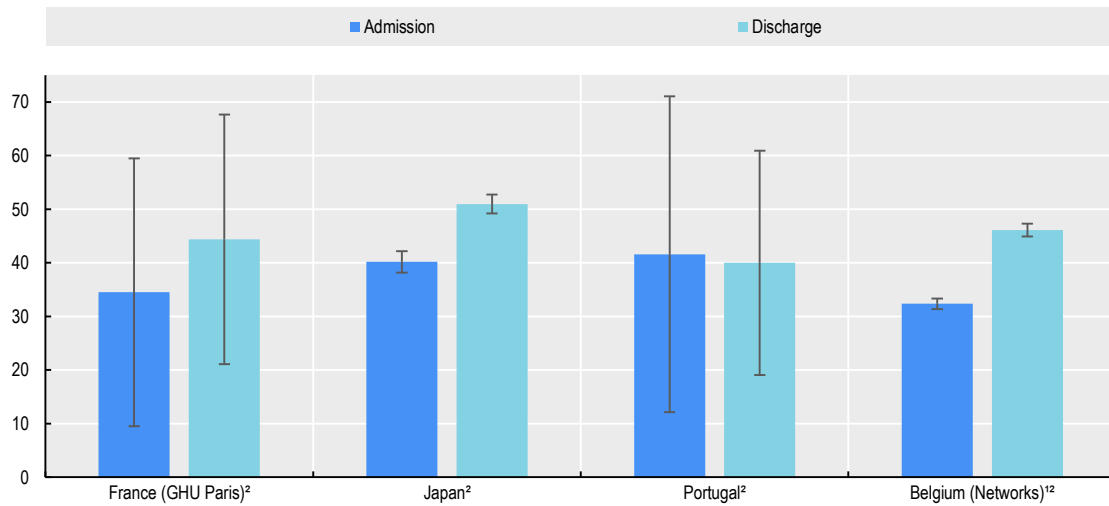
Note: The latest available year refers to 2014 for Australia and Mexico and to 2013 for Iceland and Turkey. The earliest available year refers to 2014 for New Zealand. The OECD average excludes Chile, Israel, Japan and the United States, due to a lack of available data; Korea, due to methodological differences; and Australia, Colombia, Iceland, Mexico and Turkey, as only one observation is available. Data refer to the population aged 19-69 in Korea; 18 and older in Mexico; 15 and older in Australia, Canada, Colombia and New Zealand; and 16 and older in all other cases. Data for Korea (shown in grey) have limited comparability due to the age range considered and the response format used (see Box 8.1). 2018 data for Ireland and the United Kingdom are provisional. OECD and national statistical office calculations, based on the European Union Statistics on Income and Living Conditions (EU-SILC) (database), <https://ec.europa.eu/eurostat/data/database>; the Australian General Social Survey; the Canadian Community Health Survey; Colombia's National Quality of Life Survey; the Korean Social Integration Survey; the Mexican National Survey of Household Income and Expenditure (Socioeconomic Conditions Module) and New Zealand General Social Survey. Source: How's Life?: Measuring Well-being, 2020 (OECD, 2020<sup>[37]</sup>)

39. As discussed in earlier in this section, the WHO-5 is a multi-purpose, generic tool, that can be used to assess mental well-being on the population level, but also to assess clinical outcomes in mental health services settings. On average, across participating sites there was an improvement of 8 points on the 0-100 scale of the WHO-5.

40. Several countries/sites were able to report crude values at admission and discharge, along with standard errors. Across sites/countries that were able to submit data, the average WHO-5 score was 37 at admission and 45 at discharge. This information is represented in Figure 2.17. The items included in the WHO-5 can be found in 3Annex B. Population level statistics from the 2016 European Quality of Life Survey found that the average WHO-5 score for respondents across the EU was 64—and that 22% of respondents were at risk for depression (Eurofound, 2020<sup>[27]</sup>).



**Figure 2.17. WHO-5 total score at admission and discharge for people receiving mental health services**



1. Community-based services. 2. Sample less than 500. Data included from most recent available collection spanning 2017-2021. Note: In some cases additional respondents are included in the discharge sample that were not included in the admissions sample. Source: PaRIS Mental Health Pilot Data Collection 2020-2021

### **Site specific efforts to incorporate patient-reported indicators into clinical practice**

41. As part of the pilot data collection, sites in several countries were able to commence new data collection on the PaRIS mental health recommended items. The following section describes the scope, challenges, and accomplishments of new data collection efforts to assess PREMs and PROMs in mental health care.

42. Work in France was conducted by GHU Paris psychiatry and neurosciences, the leading Parisian hospital for mental illness and neurosciences, which provides care for 60,000 Parisian users each year. Two main hospital departments (CMME and Sector 13) were involved in the PaRIS pilot study. A total of 264 inpatients were enrolled (February through June 2021), with an average response rate of 79.55%. The profile of patients in each of the two settings varied, as well as the type of care received.

43. Questions were generally well understood by users. The questionnaire completion time was 5 to 7 minutes. For users more severely ill (confused, presenting delusional symptoms, severely depressed, etc.), it was harder to complete the process, and a greater number of patients refused to be enrolled or were unable to answer the questionnaire. Data collection was performed by a single dedicated operator (clinical psychologist), with the cooperation of health professional teams, who assisted in identifying and accessing patients in a timely manner.

44. In France, the preliminary findings show that subjective psychological well-being (outcome) improved during care using the OECD Subjective Well-being Items and the WHO-5 tool. There was a weak correlation between subjective perceived outcomes and clinical improvement measured using routine practice standardized disorder-specific instruments. Additional analysis of these findings is currently underway—but initial interpretation suggests that the clinical tools used to capture data on the severity of symptoms may not be directly related to patient-reported perceptions of mental well-being. The subjective experience of care was largely positive: the highest scores relate to “being treated with courtesy and respect by care providers” (94.64% positive responses) and the lowest to “being involved as much as wanted in decisions about one’s care and treatment” (79.17%). The results vary significantly according to

the patient's profile: gender, age, diagnosis, type of hospital admission (involuntary or voluntary). Best practices in clinical management of mental disorders need to include clinical, functional recovery measures, as well as patient-reported outcome and experience measures. The results of the PREMs and PREMs pilot have been presented to the hospital leadership who wish to systematically implement these indicators within the institution. A feasibility study on a larger scale is planned (including testing tailored-made procedures for the most severely ill users).

45. In Japan, the data collection was coordinated by the Department of Community Mental Health & Law of the National Institute of Mental Health. A total of 210 patients took part in a retrospective cross-sectional web survey following discharge from a psychiatric hospital (45.7%), general hospital (35.2%), university hospital (12.4%), or others/do not know (6.7%). Patients were included if they were over 20 (adult age in Japan) and discharged from a psychiatric service within the past six months. The survey was approved by the ethics committee of the National Center of Neurology and Psychiatry. Data generated via the exercise were submitted to the PaRIS group. One of the strengths of web-based surveys is that patient responses are less susceptible to social desirability bias. At the time of discharge, patients may find it challenging to respond candidly to PREMs items.

46. In Slovenia in 2021 there were nine weeks of field work within one newly developed community mental health centre, that is established at the primary health care level. The centres treat people with psychiatric diagnoses or with potential diagnoses of mental health disorders, covering a population of 65,000 of adults (18 years and above). Pilot research has been carried out within one of the first newly established adult community health centres covering 60,135 adults. The centre is organized as an inter- as well as multi-disciplinary service provider, and includes a psychiatrist, clinical psychologist, medical nurse, social worker and occupational therapists. Finally, in Portugal, from April to June 2021, the pilot research was carried out, covering six national hospitals. Data were collected from inpatient mental health services and adult community settings.

47. More information about country specific efforts can be found in 3Annex D and described in Box 1.2.

# 3 Methodological considerations, challenges, and the way forward

## Methodological considerations

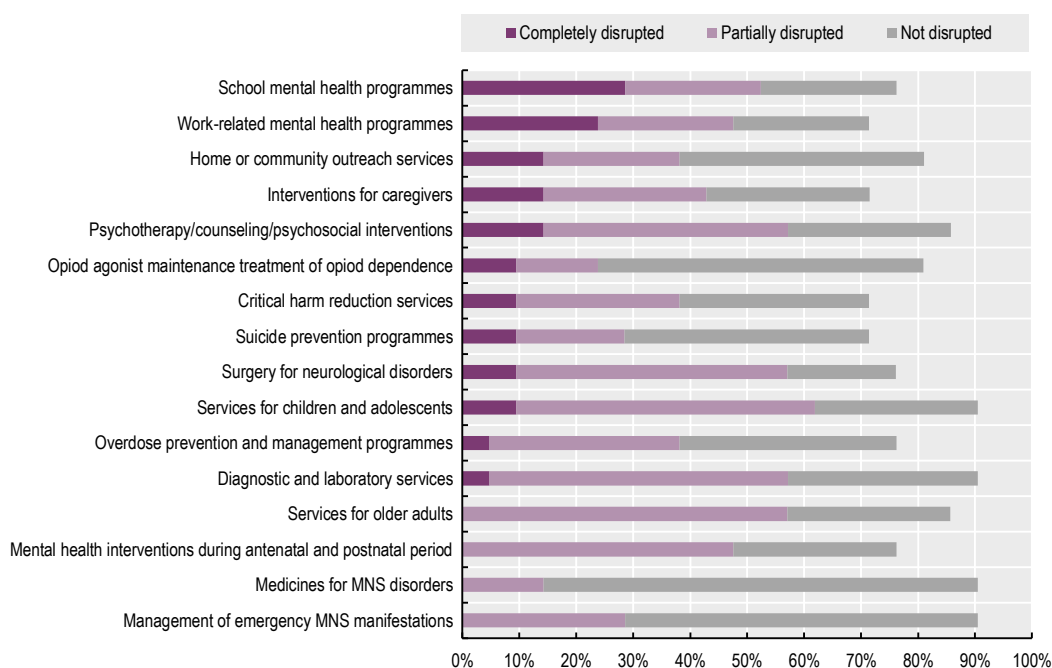
### ***High levels of heterogeneity in PROMs and PREMs in mental health care which limits interpretation for benchmarking***

48. Despite efforts to improve harmonisation for the collection of PROMs and PREMs, there is still significant heterogeneity in terms of country experiences in assessing patient-reported indicators in mental health care. This complements a recent systematic review, in which a review of 103 articles identified over 80 PROMs/ROMs initiatives in 15 countries—noting a lack for harmonisation among programs and potential challenges for sustainability (Roe, Mazor and Gelkopf, 2021<sup>[38]</sup>).

49. However, despite the heterogeneity (both within and across countries), there is significant enthusiasm among policy makers, clinicians, and researchers for further exploring the use of patient-reported indicators and integrating them into routine care.

50. In efforts to align domains across the surveys used within countries, a number of items were mapped onto the proposed items by the working group, thus including a broader number of countries who reported patient experience on the same domain, but used differently phrased survey items. Differences in these items, the response categories, as well as survey formats and processes can reduce comparability, and as such, these initial results must be interpreted with caution. Likewise, differences in the timing of the data collections may impact the comparability of the data—particularly considering that the data were collected at various time points before and during the COVID-19 pandemic depending on the site and country. This may have implications particularly considering the impact that COVID-19 had access to mental health services (Figure 3.1).

**Figure 3.1. Many mental health programmes experienced significant disruptions during the pandemic, data from 21 OECD countries**



Note: Mental health focal points within the Ministry of Health in 130 countries were surveyed by the WHO; the above figure shows outcomes for the 21 OECD countries included in the report. The OECD average includes Australia, Austria, Belgium, Canada, Chile, Colombia, the Czech Republic, Denmark, Finland, Germany, Hungary, Ireland, Japan, Latvia, Lithuania, Mexico, the Netherlands, Norway, Poland, Slovenia and the United States. Totals may not sum to 100% due to missing values.

Source: (OECD, 2021<sup>[39]</sup>)

51. Primarily, the results are to highlight countries that are measuring patient-reported outcomes and experiences on the same concepts, and to encourage further harmonisation and standardisation—working toward a common model for assessing performance, which can be dually used to for the purposes of international comparison.

### ***Moving forward—considerations for future data collections***

52. Following the completion of the first round of the PaRIS mental health working group, there are areas where additional guidance, or changes to the protocol may improve the usefulness and comparability. In the initial data collection, the secretariat asked for the average change from admission to discharge for the OECD core well-being items and WHO-5. In the future, it is recommended that the crude rate at admission and discharge for both types of items is reported by all countries. This provides added information, including information regarding average performance on the metrics both before and after—taking into account that some countries or sites may be starting at higher or lower base-lines. This would also allow for reporting by countries that are only able to collect this information at one time point (for example, following discharge).

53. Further methodological work could also be conducted to further refine standards for the timing of survey administration, definitions and classifications of types of inpatient and community mental health care, and improved mapping/standardization of items. Working group members have also proposed additional work on the development of guidance documenting best practices for survey administration, including the survey format, additional guidance on timing of request, and integration into care processes.

54. In addition, efforts are needed to broaden participation—increasing the samples from countries and sites, as well as the number of countries and sites who are able to submit data. Beyond broader participation, the group has also discussed the evaluation of a broader set of indicators—and to expand on areas identified by the working group, but not yet addressed—including relief of symptom burden, social function, and recovery support.

55. This was the first OECD data collection of PROMs and PREMs for mental health care, and as result, there were a number of changes in the data collection guidelines and processes during the process—as well as the requirement to ask for supplemental data or data in different formats. These adjustments have been useful to broaden the scope of the data collection to a point where a feasible number of sites and countries have been able to participate. However, in subsequent data collections, these specifications would be more accepted and refined, limiting the need for ad hoc adjustments.

### **Integrating patient-reported metrics into mental health system performance benchmarking**

56. There is clearly space for more internationally comparable reporting on mental health service users' experiences (PREMs) and outcomes (PROMs). Patient-reported measures show some signs of gaps between the widely held policy principle of person-centred mental health care, and the experience of mental health service users. These continuing gaps in availability of meaningful indicators of the dimensions of mental health performance that matter, as identified in the OECD Mental Health Performance Framework, underscore the importance of developing new measures (OECD, 2019<sup>[40]</sup>). However, these metrics, which include patient-reported indicators, are of critical importance for understanding mental health performance, were included in the Mental Health System Performance Benchmark and are areas where further development of internationally comparable indicators is warranted (OECD, 2021<sup>[4]</sup>; de Bienassis et al., 2021<sup>[9]</sup>)

57. A review of common barriers to implementation of PROMs in mental health care identified a number of common challenges across settings and countries: including perceptions that collecting patient-reported indicators are intrusive to clinical practice, lack of infrastructure, and health data security and management (Gelkopf, Mazor and Roe, 2021<sup>[41]</sup>). Countries should continuously prioritise people-centeredness on their policy agendas to build resilient systems and deliver appropriate care, consulting experts in the field for guidance and support in the implementation of people-centred mental health care (OECD, 2021<sup>[4]</sup>). More systematic consultation of mental health service users should be a priority in all OECD countries – through surveys of service user experience of the mental health care system, on the system priorities of service users, family and carers, and through the use of patient-reported measures of outcome and experiences at the service level.

58. Successful, sustainable adoption of systematic collection of patient-reported indicators in mental health care will require, in many cases improved health data infrastructure as well as political and organisational support to ensure that measurement programs are resourced appropriately and sustainability.

### **The way forward: future directions**

59. PROMs and PREMs are important tools to help make mental health care more responsive to the need of mental health care service users, increase the value of services, and ensure that resources are well-spent. Yet, more work is needed to fully harness the potential of patient-reported measures in mental health care settings.

60. Continued international harmonisation of PROMs and PREMs for mental health through international coordination is a key way to facilitate the sharing of national experiences, promote the use of PROMs and PREMs, and create meaningful indicators for national and international benchmarking. Furthermore, there are opportunities to expand existing efforts, such as national PREMs for hospital stays, to include mental health care. Efforts to use PROMs and PREMs for evaluating mental health can also be integrated into evaluations of primary care, a key site of mental health care delivery. Notably, the PaRIS International Survey of Patients Living with Chronic Conditions, a multi-country PROMs and PREMs survey coordinated by the OECD for patients who receive care in primary care settings includes mental health specific PROMs as well as patients with mental health conditions in the study population (OECD, 2021<sup>[42]</sup>).

## Conclusions

61. The purpose of this report is to document the pilot data collection of the PaRIS mental health working group, the developed data collection standards, and the study findings. The results, in general, show high levels of patient-reported experiences across participating sites and countries. The results also suggest improvement in patient-reported outcomes for those receiving mental health services in the settings that were able to submit data. More generally, the experience shows the potential for routine data collection of PROMs and PREMs for those receiving mental health care in inpatient and community settings—and the potential application of these initiatives for international benchmarking.

62. While there are a number of methodological, resourcing, and governance challenges that remain and potentially hinder PROMs and PREMs from fully reaching their full potential of use, there are also opportunities for the generation of new data to support patients, clinicians, and policy makers alike.

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# Annex A. The OECD PaRIS Mental Health Working Group Data Collection Guidelines and Indicator Constructs

## Data Collection Guidelines

	Pilot Specifications	Possible Expansions in Future Data Collections
National Coverage	Participation of $\geq 1$ hospital/mental health care institution in each country	National/national coverage
Target Population	Adults receiving inpatient services (for example, in hospital, psychiatric hospital, mental health care institution, or other inpatient setting) or community based mental health services. Principal diagnosis code of mental health and behavioral disorders (ICD-10 codes F10-F69 and F90-99) <i>*For PREMs items sites have the option to also report information for patients receiving community based services</i>	
Measurement	PROMs: OECD Well-Being Core Set (two items) and WHO-5 (five items/composite measure) PREMs: Adapted from OECD-Proposed Set of Questions on Patient Experiences with Ambulatory Care and Commonwealth Fund Items (four items)	Measures of domains on: <ul style="list-style-type: none"> <li>• Relief of symptom burden</li> <li>• Social Function</li> <li>• Autonomy</li> </ul>
Caseload Targets	No minimum caseload	Establish minimum case load
Time point	At admission and patient discharge or retrospectively following patient discharge or use of services.	
Risk Adjustment	Crude rates*	
Representation	Pooled and site specific mean scores	Pooled and site specific mean scores with confidence intervals Stratification by age, gender, diagnosis

\* Potential to include data resented with Hospital Level or National Average Length of Stay for Mental and Behavioural Health Disorders (National Level reported at OECD.stat)

## Indicator Constructs

### **PROMs: OECD Assessment of Subjective Well-being Core Items**

- **Coverage:** Adult survey respondents aged 16 and over (four age groups (16-24, 25-44, 45-65 and 65+) and 16+) who responded to the OECD Assessment of Subjective Well-being Core Items.
- **Numerator:** The change in total score on OECD Assessment of Subjective Well-being Core Items of survey respondents among denominator cases.
- **Denominator:** The number of survey respondents aged 16 and over who had been admitted to hospital/mental health care institution with a principal diagnosis code of mental health and

behavioral disorders (ICD-10 codes F10-F69 and F90-99) and responded the OECD Assessment of Subjective Well-being Core Items survey at admission and discharge.

***PROMs: WHO-5 Well-Being Index***

- **Coverage:** Adult survey respondents aged 16 and over (four age groups (16-24, 25-44, 45-65 and 65+) and 16+) and over who had been admitted to hospital/mental health care institution for at least two weeks who responded to the WHO-5 survey within the first 48 hours after admission and at discharge or following discharge (from 48 hours prior to 48 hours after discharge).
- **Numerator:** The change in total score on WHO-5 of survey respondents among denominator cases.
- **Denominator:** The number of survey respondents aged 16 and over who had been admitted to hospital/mental health care institution with a principal diagnosis code of mental health and behavioral disorders (ICD-10 codes F10-F69 and F90-99) and responded the WHO-5 survey at admission and discharge.
- **Note:** When there are systematic differences in measurement time than 48 hours, sites need to specify the time range used in the survey before or following discharge (*please see PROMs- Meta Data section in the Data Collection Guidelines* to report the difference)

***PaRIS Mental Health WG Recommended PREMs***

- **Coverage:** Survey respondents aged 16 and over (four age groups (16-24, 25-44, 45-65 and 65+) and 16+) who answered the specific question.
- **Numerator:** Number of survey respondents among the denominator cases who answered positively.
- **Denominator:** The number of survey respondents aged 16 and over who had been admitted to hospital/mental health care institution with a principal diagnosis code of mental health and behavioral disorders (ICD-10 codes F10-F69 and F90-99) or that received community health mental health services.

# Annex B. PaRIS Mental Health Working Group Recommended Items

## Survey Items and Response Categories

Please indicate for each of the five statements which is closest to how you have been feeling over the last two weeks. Notice that higher numbers mean better well-being.

**Example:** If you have felt cheerful and in good spirits more than half of the time during the last two weeks, put a tick in the box with the number 3 in the upper right corner.

Over the last two weeks:	All the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
1. I have felt cheerful and in good spirits	5	4	3	2	1	0
2. I have felt calm and relaxed	5	4	3	2	1	0
3. I have felt active and vigorous	5	4	3	2	1	0
4. I woke up feeling fresh and rested	5	4	3	2	1	0
5. My daily life has been filled with things that interest me	5	4	3	2	1	0

The following question asks how satisfied you feel, on a scale from 0 to 10. Zero means you feel “not at all satisfied” and 10 means you feel “completely satisfied”

6. Overall, how satisfied are you with life as a whole these days? [0-10]

Completely satisfied										Not at all satisfied
10	9	8	7	6	5	4	3	2	1	0

The following question asks how worthwhile you feel the things you do in your life are, on a scale from 0 to 10. Zero means you feel the things you do in your life are “not at all worthwhile”, and 10 means “completely worthwhile”.

7. Overall, to what extent do you feel the things you do in your life are worthwhile? [0-10]

Completely worthwhile										Not at all Worthwhile
10	9	8	7	6	5	4	3	2	1	0

During the course of your treatment:						
8. Did your care providers treat you with courtesy and respect?	Yes, definitely	Yes, to some extent	No, not really	No, definitely not	Not sure	Decline to answer
9. Did your care providers spend enough time with you?	Yes, definitely	Yes, to some extent	No, not really	No, definitely not	Not sure	Decline to answer

<b>10. Did your care providers explain things in a way that was easy to understand?</b>	Yes, definitely	Yes, to some extent	No, not really	No, definitely not	Not sure	Decline to answer
<b>11. Did your care providers involve you as much as you wanted to be in decisions about your care and treatment?</b>	Yes, definitely	Yes, to some extent	No, not really	No, definitely not	Not sure	Decline to answer

### Notes to Survey Implementers:

Item	Collect at admission	Collect at discharge or following discharge	Collect community rates (if available)
1	X	X	
2	X	X	
3	X	X	
4	X	X	
5	X	X	
6	X	X	
7	X	X	
8		X	X
9		X	X
10		X	X
11		X	X

#### Regarding items 1-5:

- More translations are available [here](#).
- **Scoring:** The raw score is calculated by totalling the figures of the five answers. The raw score ranges from 0 to 25, 0 representing worst possible and 25 representing best possible quality of life. To obtain a percentage score ranging from 0 to 100, the raw score is multiplied by 4. A percentage score of 0 represents worst possible, whereas a score of 100 represents best possible quality of life.
- **Interpretation:** It is recommended to administer the Major Depression (ICD-10) Inventory if the raw score is below 13 or if the patient has answered 0 to 1 to any of the five items. A score below 13 indicates poor well-being and is an indication for testing for depression under ICD-10.
- **Monitoring change:** In order to monitor possible changes in well-being, the percentage score is used. A 10% difference indicates a significant change (Ware, 1995<sup>[43]</sup>).

#### Regarding items 6-7:

- OECD (2013), OECD Guidelines on Measuring Subjective Well-being, OECD Publishing, Paris, <https://doi.org/10.1787/9789264191655-en>.

# Annex C. Mapping of PREM Data

**Table A C.1. Mapping item “courtesy and respect” [PREM 1]**

Country	Question	Response Categories															
OECD PaRIS Mental Health Working Group	Did your care providers treat you with courtesy and respect?	Yes, definitely Yes, to some extent No, not really No, definitely not Not sure Decline to answer															
Australia (Private Sector)	E0201 I felt welcome at this hospital. E0402 My individuality and personal preferences were respected. E0403 Staff were sensitive to my cultural background. E0603 My privacy was respected. E1102 I have been treated with respect and dignity at all times.																
Australia (Public Sector)	Q 1. You felt welcome at this service Q 2. Staff showed respect for how you were feeling Q 4. Your privacy was respected Q 5. Staff showed hopefulness for your future Q 6. Your individuality and values were respected (such as your culture, faith or gender identity, etc.) Q 7. Staff made an effort to see you when you wanted																
Canada (Whitby)	I was treated with respect by program staff.																
Ireland [Inpatient] (My Voice Matters Survey)	Throughout your inpatient experience, how often did you feel that you were treated with respect and dignity by the mental health services?	Always Most of the time Sometimes Never															
Ireland [Community] (My Voice Matters Survey)	Overall in the last 2 years, did you feel that you were treated with respect and dignity by community mental health services?	Yes, always Yes, sometimes No															
United Kingdom (CQC Community Mental Health Survey 2020)	Overall, in the last 12 months, did you feel that you were treated with respect and dignity by NHS mental health services?	Yes, always Yes, sometimes No															
New Zealand (Ngā Poutama survey for consumers)	I was treated with respect	<table border="1"> <thead> <tr> <th>Never</th> <th>Sometimes</th> <th>Always</th> <th>Don't know</th> <th>Not applicable</th> </tr> </thead> <tbody> <tr> <td>1</td> <td>2</td> <td>3</td> <td>4</td> <td>5</td> </tr> <tr> <td>6</td> <td>7</td> <td></td> <td></td> <td></td> </tr> </tbody> </table>	Never	Sometimes	Always	Don't know	Not applicable	1	2	3	4	5	6	7			
Never	Sometimes	Always	Don't know	Not applicable													
1	2	3	4	5													
6	7																
Belgium (Flanders)	My care providers respect me. (participation)																

**Table A C.2. Mapping item “care providers spend enough time with you” [PREM 2]**

Country	Question	Response Categories
OECD PaRIS Mental Health Working Group	Did your care providers spend enough time with you?	Yes, definitely Yes, to some extent No, not really No, definitely not Not sure Decline to answer
United Kingdom (CQC Community Mental Health Survey 2020)	Were you given enough time to discuss your needs and treatment?	Yes, definitely Yes, to some extent

Australia (Private Sector)	E0802 I had opportunities to discuss my progress with the staff caring for me. E0807 Hospital staff were available if I needed to talk with them.	No
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**Table A C.3. Mapping item “Care providers explain things in a way that was easy to understand” [PREM 3]**

Country	Question	Response Categories															
OECD PaRIS Mental Health Working Group	Did your care providers explain things in a way that was easy to understand?	Yes, definitely Yes, to some extent No, not really No, definitely not Not sure Decline to answer															
Canada (Whitby)	I had a good understanding of my treatment services and support plan.																
New Zealand (Ngā Poutama survey for consumers)	Staff explained things in a way that was easy for me to understand	<table border="1"> <thead> <tr> <th>Never</th> <th>Sometimes</th> <th>Always</th> <th>Don't know</th> <th>Not applicable</th> </tr> </thead> <tbody> <tr> <td>1</td> <td>2</td> <td>3</td> <td>4</td> <td>5</td> </tr> <tr> <td>6</td> <td>7</td> <td></td> <td></td> <td></td> </tr> </tbody> </table>	Never	Sometimes	Always	Don't know	Not applicable	1	2	3	4	5	6	7			
Never	Sometimes	Always	Don't know	Not applicable													
1	2	3	4	5													
6	7																
Australia (Public Sector)	Q 18. Information given to you about this service (such as how the service works, which staff will be working with you, how to make a complaint, etc.) Q 19. Explanation of your rights and responsibilities																
Australia (Private Sector)	E0202 My rights and responsibilities were explained fully in a way that I could understand. E0302 My treating psychiatrist ensured that I understood the effects of my treatment options. E0805 When I had questions, my treating psychiatrist gave helpful answers I could understand. E0806 When I had questions, hospital staff gave helpful answers I could understand.																
Netherlands	Heeft uw behandelaar u dingen op een begrijpelijke manier uitgelegd? Has your practitioner explained things to you in an understandable way?	<p>Neer, helemaal niet     Ja, helemaal</p> <p>No, totally not - 00000 - yes, completely</p>															

**Table A C.4. Mapping item “Involvement in decisions about treatment” [PREM 4]**

Country	Question	Response Categories
OECD PaRIS Mental Health Working Group	Did your care providers involve you as much as you wanted to be in decisions about your care and treatment?	Yes, definitely Yes, to some extent No, not really No, definitely not Not sure Decline to answer
Canada (Whitby)	I was involved as much as I wanted to be in decisions about my treatment services and supports.	
Belgium (Flanders)	I can participate in the decision-making process on the content of my treatment. (participation)	
Australia (Public Sector)	Q 8. You had access to your treating doctor or psychiatrist when you needed Q 10. Your opinions about the involvement of family or friends in your care were respected Q 12. You were listened to in all aspects of your care and treatment	



	<p>Q 13. Staff worked as a team in your care and treatment (for example, you got consistent information and didn't have to repeat yourself to different staff)</p> <p>Q 14. Staff discussed the effects of your medication and other treatments with you</p> <p>Q 15. You had opportunities to discuss your progress with the staff caring for you</p> <p>Q 17. You had opportunities for your family and carers to be involved in your treatment and care if you wanted</p>	
<p>Australia (Private Sector)</p>	<p>E0301 When developing my treatment plan with me, my treating psychiatrist and hospital staff ensured that it covered all of my needs.</p> <p>E0304 I have been involved in decisions about my care and treatment.</p> <p>E0305 I have been involved in planning the care I may need after I leave hospital.</p> <p>E0705 I was given information about how to manage my medication and any side-effects I may experience.</p> <p>E0803 I was encouraged to ask questions about my treatment and medication.</p>	
<p>Netherlands</p>	<p>Kon u meebeslissen over de behandeling? Were you able to participate in the decision-making process in treatment?</p>	<p>                        No, totally not - 00000 - yes, completely                 </p>

## Annex D. Additional Country Notes

Table A D.1. Additional Country Notes

Country	Notes
Australia (Public)	<ul style="list-style-type: none"> <li>• May include consumers with a principal diagnosis not listed in the data collection guidelines.</li> <li>• Note the age groups of the supplied data differ to the specifications. Supplied age groups are: 0–24, 25–44, 45–64, 65 and over. The total is all age groups combined (aged 0 and above).</li> <li>• An individual consumer may have completed the survey more than once in the reporting period.</li> <li>• Community based services include both residential mental health services and ambulatory mental health services.</li> <li>• In New South Wales, consumers are offered the YES survey during every hospital stay or community episode of care, while in Victoria and Queensland, consumers are offered the YES over a particular time of year.</li> <li>• Totals include respondents for whom information was missing or not reported.</li> <li>• Gender was reported by the respondent.</li> <li>• The percentage of respondents with a positive score was calculated as follows: For each survey response, the average score in each domain was calculated and each domain score was multiplied by 20 to get an experience score. The reported percentages indicated the number of responses with a positive (<math>\geq 80</math>) score in each domain. Surveys that do not have any answers for the questions in the domain will be included in the denominator for the percentage calculation.</li> </ul>
Belgium (Flanders)	<ul style="list-style-type: none"> <li>• Data was provided by the Flemish Institute for the Quality of Care, the official organization overseeing the development and measurement of quality indicators in Flanders (i.e. a region in Belgium) in collaboration with the Flemish Patients' Platform who developed the PREM survey. More information about publicly available PREMs on mental health care in Flanders can be found on the website of the Flemish Institute for the Quality of Care: <a href="http://www.zorgkwaliteit.be">www.zorgkwaliteit.be</a>.</li> </ul>
Belgium (Networks)	<ul style="list-style-type: none"> <li>• Patients included in this sample were treated by primary care psychologists or remedial educationalists associated with the 31 mental health care networks for both adults &amp; children and adolescents in Belgium. Each of these networks has a specific working area in Belgium and has concluded an agreement with a number of clinical psychologists and clinical remedial educationalists from the working area of the network. Primary psychological care is defined as (a series of) short-term interventions aimed at two or more of the following objectives: 1) Screening and indication, 2) General psychological care, 3) Solution-focused treatment, guided self-help, psycho-education, 4) Promotion of self-reliance, 5) Referral in case of complex problems. Per patient and per year, a maximum of 8 sessions are reimbursed, which are prescribed by the general practitioner or psychiatrist in a series of 4.</li> </ul>
Slovenia	<ul style="list-style-type: none"> <li>• In Slovenia in 2021 there was a 9-week long field trial of the survey items at one newly developed community mental health centre at the primary health care level. In centre, people with psychiatric diagnoses or with potential diagnose of mental health disorder are being treated. The mental health centre covers an adult population of approximately 65.000 (18 years and above). The centre employs a multi-disciplinary team, including psychiatrists, clinical psychologists, medical nurses, social workers and occupational therapists. PREMs indicators were collected at the Community mental health centre after one visit.</li> </ul>
Japan	<ul style="list-style-type: none"> <li>• Patients who were discharged from psychiatric hospitalisation in the past six months participated in the web survey. They retrospectively evaluated the PREMs and PROMs of their inpatient care. The same participants evaluated their current care in the community.</li> </ul>
Netherlands	<ul style="list-style-type: none"> <li>• MIND, ZN and Dutch mental health care have offered the revised CQI ambulant mental health and addiction care (VZ) to the National Health Care Institute for inclusion in the Register and associated client experience indicators are placed on the transparency calendar. This obliges health care institutions to make data based on this CQI transparent via the public database (ODB) on the Zorginstituut's website <a href="http://www.zorginzicht.nl">www.zorginzicht.nl</a>. GGZ Data Portal acts as a data broker for this.</li> <li>• General information <ul style="list-style-type: none"> <li>○ The indicators are based on the CQI questions that are filled in by the client. The CQI data is collected by GGZ Data Portal on behalf of all field parties. GGZ Data Portal only supplies the mandatory indicators of all institutions to the National Health Care Institute for publication on <a href="http://www.zorginzicht.nl">www.zorginzicht.nl</a>. The questionnaire itself and information about the development and use of the CQI GGZ or VZ can be found in the Information Document (10 September 2020, version 5.1a) at <a href="https://ggzdataportal.nl/rom-bibliotheek/">https://ggzdataportal.nl/rom-bibliotheek/</a>.</li> <li>○ The indicators are supplied at branch level in accordance with the NZa Transparency Regulation for mental health care providers with the options described therein for deviating from this if branches are located within 1 municipality or within a radius of 10 kilometres (Article 4, 1a). If only digital treatments are given, a delivery to the main establishment will suffice.</li> <li>○ A minimum number of 30 completed questionnaires has been agreed per location. The basic principle is that every client is invited. Whether branches achieve this minimum depends on the number of clients treated in the measurement period and the response.</li> <li>○ Because the delivery of CQI data to the GGZ Data Portal is aggregated and anonymized (average results at branch level based on at least 30 completed questionnaires), permission from the client is not necessary for this delivery at branch level. It is important to inform the client that, in addition to the primary goal of learning from data, the results are also used to gain national insight into the satisfaction of clients with mental health care for the purpose of the</li> </ul> </li> </ul>

choice information they receive without this being traceable to this client. Depending on how the health care organisation collects the data (internally) and whether the data is also used for other purposes, permission from the client may be required.

- Inclusion and exclusion criteria
  - Population description: the CQI has been validated for people aged 16 or older who are treated in outpatient mental health care or addiction care. The supply of the data applies to clients of 18 years or older. The CQI outpatient mental health care and addiction care applies to the entire target group referred to who receive care under the Zvw (this means not all people who receive ambulatory mental health and/or addiction care but the majority).
  - Independent contractors are not obliged to provide CQI, but institutions are. An institution is deemed to be an institution if it complies with Section III of the National Quality Charter for Mental Healthcare.
- Exclusion criteria
  - Clients who, because they turn 18, transfer to the Zvw, where it is preferable to continue previous questionnaires until a new treatment process is started.
  - Clients from certain (complex) target groups for which the questionnaire is less suitable, such as, for example, non-native speakers, illiterate people, clients with ASD, ADHD, intellectual disability or very complex problems, are not excluded in advance. The care provider can exclude such clients with arguments. This can be indicated when submitting it to the GGZ Data Portal.
  - The request for these indicators does not apply to psychiatric wards of general hospitals. Because of the target group of the CQI (clients in mental health care, outpatient mental health care and addiction care).
- Delivery in general
  - If possible, the mental health care organizations will start using the renewed CQI in the primary process from January 2021. The latest submission date is August 1, 2021, due to the submission to the National Health Care Institute. Mental health care organizations provide CQI data for the first half of 2021 at an aggregated level for transparency, without being corrected for case mix differences. This data is primarily used to support the choice of information for clients. Data are supplied per location, as has been agreed with regard to providing insight into waiting times in the NZa's Transparency Regulation for mental health care providers.

## Annex E. Representatives participating in the OECD PaRIS Mental Health Working Group

Country	Name	Organisation
Australia	Catherine Katz	Australian Commission on Safety and Quality in Health Care
Australia	Siobhan Mcfadden	Australian Commission on Safety and Quality in Health Care
Australia	Lisa Murphy	Australian Commission on Safety and Quality in Health Care
Australia	Suzanna Henderson	Australian Commission on Safety and Quality in Health Care
Belgium	Ronny Bruffaerts Leontien Jansen	UZ Leuven
Belgium	Kaat De Pourcq	Coordinator Mental Health Flemish Institute of Quality of Care
Canada	Krista Louie	Canadian Institute for Health Information (CIHI)
Canada	Greg Webster	CIHI
Chile	Alberto Larrain	ProCultura Foundation
Chile	Paula Bedregal	Universidad Catolica de Chile
Chile	Cristian Montenegro	Ministry of Health
Costa Rica	Adriana Osorio Rodriguez	Ministry of Health
Czech Republic	Petr Winkler	National Institute of Mental Health
Denmark	Jan Mainz (Chair)	Aalborg Universitetshospital
Denmark	Solvejg Kristenson	Aalborg Universitetshospital
Estonia	Jane Idavain	National Institute for Health Development
France	Marie GLOANEC	HAS
France	Cong-Tri THUONG	HAS
France	Camille LEANDRE	HAS
France	Elisabetta SCANFERLA	European Psychiatric Association/ GHU Paris psychiatry & neurosciences, Paris
Germany	Julia Thom	
Ireland	Fiona Coyle	Mental Health Reform
Ireland	Pádraig Ó Féich	Mental Health Reform
Israel	Ronit Ulriel-Mirkin, Vared Baloush	Ministry of Health
Israel	David Roe	University of Haifa
Japan	Akiko T. KIKUCHI	National Institute of Mental Health
Korea	Dr. Lee, Mrs. Ko	National Center for Mental Health
Korea	Kyoung-Hoon Kim	Health Insurance Review and Assessment Service (HIRA)
Mexico	Sebastián García Saisó	MoH - General Directorate for Quality of Healthcare and Education
Netherlands	Bea Tiemens	Radboud University
Netherlands	Marjonneke de Vetten	Dutch Association for Mental Health and Addiction Care
Netherlands	Jose Bijlholt	
Netherlands	Alexander Inia	Dutch Association for Mental Health and Addiction Care
New Zealand	Richard Hamblin	Health Quality & Safety Commission
New Zealand	Natalie Horspool	Health Quality & Safety Commission
New Zealand	Shaun McNeil	Health Quality & Safety Commission

Norway	Mario Gaarder	Directorate of Health
Norway	Hilde Hestad Iversen	Norwegian Institute of Public Health
OECD	Carrie Exton	WISE/OECD
Other	Andria Joseph	ICHOM
Portugal	Anabela Coelho	Escola Superior de Tecnologia da Saúde de Lisboa (Instituto Politécnico de Lisboa)
Portugal	Tânia Gaspar	Universidade Lusíada de Lisboa
Slovenia	Irena Makivić	National institute for Public Health Centre for Prevention and Promotion Programmes Management
Sweden	Max Koster	Linköping University
United Kingdom	Stephen Watkins	NHS Benchmarking Network
United Kingdom	Alexandra Lazaro	Department of Health and Social Care
United Kingdom	Shamim Rahman	
United Kingdom	Aradhana Rana	NHS England & NHS Improvement

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