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### OECD Health Working Papers No. 102

# Measuring patient experiences (PREMS)

### PROGRESS MADE BY THE OECD AND ITS MEMBER COUNTRIES BETWEEN 2006 AND 2016

Nicolaas S. Klazinga, Rie Fujisawa

JEL Classification: I12, I18





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#### MEASURING PATIENT EXPERIENCES (PREMS): PROGRESS MADE BY THE OECD AND ITS MEMBER COUNTRIES BETWEEN 2006 AND 2016

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JEL Classification: 112,118

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The opinions expressed in the paper are the responsibility of the authors and do not necessarily reflect the views of the OECD or its Member Countries.

### **SUMMARY**

The OECD has been leading the work on international comparisons of patient-reported experience measures (PREMs) across its member states for over a decade. This paper synthesises national developments in relation to measuring and monitoring PREMs between 2006 and 2016 across countries participating in the OECD Health Care Quality Indicator expert group. This report shows that most OECD countries measure patient experience at a national level. It also highlights that efforts to measure and report patient-reported measures which used to be conducted in an ad hoc manner previously, have been institutionalised and standardised in an increasing number of countries. This national progress has enabled the international reporting of patient experiences with ambulatory care across 17 OECD countries in the recent edition of OECD's flagship publication, Health at a Glance 2017. The scope of these indicators is currently limited, but recent national progress suggests that there is an opportunity to expand PREMs data collection in different domains for international reporting. The OECD plans to continue developing PREMs that would be useful for policy makers, and help drive improvements in health system performance for health care users, building on the PREMs work to date undertaken in consultation with countries.

### **RÉSUMÉ**

L'OCDE pilote le travail sur les comparaisons internationales des mesures du vécu du point de vue des patients (PREMs) de ses états membres depuis plus d'une décennie. Ce document résume les développements nationaux en matière de mesure et de surveillance des PREMs de 2006 à 2016 des pays participant au groupe d'experts de l'OCDE sur les indicateurs de qualité des soins de santé. Ce rapport montre que la majorité des pays de l'OCDE mesure l'expérience du patient au niveau national. Il souligne le fait que les collectes des mesures du vécu du point de vue des patients, auparavant menées de manière ad hoc, sont standardisées et institutionnalisées dans de plus en plus de pays. Ces progrès au niveau national ont permis un reporting des expériences des patients en soins ambulatoires pour 17 pays de l'OCDE dans la publication phare de l'OCDE Panorama de la santé 2017. L'étendue du répertoire des indicateurs est actuellement limitée, mais de récents progrès nationaux suggèrent qu'il y aurait une opportunité d'extension de la collecte des données dans différents domaines à un niveau international. L'OCDE compte poursuivre le développement des PREMs qui seraient utiles pour les décideurs politiques et aideraient à améliorer la performance des systèmes de santé pour les usagers, en tirant profit du travail entrepris à ce jour sur les PREMs en consultation avec les pays.

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### 1. Introduction

1. There is great potential to develop patient-reported indicators of health system performance, aiding health systems to become more knowledge-based and people-centred. Understanding the patient's view on health service delivery and their perspective on their health status is an essential component of people-centred care. The OECD High-Level Reflection Group on Health Statistics advised that there is an important gap in existing health information systems relating to data on outcomes and experiences of care reported by patients and their families. The group also advised that wider collection and reporting of patient-reported data would help present a more comprehensive picture, and enable better international benchmarking of health system performance (OECD, 2017a). OECD Health ministers in January 2017 welcomed the proposal and stressed the importance of patientreported indicators for developing better health care systems. "Measuring how care affects those outcomes that matter most to people and linking those with information already collected by the OECD, such as on expenditure, resources, safety and effectiveness of health care, will help us gain new knowledge on how to improve lives for all," they said in a joint statement (OECD, 2017b). This led to a mandate for the OECD to lead an international initiative to extend and accelerate international collaboration in the standardisation, collection and analysis of patient reported indicators of health system performance including PaRIS (Patient-Reported Indicators Surveys) (OECD, 2017c; http://www.oecd.org/health/paris.htm).

2. Patient-reported indicators measure health status or the experience of receiving health care from the patients' perspective. These measures are particularly useful for promoting and evaluating patient centred care. Patient-reported experience measures (PREMs) capture the patient's view on health service delivery (e.g., communication with nurses and doctors, staff responsiveness, discharge and care coordination); whereas patient-reported outcome measures (PROMs) provide the patient's perspective on their health status (e.g., symptoms, functioning, mental health). PREMs are used to understand patients' views on their experience while receiving care, rather than the outcome of that care. PREMs and PROMs are complementary and are meant to be used together to capture a more complete picture of the patient journey as it may be possible to have a health system which provides good outcomes but a poor experience and outcomes enables us to have a broader understanding of health system performance from patients' perspective.

3. In view of promoting patient centred care, patient satisfaction is also important data to collect and the level of patient satisfaction with health care provided is often used nationally to monitor and inform provider performance over time. However, patient satisfaction is difficult to compare internationally because it is influenced by expectation on health care delivery and system which varies widely across countries and also within countries.

4. The main purpose of this paper is to report on the progress made in measuring and using PREMs across countries participating in the OECD's Health Care Quality Indicator

(HCQI) project (Box 1.1), and how PREMs can be further developed to deliver people centred care across countries. The paper is based on information provided by country experts at HCQI meetings which are held twice a year at the OECD and qualitative data collected through a policy survey sent to participating countries in 2014 and 2016 (see Annex A for results). The results presented in this paper cover 30 OECD countries and non-OECD country (Singapore) participating in the HCQI project. The main audience of this paper is experts developing or planning to develop national and international surveys to measure and monitor PREMs.

5. The rest of this paper is structured in three sections. The next section discusses how PREMs are being measured and used within countries and explores the challenges associated with the current state of play at a national level. Section 3 reviews international work in developing comparable indicators and reporting international comparisons of PREMs. Section 4 draws conclusions on recommendations for consideration to further develop PREMs for international reporting.

### Box 1.1. OECD's HCQI project The OECD together with its member states have been making progress in measuring and evaluating different quality dimensions across health systems based on a conceptual framework, developed by the OECD's Health Care Quality Indicators (HCQI) project (Figure 1) (OECD, 2010). Figure 1.1. OECD Framework for Health System Performance Measurement Health Non-health care determinants of health lealthcare System Performance Equity ow does the health system pe Access Cost / expenditure Accessibility Efficiency Macro and micro-economic efficiency Health system design, policy and context Source: OECD (2010). In this framework, quality of health care is high when its delivery is effective, safe and responsive/patient-centred (Kelley and Hurst, 2006). The HCQI project develops indicators based on this framework and collects internationally comparable indicators from member countries to monitor and report cross-country differences in quality of health care. These data are available in the OECD database (http://www.oecd.org/els/health-systems/healthdata.htm) and selected indicators are reported in Health at a Glance (OECD, 2013a; OECD, 2015a; OECD, 2017d). Along with indicator developments and data collections (http://www.oecd.org/els/health-systems/health-care-quality-indicators.htm), in relation to

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quality of health care, the OECD also stocktakes national progress in building health information systems to measure and monitor health system performance including quality of care (OECD, 2013b OECD, 2015b), and cross-country developments in establishing mechanisms to assure health care quality (OECD, 2017e; <u>http://www.oecd.org/els/health-systems/health-care-quality-reviews.htm</u>).

### 2. National progress in measuring and reporting patient experiences

6. Understanding a patient's experience when he or she receives health care is integral to improving patient centred care. There has been an increased recognition of the importance of the patient's perspective in providing quality health care. Capturing and reporting patient experience is an important part of the overall health system performance measurement efforts. Across countries, health service providers, administrators and policy-makers have indicated a desire and need for comparable patient-reported measures to better understand and improve quality of health care service delivery and outcomes.

7. Over the last decade, increased attention has been placed on measuring and improving the health care experience of patients. The number of countries measuring patient experience has been increasing over time. Almost all OECD countries except for Greece, Hungary, Latvia, Slovenia, the Slovak Republic and Turkey have at least one national survey measuring PREMs (Annex C). In almost all of the OECD countries with national data collection, PREMs have been collected through national population-based surveys, and/or surveys covering patients who have had a recent experience either in an outpatient or inpatient care setting.

8. The majority of these countries follow criteria for developing national measures of patient experiences, which are set at the Policy Forum on Quality of Care held in 2010 at the OECD (OECD, 2010; Annex B). The rest of this section presents national progress in measuring PREMs across countries participating in the OECD's HCQI project (summary table in Annex A) in relation to these criteria and other cross-country trends.

# **2.1.** A few OECD countries established a separate organisation responsible for measuring and reporting patient experiences

9. In order to assure health system's commitment to measuring PREMs in the long term, there is a need to establish a governance structure. Several OECD countries have assigned a particular organisation responsible for measuring and reporting PREMs at the national level. In these countries, expertise in measuring and reporting PREMs has been built up and some of them such as the Netherlands, Norway and the United Kingdom (England) have an international lead in PREMs measurement and research.

- The Norwegian Knowledge Centre for the Health Services was established in 2004 to provide research evidence on improving quality of health service. This centre is responsible for measuring quality of health services including patient experience.
- In Denmark, the Center for Patient Experience and Evaluation was established and works together with Public Health and Quality Improvement on evaluations, survey development and interview-based studies within the health care system, and they are involved in collecting and reporting data on patient experience.
- In the Netherlands, the Centre for Consumer Experiences in Health Care was established in 2006 and has been developing the Consumer Quality Index (CQI). The Centre sets the national standards for measuring and reporting patient

experiences and through this mechanism around 20 surveys have been developed, tested and implemented nationally. In 2014, the Centre became an independent national quality institute (ZiN).

- In the United Kingdom (England), the Care Quality Commission (CQC), an independent health care regulator, was set up to assure the quality of care provided in the health system, and manages the national survey programme for hospitals, ambulances, and community mental health services to evaluate the quality of care which meets fundamental standards including person-centeredness. Recently, similar arrangements were set up in Scotland.
- Austria also established the *Gesundheit Österreich GmbH*, a national research and planning institute for the Austrian health care system in 2006 and it includes the Quality Institute unit.

10. In most OECD countries, however, the responsibility of measuring and reporting patient experiences is assigned to an existing institution such as the Ministry of Health or Central Bureau of Statistics. In these countries, efforts to measure and report patient experience is still centralised and expertise is built up in these existing institutions, but in some cases an emphasis on research to develop and improve patient experience measures and their reporting may not be as robust as those countries above which established a new institution dedicated for this task. The following lists some examples in which an existing institution takes responsibility for patient experience measurement work:

- The Australian Bureau of Statistics (ABS) is responsible for collecting, processing and publishing population-level patient experience data.
- The Canadian Institute of Health Information is leading the development of standard patient experience indicators and measures for pan-Canadian comparative benchmarking to inform quality improvement efforts and health system decision-making.
- In Israel, the Ministry of Health is the main body responsible for measuring and reporting patient experiences.
- In Korea, Health Insurance Review and Assessment Service is responsible for the assessment and public reporting of patient experience which is one of the domains of quality of care within the national monitoring framework.

11. In a few OECD countries including the Czech Republic, Ireland, and Germany, however, different organisations are responsible for collecting, analysing and reporting patient experience data depending on the survey. It is challenging to develop consistent and robust strategies to measure patient experience across surveys within these countries and to compare provider and system performance using these PREMs at the national level, given variable data collection modes, instruments and questions used to measure PREMs.

- In the Czech Republic, efforts to measure PREMs has started recently and the Czech Society of General Practice, the HealthCare Institute and the Ministry of Health conduct different surveys to collect data based on patient perspectives.
- In Germany, several institutions including Robert-Koch-Institute, sickness funds and their scientific institutes, the Association of Statutory Health Insurance Physicians, Private Organisations or the Bertelsmann Foundation collect data on patient experience and/or their satisfaction with the health care system.

# **2.2.** More countries involve patients during PREMs survey development but there are still some exceptions

12. Patient experience survey instruments should be formulated with the input of patients themselves to make sure the specific items and dimensions included in surveys are both relevant and important to them. About half of surveyed countries reported involving patients and patient groups during development of all existing PREM survey instruments, and they include Australia, Belgium, Canada, Denmark, France, Germany, Israel, the Netherlands, Norway, Poland, Singapore, Spain and the United Kingdom (England) (Annex A). These countries usually involve patients through focus group discussions or interviews of representative patient groups.

- In the Netherlands, patient involvement in questionnaire development is part of the standard procedures for any Consumer Quality Index (CQI) questionnaire and this is specified in a CQI manual. According to the standard procedure, a questionnaire is developed based on focus group discussions, interviews with patients and patient groups, and a review of existing questionnaires and the literature.
- In Singapore, when developing the Patient Experience Survey by adopting the US Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey, health care users were involved in translating the questionnaire into multiple languages in order to adapt the American survey to the local context.

13. In about a quarter of OECD countries, patients are involved in developing some survey questionnaires. This group of countries include the Czech Republic, Germany, Korea, Mexico, and New Zealand. In Germany, for instance, although many of the existing survey instruments have been developed based on the input from patients and patient groups, not all of them have benefited from such input in a systematic manner.

14. Despite the cross-country trend in involving patients in PREM survey developments in recent years, Austria, Estonia, Japan and Switzerland are still lagging behind, as patients are not yet involved during the development of any surveys collecting PREMs in these countries. In order to assure that surveys measure important and relevant aspects of health care experiences to patients themselves and to drive changes in health care delivery based on patient perspectives, surveys in these countries would benefit from patient input during instrument development as in other countries.

# **2.3.** Most countries use patient experience measures to compare and monitor health systems, assure provider performance and inform the public

15. All surveyed countries have specified goals for measuring patient experiences. However these goals vary between and within countries. PREMs has been broadly used

- 1. to monitor care delivery and patient experience 'ratings' at the system level,
- 2. to compare the care experiences delivered by different providers in view of promoting higher quality of health care among providers, and
- 3. to facilitate and empower patient decision-making about their care, e.g., provision of comparable data to help patients decide which health care provider/system they will use.

16. Some OECD countries use PREM surveys for other purposes than those stated above. A number of OECD countries also use PREMs to monitor care delivery for hospital and primary care inspection, regulation and accreditation. Canada, Denmark, France and

Israel use PREMs for hospital accreditations and in some countries, such as Australia, the Czech Republic and the United Kingdom (England), the use of PREMs is extended to quality regulation in the primary care sector.

- The Canadian Patient Experience Survey-Inpatient Care (CPES-IC) tool was developed together with experts from Accreditation Canada so that patient experience measures could be used for accreditation, and they are linked to hospital accreditation in some jurisdictions. Accreditation Canada has also mandated client experience reporting requirements on long-term care facilities in 2015.
- Denmark uses national surveys on patient experience in somatic and psychiatric hospitals and relative's satisfaction assessment related to psychiatric care as part of the accreditation process for these hospitals.
- Similarly in Israel, the collection of PREMs has been intensified in recent years in view of presenting certificates of excellence/citations to hospitals which maintain a high quality service.
- France has also started to use Patient Experience Survey, called eSATIS, for accreditation and this is now compulsory for all hospitals.
- In the United Kingdom (England), patient survey data have been used as part of surveillance and monitoring by the regulator (Care Quality Commission, CQC) in assessing compliance against the essential standards of quality across all providers including those in primary care.
- In Australia, patient experience measurement, in the form of patient feedback system, is mandated as part of the hospital accreditation process, and in the primary care setting, Practice Accreditation and Improvement Survey which collects patient feedback is used as part of evaluating accreditation standard for providers seeking accreditation.
- Since 2010, the Czech Ministry of Health has been awarding "Satisfied Patient" certificates to the health care facilities with outstanding performance based on patient experience.

17. Several OECD countries also reported using PREMs for funding allocation and pay-for-performance based on comparisons of patient care experience between hospitals or primary care providers. PREMs are linked to hospital funding in Korea and Norway and in some jurisdictions in Canada, and they are used in the payment mechanisms for primary care in the United Kingdom (England) (Box 2.1) and Sweden. But generally, for making financial decisions, PREMs are not used alone but together with other indicators.

- In Korea, an assessment of district public hospitals is performed by the National Medical Center partly based on the data from Patient Experiences Survey for Inpatient and Ambulatory Care. The composite score of patient experiences and other quality of care score such as appropriateness and comprehensiveness of health care services, management and governance are used as part of the overall assessment of public hospitals and these scores are used to allocate funds for facilities and equipment.
- Sweden rewards primary care providers based on PREMs together with waiting time, provision of preventive services, registration in national quality registries and efficient care delivery such as prescribing of generic drugs (OECD, 2013c).

### Box 2.1. Measuring patient experiences for pay-for-performance in the United Kingdom (England)

England introduced a national framework, called Commissioning for Quality and Innovation payment framework (CQUIN) in 2009 and under this framework, providers could receive additional payments for their performance relative to the local quality improvement goals, agreed on an annual basis. In 2010/11, the NHS Operations Board decided to support local health systems by providing a consistent national approach to delivering improvement in patient experiences, and patient experience indicators were included in CQUIN to reward patient-centred care particularly on clinician's behavioural and relational aspects.

- Within CQUIN, the following five patient experience indicators were used from the adult inpatient survey coordinated by CQC.
- Were you involved as much as you wanted to be in decisions about your care and treatment?
- Did you find someone on the hospital staff to talk to about your worries and fears?
- Were you given enough privacy when discussing your condition or treatment?
- Did a member of staff tell you about medication side effects to watch for when you went home?
- Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?

These five indicators were selected because they reflect service issues that are consistent priorities for patients and are applicable to most patients. In addition, there is room for improvement in these five behavioural and relational aspects of patient experiences as they have least changes nationally over the past 6-7 years but there is a wide variation across individual trusts.

The scores of 5 questions are aggregated to construct a single score and this is used for payfor-performance, which amounts to approximately 1-2% of provider's total income. The score had statistically significant improvement between 2009/10 and 2010/11, so this payment was considered as success and it was repeated in 2011/12.

Source: OECD HCQI meetings.

18. In a few cases, PREMs has also been used for planning: quality improvement initiatives as well as workforce development. This process involves providing feedback back to providers and requiring them to develop programmes for quality improvement or workforce planning.

- In Canada, hospitals receive PREM survey results at the unit level, and some jurisdictions set up Patient Experience Quality of Care Committees in hospitals which use the results to provide feedback and inform best practices. Some jurisdictions also mandate the Committee to report measures taken for quality improvement to the provincial ministry levels.
- In France, Patient Experience Survey collects quantitative and qualitative data from patients discharged from hospitals, and hospitals are required to use the findings to launch quality improvement programmes.

- In Denmark, based on the findings of national surveys on patient experience in somatic and psychiatric hospitals and relative's satisfaction assessment related to psychiatric care, providers are required to develop an action plan for quality improvement.
- In Australia, the Patient Experience Survey data is used by local areas to assist in modelling health workforce planning.

19. Only few OECD countries use them to inform health care funding agencies for selective contracting. The Netherlands and Switzerland are exceptions. For example, in Switzerland, since 2009, it is mandatory to monitor PREMs based on a quality contract between providers, health insurance companies and regional authorities, *cantons*.

# **2.4.** Cognitive testing and psychometric analysis are conducted for all surveys collecting PREMs only in a few countries

20. Although patient measurement tools should undergo cognitive testing and the psychometric analyses to assure reliability and validity of data during survey instrument developments, only six surveyed countries (Australia, Belgium, Israel, the Netherlands, Norway and Singapore) have developed standard procedures for all surveys collecting PREMs. For each survey, cognitive testing was undertaken to assure correct and consistent interpretation of survey questions across respondents, and psychometric analysis to assure that survey items measure the construct they intend to measure (Annex A).

- In Norway, standard procedures in questionnaire development include content validity ensured through literature review, cognitive interviews to ensure content validity, and cognitive testing. Patients and patient groups as well as health professionals are involved in in-depth interviews during the questionnaire development to identify important and relevant questions or themes. The questionnaire is subsequently tested and the quality of pilot data, particularly missing responses, is evaluated. The dimensionality is assessed, based on factor analysis, the reliability of the survey instrument is evaluated by examining internal consistency and test-retest reliability, and the validity of the data collected is also assessed.
- Similarly in the Netherlands, elaborated instructions have been developed for cognitive testing, and psychometric analysis includes assessment on skewness and item non-response, factor analysis and reliability analysis. Even though standard procedures for cognitive testing and psychometric analysis methods were established, they are assessed continuously in order to identify and apply the most appropriate methods for measuring PREMs.

21. In most countries, however, cognitive testing and psychometric analysis are undertaken for some surveys but not all. These countries include Austria, Canada, Denmark, Estonia, Germany, Korea, New Zealand, Poland, Singapore, Switzerland and the United Kingdom (England).

- In Germany, for instance, many questionnaires have been tested and validated but cognitive testing and psychometric analysis are not always part of standard procedures for survey instrument development.
- Singapore has involved patients in cognitive testing of its questionnaire as this was particularly important for a country consisting of populations with different cultural, ethnic and linguistic backgrounds, but it does not have a standardised approach in undertaking psychometric analysis.

22. Among these countries, although cognitive testing and psychometric analysis are not undertaken for all surveys measuring PREMs, in practice cognitive testing is done relatively more systematically than psychometric analyses, across surveys. This may be because these countries use survey questions which have been already validated but for newly developed questions or survey, it is recommended to undertake psychometric analysis to assess validity of the data collected.

23. Several OECD countries including the Czech Republic, Japan and Mexico have not developed processes of validating survey instruments which measure PREMs, and have not conducted cognitive testing and psychometric analysis for any of the surveys collecting PREMs. In order to collect high quality self-reported PREM data, there is a need to assess if these measurement tools meet the basic scientific criteria of validity and reliability.

# **2.5.** Across countries, methods for data collection and analysis are generally standardised for each survey collecting PREMs

24. The majority of countries have developed standardised methods for data collection including target population, sampling, data collection modes (such as telephone survey, postal survey, face-to-face interviews, and online survey), phrasing of survey questions and response categories to collect comparable data across surveys and over time. They also developed methods for analysing PREMs surveys to assure data reliability and reproduction over time. These countries include Australia, Austria, Belgium, Denmark, Germany, Israel, Japan, the Netherlands, New Zealand, Norway, Poland, Singapore, Spain, Switzerland and the United Kingdom (England) (Annex A). In these countries, standardised analysis approaches are developed for each survey measuring PREMs to ensure data comparability across providers and data consistency across surveys conducted over time.

25. Several OECD countries including Australia, Canada, Ireland, and Switzerland also try to standardise the data collection and analysis process across surveys conducted by different providers or regional administrations at the national level.

- In Australia, most hospitals used to conduct surveys to monitor and improve patient experience, using a range of instruments and methodologies without nationally consistent approaches in measuring hospital patient experience, but the Patient Experience Information Development Working Group specified a set of national core, common patient experience questions based on expert and consumer consultation, literature review, cognitive testing and validation. The question set, which contains 13 patient experience questions and 5 standardisation questions, was approved as a non-mandatory standard for measuring patient experience in hospitals, and since then, most jurisdictions plan to implement this core, common patient experience questions in some form in the near future.
- To promote consistency across 13 Canadian jurisdictions and to assure reliable pan Canadian benchmarking, the Canadian Institute of Health Information (CIHI) has developed a manual on survey processes and the Canadian Patient Experience Survey-Inpatient Care (CPES-IC) survey tool, procedure manual and data dictionary manual and they provide guidelines and specifications for standardised survey data collection in maternity, medical and surgical inpatient care.
- In Switzerland, the Association nationale pour le développement de la qualité dans les hôpitaux et les cliniques (ANQ), an organisation of the associations of hospitals, insurers and cantons, has taken an initiative to develop a short key questionnaire and standardised approach in collecting PREMs was developed. In 2009, the use of

this questionnaire became mandatory for all providers and since then, comparable PREM data have been collected.

• In Ireland, many providers conduct data collection and analysis in order to improve their own performance by comparing PREMs over time, and methods applied for data collection and analysis are not always standardised across providers, leading to difficulties in comparing the quality of health care in terms of patient experience across providers in a systematic and informative way. In order to provide support on data analysis, interpretation and data triangulation, however, currently, the National Advocacy Unit is developing a plan which will prescribe how providers should measure patient experience systematically using specific methods and questions.

26. However, there are some exceptions and standardised methods are available for some surveys but not others in a few countries such as the Czech Republic, Korea and Mexico. In the Czech Republic, for example, methodologies for data collection and analyses were developed for the Survey on Attitudes of Czech Citizens to Health Service and Healthy Life Style and the Best Czech Hospital Survey, but standardised data analysis methods have not been established yet for Online Survey of Patient Satisfaction in Outpatient Care which started in 2015.

# **2.6.** Provider-level PREMs are available in more than half of OECD countries and they are increasingly available online

27. In almost all OECD countries, standardised reporting formats are in place for all surveys measuring PREMs (Annex A). Some exceptions are Estonia, Korea and Mexico, but in Korea and Mexico, reporting and disseminating methods ensuring adequate formats for different audience are developed at least for some surveys collecting PREMs.

28. PREMs are often reported to compare differences in provider performance, and over half of OECD countries (Australia, Austria, Belgium, Canada, the Czech Republic, Denmark, France, Germany, Israel, Korea, Mexico, the Netherlands, New Zealand, Norway, Poland, Spain, Sweden, Switzerland and the United Kingdom (England)) report them at a granular level to inform providers and the public on patient-reported provider performance and to increase provider accountability.

- In Canada, PREMs are usually reported not only at the regional and provincial levels but also at the hospital and at the individual unit.
- Denmark also uses national surveys on patient experience in somatic and psychiatric hospitals for benchmarking hospitals and reports the results at the individual unit and department levels. In primary care, Danish Patients Evaluate General Practice Survey has been used to report PREMs not only by practice and region but also by individual doctor.
- In the United Kingdom (England), outside of national collections, there is a small but growing move towards presenting individual consultant level data online. Some clinical specialties, notably cardiologists, are moving towards reporting patient feedback on individual consultants, although this is not yet a feature of national programmes.

29. Patient experience data are available on public websites to facilitate consumer choice, improve transparency and accountability in most countries (Box 2.2). There has also been an increased use of online platforms to disseminate PREMs to health care providers.

- In Austria, for the nationwide standardised cross-sectorial Patient Satisfaction Survey 2010/2011, an interactive online tool was developed for all participating hospitals and this software provides all users to view, analyse and use their own results as well as undertake anonymised benchmarking.
- In Israel, all hospitals are connected to an information system and can view their data in comparison with other hospitals. The Ministry of Health in Israel is also in the process of developing a national system for the use of the general public.

#### Box 2.2. Making patient experience data available to the public

A number of countries have been making PREMs available in the public domain. In the United Kingdom (England), patient experience data are presented at the Department of Health websites and NHS choices (www.nhs.uk), the main website which contains a subset of data from various national survey programme and GP survey programme to help patients compare services and choose between them. On the website, the public can use the care directory scores on different aspects of health care rated by patients to search for a hospital, care home, dentist and/or local service. In the Czech Republic, comparative survey results covering eight quality dimensions (i.e., access to care, respect for patient, coordination of care, information and education, physical comfort, emotional support, involvement of family and friends, discharge and aftercare) are available up to the level of organisational unit of each hospital on the website of the Ministry of Health (www.mzcr.cz) and the project website (www.hodnoceni-nemocnic.cz) for professionals and the general public/patients. Furthermore, Germany has a specific website, and results of survey conducted by hospitals and physician offices are published via Quality Reports and available to the public for benchmarking, and the Netherlands makes patient experience data available to facilitate public choice at http://www.kiesbeter.nl/. In Flanders in Belgium, many hospitals report their own data on their website, and from 2015 a central website hosted by the Flemish government, provides the data of the hospitals that are willing to publish these data. More recently from the end of 2016, France has made Patient Satisfaction survey (eSATIS) data available on the website (http://www.scopesante.fr/) along with accreditation results.

Public reporting of patient experience data is also common in Nordic countries. In Sweden, comparative data on patient experiences in primary care units across county councils are published at <u>www.indikator.org/publik</u> and <u>www.1177.se/</u>. Results of telephone interviews assessing people's attitudes, knowledge and expectations to the Swedish health care are also available and comparative data across county councils and regions are published at <u>www.vardbarometern.se</u>, allowing the public to use these results to choose their primary health care unit. The Swedish Association of Local Authorities and Regions presents the national data on a website where comparisons with other units or hospitals in other county councils are possible. In Denmark, since 2009, survey results for somatic inpatient and outpatient care are available to the public on the homepages (<u>www.patientoplevelser.dk</u> or <u>www.sundhed.dk</u>) and in Norway, provider-level data are available on the website (<u>www.sykehusvalg.no/start</u>) to facilitate consumer choice.

Some OECD countries are in the process of developing strategies for public reporting. In Canada, for example, data are used within each province for quality improvement and public reporting on their websites but CIHI is exploring a potential to embed relevant patient experience indicators on the Health System Performance website (Your Health System in depth <u>http://yourhealthsystem.cihi.ca/hsp/indepth?lang=en#/</u>). It is also developing aggregate comparative report templates to inform quality improvement efforts and to make available pan-Canadian benchmarking indicators. In Israel, the Ministry plans to openly publish the clinical outcome findings, and service and quality findings from both the National Program for Quality Indicators in hospitals and the patient experience survey data to allow informed choices regarding healthcare among health care users.

Source: OECD HCQI meetings and Questionnaires on National Developments in Measuring Patient Experiences.

#### 2.7. The reporting of patient experience needs further development in most countries

30. The reporting method of patient experiences measurements should be chosen with care as the same PREM can serve different purposes and audiences. As mentioned in Section 2.3, most OECD countries have several goals in relation to measuring and reporting patient experience data. PREMs are used for not only multiple different objectives, including provider performance and health system performance assessment, provider choice, regulation and accreditation, financial incentives and selective contracting, but also for different audiences includes policymakers at the system level, management at the provider levels, health care professionals as well as public, the media and less commonly payers and insurers. Measuring PREMs can pose practical problems when there are multiple goals in terms of reporting of patient experience, and reporting methods and formats need to be chosen carefully for each goal and each target audience.

31. In some countries such as the Netherlands, Norway and the United Kingdom (England), research has been conducted to increase the impact of reporting performance measures including PREMs and to identify suitable ways to present PREMs for different objectives and audiences. They try to synthesise complex and heterogeneous data in a more understandable format with valid and clear messages for data users.

- In Norway, new standard reporting formats were introduced after an evaluation in 2005 and since then patient experience indicators have been reported in the national indicator system, comparing the performance of each institution by using traffic light colours. Statistical profile and composite performance scores for all institutions are also included for benchmarking so that directors of hospitals or health care professionals can quickly understand their performance compared to that in other institutions.
- In the Netherlands, the CQI manual specifies the presentation of data for consumer information such as star ratings showing relative performance compared with the national average (\* for below average, \*\* for average, \*\*\* for above average) and bar charts describing frequencies of positive and negative patient experiences.
- In the United Kingdom (England), most surveys provide benchmark results back to providers, showing graphical presentations of how they compare to other NHS providers. In the past those graphs presented red, amber, and green (RAG) bands based on percentiles (0-20th, 20th-80th, 80th-100th) of the overall distribution, but more recently RAG ratings based on an expected range are reported by using an adaptation of a funnel plot methodology to estimate whether providers' performances are better or worse than expected based on the national distribution and on national and local variance. This presentation approach has been well received as it is considered easy for untrained staff at provider trusts to make inferences about the statistical or practical importance of differences.

32. Across countries, reporting methods and formats need continuous developments in order to cater for different survey goals and changing needs of audiences as well as to ensure that different stakeholders are making better use of the data. To illustrate one of good practices, in the Netherlands, a large amount of PREMs have been collected and the Scientific Advisory Board of the Centre for Consumer Experience in Healthcare continues to conduct research to assess the suitability of each instrument for each of the survey goals set. For instance, if all health care providers begin to score more or less the same in relation to PREMs, this may be still informative for certain audience, such as patients and the public, but this may not be very helpful for insurers for differentiated contracting. Based

on the findings, instructions on measurement and reporting are revised. Other OECD countries can follow this example and try to improve PREMs reporting.

# **2.8.** More countries collect PREMs through different surveys, from various patient groups and in different domains

33. An increasing number of countries are collecting patient experience measures not only through a population-based survey but also through specific surveys focusing on patients with certain diseases and/or health care settings to drive changes in the delivery of care in practical terms based on patients' perspectives (Annex C). National populationbased surveys, covering patients with a wide range of illnesses are important to understand how successfully or poorly health systems are providing patient centred care in general. However, in order to identify areas for quality improvement and to formulate actionable measures, more specific information is needed for instance for priority diseases such as cancer, diabetes, stroke and mental health and specific provider settings such as general practice, emergency care, acute curative care and long-term care. Data collection efforts target more specific patient groups in several OECD countries including Australia, the Czech Republic, Denmark, Ireland, Israel, Korea, the Netherlands, Norway and the United Kingdom (England).

- In the Netherlands, PREMs are collected from people with diabetes, asthma, heart failure and cancer, covering providers such as GPs, physiotherapists, hospitals and nursing homes.
- In the United Kingdom (England), experiences of specific patient groups such as those with diabetes and stroke are collected and evaluated.
- In Norway surveys are conducted focusing on people with specific illnesses including adult and child patients who received mental health care in inpatient and/or outpatient and cancer patients at hospitals.

34. While efforts to collect PREMs have been expanded to specific group of patients, some countries including the Netherlands, Norway and the United Kingdom (England) have also developed a core set of patient experience questions and indicators and incorporated them in various surveys within the country in order to take a systematic approach in collecting, monitoring and reporting patient experiences across surveys for different patient groups and care settings. This allows standardised sets of patient experience measures to be collected from different settings including primary care, out-of-hours services, dental care, hospital care, outpatient care, accident and emergency services, maternity services and end-of-life care.

35. Another development is that across OECD countries, the collection of patientreported information has been expanding, particularly in policy priorities such as integrated care and patient safety. Measuring patient experience throughout the patient care journey may provide insights on how integrated care is performing and PREMs may also help identify weaknesses in health systems such as poor coordination and communication between specific providers and medical errors and risks.

36. Several OECD countries have developed frameworks for monitoring patient experiences with care coordination, integrated care and follow-up after care as part of health system performance assessment framework.

• In the United Kingdom (England), the integration of health and social care including long-term and end-of-life care is a major priority in order to respond to

the growing need of patients with long-term conditions, and seek provision of better and cost-effective care. England uses a broad definition, called person-centred coordinated care across health, social and long-term care and home care support, and in the NHS Outcome Framework, user experiences of integrated care are already included.

• In New Zealand, the Integrated Performance and Incentive Framework includes a domain of patient experience, particularly in relation to integration and coordination of care from the primary care perspective, as it is a major priority.

37. The number of countries measuring patient experiences with integrated care through their national surveys is growing and these include Australia, France, Ireland, Japan, the Netherlands, New Zealand, Norway, Singapore, Sweden and the United Kingdom (England) (Annex E). The survey questions generally relate to care coordination among health care providers (information sharing/management), patient empowerment/enablement/involvement, discharge planning, and coordination with social services/informal carers, out-of-hour care and emergency care.

- In the United Kingdom (England), Picker Institute Europe developed 18 core questions in integrated care in the domains of outcomes, planning, communication, access to information and support, decision making including budgets, and transitions (King et al, 2013) and these new questions are included in a range of health and social surveys such as those collecting person's experiences with primary care, inpatient care, cancer care, mental health care, home care and home support services in the country.
- Australia also considers the importance of measuring and monitoring care coordination and continuity of care. Recently ABS has developed questions in these areas and conducted cognitive testing of these questions and data collection with a possibility of integrating them into future ABS health surveys.
- Singapore has decided to measure patient experiences to monitor if care is provided in a coordinated way across providers.

38. Patient safety is another area where there has been development of PREMs across countries. While countries generally still rely on conventional data sources such as provider reporting and patient complaints and providers' own efforts to analyse safety challenges, systematic data collection and monitoring of medical safety across providers through patient-reported measures has emerged and is expanding across countries. A significant number of OECD countries include Australia, Belgium, Canada, the Czech Republic, Denmark, Estonia, France, Germany, Ireland, Israel, Korea, the Netherlands, New Zealand, Norway, Poland, Singapore, Spain, Sweden, Switzerland, and the United Kingdom (England and Scotland) have developed survey questions to evaluate safety based on patient experience in areas such as risk prevention, medication safety, medical incidents and accident, incident reporting, and incident management and collect them through surveys (Annex E).

• In the United Kingdom (England), patient experiences in relation to safety have been monitored and reported over years as the system of measuring patient experience started initially to regulate health care quality. The English Patient Experience Survey collects and assesses risks to patient safety and quality of care of providers, and if a provider is found underperforming or not meeting essential standards based on the assessment of these data, CQC has the authority to inspect their services.

- In the Netherlands, Patient Experience Survey data have been used to evaluate adverse events reported by hospitals and doctors.
- In Norway, the Patient Experience Survey, conducted every year, includes patientperceived safety questions to monitor changes during the national patient safety campaign. In addition, 13 key items about patient reported incidents in hospitals were identified and they can be used to construct an index for provider performance assessment (Strømseng Sjetne et al, 2011).
- In Denmark, the national survey asks patients if they experienced any mistakes, faults or flaws as part of their visit or stay at the hospital and if such incidence resulted in any harm to the patient or a prolonged stay. These questions are used in a range of surveys on a voluntary basis to collect safety information through patient's perspective.

# **2.9.** Political commitment is also needed across countries to make collection, analysis and reporting of PREMs as part of routine activities in the health system,

39. Although a number of OECD countries have tried to institutionalise efforts to measure, monitor and report PREMs in recent years, they do not always ensure the sustainability of these activities. This is because of weak political commitment and buy-in from different players in the context in which patient views are at times not considered as important:

- In Israel, although clinical outcome indicators have legislative backing, no legislation has been passed for quality and service indicators, and despite the fact many surveys are measuring patient experience, a lengthy process of passing legislation is still required to anchor these activities by law as part of a national monitoring system.
- In Belgium, although a module of measuring patient experience was incorporated in the national health survey undertaken by the Scientific Institute of Public Health for the first time in 2013, there is no guarantee that this will be included regularly to monitor the progress.
- Germany also faces a similar challenge with regards to a regular collection of nationally-representative patient experience measures.

40. Financial sustainability is also an issue in OECD countries including those with relatively long history of measuring and using PREMs such as Australia, the Netherlands, Norway and the United Kingdom (England).

- In the Netherlands, health care providers and/or insurance companies finance national surveys, but recently their willingness to pay for national data collection is diminishing.
- Even though political commitment exists in the United Kingdom (England), due to the budgetary constraints, it is difficult to expand the work such as collection of more detailed data, so efforts would need to be made to maximise the value of the present scope of work.
- In Norway, although financial resources for the Norwegian Knowledge Centre for the Health Services are secured through the state budget as research and development are considered crucial for measuring patient experiences, the cost of data collection remains a concern for assuring a regular collection of patient experience measures.

41. These situations in which the sustainability of PREMs collection, analysis and reporting is not assured may reflect that compared with administrative data collected from health care professionals and providers, patient-reported measures are not still considered to provide important input for further developing health systems across countries.

### **3. International reporting of Patient Experience Data**

42. Initiatives to collect and report patient experience indicators at an international level have gained momentum since the late nineties alongside national progress described in the previous section. This section summarises important developments made by different international players in relation to international reporting of patient experiences. It also describes the progress made by the OECD which led to the publication of patient experience indicators as part of regular international assessment of health system performance across OECD countries in recent editions of *Health at a Glance*.

# **3.1. International efforts to measure and report patient experiences have gained momentum over the last two decades**

43. Since 2000, significant efforts have been made to measure PREMs in an internationally comparable manner. This has been aided by the development of standardised and validated questionnaires. The Picker Institute developed the Patient Experience Questionnaire to compare patients' perceptions of the quality of acute hospital care, and the US Agency for Healthcare Research and Quality (AHRQ) developed the Consumer Assessment of Healthcare Providers and Systems (CAHPS) method. These questionnaires have been used as a model to develop national surveys in several countries.

44. Two organisations have directly collected patient experience data internationally using a standardised questionnaire. The Commonwealth Fund's (CWF) International Health Policy Survey has started collecting patient experience data from its participating countries since 1998 with a data collection every three years. Currently, the survey is conducted in 11 OECD countries. The WHO collected different dimensions of patient experience (respect, including dignity, confidentiality and autonomy, and client-orientation including prompt attention, quality of amenity, access and choice of provider) from a number of countries through the World Health Survey 2000 and Multi-country Survey Study on Health and Health System's Responsiveness 2000-2001.

45. The work on measuring patient experience started at the OECD in 2006, building on these important international efforts, and subsequently the OECD's HCQI has undertaken four work streams.

- 1. A structured review of national and cross-national surveys related to the measurement of patient experiences (Garratt et al., 2008). This paper found that despite the existence of numerous instruments, very few had been tested for international comparisons.
- Development of a set of principles for establishing national systems of patient experience measurement by drawing on country experiences, in 2009/10 (Annex B).
- 3. Development of an OECD-proposed set of questions to measure patient experiences with ambulatory care in 2010 (Annex F). The aim was to measure health care experience of the general population that could be used in national surveys. The

questions focused on experience related to access, autonomy and communication. These questions were incorporated in the CWF International Health Policy Survey, 2010. Pilot data were collected from 13 countries (11 countries participating in the CWF survey and the Czech Republic and Luxembourg), and based on the psychometric analysis, the questions were found fit for international use.

4. Monitoring of cross-national developments in measuring patient experience since 2011. The OECD has been collecting information on the process of institutionalising and standardising the efforts of measuring patient experience, challenges which countries have encountered and recent developments in relation to measuring and using PREMs. OECD also provides technical assistance to countries developing survey questionnaires to collect patient experience, and this has resulted in an increase in the number of countries collecting PREMs in an internationally comparable way.

# **3.2.** In recent years, OECD has been leading international efforts to measure and monitor patient experiences

46. The OECD developed patient experience indicators related to access to health care, autonomy in care and treatment decisions and communication with physician during ambulatory care due to their relevance and importance across health systems (see Table 3.1 for the list of indicators and Annex G for indicator definitions). These indicators were developed based on the OECD-proposed set of questions as mentioned above which drew from existing patient experience measurements across countries and the pilot data collection and psychometric analyses which confirmed the validity of these data for international reporting. The set of indicators covers important aspects of patient-centred care which are common across health systems such as patient participation/involvement, good relationship between the patient and health professionals including clear and open communication, and the appropriate context in which care is delivered including access to care (Kitson et al., 2012). The domains of these OECD indicators, particularly communication and access to care, are considered to be important dimensions of health care quality (Mohammed et al., 2014).

Indicator name				
Waiting time of more than 4 weeks for getting an appointment with a specialist				
Consultation skipped due to costs				
Medical tests, treatment or follow-up skipped due to costs				
Prescribed medicines skipped due to costs				
Doctor spending enough time with patients during the consultation				
Regular doctor spending enough time with patients during the consultation				
Doctor providing easy-to-understand explanations				
Regular doctor providing easy-to-understand explanations				
Doctor giving opportunity to ask questions or raise concerns				
Regular doctor giving opportunity to ask questions or raise concerns				
Doctor involving patients in decisions about care or treatment				
Regular doctor involving patients in decisions about care or treatment				

Source: OECD HCQI Data Collection 2016-17.

47. Since 2013, data for these indicators have been collected through OECD's HCQI's regular data collection, which takes place every two years. A number of countries reporting

data collected through international or national surveys are increasing in recent years. Eleven countries (Australia, Canada, France, Germany, the Netherlands, New Zealand, Norway, Sweden, Switzerland, the United Kingdom, and the United States) collect data through the Commonwealth Fund's International Health Policy Surveys every three years. Two countries (the Czech Republic and Luxembourg) collected data using the OECD-proposed set of questions as a stand-alone survey in 2010 and 2011, respectively. 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.

48. The OECD provides technical assistance to countries which collect PREMs through their national surveys to assure and enhance international comparability of these data and to create synergy and promote mutual learning across countries. Countries such as Chile, France, Israel, Korea and Mexico have included at least some OECD-proposed questions in their national surveys recently. For example, following technical assistance, Chile pilot tested a survey including some OECD-proposed questions after forward and backward translation of these questions. Following the data collection using OECD-proposed questions in 2011, the Czech Republic has developed a national survey including these questions to collect PREMs regularly. This makes the number of countries which include at least one OECD-proposed question in the national health survey to 22 (Australia, Austria, Belgium, Canada, Chile, the Czech Republic, Estonia, France, Germany, Iceland, Israel, Italy, Japan, Korea, Luxembourg, Mexico, the Netherlands, New Zealand, Poland, Portugal, Spain and Switzerland). Further details of national efforts in developing surveys to measure patient experiences are available in Annexes C and D.

49. The OECD has been also providing technical assistance to international players developing surveys collecting PREMs and these include the Commonwealth Fund, the European Union and World Health Organization to assure comparability of PREMs collected through different international surveys. Based on the expertise gained from assisting the development of national and international surveys, the OECD makes sure that phrasings of questions and response categories to collect PREMs are consistent across surveys.

50. Following the first PREMs data collection through HCQI, the OECD has been reporting PREMs for international comparisons and to inform the importance of patient point of view in assessing quality of health care and monitoring health system performance. In the 2013 edition of OECD's *Health at a Glance*, four patient experience indicators were presented for the first time to assess the extent of patient-centred health care delivery and its cross-country variations. This provided a different aspect on an important domain of health care quality and health system performance across countries. These indicators were reported in the 2015 and 2017 edition as well. The number of countries which report PREMs to the OECD through the HCQI data collection has increased over the years and all twelve indicators are made available to the public through OECD's database (<u>http://stats.oecd.org/index.aspx</u>). Currently, the OECD database includes data from as early as 2005 for some countries while data for most countries is available since 2010.

51. To build on the progress made internationally and also recent national developments, the OECD can expand indicator developments for PREMs. An extensive review of national and international surveys has identified a possibility of expanding PREMs indicators to different dimensions including patient safety. For instance, CWF's International Health Policy survey, for which 11 OECD countries participate, include questions related to incident prevention and medical incidents for different target groups,

and this allows an evaluation of cross-country differences in patient-reported medical incidents. The survey findings suggest a wide variation in patient safety measures reported by patients across countries. For example, its 2011 survey targeted sicker adults and found that the share of sicker adults who experienced a medical mistake or a delay in receiving abnormal test results or had wrong medication or dose or lab test errors over two years ranged from 8% in the United Kingdom and 9% in Switzerland to 25% in Norway, followed by 22% in the United States and New Zealand (Schoen, 2012). Based on input provided by national and international experts including patient groups recently, areas such as information-sharing/management, incident prevention, medication safety, diagnosis and treatment-related incidents, incident reporting and incident handling are considered relevant and important for national and international reporting in the near future. As done previously for PREMs indicators currently collected for international comparisons, the OECD can expand the indicator development work by developing a set of questions to measure these additional aspects of patient experience together with national and international experts, undertaking pilot data collection and assessing the data validity for international comparisons through psychometric analysis.

#### 4. Conclusion

52. National efforts to monitor patient-reported experience have been intensified over the past decade. Most OECD countries are now collecting nationally representative data on patient experience in a regular and systematic way, partly through assistance by the OECD. This is a major shift from the early 2000s when patient experience data were collected only in a few countries either in an ad-hoc manner or in a restricted group of providers such as hospitals.

53. In recent years, many countries have made progress in developing national systems of measuring patient experience. Countries have either set up an organisation or identified institutions responsible for measuring and reporting PREMs. Patients are involved in questionnaire developments for all surveys measuring PREMs in about half of OECD countries, and at least for some PREM surveys in a quarter of OECD countries. All countries have specific goals for measuring patient experience such as monitoring health systems, assuring provider performance and informing patient and the public for their provider choice, and some uses the data to promote patient-centred care through resource allocation. An increasing number of countries have developed standardised procedures for data collection, analysis and reporting to assure data comparability over time and across surveys. Over half of OECD countries report PREMs data by provider and they are made available increasingly online in the public domain, to increase provider accountability and to facilitate patient's provider choice.

54. Countries need to continue their efforts in developing appropriate tools for collecting, analysing, reporting and utilising these data. For systematic production of high quality, comparable patient-reported data over time, countries need to involve patients during questionnaire developments systematically for all surveys measuring PREMs and conduct cognitive testing also for all surveys. Psychometric analyses need to be undertaken particularly for instruments which have not been validated and newly developed surveys, even if each survey question has been validated already elsewhere. Reporting methods and formats also need to be continuously developed to cater for different goals of reporting PREMs, to meet changing needs of target audiences as well as to ensure better use of data by different stakeholders.

55. Despite the importance in measuring and using the voice of patients and their families to make health systems more people-centred, there is also a risk that countries cannot maintain a regular collection of PREMs as these measures are not still considered as key indicators for assessing health system performance. Measuring and reporting PREMs is the first and important step to further develop health systems to respond to the needs of people, so countries need to make a political commitment to assure the sustainability of the national systems for measuring patient-reported information and their further developments.

56. At the international level, in recent years, the OECD has been leading efforts to collect PREMs from its member states and other countries participating in the HCQI project by providing technical assistance to countries to develop national health information

systems in collecting, monitoring and reporting PREMs and assuring cross-country comparisons of patient experience data. The OECD regularly reports these indicators which reflect key aspects of delivering patient-centred health care in its flagship publication, *Health at a Glance*, which evaluates performance of health systems across OECD countries as well as in its database which is publically available.

57. To advance PREMs agenda internationally, additional dimensions of patient experiences can be measured and their cross-country variations can be monitored and evaluated. In recent years, a number of countries have intensified their efforts to measure and monitor patient experience with health care delivery, and in order to address the challenges of providing integrated and safe care to patients, particularly those in need of health care by multiple providers, an increasing number of OECD countries collect and utilise information based on patient's experience with care coordination and medical safety. They measure dimensions including information sharing and management, incident prevention, medication safety, diagnosis and treatment-related incidents, incident reporting and incident management. As these are critical areas faced across health systems, international efforts to develop and collect PREMs in these dimensions would be relevant and useful for countries. As done in the past, the OECD can advance this international agenda by developing a set of survey questions to measure these important dimensions of patient health care experience together with experts including patients themselves, seeking opportunities to embed these questions in national and international surveys and to participate pilot collection and conducting psychometric analysis to assess the validity of these data for international reporting. Based on these activities, the OECD can develop additional, comparable PREM indicators and collect and report them, and monitor the progress in delivering patient centred care across health systems.

58. Recent cross-country developments in relation to monitoring, reporting and using PREMs are important, but commitment to change is also needed among all stakeholders including decision-makers and providers to reorient health care system to provide peoplecentred care. Based on PREMs, countries have made progress in promoting patient-centred health care by using patient voices in assessing health system and provider performance, channelling resources through pay-for-performance payments for patient-centred care delivery, monitoring performance and providing feedback to increase provider accountability to patients and the public. Measuring and reporting PREMs is just a start and additional support and commitment are needed to actually drive changes in health care delivery. For instance, countries need strong clinical and managerial leadership committed to shift toward people-centred care at different levels. The identification of dedicated champions, the engagement of patients, their families and carers in health care, and a capacity-building of health care professionals are also crucial in improving patient experience and putting people at the centre of health care (Coulter et al., 2014; Graham et al., 2015). For coherent shift towards people and person centred health care delivery across providers, systematic national and international guidance will continue to be useful.

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Country	Patients are involved during survey instrument developments	Cognitive testing and psychometric analyses are undertaken for PREMs survey	Measurement and analyses of patient experiences are standardised for PREMs survey	Reporting method are standardised for PREMs survey
Australia	Yes	Yes, but psychometric analysis not always done	Yes	Yes
Austria	No	Yes, but not for all surveys	Yes	Yes
Belgium	Yes	Yes	Yes	Yes
Canada	Yes	Yes, but psychometric analysis not always done	Yes, but not for all surveys	Yes
Czech Republic	Yes, but not for all surveys	No	Yes, but not for all surveys	Yes
Denmark	Yes	Yes, but psychometric analysis not always done	Yes	Yes
Estonia	No	Yes for cognitive testing but no for psychometric analysis	No	Yes
France	Yes	NA	NA	NA
Germany	Yes, but not for all surveys	Yes for psychometric analysis but cognitive testing not always done	Yes	Yes
Israel	Yes	Yes	Yes	Yes
Italy	NA	NA	NA	NA
Japan	No	No	Yes	Yes
Korea	Yes, but not for all surveys	Yes, but cognitive test not always done and no for psychometric analysis	Yes, but not for all surveys	Yes, but not for all surveys
Mexico	Yes, but not for all surveys	No	Yes, but not for all surveys	Yes, but not for all surveys
Netherlands	Yes	Yes	Yes	Yes
New Zealand	Yes, but not for all surveys	Yes, but psychometric analysis not always done	Yes	Yes
Norway	Yes	Yes	Yes	Yes
Poland	Yes	Yes, but cognitive test not always done and no for psychometric analysis	Yes	Yes
Portugal	NA	NA	NA	NA
Singapore	Yes	Yes	Yes	NA

### Annex A. National progress in relation to measuring and monitoring PREMs

		-		
Spain	Yes, but not for all surveys	Yes, but cognitive test not always done and NA for psychometric analysis	Yes	Yes
Sweden	NA	NA	NA	Yes
Switzerland	No	Yes for cognitive testing but no for psychometric analysis	Yes	Yes
United Kingdom (England)	Yes	Yes for cognitive testing but no for psychometric analysis	Yes	Yes

Note: NA refers to not available.

Source: OECD HCQI meetings, HCQI data collections 2012/13, 2014/15 and 2016/17 and Questionnaire on National Developments in Measuring Patient Experiences.

### Annex B. Principles for establishing national systems of patient experience measurement proposed by the HCQI Project

Following seven principles were first discussed during the Subgroup meeting in 2009, and upon experts' endorsement, they were published in the OECD publication "Improving Value in Health Care: Measuring Quality", prepared for the Forum on the Quality of Care held in October 2010 preceding an OECD Ministerial meeting.

#### Principle 1. Patient measurement should be patient-based

Patient experience survey instruments should be formulated with the input of patients themselves. This can be done through focus groups or interviews of representative patient groups. Doing so will ensure that issues included in the survey are relevant and important. It is also useful to assess the relative importance of the priority areas that have been identified. Items included in the survey should reflect "demand" side characteristics rather than "need" side characteristics. Finally, for the measured results to be taken seriously it is important that the institution(s) in charge of the work have public credibility.

#### Principle 2. The goals of patient measurement should be clear

Patient measures can be used for a variety of goals. Some systems are set up for "external" reasons such as the provision of consumer information to increase patient choice, accountability towards the general public on performance or as information used by financiers in pay-for-performance schemes. Other initiatives have more "internal" goals such as quality improvement by the providers. Although specific measures can be used for various goals, it is important to be explicit about the goals before developing the measurements. For example, if the goal is quality improvement, the instrument should deal with the actionable aspects of the care delivery process. By doing so the results will be tailored in such a way so as to enable health care providers to learn lessons and improve. When the goal is to facilitate choice, the measures should be able to show meaningful differences between health care providers.

# Principle 3. Patient measurement tools should undergo cognitive testing and the psychometric properties should be known

Like all indicators, patient measurement tools such as surveys should meet the basic scientific criteria of validity. Documentation should exist on the testing of the tools, including the results of cognitive testing (e.g. assuring correct and consistent interpretation of the questions) and the psychometric properties (e.g. assuring that the items used in the questionnaire actually measure the constructs they pertain to measure). Changes in questionnaires should be documented and when necessary re-tested.

## Principle 4. The actual measurement and analyses of patient experiences should be standardised

The methodology of patient experience measurement does not only apply to the development of measurement tools but also to the actual measurement (e.g. via mail survey, telephone survey, structured interview), the analyses of data and the reporting. To ensure reliability, the data collection methods and analyses must be standardised and reproducible. Several countries working with systematic measurement of patient experiences have introduced accreditation procedures for the various agencies/vendors who conduct surveys.

# Principle 5. The reporting method of findings of patient experiences measurement should be chosen with care

In presenting the results of patient experience measurement there is always a tension between presenting a clear and easy-to-understand message and the methodological limitations of drawing certain conclusions. There is a good deal of literature available on the reporting of patient experience information, and this body of knowledge should be taken into account when choosing a particular reporting format.

# Principle 6. International comparability of measurement of patient experiences should be enhanced

Methodological efforts by countries to develop and use systematic ways of measuring patient experience information are diverse and plentiful. Experience indicates that countries are keen to copy and adjust questions and questionnaires applied elsewhere. Given the OECDs work in this field and its position as a central broker of quality improvement initiatives, it is ideally placed to facilitate shared learning of national experiences in this regard. To this end, the HCQI Project will continue to act as a repository and disseminating centre for patient experience expertise.

# Principle 7. National systems for the measurement of patient experiences should be sustainable

A national system for the measurement of patient experience should monitor trends longitudinally. This requires long term health system commitment and resourcing. Therefore, sustainability of the organizational and research and development infrastructure is an important condition for its success.

Source: OECD (2010).

## Annex C. National surveys measuring patient experiences

Country	CWF survey	Nat'l population- based survey	Nat'l survey: outpatient care	Nat'l survey: inpatient care	Details
Australia	Yes	Yes	Yes	No	Patient Experience data are collected through a range of different surveys. The Australian Bureau of Statistics conducts a population-based survey called the Patient Experience Survey. This survey has been conducted annually since 2009. Most Australian States and Territories have their own outpatient survey. Since 1997, Western Australia conducts Patient Evaluation of Health Services which covers both patient experiences with inpatient and outpatient care. In addition, the private hospital sector (which accounts for approximately one-third of all hospital admissions) typically use commercial patient experience survey companies for both admitted and outpatients. Practice Accreditation and Improvement Survey, started in 1998, collects patient feedback for GP practice seeking accreditation. Pharmacy Patient Questionnaire which is conducted on a voluntary basis from 2011, is also used to gather feedback from customers.
Austria	No	Yes	Yes	Yes	Austrian Health Interview Survey, conducted in 2006/07 and 2014, included some questions related to waiting time and access to care. In 2011, Austria conducted the first nationwide patient survey in which hospitals could take part on a voluntary basis. Forty- nine hospitals took part. Since then, Patient Satisfaction Survey has been conducted to patients who received inpatient and outpatient care but on an irregular basis and the results are published on the Ministry's website. Population Survey also includes some questions on patient experiences and was conducted in 2015 and the next survey year has not been decided.
Belgium	No	Yes	No	No	Belgian Health Interview Survey has been conducted since 1997 every 4 to 5 years and in 2013 a module on patient experiences was included for the first time. In Flanders, the Flemish Patient Inquiry for inpatient care was conducted for the first time in 2012 and it is conducted twice a year.?
Canada	Yes	Yes	Yes	Yes	Patient experiences have been measured through a national population-based survey as well as other national surveys such as Canadian Patient Experience Survey-Inpatient Care (acute-care hospital patient experience survey), Canadian Community Health Survey (patient experience questionnaire were added for the 2015 cycle and conducted every two years)Primary Health Care Survey for Patient Experiences and a pilot of the interRAI Quality of Life (QoL) survey in long-term care.

Chile	No	Yes	Yes	-	OECD proposed questions have been included in a national survey.
Czech Republic	No	No-	Yes	Yes	Data on experiences in inpatient care have been regularly collected through standardised survey from patients discharged from hospitals (from 2005), psychiatric clinics (from 2008) and rehabilitation facilities (from 2009). In addition, in 2008 and 2009, a pilot project developed methodology and questionnaire to measure patient experiences in outpatient care. In 2010, a stand-alone survey using OECD-proposed questions on patient experiences was conducted. Based on this experience, a survey on attitudes of Czech citizens to the health service and healthy life style was developed by the Czech Society of General Practice and data were collected in 2015, but the periodicity of this survey is not yet known. In 2015, the Czech Ministry of Health also developed an online survey of patient satisfaction in outpatient care and collects data from patients on an ongoing basis. Since 2006, the Health Care Institute also collects data on experiences with outpatient and inpatient care from patients and hospital employees every year.
Denmark	No	No	Yes	Yes	Several surveys are conducted in the areas including ambulatory care, hospital care, psychiatric care, relative's satisfaction, GP care, emergency care and maternal care. For example, the National Danish Survey of Patient Experience for inpatient and outpatient care was developed in 2000 and since 2009 data are collected annually. Since 2001, a patient satisfaction survey called DANPEP (Danish Patients Evaluate Practice) has been used to systematically collect patient reported measures of the quality of primary care, including experience of the patient journey, degree of involvement in decisions about their care and co-ordination of care.
Estonia	No	Yes	No	No	Patient Experience and Opinion Surveys have been conducted annually since 2001.
Finland	No	Yes	No	No	Patient experience data have been collected through national health surveys regularly.
France	Yes	Yes	Yes	Yes	Enquête santé et protection social (ESPS), a population-based survey, conducted every two years since 1989, included some OECD-proposed questions in 2010. From 2015, eSatis collects data on patient experiences with inpatient care every year and in 2016, this survey has expanded to measure patient experiences with outpatient care.
Germany	Yes	Yes	Yes	Yes	Patient experience data have been collected through a national survey run by the Robert Koch Institute (RKI), a central federation institute responsible for disease control and prevention since 2009 but it is not conducted regularly. Since 2001, Patient satisfaction survey in ambulatory and hospital care has been also undertaken by sickness funds in co-operation with Bertelsmann-Foundation, twice a year. There is also a survey organised by the National Association of Statutory Health Insurance Physicians every other year. Internal Quality of Health Care, hospitals and physicians offices also undertake surveys. Furthermore, hospitals and physician offices conduct a survey regularly.
Greece	-	-	-	-	-
Hungary	-	-	-	-	-
Iceland	No	Yes	-	Yes	Health and Wellbeing of Icelanders follow-up survey 2009 (household survey) included an OECD-proposed question on access to care.
Ireland	No	-	-	Yes	Since 2000 the Irish Society for Quality and Safety in Healthcare has undertaken a Patient Experience and Perception Survey for acute hospital care patients. Patient experience surveys in the area of emergency care and primary care were conducted in 2006 and 2007 and surveys of patient experience with acute hospital inpatient care and mental health care were undertaken in 2010 and

			-	-	2011. In addition, a survey tool for maternity hospitals was developed. Individual services are also developing local solutions for measuring patient experience.
Israel	No	Yes	Yes	Yes	Seven national surveys were conducted or are being conducted to monitor patient experience and they include The Patient Experience Survey for Patients Discharged from General Hospitals (from 2014, every two years, ), Patient Experience Survey for Patients Discharged from Geriatric Hospitals, Patient Experience Survey for Patients Discharged from Psychiatric Hospitals (from 2015, every two years), Patient Experience Survey for Patients Discharged from Emergency Departments (from 2015, every two years), Patient Experience Survey for Patient Experience Survey for Rehabilitation Centers and Patient Experience Survey for Outpatient Clinics. Health care plans also conduct surveys to collect PREMs.
Italy	No	Yes	-	-	Health Conditions and Use of Medical Services Survey (Italian Health Interview Survey) which includes some aspects of patient experiences, particularly access to care, has been conducted in 1999-2000, 2004-2005 and 2012-2013,
Japan	No	Yes	Yes	Yes	National Patient Experience Survey has been conducted to collect data from patients discharged from hospitals (both inpatient and outpatient care) every three years since 1996. Household Health Survey (Comprehensive Survey of Living Conditions) is also conducted regularly and some OECD-proposed questions can be integrated in the survey.
Korea	No	Yes	Yes	Yes	The annual evaluation of public hospitals includes assessment on patient experiences, and the Korea Health Insurance Review Agency (HIRA) has undertaken the collection of patient experience data for medical and psychiatric hospital services and also specialised hospital inpatient care through Patient experiences survey for inpatient and ambulatory care in district public-hospital (from 2006, every year) and Patient experiences survey in quality assessment for psychiatric hospitals for medical aid patient (from 2011 every two years). Korea National Health and Nutrition Examination Survey which incorporated OECD-proposed questions has been conducted every year since 2015.
Latvia	-	-	-	-	-
Luxembourg	No	Yes	No	Yes	The first national household survey on patient experience was conducted in 2011 and used the OECD-proposed set of questions on patient experience in primary care. In 2009, a Picker survey was run on inpatient experiences and there is a plan to repeat this survey in 2013. Data on patient experiences with hospital care have been collected since 2008.
Mexico	No	No	Yes	Yes	Since 2002 the patient experience survey has been conducted and data are collected from patients with inpatient and outpatient care quarterly. ?
Netherlands	Yes	Planning	Yes	Yes	Patient experience data have been collected through several national surveys (Consumer Quality Index (CQI)) in various care settings such as hospital care, nursing homes, homes for elderly, home care, and different conditions such as mental health, breast cancer, and specific procedures including cataract. For example, CQI survey for cataract surgery was first conducted in 2007 and undertaken every two years while annual PREM Oncology includes patient experience questions for breast cancer patients from 2009 and for colon cancer patients from 2015. There are also other surveys, conducted not at the national level, and they cover different services including preventive care, acute curative care, chronic care, long-term care/care for the elderly, social care and palliative care.
New Zealand	Yes	Yes	Yes	Yes	New Zealand Health survey, a population-based survey conducted every year since 2011, includes questions on patient experiences including experiences with integrated care. Inpatient Experience Survey, started in 2014, and Primary Care

-					Experience Survey, started in 2016, are both conducted by Health Quality and Safety Commission every quarter.
Norway	Yes	Yes	Yes	Yes	Hospital-based patient experience surveys (PasOpp) are part of a long standing national programme for measuring patient experiences with health services. The Norwegian Knowledge Centre for Health Services has carried out more than 20 national surveys in the last 10 years, including generic surveys (e.g., hospital inpatient care (from 2013 and conducted every year) and outpatient care), diagnostic specific surveys (e.g., psychiatric patients and cancer patients), surveys in primary health care settings, and survey for adults with interdisciplinary inpatient treatment for substance dependence, and has also been responsible for the Norwegian part of the Commonwealth Fund's health policy surveys since 2009. In addition to surveys conducted by the Knowledge Centre, Norway has several population surveys that include patient experiences and patient satisfaction.
Poland	No	Yes	NA	Yes	Patient Satisfaction Surveys have been undertaken since 1994, and a population-based survey called Health Care in Households held in 2010 and 2013 contain some relevant questions on patient experiences. Patient satisfaction survey has been also conducted for inpatient care since 2003. Patient Satisfaction Survey for hospital care, started in 2003, is conducted on a voluntary basis and periodicity depends on participating hospitals.
Portugal	No	Yes	No	No	A population-based survey called Satisfaction of Health System Users was conducted in 2013.
Singapore	No	Yes	Yes	Yes	Patient Experience Survey was developed in recent years to capture experiences of patients in local hospitals, focusing on patient factors, staff interaction with patient, and physical environment. In addition, Consumer Satisfaction Survey is undertaken every year by the Ministry of Health. Furthermore, national household survey has been conducted every three years.
Slovak Republic	No	-	-	-	-
Slovenia	No	-	-	-	-
Spain	No	Yes	No	No	Patient experience data have been collected through a population-based Health Barometer Survey which has been conducted annually since 1995. From 2008, the community of Madrid conducts an annual evaluation of satisfaction of use of outpatient and inpatient services.
Sweden	Yes	Yes	Yes	Yes	Sweden has three national surveys that cover questions about the Swedish health care; a national population-based household survey, a national household survey about public health, and a national patient survey. The National Patient Survey was first conducted in 2009, covering primary care. This annual survey alternates its focus between primary care in one year and hospital and specialised care (in- and outpatients) the other year.
Switzerland	Yes	No	No	Yes	Swiss hospitals collect data on patient experience through ANQ, an annual survey conducted first in 2009. The Swiss patient safety agency has piloted a patient questionnaire on the topic of patient safety experience in several hospitals, and it is planned to promote this questionnaire nationally.
Turkey	No	-	-	-	-
United Kingdom	Yes	Yes	Yes	Yes	National surveys have been conducted in England since at least 2002. They cover hospital inpatients, emergency services, outpatient, maternity, community mental health, general practice and include patients with some conditions such as diabetes and strokes. The equivalent programme in Scotland ('Better Together') was launched in 2008 and currently covers general practice and hospital inpatients with a planned maternity survey in 2013. A national population survey for Wales began in 2012 and includes

			-		some questions on local health services. Northern Ireland does not currently have a systematic patient survey programme. In addition, in England, a revised national maternity survey is planned and a new ambulance service user survey is being designed. Scotland has Care Experience Surveys Patient and care-user experiences of their care: Care Experience Survey Programme. It also conducts Health and Care Experience Survey covering GP care, out of hour care, social care and caring and Inpatient Experience Survey, Maternity Care Survey, Radiotherapy Patient Experience Survey and Cancer Patient Experience Survey.
United States	Yes	-	Yes	Yes	Provider surveys focusing on ambulatory care and hospital care have been undertaken.

Note: Countries with "Planning" refer to those which would like to conduct the data collection but it is not sure if it will be actually carried out. "-" means that information is not available.

Source: OECD HCQI meetings, HCQI data collections 2012/13, 2014/15 and 2016/17 and Questionnaire on National Developments in Measuring Patient Experiences.

# Annex D. National efforts for reporting patient experience indicators in an international comparable manner

Country	Status
Australia	Patient Experience Survey, a population-based survey, has been conducted, and the survey incorporated some OECD-proposed questions. Western Australia Patient Evaluation of Health Service for admitted adults, Practice Accreditation and Improvement Survey for general practice, and Pharmacy Patient Questionnaire also include some OECD-proposed questions.
Austria	Austrian Health Interview Survey and Patient Satisfaction Survey include several OECD-proposed questions.
Belgium	Some of the OECD-proposed questions are included in the Belgium Health Interview Survey. Flemish Patient Inquiry also includes some OECD-proposed questions.
Canada	Canadian Community Health Survey (from 2015), and Primary Health Care (PHC) Survey for Patient Experiences include some OECD-proposed questions. Canadian Patient Experiences Survey-Inpatient Care (CPES-IC) includes some OECD-proposed questions adapted to inpatient care settings.
Chile	OECD-proposed questions was translated and tested and data were collected using these questions in the national survey.
Czech Republic	The national household survey on patient experience, conducted in 2010, used the OECD-proposed set of questions on patient experiences with ambulatory care. Following this, Survey on attitudes of Czech citizens to the health service and healthy life style was developed and it includes OECD-proposed questions to allow calculating eight indicators for international comparisons.
Denmark	The National Danish Survey of Patient Experience for inpatient and outpatient care and National Survey of patients and their relative in Danish psychiatric care include some OECD-proposed questions.
Estonia	Patient Experience and Opinion Survey has been conducted since 2001 and a few OECD-proposed questions have been included in the survey since 2012.
Finland	There is a general interest in the development of the OECD's work in measuring patient experiences, but no actual plan is made at the moment to include OECD-proposed questions in its national surveys. But similar question items have been included in national health surveys. Following national trends based on existing survey questions and using questions that focus on national interest have been considered more important than international comparability, but there may be opportunities to include at least some OECD-proposed questions in future surveys.
France	Enquête santé et protection social (ESPS) 2010 included some OECD-proposed questions. In 2015, some OECD-proposed questions are incorporated in a survey called eSatis in an inpatient setting and there is a plan to expand this survey to measure patient experiences with outpatient care.
Germany	All OECD-proposed questions were included in the surveys but with different wording. Some OECD- proposed questions could be considered to be included in the national household survey but this may depend on the interest and the financial resources of various institutions.
Iceland	One OECD-proposed question is included in Health and Wellbeing of Icelanders, follow-up survey 2009.
Ireland	A short omnibus survey is being undertaken and it can be examined to see a possibility of including OECD-proposed questions.
Israel	Patient Experience Surveys, Consultant Community Medicine Survey, Primary Community Medicine Survey and Diamond Clarit Inpatient Survey include some OECD-proposed questions (either in its original version or adapted version particularly for inpatient survey) and questions from Expanded Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) Survey, developed by Agency for Healthcare Research and Quality (AHRQ) from 2013.

Italy	Italian National Institute of Statistics (ISTAT) has expanded the collection of patient experience indicators in periodic surveys by including some OECD-proposed questions.
Japan	Some OECD-proposed questions are included in the National Patient Experience Survey. Househol Health Survey (Comprehensive Survey of Living Conditions) is also conducted regularly and some OECD-proposed questions can be integrated in the survey.
Korea	In 2012, pilot data collection was conducted using the OECD-proposed set of questions in one publi hospital after forward and backward translation. Subsequently, OECD-proposed questions were included in the Korea National Health and Nutrition Examination Survey and data were collected in 2015.
Luxembourg	The first national household survey on patient experience, conducted in 2011, used the OECD proposed set of questions on patient experiences with ambulatory care.
Mexico	National Healthcare Indicator System (INDICAS) has conducted a patient experience survey since 2002. In 2015, it was redesigned and includes eight questions from OECD-proposed questions. Eff and Inpatient survey includes five questions adapted from the OECD-proposed questions.
Netherlands	Some OECD-proposed questions were included in CQI and some OECD-proposed questions can be also integrated in Dutch national survey of health insurers' quality.
New Zealand	Several OECD-proposed questions (either in its original forms or adapted forms particularly for inpatient surveys) are included in the Ministry of Health's national health survey, hospital survey and primary care survey and Health Quality and Safety Commission's inpatient experience survey and primary care experience survey.
Norway	Norway takes part in the Commonwealth Fund's International Health Policy Survey and considers that this survey is the instrument which can include OECD-proposed questions. There is no plan to include OECD-proposed questions in any of the national surveys on patient experiences, but may conside including them in a national survey in the future.
Poland	Many OECD-proposed questions are included in the population-based health surveys in 2010 and 2013. Some OECD-proposed questions are adapted for inpatient settings and included in Patien Satisfaction Survey.
Portugal	Some OECD-proposed questions are included in the population-based survey on Satisfaction of Health System Users in 2013. Portugal is seeking ways to test and include OECD-proposed question in national household survey.
Singapore	Patient Experience Survey includes some OECD-proposed questions. Several OECD-propose questions can be included in three-yearly national household survey as well.
Spain	Some OECD-proposed questions are included in the Health Barometer Survey. Some more or a OECD-proposed questions may be included in the national survey. User satisfaction survey conducter in Madrid also includes several OECD-proposed questions.
Sweden	In order for any of the OECD-proposed questions to be used in a Swedish national survey, the question will need to be discussed thoroughly by different stakeholders involved in national surver developments. The National Board of Health and Welfare plans to put forward the OECD-propose questions so that they can be considered when formulating the content of the new national patient survey.
Switzerland	One OECD-proposed question is included in ANQ.
United Kingdom (England, Scotland and Wales)	In England, Patient Survey, Outpatient Survey, and Community Mental Health Survey, Coronary Hear Disease Survey include some OECD-proposed questions but with different wording. It took years to come to the questions with specific phrasing, so it is difficult to make even small changes as they are likely to make changes in results. Questions for patient survey will be revised and there may be room to include some OECD-proposed questions. In Scotland, some OECD-proposed questions (either in it original forms or adapted forms) are included in Health and Care Experience Survey, Inpatient Patier Experience Survey, Maternity Care Survey and Cancer Patient Experience Survey. In Wales, some OECD-proposed questions are included in Patient Experience Survey (cancer).

Source: OECD HCQI meetings and Questionnaire on National Developments in Measuring Patient Experiences.

# Annex E. List of Survey Questionnaires including questions related to integrated care and patient safety

#### Questions related to integrated care

Agency f Australia	for Healthcare Research and Quality: Expanded HCAHPS Survey
Austrant	ABS Patient Experience Survey (Household Based Population Survey)
England	
-	Final set of measures of people's self-reported experiences of integrated care
France:	Questionnaire on satisfaction of hospitalized patients
	Questionnaire Saphora-MCO (version 2009)
Ireland:	Questionnune Suphoru (reision 2007)
	Inpatient Survey
Japan:	
Netherla	Patient Experience Survey (Inpatient Care)
Inetheria	Module Integrated care for chronically ill (version 8 October 2012)
Norway:	
·	Survey on Patients' Experiences of Hospital Stay 2011
Sweden:	
	National Patient Survey on Primary Care National Patient Survey on Specialist Care
Singapor	
Singupoi	Patient Experience Survey
	The Commonwealth Fund: International Health Policy Survey 2014 Questionnaire
	Questions related to patient safety
Agency f Australia	for Healthcare Research and Quality: CAHPS Hospital Survey (HCAHPS)
i iusti uiit	New South Wales Patient Survey: Outpatient Cancer
	Patient Experience Survey 2011/12
	Western Australia Admitted Adult 2013/14
Belgium	
Canada	Flemish patient poll
Cunudu	Canadian Community Health Survey 2011
	Measuring Patient Experiences in Primary Health Care Survey
a	Patient Experiences Survey Inpatient Care
Czech R	epublic: Inpatient 2016
	inputent 2010

	Outpatient 2016
Denmark	
	National Survey on Psychiatry Inpatient: Parents and Children
	National Survey on Psychiatry Outpatient: Adults
	National Survey on Psychiatry Outpatient: Children
	National Survey on Psychiatry Outpatient: Parents and Children
England:	
	2014 Inpatient Survey
	Accident and Emergency Department survey
	Adult Inpatient Survey Cancer Patient Survey
	Children's Inpatient and Day Case Survey
	Children's Section Survey
	Community Mental Health Survey 2013
	Coronary Heart Disease 2004
	GP Patient Survey
	Local Health Services Survey 2008
	Maternity Care Survey
	National Ambulance Survey
	National survey coronary heart disease
	National Survey programme Adult outpatient question bank
	Outpatient Survey
	Outpatients Questionnaire (CORE)
	Young Person's Questions
Estonia:	
Б	Estonian's opinion on health care 2013
Europear	n Commission:
France:	Eurobarometer 2009
France.	Questionnaire Saphora-MCO 2009
Germany	
Germany	Bertelsmann health monitor
	Information Status and Self-determination of Citizens and Patients
Ireland:	
	Inpatient Survey
Israel:	1 5
	Brookdale questionnaire
	Diamond Clarit Inpatient
	Patient Satisfaction survey
	Patient Satisfaction Survey
Korea:	
	Operation assessment for district public-hospital
	Patient experience survey for mental healthcare service
Netherla	
N 7	Module Integrated care for chronically ill
New Zea	
	National Patient Experience Survey (Inpatient)
	New Zealand Health Survey Child Questionnaire
Norway:	Primary Care Survey
inoiway.	

2013 National Survey on Somatic Inpatient in Norwegian hospitals Patient-reported Incidence Survey on patients' experiences of hospital stay 2011 Picker Patient Experience Questionnaire Poland: Patient Satisfaction Survey Scotland: Inpatient Patient Experience Survey Cancer Patient Experience Survey Health and Care Experience Survey Singapore: Patient Experience Survey Spain: Sanitary Barometer Sweden: Somatic Patient Inpatient survey National Patient Primary Care Choice: doctor Visits Switzerland: Swiss Patient Safety Foundation survey Switzerland Benchmarking Patient Safety Survey The Commonwealth Fund: International Health Policy Survey 2011, 2016, 2017

### Annex F. OECD-proposed Set of Questions on Patient Experiences with Ambulatory Care

#### Introduction and screening

We would like to ask you a few questions about your experiences with access to and use of health care over the past 12 months.

Q1 Are you 18 years or older and have been living in <insert country name> for at least the past 12 months?

1 Yes  $\Box$  Continue

2 No, but there is another person 18 years or older in the household who is available  $\square$  Continue

3 No, and there is not another person 18 years or older in the household who is available  $\Box \Box Ask$  Q2 and Q3 only then end of questionnaire.

4 Decline to answer  $\Box \Box Ask Q2$  and Q3 only then end of questionnaire.

Q2 First, what is your year of birth? If the response to Q1 is 3, how old are you? [range 1901 – 9999, decline or unable to answer = 9999  $\rightarrow$  end questionnaire]

Q3 Are you male or female? In face-to-face interviews: Interviewer observation. In telephone interviews: If one is obviously talking to a child (year of birth 1998 >) ask: Are you a boy or a girl?

- 1 Male
- 2 Female

#### Access to care

Q4 When was the last time that you had a consultation with a doctor, nurse or allied health professional (interviewer clarification required) to get care for yourself? Include both consultations over the phone and consultations in a doctor's office, a clinic, or the outpatient department of a hospital Do not include:

- care you got when you stayed overnight in a hospital.
- times you went for dental care visits.
- accident and emergency care or
- care received in your home.
- 1 In the last 30 days
- 2 Between 1 and 3 months ago
- 3 More than 3 but less than 6 months ago
- 4 Between 6 and 12 months ago
- 5 Between one and two years ago  $\Box \Box Ask Q5-Q9$  then go to Q21
- 6 More than two years ago  $\Box \Box Ask Q5-Q9$  then go to Q21

- 7 Not sure  $\Box \Box Ask Q6-Q9$  then go to Q21
- 8 Decline to answer  $\Box \Box Ask Q6-Q9$  then go to Q21

Interviewer explanation:

Allied health professional include: to be confirmed but intended to also include allied mental health practitioners.

Q5 Was it at a GP/family practice, health centre, or clinic that you usually go to for most of your medical care?

- 1 Yes
- 2 No, not at my usual place for medical care
- 3 No, do not have a usual place for medical care
- 4 Not sure
- 5 Decline to answer

Q6 During the last 12 months, was there a time when you had a medical problem but did not visit a doctor, nurse or allied health professional because of difficulties in travelling to a doctor's office, clinic or the outpatient department of a hospital?

- 1 Yes
- 2 No

3 Not applicable, I had no medical problem in the last 12 months  $\Box \Box$  skip to Q9/10 or Q21 (depending on answer to Q4)

4 Not sure

5 Decline to answer

Q7 During the last 12 months, was there a time when you had a medical problem but did not visit a doctor, nurse or allied health professional because of cost [explanation by interviewer: actual out-of-pocket payments for services]?

- 1 Yes
- 2 No
- 3 Not applicable
- 4 Not sure
- 5 Decline to answer

Q8 During the last 12 months, was there a time when you skipped a medical test, treatment (excluding medicines), or other follow-up that was recommended by a doctor, nurse or allied health professional because of the cost [explanation by interviewer: actual out-of-pocket payments for services]?

- 1 Yes
- 2 No
- 3 Not applicable
- 4 Not sure
- 5 Decline to answer

Q9 In the last 12 months, was there a time when you did not fill a prescription for medicine/collect a prescription for medicine, or you skipped doses of your medicine because of the cost [explanation by interviewer: actual out-of-pocket payments for medicines]?

- 1 Yes
- 2 No
- 3 Not applicable
- 4 Not sure
- 5 Decline to answer

I now want to ask some questions about the last time that you had a consultation with a doctor, nurse or allied health professional to get care for yourself. This can be a consultation over the phone or a consultation in a doctor's office, a clinic, or the outpatient department of a hospital.

Do not include:

- care you got when you stayed overnight in a hospital.
- times you went for dental care visits.
- accident and emergency care or
- care received in your home.

Q10 Thinking about this last consultation, which of the following best describes the type of care you principally received? [Interviewer instruction: if respondent has seen 2 or more --> ask respondent to name the principal provider; respondent must choose]

- 1 General practitioner / family physician at a doctor's office
- 2 Specialist at an outpatient department of a hospital
- 3 Specialist at a doctor's office
- 4 Nurse at outpatient department of a hospital
- 5 Nurse at a doctor's office
- 6 Nurse at a community based clinic
- 7 Allied health professional at outpatient department of a hospital
- 8 Allied health professional at a doctor's office
- 9 Allied health professional at a community based clinic

10 Telephone consultation either by general practitioner/family physician, specialist, nurse, or allied health professional  $\square$  Skip to Q 15

[Professional categories adapted to countries participating in the survey]

Interviewer explanation:

Allied health professional include: to be confirmed but intended to also include allied mental health practitioners.

Q11 How quickly did you get an appointment to see this <healthcare provider>? [Interviewer instruction: use description of provider who was named in Q10] [Open question with immediate (re)coding by interviewer into days]

[Open question with immediate (re)coding by interviewer into days]

- 1 0 days ( $\approx$  same day)  $\Box \Box Q13$
- 2 1 day ( $\approx$  next day)
- 3 2 to 5 days ( $\approx$  couple of days)
- 4 6 to 7 days ( $\approx$ just less than a week)

- 5 8 to 14 days ( $\approx$  more than 1 week)
- 6 15 to 30 days ( $\approx$  more than 2 weeks)
- 7 31 to 60 days ( $\approx$  more than 1 month)
- 8 61 to 90 days ( $\approx$  more than 2 months)
- 9 91 days or longer ( $\approx$  more than 3 months)
- 10 I did not make an appointment, I went directly to the doctor/nurse $\rightarrow$ Q13
- 11 Not sure
- 12 Decline to answer

Q12 Was the time you waited for the appointment a problem for you?

- 1 Yes
- 2 No

Q13 On the actual day of the consultation, how long did you wait (for example in the doctor's waiting room) before you were actually seen?

- 1 Up to 15 minutes ( $\approx$ up to quarter of an hour)  $\Box \Box Q15$
- 2 More than 15 and up to 30 minutes ( $\approx$ up to half an hour)
- 3 More than 30 and up to 60 minutes ( $\approx$ up to an hour)
- 4 More than 1 and up to 2 hours
- 5 More than 2 and up to 4 hours
- 6 More than 4 and up to 8 hours
- 7 More than 8 hours
- 8 I left before seeing the health care provider that day  $\Box \Box Q15$
- 9 Not sure
- 10 Decline to answer

Q14 Was the time you waited to be seen a problem for you?

1 Yes

2 No

#### **Patient experiences**

Now, the following questions still refer to the last time you had a consultation with this < doctor/nurse/allied health professional> [Interviewer instruction: use description of provider who was named in Q10].

Q15 Did this <doctor/nurse/allied health professional> spend enough time with you?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, not really
- 4 No, definitely not
- 5 Not sure
- 6 Decline to answer

Q16 Did this <doctor/nurse/allied health professional> explain things in a way that was easy to understand?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, not really
- 4 No, definitely not
- 5 Not sure
- 6 Decline to answer

Q17 Did this <doctor/nurse/allied health professional> give you an opportunity to ask questions or raise concerns about recommended treatment?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, not really
- 4 No, definitely not
- 5 Not sure
- 6 Decline to answer

Q18 Did this <doctor/nurse/allied health professional> involve you as much as you wanted to be in decisions about your care and treatment?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, not really
- 4 No, definitely not
- 5 No, did not want to be involved
- 6 Not applicable: no decisions about treatment were made
- 7 Not sure
- 8 Decline to answer

Q19 Overall, how would you rate the quality of this consultation?

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor
- 6 Not sure
- 7 Decline to answer

#### **Additional Demographics**

Finally, we would like to ask you a few more questions about yourself.

Q20 What is the highest level of education you have completed to date? [Categories adapted to countries participating in the survey]

Q21 The average household income of families in [the name of the country] is around [XX] a year. By comparison, is your household income...?

1 Much above average

- 2 Somewhat above average
- 3 Average
- 4 Somewhat below average
- 5 Much below average
- 8 Not sure
- 9 Decline to answer

Q22 In general, how would you describe your overall health?

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor
- 6 Not sure
- 7 Decline to answer

## Annex G. OECD HCQI on Patient Experiences: definitions

#### Definitions

#### Consultation skipped due to costs [COSKCOST]

**Coverage:** Survey respondents aged 16 and over (4 age groups (16-24, 25-44, 45-65 and 65+) and 16+) who answered the specific question.

Crude rate (weighted) is calculated based on the following definitions:

• **Numerator**: Number of survey respondents among denominator cases who answered not having visited a health professional (e.g., doctor, nurse or allied health professional) because of costs (i.e., actual out-of-pocket payments for services).

• **Denominator**: Number of survey respondents who reported having had a medical problem in the reference year and answered "Yes" or "No" to a survey question on whether consultation was skipped due to costs.

Standard errors should be calculated **based on the sample design**.

#### Medical tests, treatment or follow-up skipped due to costs [MTSKCOST]

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• **Denominator**: Number of survey respondents who answered "Yes" or "No" to a survey question on whether recommended medical tests, treatment or follow-up was skipped due to costs in the reference year.

Standard errors should be calculated **based on the sample design**.

#### Prescribed medicine skipped due to costs [PMSKCOST]

**Coverage:** Survey respondents aged 16 and over (4 age groups (16-24, 25-44, 45-65 and 65+) and 16+) who answered the specific question.

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• **Denominator:** Number of survey respondents who answered "Yes" or "No" to a survey question on whether prescribed medicine was skipped due to costs in the reference year. Standard errors should be calculated **based on the sample design**.

#### Waiting time of more than 4 weeks for getting an appointment with a specialist [WAITGEAP]

**Coverage:** Survey respondents aged 16 and over (4 age groups (16-24, 25-44, 45-65 and 65+) and 16+) who answered the specific question.

Crude rate (weighted) is calculated based on the following definitions:

• **Numerator:** Number of survey respondents among denominator cases who reported having waited for four weeks or more for getting an appointment with a specialist.

• **Denominator:** Number of survey respondents who reported having had an appointment with a specialist in the reference year and provided a duration of the waiting time.

Standard errors should be calculated **based on the sample design**.

#### **Doctor spending enough time with patient during the consultation** [HPRTIPAT]

**Coverage:** Survey respondents aged 16 and over (4 age groups (16-24, 25-44, 45-65 and 65+) and 16+) who answered the specific question.

Crude rate (weighted) is calculated based on the following definitions:

• **Numerator:** Number of survey respondents among denominator cases who answered that a doctor spent enough time with them.

• **Denominator:** Number of survey respondents who reported having had a consultation with a doctor in the reference year and answered "Yes" or "No" to a survey question on whether a doctor spent enough time with them.

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**Coverage:** Survey respondents aged 16 and over (4 age groups (16-24, 25-44, 45-65 and 65+) and 16+) who answered the specific question.

Crude rate (weighted) is calculated based on the following definitions:

• **Numerator:** Number of survey respondents among denominator cases who answered that a regular doctor always or often spent enough time with them.

• **Denominator:** Number of survey respondents who reported having had a regular doctor in the reference year and answered a frequency to a survey question on how often a regular doctor spent enough time with them.

Standard errors should be calculated **based on the sample design**.

#### **Doctor providing easy-to-understand explanations** [HPREXCLA]

**Coverage:** Survey respondents aged 16 and over (4 age groups (16-24, 25-44, 45-65 and 65+) and 16+) who answered the specific question.

Crude rate (weighted) is calculated based on the following definitions:

• **Numerator:** Number of survey respondents among denominator cases who answered that a doctor explained things in a way that was easy to understand.

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#### Doctor giving opportunity to ask questions or raise concerns [HPRGOASK]

Coverage: Survey respondents aged 16 and over (4 age groups (16-24, 25-44, 45-65 and 65+) and 16+) who answered the specific question.

Crude rate (weighted) is calculated based on the following definitions:

Numerator: Number of survey respondents among denominator cases who answered that a doctor gave an opportunity to ask questions or raise concerns about recommended treatment.

Denominator: Number of survey respondents who reported having had consultation with a doctor in the reference year and answered "Yes" or "No" to a survey question on whether a doctor gave an opportunity to ask questions or raise concerns about recommended treatment. Standard errors should be calculated **based on the sample design**.

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Denominator: Number of survey respondents who reported having had a regular doctor in the reference year and answered a frequency to a survey question on how often a regular doctor gave an opportunity to ask questions or raise concerns about recommended treatment.

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#### **Doctor involving patient in decisions about care and treatment [HPRIPDEC]**

Coverage: Survey respondents aged 16 and over (4 age groups (16-24, 25-44, 45-65 and 65+) and 16+) who answered the specific question.

Crude rate (weighted) is calculated based on the following definitions:

Numerator: Number of survey respondents among denominator cases who answered that a doctor involved them as much as they wanted to be in decisions about their care and treatment.

Denominator: Number of survey respondents who reported having had consultation with a doctor in the reference year and answered "Yes" or "No" to a survey question on whether a doctor involved them as much as they wanted to be in decisions about their care and treatment. Standard errors should be calculated **based on the sample design**.

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