Call for expertise:

PaRIS – Survey of Patients with Chronic Conditions treated in Primary Care

The OECD Secretariat is calling for expertise to help with the development of a new international survey of patient reported outcomes and experiences for patients with chronic conditions.

*The PaRIS initiative*

Health Ministers of OECD member countries asked the OECD Health Committee to lead an effort to develop and analyse cross-country comparative measures of patients’ own experiences of medical care and health care outcomes. This mandate draws from the recommendations of a High-Level Reflection Group on Health Statistics (HLRG), convened by the Health Committee in 2015.

Moving forward on the ministerial mandate, the OECD Health Committee at its meeting of 25-26 June 2017 launched the Patient Reported Indicators Survey (*PaRIS*) initiative. PaRIS is intended to complement the data already collected by the OECD on health system performance, with information on patient-reported outcomes and experiences. PaRIS will also fill the information gap in neglected areas and emerging health system challenges, particularly around the effective management of people with chronic conditions.

- In areas where patient-reported indicators such as PROMs and PREMs already exist, the first work stream supports countries to accelerate the adoption and reporting of validated, standardised, internationally-comparable patient-reported indicators. The working party on Health Care Quality Indicators and Outcomes (HCQO) coordinates this work and three international working groups have started in early 2018 to discuss instruments, definitions and data collection strategies in three areas: breast cancer, hip and knee replacements and mental health.
- To address the need to understand the outcomes and experiences of patients with one or more chronic conditions, the second work stream is to develop a new international survey. The survey would be of patients whose chronic conditions are, for an important part, being managed in primary care.

*Two work streams*

PaRIS has two streams of work:

1. In areas where patient-reported indicators such as PROMs and PREMs already exist, the first work stream supports countries to accelerate the adoption and reporting of
validated, standardised, internationally-comparable patient-reported indicators. The working party on Health Care Quality Indicators and Outcomes (HCQO) coordinates this work and three international working groups have started in early 2018 to discuss instruments, definitions and data collection strategies in three areas: breast cancer, hip and knee replacements and mental health.

2. To address the need to understand the outcomes and experiences of patients with one or more chronic conditions, the second work stream is to develop a new international survey. The survey would be of patients whose chronic conditions are, for an important part, being managed in primary care.

This call for expertise applies to the second work stream, the survey of patients with chronic conditions treated in primary care.

**The survey of patients with chronic conditions treated in primary care**

This PaRIS Survey will be the first international survey of the health outcomes and experiences of patients with chronic conditions. The survey would support countries’ efforts to foster patient engagement and people-centred care by enabling national and international monitoring of health system performance from the patient’s perspective.

The survey has two key objectives:

- To report internationally comparable indicators of health care outcomes and experiences of patients with chronic conditions that inform about the variation within and between countries to support national health care system improvement.
- To support the analysis of variation in the outcomes and experiences of patients across patients, providers and health systems that identifies factors contributing to more positive outcomes and experiences that could influence policy reforms.

The survey will have a multi-level structure. This enables to relate outcomes and experiences of patients to characteristics of their providers and to characteristics health systems.

**Key principles**

There are six key principles that will guide the PaRIS initiative and likewise the development of the PaRIS survey. These guiding principles reflect the starting point and conditions for the PaRIS work and are based on the Ministerial Statement that provided the mandate for this work. The principles are:

- **Inclusive development**
  Instruments and indicators that are being developed should be relevant and valuable for patients, health care providers and policy makers. These key stakeholders will be involved in all stages of the project. To assure that cultural differences and differences between systems are taken into account, as many as possible countries will be involved.
• **Supporting people-centred health systems**
  PaRIS will produce information that is actionable and that enables stakeholders to understand variation in health outcomes and health care experiences and to identify policy actions to really improve care.

• **Alignment with national directions**
  In several countries, patient reported outcomes are already being collected. PaRIS is building on this experience. To the extent possible, implementation of PaRIS should be aligned with national initiatives that are already underway.

• **A multi-level approach**
  Factors that influence patient experiences and outcomes can be identified on different levels: the level of patients, the level of health care professionals, the level of health care organizations and the level of health systems. Therefore, it is essential that patient-level data can be linked to these higher levels. Depending on the system, regional levels may also be included.

• **A phased approach**
  PaRIS will progress through several developmental phases that will be described in the programme of work and budget for the project. The first phase will be the development phase, the second a field trial in participating countries, and the third the implementation of the survey in all OECD countries.

• **Future proof**
  The future of data collection and record keeping will be digital. Data collection should take place preferably electronically, with a user-friendly and safe interface. Effective ICT solutions are needed that support the collection and sharing of data.

  Technological barriers can hamper the adoption of patient reported outcome measures. In ideal circumstances, data collection should be integrated into the electronic health record (EHR) system so that they are actionable for care providers and to link outcomes to relevant patient characteristics.

*Developing a survey proposal*

The survey is in an early design phase and the Secretariat is seeking input to the design in order to take a decision in June 2018 regarding the feasibility of proceeding to develop and launch the survey.

The Secretariat is consulting with patients, health care providers, policy makers and international experts in the measurement of patient reported outcomes and patient experiences and in the design and conduct of international surveys. The Secretariat is seeking input regarding the following topics:

• Definition and sampling of eligible patients and primary care providers for inclusion within the survey scope;
Which selection criteria should be used in terms of demographic characteristics?
Which selection criteria should be used in terms of diagnoses?
What selection criteria should be used in selection of eligible providers?

- Designing a multi-stage sample design involving selection of areas, primary care providers and patients;
  - What would be possible sources of bias in a multi-staged design and how best to tackle these?
  - What are relevant provider and systems characteristics to include?
- Strategies on recruitment of providers and patients;
  - Which incentives would be most effective to recruit primary care providers and to increase response rates?
- Development and validation of instruments for measuring patient reported outcomes and experiences;
  - What are relevant dimensions to include (such as pain, physical functioning, etc?)
  - What existing instruments may be useful?
- Statistical analyses;
  - Power analysis: what would be the minimal sample size to detect relevant variation between providers and between countries?
  - What innovative statistical methods should be used for scale construction analysis of variation on different levels?
- Software and ICT solutions;
  - Which software solutions offer user-friendly and secure interface for data collection?
  - Which software solutions are able to easily link data on patient outcomes to electronic health records?
  - How best to guarantee privacy and data security?
- Stakeholder engagement and communication;
  - How best to engage relevant stakeholders such as patients, health care providers, payers and policy makers?

Input that is freely given to this early design phase is welcome before **15 May 2018** so that it can be taken into consideration in time for the June meeting. More detailed information about the proposed survey is available upon request.

Following a positive decision of the Health Committee in June 2018 to develop and implement the survey, a governance of the project will be initiated and it may include a call for tender and selection of a lead contractor (and sub-contractors) to manage the survey to ensure the project milestones are achieved.

See for more information about PaRIS, the OECD [PaRIS-website](http://www.oecd.org).

**CONTACT US**

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