



The Danish National Work on Patient Reported Outcomes



What are PRO-data?

PRO-data are the patients' self-reported contributions to knowledge about their own state of health. The patient reported knowledge – the data – can be actively incorporated in the encounter between patient and healthcare professional, where the data can be used for clinical decision support or to help steer the dialogue towards what is most relevant for the patient. PRO-data can be shared between healthcare providers across sectors and may also be used for purposes such as research, improvement of clinical quality and value based decision-making.

For further information on the national work on PRO-data, please consult www.PRO-danmark.dk

The Danish National Work on PRO

Based on the financial agreement of 2017, the state, regions and municipalities of Denmark have decided to standardize and further the national use of PRO-data within the healthcare sector. The aim is to support the use of PRO-data in everyday clinical encounters as well as in quality improvement processes within public healthcare.

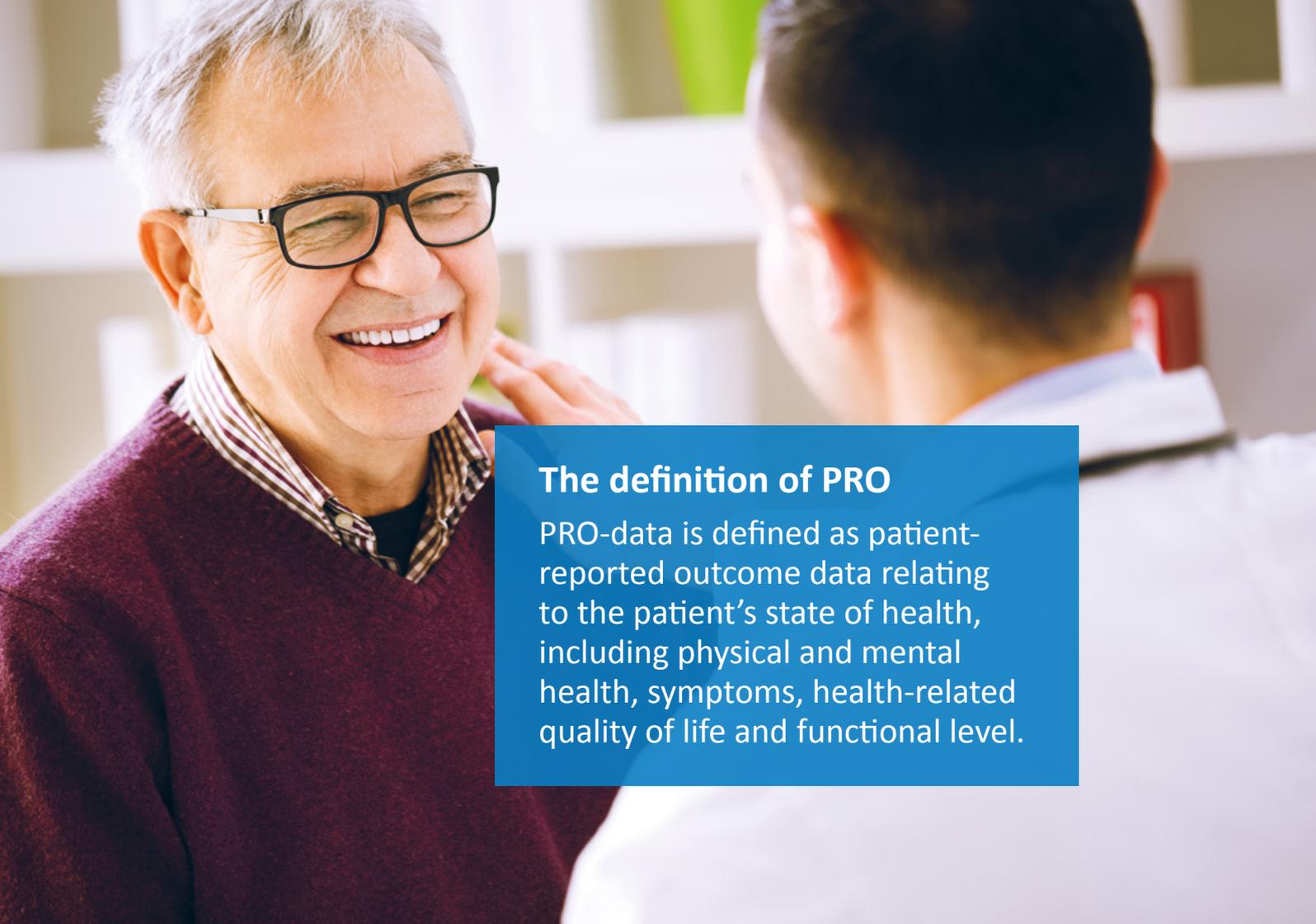
To this end, standardized healthcare questionnaires and algorithms are under development. Also, an IT infrastructure to carry data across sector boundaries and different IT-systems of healthcare providers has been established. As part of this work, standards that enable the sharing and comparing of data are developed.

The effort to further the nationwide use of PRO-data is managed by a national steering committee, which is supported by a national PRO secretariat placed under The Danish Health Data Authority.

In the spring of 2017, work commenced on the three focus areas of apoplexy, knee/hip osteoarthritis and early detection of depression.

In 2018, work began on the areas of diabetes, heart rehabilitation and pregnancy/maternity, followed by the focus area psoriasis in 2019 and palliative care in 2020.



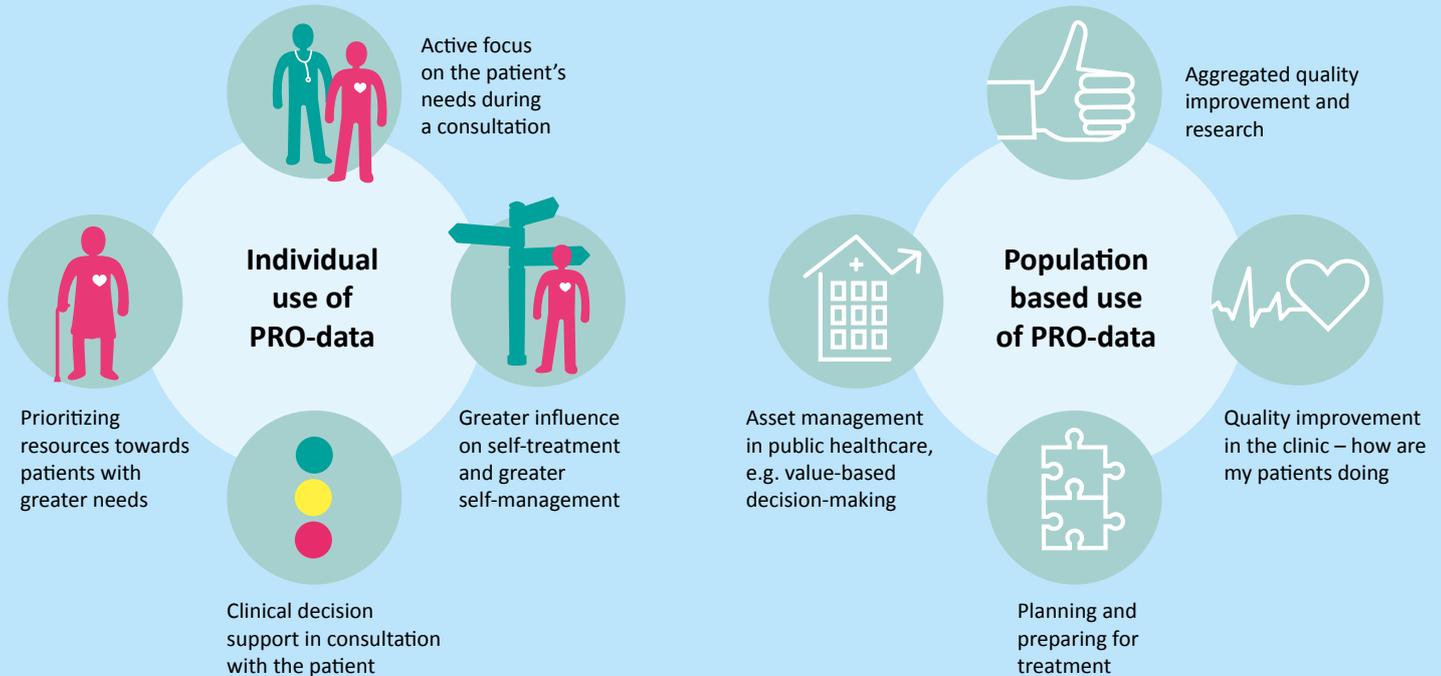


The definition of PRO

PRO-data is defined as patient-reported outcome data relating to the patient's state of health, including physical and mental health, symptoms, health-related quality of life and functional level.

Why PRO?

PRO-data have a wide range of uses.



Development of questionnaires

In order to develop questionnaires and algorithms, clinical coordination groups are established. All relevant stakeholders are represented in the clinical coordination groups. Participants are healthcare professionals from regions, municipalities and primary health care, medical science organisations, clinical databases, patient organizations, as well as patients themselves. The representatives participate in 3-5 workshops, where the group identifies when and how it is beneficial to apply PRO-data to a treatment plan.

The clinical coordination groups develop questionnaires for cross-sector use based on experience and, when possible, on validated questionnaires that are already in use. To attain a broader perspective and enhance patient involvement, additional workshops are conducted with patients.

Questionnaires are tested on two levels. Patients test that questions are comprehensible and meaningful, while the health professionals pilot test that the questionnaire and associated algorithms perform as intended in clinical practice.

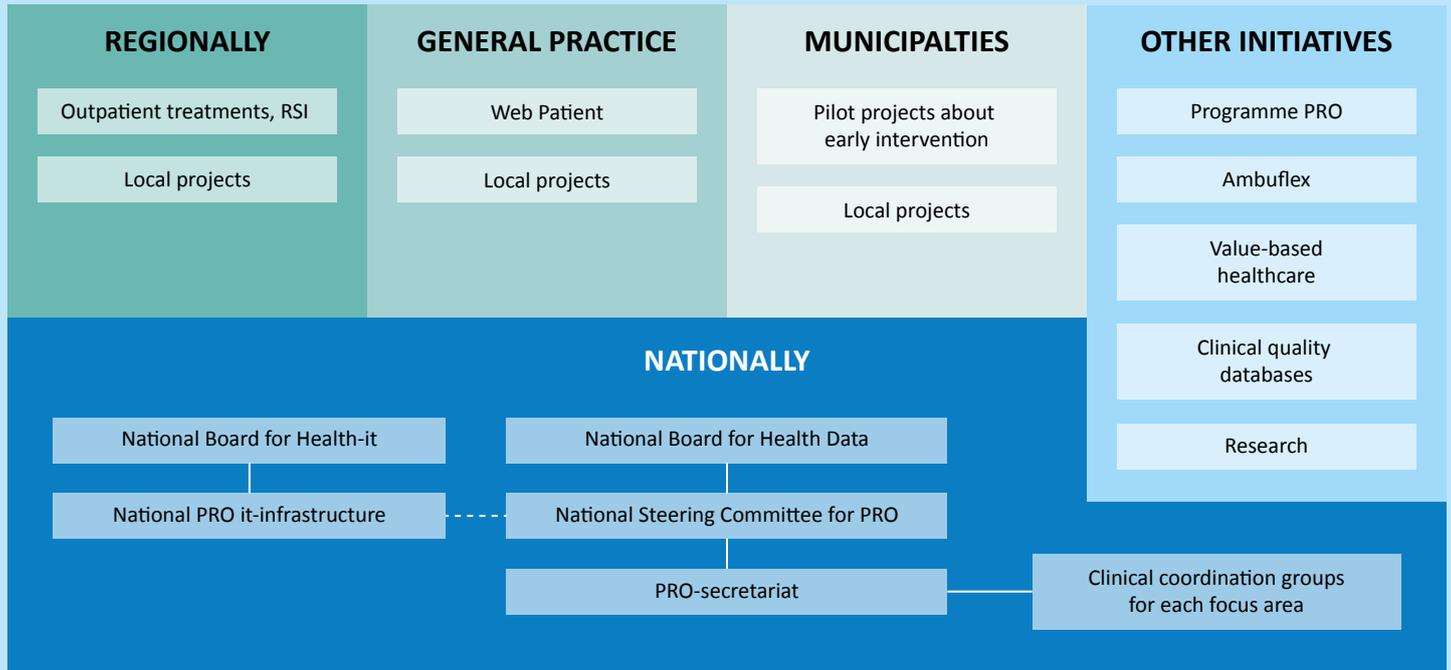
IT infrastructure for PRO-data

In order to attain the full benefit from PRO-data, data must be shared across health sector boundaries. Therefore, a national IT infrastructure to share data between different sectors has been established and is being tested. This enables patient responses handed over to one healthcare provider to be visible in the clinical records of the patient's other relevant healthcare providers.

In addition, questionnaires are shared through a national questionnaire bank. A provider can download a questionnaire from the bank and set it up in the local electronic health record system. From here the healthcare professional can "administer" a PRO-questionnaire to the patient. The patient's answers will be integrated into the system and shared through the infrastructure. The patient can follow his or her questionnaire responses and other health record data on the national patient platform, Sundhed.dk.

On top of this, clinical quality databases, and other such services with the appropriate licensing, can gain access to data with regards to clinical quality improvement and research.

The PRO-landscape



PRO-Secretariat

Danish Health Data Authority
Ørestads Boulevard 5
2300 Copenhagen S
Denmark

T +45 91 33 48 07

T +45 91 33 48 08

PROsekr@sundhedsdata.dk

PRO-danmark.dk

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