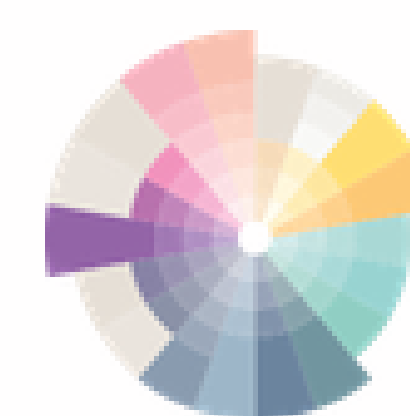


DELIVERING A SWEDISH PROMIS® TO THE NATIONAL QUALITY REGISTRIES (QRs)

Evalill Nilsson¹, John Eric Chaplin^{1,2}

¹Quality Register Centre QRC Stockholm, Stockholm;

²Inst. Clinical Sciences, Sahlgrenska Academy at Gothenburg University, Sweden



NATIONELLA KVALITETSREGISTER

Kunskap för bättre vård och omsorg

For additional information, please contact: evalill.nilsson@ki.se or john.chaplin@gu.se

Swedish national Item bank project

Aim

to obtain systematic knowledge about the patient's experience of health and healthcare, as a basis for continuous learning and improvement through using PROMIS item banks.

What is a QR?

An automated and structured collection of personal data that were initiated with the purpose to systematically and continuously develop and safeguard quality of care.

Organization

Mostly initiated by health professionals.

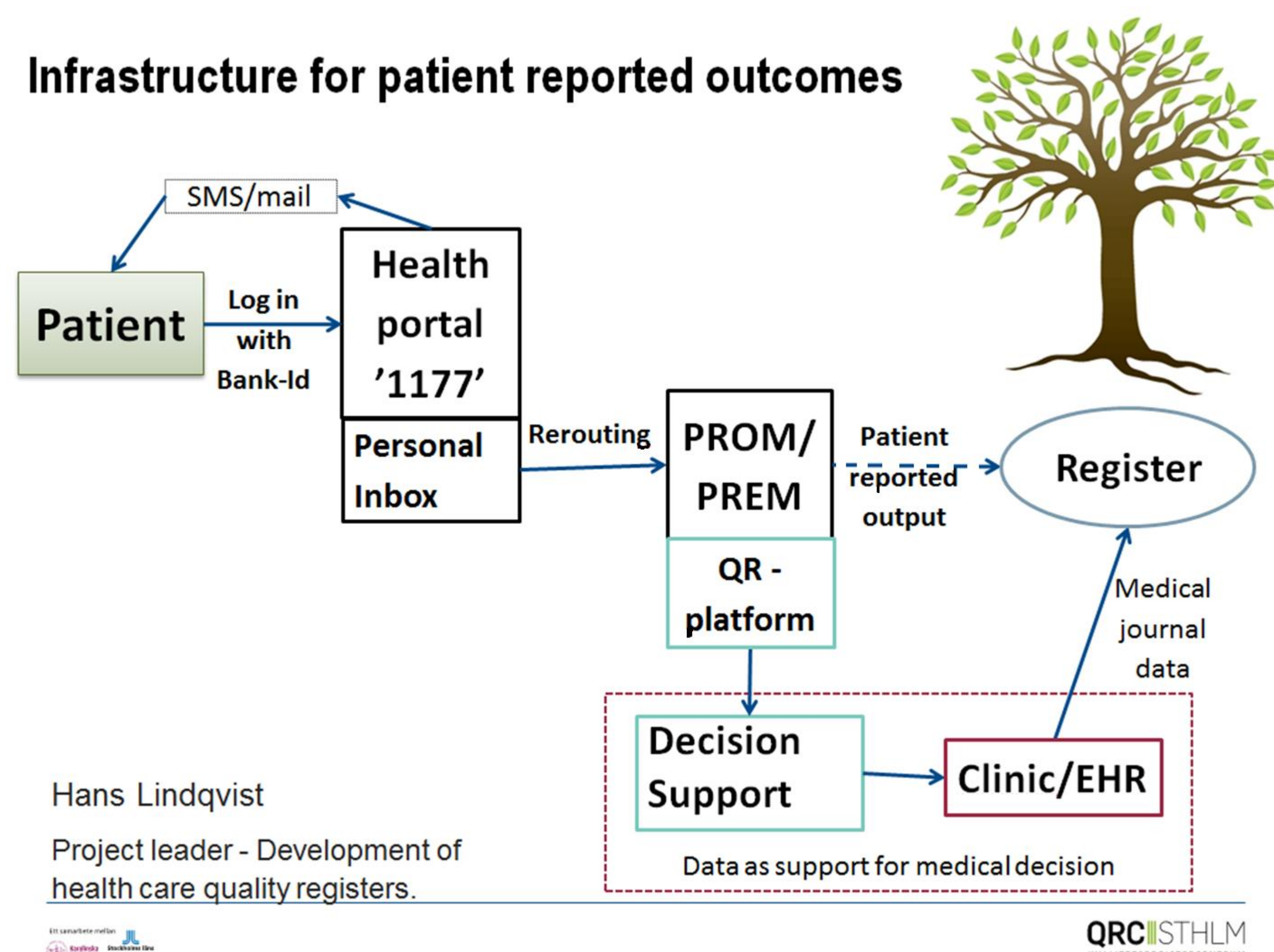
Six regional competence centres for the national QRs promote the development of new registries and create synergistic effects by providing a service to and facilitating collaboration between registries.

Method

Initial phase has the goal of having the first functional item bank started at the end of 2016.

- ❖ translation of PROMIS item banks
- ❖ creation of a secure national data collection methodology,
- ❖ Establishment of a Swedish network of active users and researchers working with item banks in general
- ❖ Validation of PROMIS domains according to a priority list.

Infrastructure for patient reported outcomes



Conclusion

In order to achieve a self-sustaining movement towards the adoption of item-banking in Sweden it is necessary to involve multiple stakeholders at different levels in the early formulation of the approach in order to build a sense of ownership.

Results

- ✓ Translation of PROMIS/ NeuroQoL pediatric and adult item banks, profiles and short forms according to a priority list – including Global Health measures.
- ✓ Support of independent translation projects incl. Paediatric profile-25
- ✓ Established contact with a range of stakeholders and experts.
- ✓ Swedish and Nordic collaboration initiated.
- ✓ Collaboration with International Consortium for Health Outcomes Measurement (ICHOM) & National Patient Survey (NPE).
- ✓ Need for a central administration has been recognised, comprising: technical management; knowledge management and administrative support
- ✓ Cognitive debriefing carried out and protocols established.
- ✓ Established a methodology for CAT
- ✓ Validation studies at three hospital sites and within registries.
- ✓ An outline of a national strategy for the establishment of patient reported outcomes via item banking in Sweden from 2017 and forward.
- ✓ Application for continued support for the establishment of a Swedish item bank with National Quality Registries.
- ✓ A participation prospectus has been written explaining how to actively participate in the project - assisting in data collection; implementation, analysis and publication.

Steering group



Staffan Lindblad (QRC Stockholm), Jack Lysholm (RCN), Anders Tennlind (RCSO), Thomas Tröeng (RC Syd), Ulrika Frithiofsson (RC VGR) and Monica Sterner (UCR); representing each of the six regional competence centers.

QRC ITHLM
KVALITETSREGISTERCENTRUM



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