Perspective on network based improvement:

Using health-related quality of life instruments for children with long-term conditions – based on the NQR system

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What is a National Quality registry?

- Problems/diagnoses/measures concerning outcomes for a specific group of individuals
- Enables learning and continuous improvements
- Follow up achievements in care (specific county areas, hospitals and clinics)
- Driven by professionals

www.vardenisiffror.se
Why using a national quality registry (NQR)?

The NQR are used integrated and actively for continuous learning, improvement and research as well as for management and evidence-based practice in health care. This will create the best possible health, care and welfare together with the individual.
Measures in NQR (Example from the Swedish Pediatric Rheumatology registry)

**CLINICAL OUTCOMES**
- CRP, SR (clinical measures)
- Morbidity

**FUNCTIONAL OUTCOMES**
- Quality of life
- Pain assessment

**SATISFACTION**
"Do you feel understood of those who care for you"?

**COSTS**
- Direct (hospital admissions)
- Indirect (being presence in school)
The use of Clinical dash-boards
Evaluating the implementation of the HRQOL instrument

Interviews with children (10-17 years old) about sharing their data with professionals during encounters

Results: Providing insights about my health which constitute a motivation for change
Encouraging if outcomes are requested and discussed with professionals

Video-recordings of 21 encounters (RN and Pediatricians)

**Instructing approach**
The visual picture are used to capture an overview of the child’s situation.

**Inviting approach**
Children are selected domains to discuss, visual image is used as a starting point for further discussions.

**Engaging approach**
Each underlying item is explored and professionals seek a common interpretation together with the child.

Conclusions....

• NQR is an powerful tool in continuous improvement
• Data from different perspectives are needed to understand the patients health condition
• To promote involvement is a core aspect of healthcare and needs attention when healthcare delivery is developing in the future