

PROM at the Swedish National Diabetes Registry NDR

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SKL, Stockholm 10 September 2015

- Background
- Overall aims
- Questionnaire development
 - Phase I - the pilot questionnaire
 - Phase II - the new questionnaire
- Next & future steps

Background

- The Swedish National Diabetes Register (NDR)
 - Founded in 1996 to improve diabetes care.
 - Allows comparisons between healthcare providers.
 - Covers 360 000 Swedish diabetes patients.
 - Records patient characteristics, biomarkers, complications, treatments, ...
 - Used as an essential part of daily routines at healthcare centers across Sweden.

Overall aims of NDR's work with PROM

- Use PROM in NDR's evaluation of diabetes care and its effects:
 - to manage individual patients
 - to compare healthcare providers, ...
- Including one specific aim:
 - To develop a questionnaire capable of measuring patient abilities and judgements on scales suitable for detecting and quantifying change.

Questionnaire - Phase I

- A pilot questionnaire was developed
 - Item Response Theory used for estimation of patient abilities and judgements.
 - Description of a Swedish Diabetes patient sample.
 - Explorative identification of patients with a need for improvement.

Pilot questionnaire scales

- Patient abilities
 - Self management
 - Sense of security (free of worries)
 - Daily activities
- Patient's judgment of healthcare
 - Service and information
 - Access
 - Involvement

Questionnaire - Phase II

- Second questionnaire
 - Adults with diabetes were interviewed to identify aspects important in their lives.
 - Selection of domains and items
 - Piloted 2015, measurement works well.
 - Finalization is ongoing.

Questionnaire scales (preliminary)

- 1. How you feel, and manages with diabetes
 - How you feel
 - Worries
 - Managing diabetes
 - Barriers in life
 - Support from others
- 2. How healthcare supports you
 - Healthcare support, access, and continuity
 - Medical treatment and medical device

Next and future steps

- Take more into account in evaluating the outcomes of diabetes care.
- Potentially use this to optimize healthcare resource allocation.
- PROM collection in connection to GP visits.
- Good ways to present of complex data to patients and staff.

Thank you for listening

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