

Three National PROM-projects in Sweden

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Acknowledgement: Evalill Nilsson who produced most of the slides

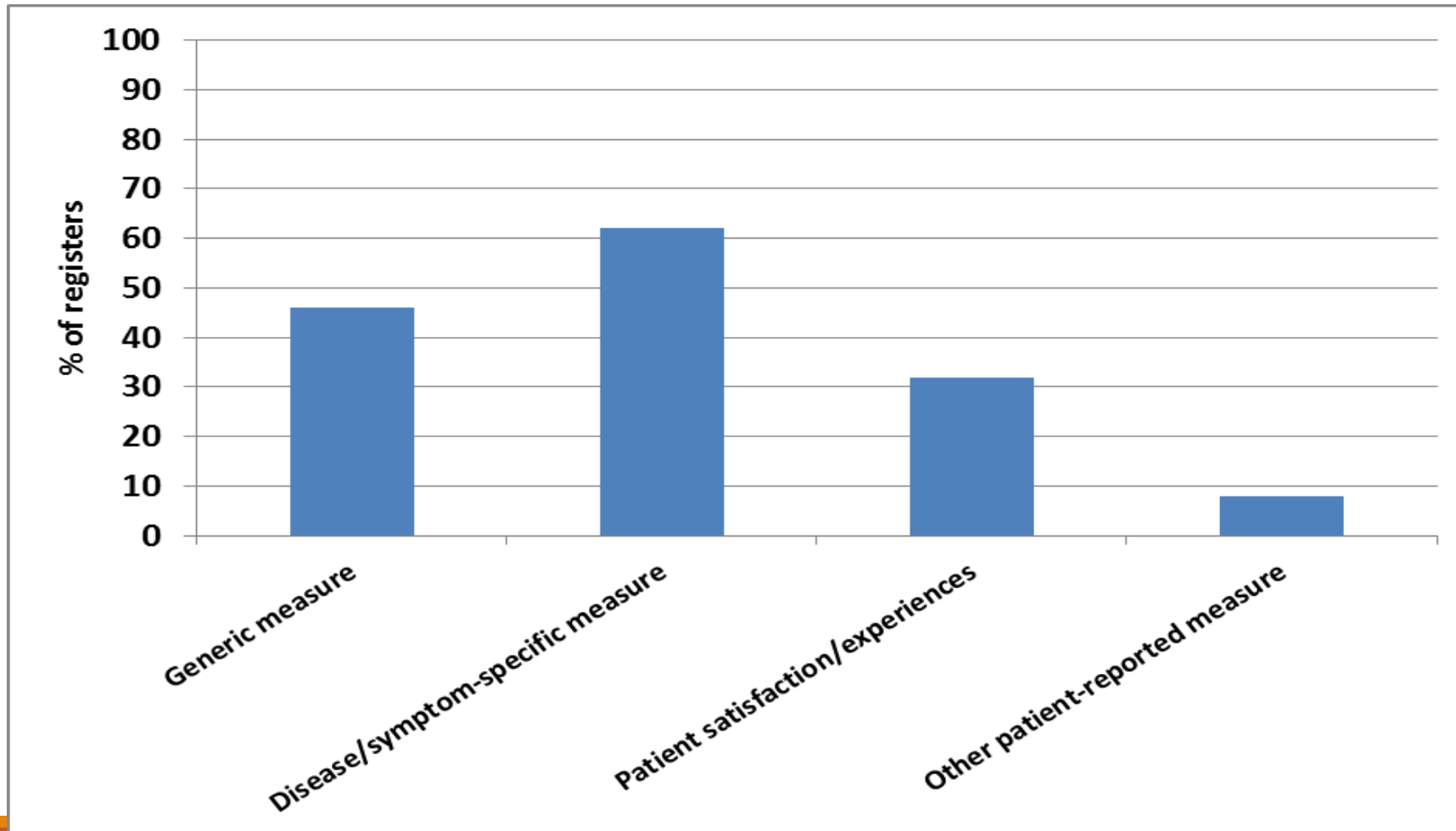
Why national PROM projects?

To be certified at level 2 (of 3) a National Quality Register needs to incorporate patient reported measures.

About 90% of the registers incorporate such measures today, and soon probably all.

Almost half of the registers use generic measures, mostly EQ-5D (about 35% of the registers) and SF-36 (about 10%)

PROM/PREM in the national quality registers (self-reported data from the 108 annual applications for funding, 2015)



The Three National Projects

SF-36/RAND-36

- Problem: expensive license (QualityMetric, USA)

EQ-5D

- Problem: expensive license (EuroQol Foundation, the Netherlands)

National item banks in Sweden

- Preparing for the future

*Do not hesitate to contact the project coordinator if you have any questions!
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SF-36/RAND-36

RAND-36

- The creation of a free Swedish version of the SF-36
 - validation study soon to be published
- Additional features:
 - electronic version of RAND-36
 - RAND-12
 - "RAND-6D"

Order RAND-36 from www.promcenter.se
(available for everyone, not only the quality registers)

SF-36/RAND-36: validation

The original American SF-36 and RAND-36 have identical items but the scoring algorithm differs somewhat

- means of translation from SF-36 to RAND-36 is available

The new Swedish RAND-36 is a more modern translation than the older Swedish SF-36 (but still very similar)

The validation study has so far shown that RAND-36 is reliable and responsive; the next step is to compare SF-36 and RAND-36 data from a general population

SF-36/RAND-36: e-version

- Suitable for computers and tablets, not automatically adaptable to small screens like smartphones
- Equivalence testing in August-September (cognitive debriefing and usability testing)

SF-36/RAND-36: RAND-12

The SF-12 consists of twelve items from the SF-36

The SF-12 does not generate eight dimension, only component scores Physical Component Summary (PCS) and Mental Component Summary (MCS)

Currently we do not provide RAND-12 because we have not fully investigated the different options for scoring PCS and MCS

If we find suitable scoring algorithms we will of course immediately start to provide RAND-12, and also the possibility to score PCS and MCS from RAND-36 (not available today)

SF-36/RAND-36: "RAND-6D"

SF-6D is an alternative to EQ-5D

It is not an instrument per se, but instead an algorithm computing an index value (like the EQ-5D index) from SF-36 or SF-12 data

There is no consensus about which one is to prefer, SF-6D or EQ-5D (the discussion is ongoing)

- differences depends to some extent on the patient group; SF-6D seems to be somewhat more sensitive for those less ill and EQ-5D somewhat more sensitive for those worse off

It is legal to use the existing SF-6D algorithm on RAND-36

- Order from <https://www.shef.ac.uk/scharr/sections/heds/mvh/sf-6d>

SF-36/RAND-36; future

Veteran RAND? Or our own Swedish equivalent to SF-36 version 2, i.e. RAND-36 v2?

Testing SF-6D as an instrument?

Should the national quality registers change from EQ-5D to "RAND-6D" (through perhaps RAND-12) because of the license problem?

EQ-5D

Negotiations with the EuroQol Foundation has been ongoing for several years; however, in July 2015 we finally reached a 5-year agreement!!

EQ-5D can now be used for free by all national quality registers that in turn sign an agreement with the registry center QRC Stockholm (on behalf of the national quality register organization)

EQ-5D: the 5-year agreement in short

All national quality registers may use all versions of EQ-5D in many different languages for free within the scope of the register (*the PROMs Program*)

Sweden may create its own national e-version (through My Health Contacts)

In return, Sweden must finance and do EQ-5D related research of mutual benefit for Sweden and the EuroQol Foundation (*the Research Program*)

- The first project will be to create a Swedish value set for the EQ-5D (methodological research)

EQ-5D: preliminary terms of use in short

Do not change any wording or layout

Do not disseminate outside the register

Participate in the Research program if asked by the Research team (e.g. by providing existing register data)

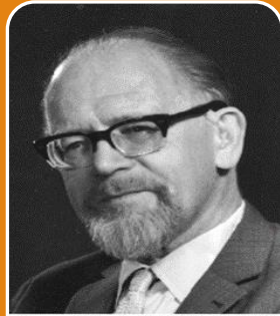
- The head of the Research team is Kristina Burström, Karolinska Institute
- Quality register "EQ-5D"-interested researchers are very welcome to join the team!

The Item-bank project, why?



First generation (Rensis Likert)

- Fixed items
- Fixed scores



Georg Rasch (1901-1980)

Second generation (George Rasch)

- Fixed items
- Adjusted scores



Third generation (item banking)

- Adapted items
- Adjusted scores

Thank you National item banks

An investigation about if national item banks could and should be implemented in Sweden

Both generic (e.g. PROMIS) and disease-specific item banks will be considered, and also item banks for children

A report will be presented by the end of the year

Project leader: Mats Lundström