
PROM in The Swedish National Cataract Register



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History

The National Swedish Cataract Register (NCR) started in January 1992

Only preoperative and surgical data were reported in the first years

The idea of collecting clinical follow up data and patient-reported outcome measures (PROM) existed from the very beginning

No suitable PROM instrument existed

Item construction started by searching literature and interviewing patients waiting for cataract surgery

Lundström M, Fregell G, Sjöblom A. Vision related daily life problems in patients waiting for a cataract extraction. Br J Ophthalmol. 1994;78:608-611.

First generation instrument – Catquest – was created in 1994

Lundström M, Jensen S, Fregell G, Roos P. Catquest questionnaire for use in cataract surgery care: Description, validity and reliability. J Cataract Refractive Surg. 1997; 23:1226-1236.

Catquest

Catquest was in use in NCR 1995-2006

Clinics were invited to participate during one month, the month of March.

Preoperative questionnaire before surgery and 6 months after surgery.

Lessons learned about patient-reported outcomes

- For the elderly
- For second-eye surgery
- For patients with age-related macular degeneration
- Risk factors for patient-reported poor outcome
- Strategy to reduce patient-reported poor outcome

Described in 6 publications and numerous abstracts



2nd generation Catquest – Catquest-9SF

After 10 years in use, we felt that the Catquest needed to be modernized

I met Konrad Pesudovs in San Diego 2007 and learned about Rasch analysis

Revision was performed in 2007 through cooperation with Konrad

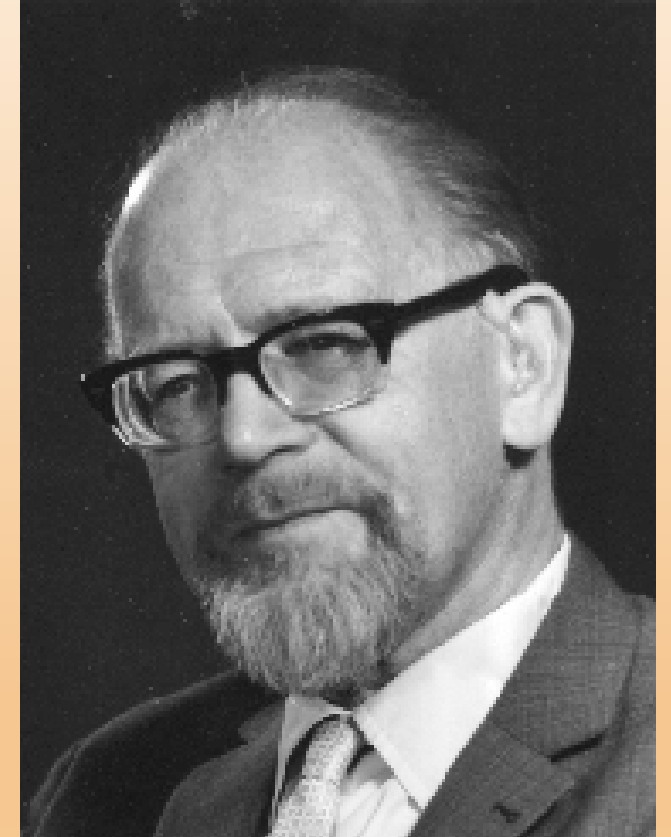
New Rasch analyzed Catquest-9SF was tested in four clinics in 2008



Why Rasch?

Psychometric properties

- Response categories
- Dimensionality
- Measurement precision
- Item fit statistics
- Differential item functioning
- Targeting
- Raw score transformed to Rasch score



Georg Rasch (1901-1980)

Catquest-9SF

Lundström M, Pesudovs K. Catquest-9SF patient outcomes questionnaire. Nine-item short-form Rasch-scaled revision of the Catquest questionnaire. J Cataract Refract Surg. 2009;35:504-513.

A. Do you find that your sight at present in some way causes you difficulty in your everyday life?

Yes, very great difficulty	Yes, great difficulty	Yes, some difficulty	No, no difficulty	Cannot decide
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

B. Are you satisfied or dissatisfied with your sight at present?

Very dissatisfied	Fairly dissatisfied	Fairly satisfied	Very satisfied	Cannot decide
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C. Do you have difficulty with the following activities because of your sight?

If so, to what extent? In each row place just one tick in the box which you think best corresponds to your situation.

	Yes, very great difficulty	Yes, great difficulty	Yes, some difficulty	No, no difficulty	Cannot decide
Reading text in newspapers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Recognising the faces of people you meet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Seeing the prices of goods when shopping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Seeing to walk on uneven surfaces, e.g. cobblestones	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Seeing to do handicrafts, woodwork etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reading subtitles on TV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Seeing to engage in an activity/hobby that you are interested in	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you very much for taking part.

Use of Catquest-9SF

In the registry from 2009 and ongoing

Clinics are invited, participation optional

On average 40 clinics and 5000 questionnaires annually

Publications

Lundström M, Behndig A, Kugelberg M, Montan P, Stenevi U, Pesudovs K. The outcome of cataract surgery measured with the Catquest-9SF. *Acta Ophthalmol.* 2011 Dec;89(8):718-23.

Rönbeck M, Lundström M, Kugelberg M. Study of Possible Predictors Associated with Self-Assessed Visual Function after Cataract Surgery: A Swedish National Cataract Register Study. *Ophthalmology.* 2011 Sep;118(9):1732-8.

Grimfors M, Mollazadegan K, Lundström M, Kugelberg M. Ocular comorbidity and self-assessed visual function after cataract surgery. *J Cataract Refract Surg.* 2014; 40:1163–1169.

Mollazadegan K, Lundström M. A study of the correlation between patient-reported outcomes and clinical outcomes after cataract surgery in ophthalmic clinics. *Acta Ophthalmol.* 2014 Jun 29. doi: 10.1111/aos.12490. [Epub ahead of print].

International Catquest-9SF

English (AUS):

Gothwal VK, Wright TA, Lamoureux EL, Lundström M, Pesudovs K. Catquest Questionnaire: Re-validation in an Australian cataract population. Clin Experiment Ophthalmol 2009;37:785-794.

German (DE + AT):

Harrer A, Gerstmeyer K, Hirnschall N, Pesudovs K, Lundstrom M, Findl O. The impact of bilateral cataract surgery on vision-related activity limitations. J Cataract Refract Surg. 2013;39:680-685.

Italian:

Skiadaresi E, Ravalico G, Polizzi S, Lundström M, González-Andrades M, McAlinden C. The Italian Catquest-9SF cataract questionnaire: translation, validation and application. Manuscript, submitted.

Dutch:

Visser MS, Dieleman M, Klijn S, Timman R, Lundström M, Busschbach JJV, Reus NJ. Validation, norm scores and test-retest for the Dutch Catquest-9SF. Manuscript, submitted.

Mandarin:

Lin X, Li M, Wang L, Zuo Y, Zhu S, Zheng Y, Lin X, Yu M, Lamoureux EL. Validation of Catquest-9SF Questionnaire in a Chinese Cataract Population. PLoS One. 2014 Aug 1;9(8):e103860

Also available in Slovakian and Spanish (validation is ongoing).

Using Catquest-9SF – Findings 1

Relationship between clinical data and patient-reported outcome

Several clinical factors were related to patients' self-assessed benefit of cataract surgery: ***Age, preoperative and postoperative visual acuity, ocular co-morbidity, first-or second-eye surgery, gender and achieved postoperative refraction.***

Relationship between clinical data and poor patient-reported outcome

No perceived problems before surgery, refractive problems after surgery, surgical complications and ocular co-morbidity were related to a poor patient-reported outcome.

Using Catquest-9SF – Findings 2

Clinical outcomes and patient-reported outcomes disagree

- More specifically clinical outcome good but patient-reported outcome poor.

Reasons:

More problems with near vision after surgery – need of spectacles for near and intermediate vision

Using Catquest-9SF – Findings 3

For single clinics:

Different clinical data were related to a poor patient-reported outcome for different clinics

Examples: Poor refractive outcome, surgical complications, a large amount of patients with few or no problems before surgery

For some clinics this information is used to

- **Improve quality**
- **Adjust indications for surgery**

Future?

Increase usability of the instrument

- Define MID (Minimum Clinically Important Difference)

Improve psychometric properties (include more difficult items – Catquest-9SF v.2)

Thank you