



REGISTERCENTRUM
SYDÖST



QRC || STHLM
KVALITETSREGISTERCENTRUM



Itembanker – framtidens PROM!

Projektteam:

Evalill Nilsson, QRC (*projektledare*)

John Chaplin, GU

[> Employment policies and data](#)[> Health policies and data](#)[> Social policies and data](#)[> Families and children](#)[> Pension systems](#)[> International migration policies and data](#)

Patient-Reported Indicators Survey (PaRIS)

Health care seeks to improve people's well-being and their ability to play an active role in society. Yet health systems know very little about how often they achieve this. The success of health care is typically measured by survival rates, or rates of cure, after treatment. Often, though, differences between the best- and worst performing hospitals are small. It is only when we measure outcomes reported by patients themselves – such as quality of life – that important differences in the outcomes of care emerge.

We need to better understand what patients themselves think of health care:

- The OECD benchmarks some aspects of patient experience in 19 countries, in ambulatory care... but we need to expand this survey to other care settings (such as in-patient and mental health care facilities), and to more countries.
- Patient-reported outcome measures are in use for some conditions, such as hip and knee surgery... but different measures in different countries make international comparisons difficult.
- And the biggest users of health care – people with multiple, long-term conditions – are not being asked at all.

The OECD is a global leader in collecting, reporting and benchmarking health system performance and health care quality indicators. The Patient-Reported Indicators Survey (PaRIS) will address these critical information gaps and build a patient-centred view of health system performance.



Vad vill OECD mäta med?

- PROM (*Patient-Reported Outcome Measures*)
 - Hälsa, hälsorelaterad livskvalitet
 - Funktionsförmåga
 - Sjukdomssymptom
- PREM (*Patient-Reported Experience Measures*)
 - tillgänglighet, information, bemötande, behandlingsgenomförande, behandlingsresultat etc
 - Nöjdhet, tillfredsställelse
 - Upplevelser
- PAM (*Patient Activation Measures*)
 - Delat beslutsfattande (SDM), egenvård, hälsolitteracitet etc
- PRIM (*Patient-Reported Incident Measures*)

OECD Generic PROMS Workshop

Date: Wednesday 8th November 2017

Location: Multiburo, 14 avenue d'Eylau, 75016 Paris (Métro Trocadéro)



What are generic PROMS about and why do we need them for the PaRIS initiative?

The OECD Secretariat will give a short presentation covering the following:

- What is the purpose of generic PROMS in general? Brief history of generic PROMS: What were they designed for? How have they been used so far?
- Why are generic PROMS needed for PaRIS? How are they linked to the PaRIS initiative and to PREMS, other PROMS and PRIMs? How are they related to the two PaRIS work streams?

How do we measure generic PROMS?

Short presentations will be provided by invited experts (tbc) on specific instruments (e.g. PROMIS Global 10, EQ5D, SF-36, & EORTC QLQ-C30):

- How are these generic PROMS measured?
- In what areas have these instruments been used for? Mapping across countries, disease areas, patient groups and instrument domains.

Can we compare them internationally?

The OECD Secretariat will provide opening remarks followed by a presentation from representatives of the International Consortium on Health Outcomes Measurement (ICHOM) and then a plenary discussion on key related issues, including:

- Fitness of use for international comparisons for PaRIS
- Mapping within and between countries
- Language and culture issues

Where are the knowledge gaps?

The OECD Secretariat will facilitate a gap analysis discussion on the use of generic PROMs for the PaRIS initiative, including consideration of:

- Is it valid to compare generic PROMS across countries, diseases, and patient groups?
- How generic PROMS been used to evaluate outcomes of health care organisations (or systems)?
- How are they linked to patient centered care and knowledge based health systems?
- Future R & D needs?

THE GLOBAL STANDARD – INTERNATIONAL COLLABORATION IS IN OUR DNA



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Patientrapporterade utfallsmått (PROM) i kvalitetsregister för långvariga sjukdomstillstånd

Generella mått och indikatorer -
utvecklingsförslag

Rekommendationerna i denna rapport är baserade på en omfattande litteraturgenomgång och samtal med kvalitetsregister och nyckelpersoner inom och utom Sverige.

Evalill Nilsson
2014-03-03



Itembankprojektets leveranser

- Översättning
- Nätverk av PROMIS-forskare/översättare i Sverige
- Information, workshops mm
- Elektronisk datainsamlingsmetodik
- Framtida hållbar förvaltning

PROMIS inom kvalitetsregistren?

- Bröstcancerregistret
- Melanomregistret
- Psoriasisregistret
- SIR
- SkaPa
- Psykiatriska register
- Ortopediska register
- Reumaregistret
- Svenska Neuroregister (NeuroQol)
- Pediatriska register
- Primärvårdskvalitet

Tabell över pågående och planerade PROMIS-projekt i Sverige

projektnamn	ansvarig	PROMIS mått/motsv	När	Var
Validering av Global Health 10 och mapping till EQ-5D indexvärden	Evalill Nilsson, Peter Fritzell och Maria Stauffer; Swespine	Global Health 10	2017-18	Capio St Göran Ortopedi
Validering av GH-10 Kan GH-10 prediktera återinläggning?	Evalill Nilsson och Katarina Meijers	Global Health 10 och/eller fler mått	2017	KS Huddinge MAVA
Uppföljning med patientrapporterade data vid bröstcancer. Jämförelser mot QLQ-C30 (som är ett licensbelagt och ej kostnadsfritt instrument).	Evalill Nilsson, Lena-Marie Petersson, 4D-forskare; Bröstcancerregistret	Flera PROMIS-banker	2017-18	4D-projektet Radium-hemmet
Validering av NEUROQoL	John Chaplin, Jan Hillert, Karin Lycke, Lillemor Bergström, Eva Helmersson, Leszek Stawiarz	NeuroQoL – trötthet/fatigue, kognition, Kort vers. Mobilitet, välbefinnande, deltagande i sociala aktiviteter	pågående	SMS/ Neuroregister KI, Stockholm
Validering av fyra pediatrika itembanker. Alla astmapatienter 8-16 i Örebro universitets sjukhus under 2015-06 till 2016-09 (n=389)	Martin Stackelberg, Karin Blomberg, Mats Eriksson, John Chaplin	Pediatrika banker: oro/ångest, relationer, trötthet/fatigue,	pågående	Örebro

Validering av pediatrik Profil-25	Aina Danielsson, John Chaplin, Karin Enskär.	Kortversioner av pediatrika banker: oro/ångest, relationer, trötthet/fatigue nedstämdhet, mobilitet, smärta	Jan 2017	SROQ register / Göteborg
Validering av pediatrik Profil-25	Gunnel Viklund, John Chaplin	<i>Som ovan</i>	pågående	Astrid Lindgrens Sjukhus, Stockholm
Validering av pediatrik Profil-25	Peter Adolfsson, John Chaplin	<i>Som ovan</i>	Planerad start jan/feb 2017	Halland
Validering av Sexuell funktion itebankerna	Lena Wettergren, Lars E Eriksson	Selekterade items från 11 banker	pågående	Karolinska Institutet, Stockholm
Översättning av PROMIS profile-29	Dirk Marcus Wuttge	Kortversioner av Vuxen oro/ångest, relationer, trötthet/fatigue, nedstämdhet, mobilitet, smärta, sömn	pågående	Lund
Översättning vuxen kort vers. trötthet	Jan Lexell	Trötthet/fatigue	pågående	Lund

PROMIS Adult - June 2017

PROMIS	Item banks	Num. of Items	Patient group	Research group	Item bank project 2016
Fatigue short form-7		7	post-polio	Department of Rehabilitation Medicine, Skåne University Hospital in Lund	95 items + cancer version
Sexual function (selected items)		43/72	cancer patients & gen pop 16-39yrs	Dept. Neurobiology, Care Sciences and Society, Karolinska Institutet, Stockholm	
Global-10		10	Ortopedics / Breast cancer	Capio St Göran KS Huddinge	
PROMIS-29 profile		29	Systemic sclerosis	Department of Clinical Sciences, Dept of Rheumatology Lund University (SMBD Jewish General Hospital, Montreal, Quebec, Canada.)	
	Emotional Distress – Anxiety	4			
	Emotional Distress – Depression	4			28 items + cancer
	Fatigue	4			95 items
	Pain – Interference	4			40 items + cancer
	Pain – Intensity	1			
	Physical Function	4			121 items + cancer + mobility + upper body + movement disabled
	Sleep Disturbance	4			
	Ability to Participate in Social Roles and Activities (v2.0)	4			35 items

Nordic connections

PROMIS	Item banks	Item bank project 2016	Nordic connections
ADULT	Fatigue short form-7	95 items + cancer version	PROMIS-57v2 Norway Fatigue 8a
	Sexual function (selected items)		
	PROMIS-29 profile		
	Emotional Distress – Anxiety		PROMIS-57v2 Norway Anxiety 8a NIH Toolbox Emotion - Clinical Neuropsychology, Helsinki Uni
	Emotional Distress – Depression	28 items + cancer	PROMIS-57v2 Norway Depression 8a
	Fatigue	95 items	PROMIS-57v2 Norway Fatigue 8a
	Pain – Interference	40 items + cancer	PROMIS-57v2 Norway Pain Interference 8a
	Pain – Intensity		PROMIS-57v2 Pain Intensity item (Global07)
	Physical Function	121 items + cancer + mobility + upper body + movement disabled	PROMIS-57v2 Norway Physical Function 8b PROMIS Adult Physical function - National Institute for Health and Welfare, Finland, Helsinki
	Sleep Disturbance		PROMIS-57v2 Norway Sleep Disturbance 8a PROMIS Sleep Disturbance 8b Helsinki University Finnish Psychiatric Association
	Ability to Participate in Social Roles and Activities (v2.0)	35 items	PROMIS-57v2 Norway Ability to Participate in Social Roles and Activities 8a

Neuro-QoL

Adult

NeuroQoL	Item banks	Num. of Items	Patient group	Research group	Item bank project 2016
Adult	Fatigue	19		Commercial company	
	Cognition general concerns	18	Multiple sclerosis	SMS/ Neuroregister Dept of Clinical Neuroscience, Karolinska Institute	
	Ability in social roles and activities	8			
	Participation in social roles and activities	8			
	Lower extremity function	8			
	Upper extremity function	8			
	Positive affect and well-being	9			

PROMIS Child

PROMIS	Swedish translations	Items translated	Patient group	Research group	Item bank project 2016
PEDIATRIC	Emotional distress- Anxiety + proxy	13	Asthma	Center for Health Care Sciences Örebro University Hospital, Örebro	
	Emotional distress – Depression + proxy	13			
	Peer Relationships + proxy	15			
	Fatigue + proxy	22			
	Pediatric Profile-25		Orthapedic Musculoskeletal Diabetes	Swedish pediatric orthopedic register (SPOQ) Astrid Lindgren's children's hospital Halmstad children's hospital	23 items + upper body
	Physical Function Mobility	4			
	Anxiety	4			
	Depression	4			
	Fatigue	4			
	Peer relationships	4			
	Pain Interference items	4			
	Pain Intensity item	1			

Nordic connections

PROMIS	Swedish translations	Item bank project 2016	Nordic connections
PEDIATRIC	Emotional distress- Anxiety + proxy		NIH Toolbox Emotion Clinical Neuropsychology, Helsinki Uni
	Emotional distress – Depression + proxy		
	Peer Relationships + proxy		
	Fatigue + proxy		
	Pediatric Profile-25		
	Physical Function Mobility	23 items + upper body	PROMIS Pediatric Mobility - National Institute for Health and Welfare, Finland, Helsinki
	Anxiety		
	Depression		
	Fatigue		
	Peer relationships		
	Pain Interference items		
	Pain Intensity item		

Framtida förvaltning i tre delar

- Informationsförvaltning
 - Via RCO, PROM-nätverket
- Kunskapsförvaltning
 - Via universiteten, PROMIS-nätverket
 - KI, GU, LiU, Umeå, Örebro, Lund.....
 - Koordinator John Chaplin, GU
- Teknisk förvaltning
 - Via Inera, men ännu i projektform

International collaboration

- PHO International
- The Netherlands
- The Nordic countries, especially Norway
- US
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