PROMs en DROMs

19 mei 2022, 10:15 – 11:15

Leo van de Watering, Afdeling UTG, Sanquin

PROMs

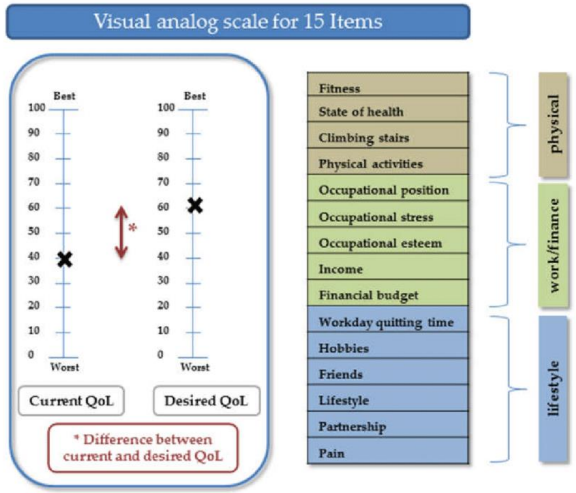
PROMs (Patient Reported Outcome Measures) zijn vragenlijsten waarin wordt gevraagd hoe de patiënt zich voelt en hoe het met hem of haar gaat. Hierin staan vragen over bijvoorbeeld pijn, vermoeidheid en emotionele toestand. Patiënten (of naasten) vullen deze vragenlijsten in op verschillende momenten in het zorgtraject.

https://nfk.nl/promprem

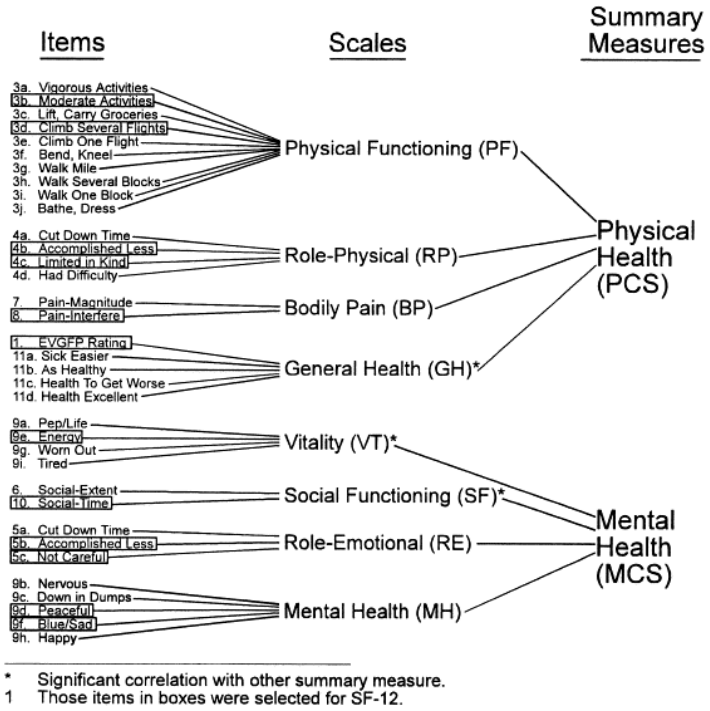
PROMs

NIET: Objectief bepaling	WEL: Subjectief beleven
Hb	Pijn
Saturatie	Vermoeidheid
% HbS	Dagelijks functioneren
Ademfrequentie	Kwaliteit van leven
Door fysiek te meten	Door patiënt ervaren

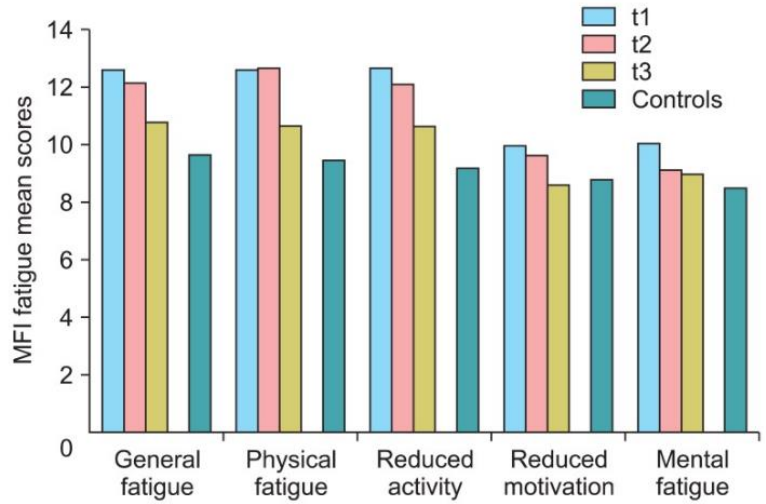
PROMs



VAS
Algemeen QoL



SF-36
Breed HQoL



Multidimensional Fatigue Inventory (MFI) fatigue mean scores for patients and controls (general population). t1, stay at hospital; t2, two weeks after discharge; t3, three months after discharge.

MFI
Specifiek HQoL

WHOQOL-100

https://www.who.int/tools/whoqol/whoqol-100

WHO defines Quality of Life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.

Title	Type	Size	
Arabic_WHOQOL-100	zip	244 KB	Download
Cantonese_WHOQOL-100	zip	2282 KB	Download
Croatian_WHOQOL-100	zip	231 KB	Download
Czech_WHOQOL-100	zip	401 KB	Download
Danish_WHOQOL-100	zip	7420 KB	Download
Dari_WHOQOL-100	zip	206 KB	Download
Dutch_Netherlands_WHOQOL-100	zip	148 KB	Download
English_Australia_WHOQOL-100_&_BREF	zip	845 KB	Download
French_WHOQOL-100	zip	155 KB	Download
German_WHOQOL-100	zip	291 KB	Download
Hindi_WHOQOL-100	zip	1538 KB	Download
Hungarian_WHOQOL-100	zip	105 KB	Download
Italian_WHOQOL-100	zip	215 KB	Download
Japanese_WHO-100	zip	284 KB	Download
Kiswahili_WHOQOL-100	zip	159 KB	Download
Korean_WHOQOL-100	zip	163 KB	Download
Lithuanian_WHOQOL-100	zip	353 KB	Download
Norwegian_WHOQOL-100	zip	142 KB	Download
Polish_WHOQOL-100	zip	376 KB	Download
Portuguese_Brazil_WHOQOL-100	zip	320 KB	Download
Portuguese_Portugal_WHOQOL-100	zip	397 KB	Download
Russian_WHOQOL-100	zip	226 KB	Download
Serbian_WHOQOL-100	zip	448 KB	Download

PROMs

RBC transfusies

<u>Polytransfusees</u>:

MDS
Sikkelcel
“Out-patients”

<u>Acute anemie</u>:

Post-partum

ORIGINAL ARTICLE

Quality of life, physical function and MRI T2* in elderly low-risk MDS patients treated to a haemoglobin level of ≥120 g/L with darbepoetin alfa ± filgrastim or erythrocyte transfusions

Herman Nilsson-Ehle, Gunnar Birgegård, Jan Samuelsson, Petar Antunovic, Jan Astermark, Hege Garelius, Lena M. Engström, Lars Kjeldsen, Lars Nilsson, Anna Olsson, Mette Skov-Holm ... See all authors

First published: 30 May 2011 | https://doi.org/10.1111/j.1600-0609.2011.01654.x | Citations: 47

Hb-Target: 12 g/dl (= 7,5 mmol/l)

Epo + G-CSF (+ bloedtransfusies)

“QoL scores for fatigue, dyspnoea, constipation, and physical, role and social functioning improved significantly during study, in transfused and non-transfused patients“

Outpatient transfusions for myelodysplastic syndromes

Erica M. Wood and Zoe K. McQuilten
Monash University, Melbourne, Australia

| Hematology 2020 | ASH Education Program

Table 1. Goals of RBC and platelet transfusion in MDS

Transfusion type	Goal of transfusion	Measured by	Desired outcomes
Red cell transfusion	• Improve acute and chronic symptoms of anemia (fatigue, dyspnea, chest pain, palpitations, effects on cognitive function) • Minimize major complications of (severe) anemia • Improve functional outcomes	• Hemoglobin and hematocrit • Functional measures using standardized tool (eg, fatigue score, walk distance, grip strength) or self-report	• Control of symptoms • Better functional status in activities of daily living • Increased ability to participate in work or social and community interests

Table 2. Important questions that need answers in optimizing transfusion support for patients with MDS

Red cell transfusion
1. To what degree does anemia (hemoglobin below the reference range, a laboratory result) need to be corrected to see clinical benefit?
2. When should RBCs be transfused in MDS? What are the optimal hemoglobin thresholds and targets? Are they applicable to all patients, or are there subgroups, such as older patients or those with cardiovascular or respiratory comorbidities, who need special consideration?
3. What is the optimal RBC transfusion schedule? Is a more stable hemoglobin better (should we aim to avoid the peaks and troughs of hemoglobin), and if so, why, and how can we achieve it?
4. What is the optimal RBC product for transfusion in MDS (eg, improved oxygen delivery or lifespan, or degree of RBC antigen matching)?

= Individualized medicine

Published in final edited form as:
Am J Hematol. 2015 February ; 90(2): 139–143. doi:10.1002/ajh.23877.

Health-related quality of life in children with sickle cell anemia: impact of blood transfusion therapy

Lauren M. Beverung[1], John J. Strouse[2], Monica L. Hulbert[3], Kathleen Neville[4], Robert I. Liem[5], Baba Inusa[6], Beng Fuh[7], Allison King[3], Emily Riehm Meier[8], James Casella[2], Michael R. DeBaun[9], and Julie A. Panepinto[1] for the SIT trial investigators

Pre-existent: stil cerebraal infarct

2 Randomisatie-armen
- Maandelijks BT
- Observatie

FU 36 maanden

Multicenter Silent Infarct Transfusion Trial

Primaire analyses:

- 58% relative risk reduction in infarct recurrence
- Lagere incidentie pijn events/acute chest syndrome

Lasten?:
- Regelmatig Zh bezoek en transfusies

Secundaire analyses:

- HRQL (Health Related Quality of Live)

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Children with SCA who received chronic blood transfusion therapy had better overall parent-reported HRQL than children in the observation group.

BT = maandelijkse transfusie
Observatie = 3-maandelijks poli-bezoek

CHQ_PF50:
Child Health Questionnaire Parent Form 50
Kinderen 5-18 jr

- Global health
- Physical functioning
- Social limitations (Emotional/Physical)
- Pain/Discomfort
- Behavior
- Mental health
- Self-esteem
- General health perception
- Change in health
- Parental impact
- Family limitations in activities

Change in Patient-Reported Outcomes in Single-Unit Transfusion Comparable with Double-Unit Transfusion

Ka Lok Chan, MBBS (HK), MRCP (UK),[1] Wai Man Vivien Mak, MBBS (HK), PDipID (HK); MRCP (UK); FHKCP; FHKAM (MDcine),[*,1] Yat Hung Tam, MBChB(CUHK), MPH(HK), MSc(InfectDis)(Lond), MBuddhStud(HK), FHKCCM, FHKAM(Community MDcine), FFPH,[*,2] Harold Kwok Kuen Lee, BSc (W. Ont.), MBChB (CUHK), FHKCP, FHKAM (MDcine), FRCPI[*,1]

[1]Division of Haematology, Department of Medicine and Geriatrics, Princess Margaret Hospital, Hong Kong, Hong Kong

[2]School of Public Health, The University of Hong Kong, Hong Kong, Hong Kong

Blood (2016) 128 (22) : 2636.

Factors affecting patient-reported outcomes after red blood cell transfusion in medical patients

Ka Lok Luke Chan,[1] Wai Man Vivien Mak,[1] Yat Hung Tam,[2] and Kwok Kuen Harold Lee[1]

TRANSFUSION 2018;58;158–167

HRQoL scales

SF12-v2
PCS : Physical Component Summary (lft; geslacht)
MCS : Mental Component Summary (lft; geslacht)

FACT-AnS: **Functional Assessment of Cancer Therapy, Anemia Subscale**

TABLE 2. Change in HRQoL scores from Day 0

	Day 1 (n = 95)			Day 7 (n = 78†)		
HRQoL scale	Δ	p value	Effect size	Δ	p value	Effect size
PCS	2.6	0.14	0.15	3.8	0.05*	0.23
MCS	0.5	0.78	0.03	1.9	0.38	0.10
FACT-AnS	4.3	<0.01*	0.41	4.8	<0.01*	0.38

* $p < 0.05$.
† PCS and MCS scores were available in 77 subjects on Day 7.
Δ = change in HRQoL scores.

Bedenk goed welke vragenlijst je gaat gebruiken!!

- Beste voorspeller Δ HRQoL: Slechte HRQoL op dag 0
- Δ HRQoL: 1 RBC is 2 RBC

Early and sustained improvement in fatigue-related quality of life following red blood cell transfusion in outpatients

Roberta Bruhn[1,2], Matthew S. Karafin[3], Joan F. Hilton[2], Zhanna Kaidarova[1], Bryan R. Spencer[4], Lirong Qu[5], Edward L. Snyder[6], Rebecca Olin[2], Edward L. Murphy[2,1], Elizabeth St. Lezin[2,7] NHLBI Recipient Epidemiology and Donor Evaluation Study (REDS)-III Program

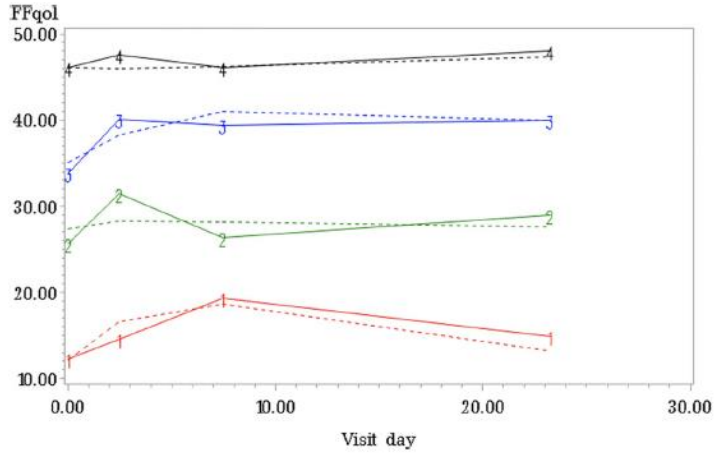
Published in final edited form as:
Qual Life Res. 2020 October ; 29(10): 2737–2744. doi:10.1007/s11136-020-02517-2.

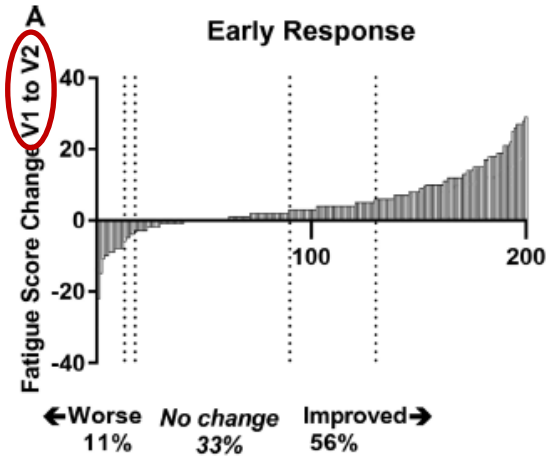
FACIT-Fatigue scale

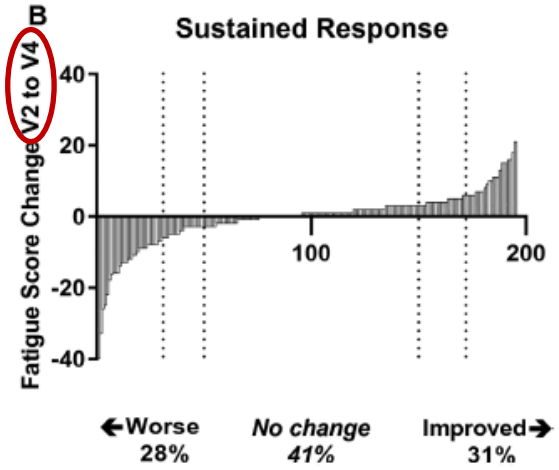
Een “self-report” vragenlijst specifiek gevalideerd voor gebruik bij ouderen.

De Functional Assessment of Chronic Illness Therapy (FACIT) Fatigue Scale is een 13-item, makkelijk te gebruiken tool dat iemands vermoeidheid bepaalt bij de gewone dagelijkse activiteiten gedurende de afgelopen week.

De mate van vermoeidheid wordt gescoord op een 4 punts Likert schaal
(4 = totaal niet vermoeid; 0 = zeer vermoeid)

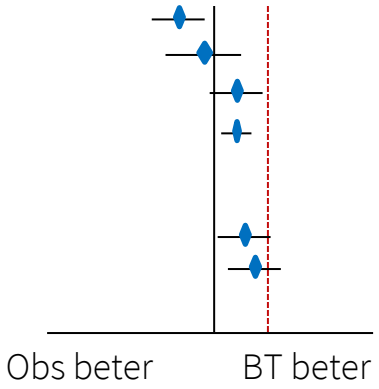






WOMB-studie

BJOG 2014 Jul;121(8):1005-14. DOI: 10.1111/1471-0528.12531.



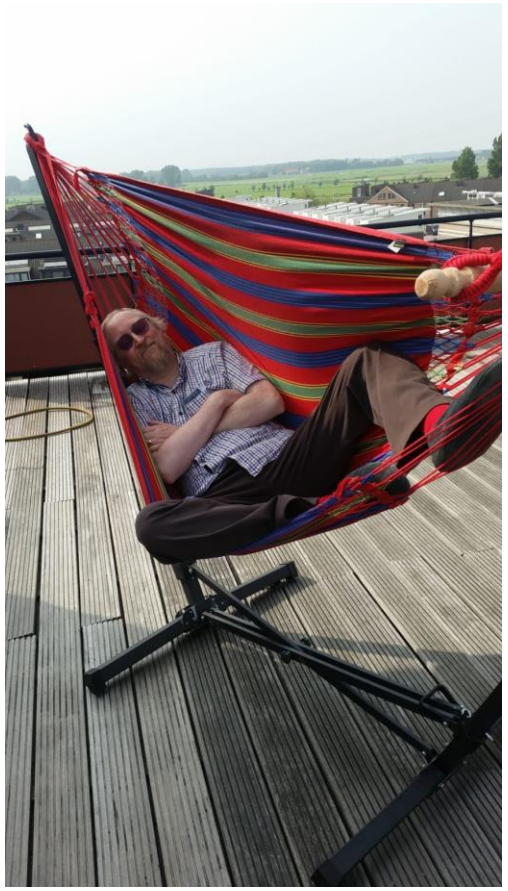
Design: Gerandomiseerde non-inferiority trial in 37 Nederlandse ziekenhuizen
Populatie: Vrouwen met acute anaemie (Hb 3.0-4.9 mmol/l), 12-24 uur postpartum zonder ernstige anaemie symptomen of ernstige comorbiditeit.
Randomisatie: RBC transfusie vs observatie.

Uitkomst variabelen: primair: Multidimensional Fatigue Inventory (MFI), op dag 3 pp
secundair: Health-related quality of life (Euro-Qol, SF-36, MFI), 5x tot wk 6 pp.

Resultaten: Vermoeidheidsklachten (MFI) iets minder in RBC-arm (dg3: 0,8; dg7: 1,06), Marge 1,3
Secundaire uitkomsten waren vergelijkbaar

Samenvatting PROM-RBC

- Ervaring van de patiënt (of naaste)
- “Subjectief”
- Persoonlijke optimalisatie



- Heel veel verschillende (H)QoL vragenlijsten
  Let bij keuze op doelpopulatie en eindpunt.