

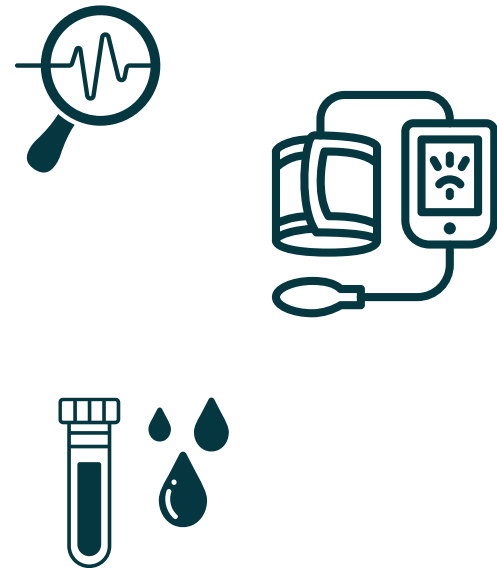
The Amsterdam PROM Implementation Strategy: Policy and Pathway





Understanding the impact of a disease

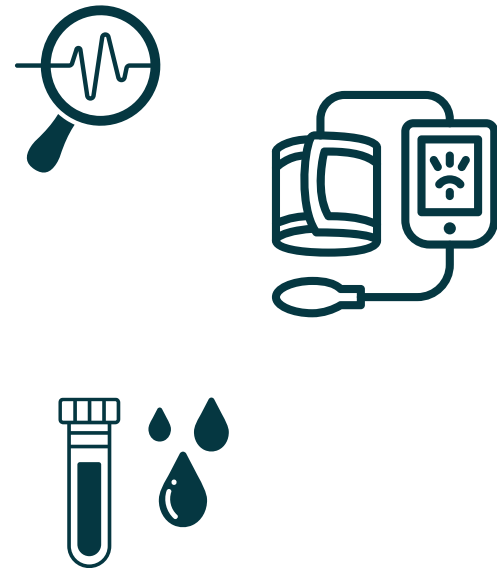
Clinical outcomes





We also need to measure PROs

Clinical outcomes



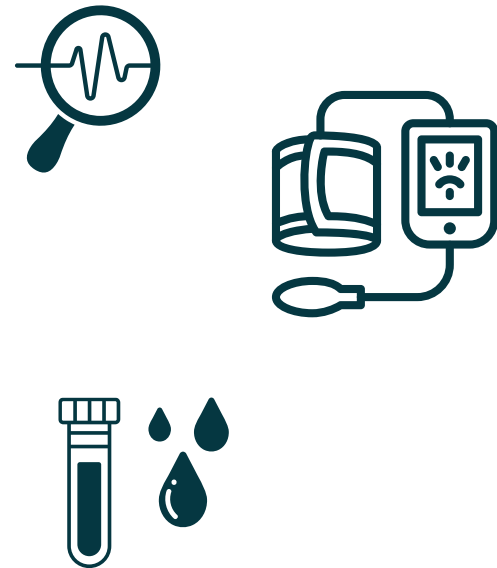
Patient Reported Outcomes PROs





We also need to measure PROs

Clinical
outcomes



Patient Reported Outcomes
PROs



Patient Reported Outcome Measures
PROMs





Goals PROMs



Scientific research

- Treatment effects in RCTs
- Natural history data
- Identify unmet needs
- New research areas

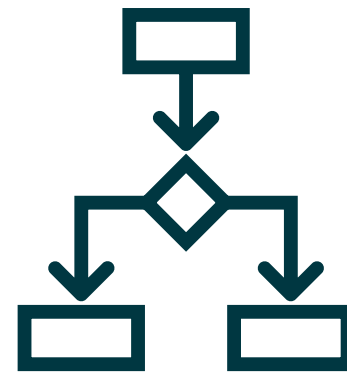


Goals PROMs



Scientific research

- Treatment effects in RCTs
- Natural history data
- Identify unmet needs
- New research areas



Policy

- Developing clinical guidelines
- Decision-making in healthcare funding

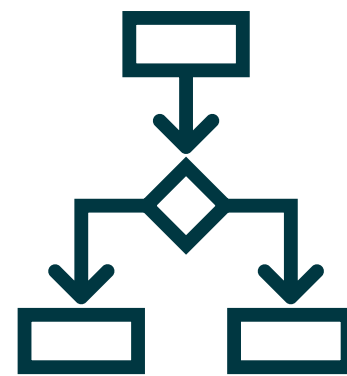


Goals PROMs



Scientific research

- Treatment effects in RCTs
- Natural history data
- Identify unmet needs
- New research areas



Policy

- Developing clinical guidelines
- Decision-making in healthcare funding

Comment

<https://doi.org/10.1038/s41591-025-03906-1>

Patient-reported outcome measures add value as clinical trial endpoints

Norah L. Crossnohere, Anne L. R. Schuster, Jeffrey Bruckel, Ronald C. Chen, Amy M. Cizik, Samantha Cruz Rivera, Christopher Muth, Linda Nelsen, Derek Kyte, Albert W. Wu, Elissa Thorner, Claire Snyder & Michael Brundage

Check for updates

Asking patients about their symptoms, functioning and well-being during clinical trials can influence trial outcomes, regulatory decisions and clinical practice.

total score from the St. George's Respiratory Questionnaire (SGRQ), a respiratory-specific HRQoL measure that assesses symptoms, activities and impact. Mepolizumab demonstrated a benefit in total SGRQ score compared with placebo, as determined by mean change in score from baseline (15.6-point improvement for mepolizumab versus 7.9 for placebo). Findings from the MUSCA trial were included in the FDA label for mepolizumab and provided insights into the impact of experiencing multiple exacerbations beyond a simple count of days with exacerbation events. This was the first time a label for an asthma treat-

Randomized clinical trials (RCTs) are the gold standard for assessing novel interventions in health. Traditionally, RCTs have used endpoints

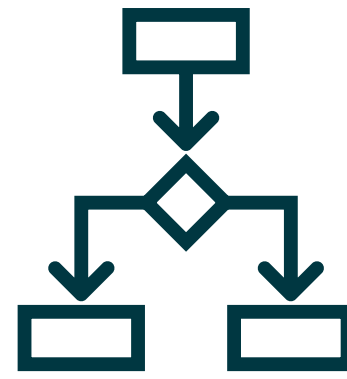


Goals PROMs



Scientific research

- Treatment effects in RCTs
- Natural history data
- Identify unmet needs
- New research areas



Policy

- Developing clinical guidelines
- Decision-making in healthcare funding



Quality

- Aggregated level to gain insight in quality of care
- Benchmarking

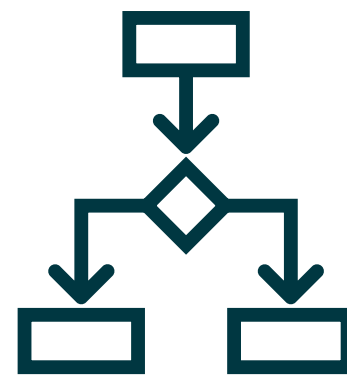


Goals PROMs



Scientific research

- Treatment effects in RCTs
- Natural history data
- Identify unmet needs
- New research areas



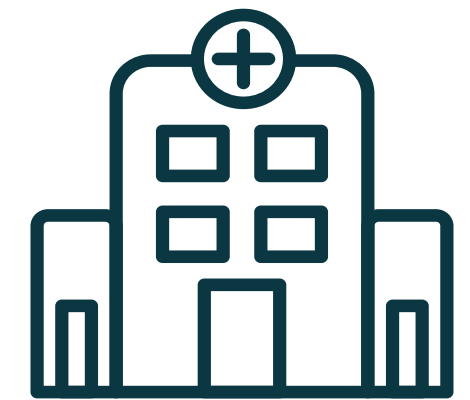
Policy

- Developing clinical guidelines
- Decision-making in healthcare funding



Quality

- Aggregated level to gain insight in quality of care
- Benchmarking



Daily clinical care

- Individual patient care

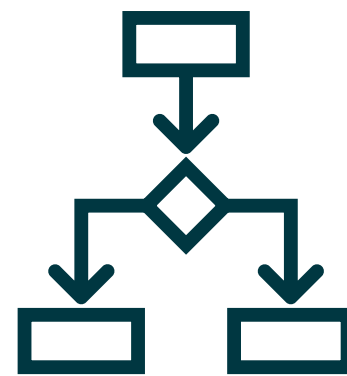


Goals PROMs



Scientific research

- Treatment effects in RCTs
- Natural history data
- Identify unmet needs
- New research areas



Policy

- Developing clinical guidelines
- Decision-making in healthcare funding



Quality

- Aggregated level to gain insight in quality of care
- Benchmarking

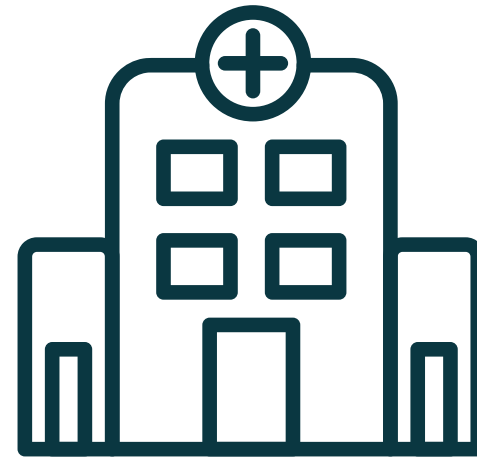


Daily clinical care

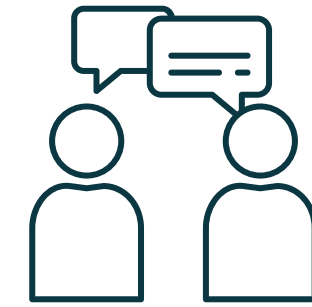
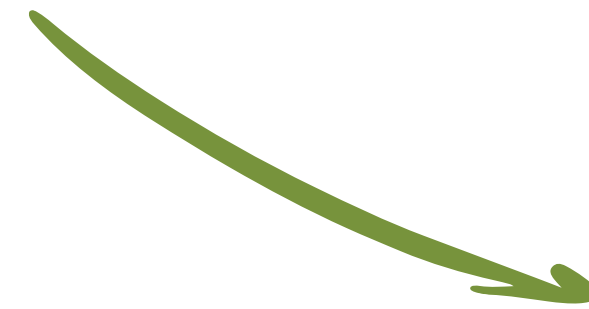
- Individual patient care



Effect studies PROMs



Daily clinical practice



Communication



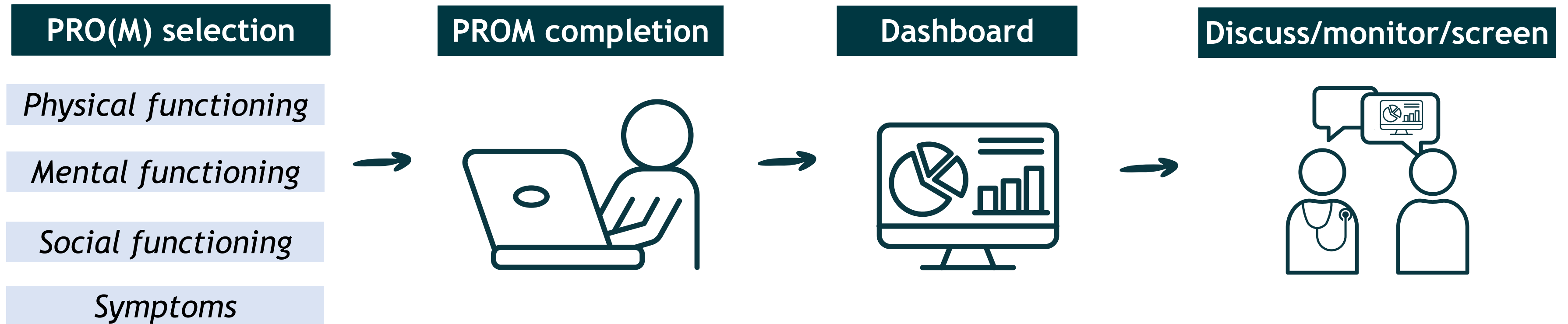
Quality of Life



Survival



How are PROMs used in daily clinical care?





KLIK PROM portal

Development & Scope

Developed in 2008

Main focus on pediatric patients

> 20 years of research on implementation and effectiveness

National level in the Netherlands

Reach & Adoption

> 40 hospitals across the country

> 66 medical conditions

> 60,000 patients

> 2,500 healthcare professionals trained in daily use





Individual item feedback

Child	
<input type="radio"/> 03-11-2016 <input checked="" type="radio"/> 03-06-2017 <input type="radio"/> 23-12-2017 <input checked="" type="radio"/> 26-04-2018	
Physical	03-06-2017
It is hard for me to walk more than one block	Sometimes ●
It is hard for me to run	Often ●
It is hard for me to do sports activity or exercise	Often ●
It is hard for me to lift something heavy	Sometimes ●
It is hard for me to take a bath or shower by myself	Never ●
It is hard for me to do chores around the house	Almost always ●
I hurt or ache	Almost never ●
I have low energy	Often ●
Emotional	03-06-2017
I feel afraid or scared	Never ●
I feel sad or blue	Never ●
I feel angry	Almost never ●
I have trouble sleeping	Never ●
I worry about what will happen to me	Never ●
Social	03-06-2017
I have trouble getting along with other kids	Never ●
Other kids do not want to be my friend	Never ●
Other kids tease me	Never ●
I cannot do things that other kids my age can do	Sometimes ●
It is hard to keep up when I play with other kids	Never ●
School	03-06-2017
It is hard to pay attention in class	Never ●
I forget things	Almost never ●
I have trouble keeping up with my schoolwork	Sometimes ●
I miss school because of not feeling well	Sometimes ●
I miss school to go to the doctor or hospital	Sometimes ●



Individual item feedback

Child

03-11-2016 03-06-2017 23-12-2017 26-04-2018

Physical

It is hard for me to walk more than one block
It is hard for me to run
It is hard for me to do sports activity or exercise
It is hard for me to lift something heavy
It is hard for me to take a bath or shower by myself
It is hard for me to do chores around the house
I hurt or ache
I have low energy

It is hard for me to take a bath or shower by myself

Never

It is hard for me to do chores around the house

Almost always

I hurt or ache

Almost never

I have low energy

Often

Emotional

03-06-2017

Emotional

I feel afraid or scared
I feel sad or blue
I feel angry
I have trouble sleeping
I worry about what will happen to me

I feel afraid or scared

Never

I feel sad or blue

Never

I feel angry

Almost never

I have trouble sleeping

Never

I worry about what will happen to me

Never

Social

03-06-2017

Social

I have trouble getting along with other kids
Other kids do not want to be my friend
Other kids tease me
I cannot do things that other kids my age can do
It is hard to keep up when I play with other kids

I have trouble getting along with other kids

Never

Other kids do not want to be my friend

Never

Other kids tease me

Never

I cannot do things that other kids my age can do

Sometimes

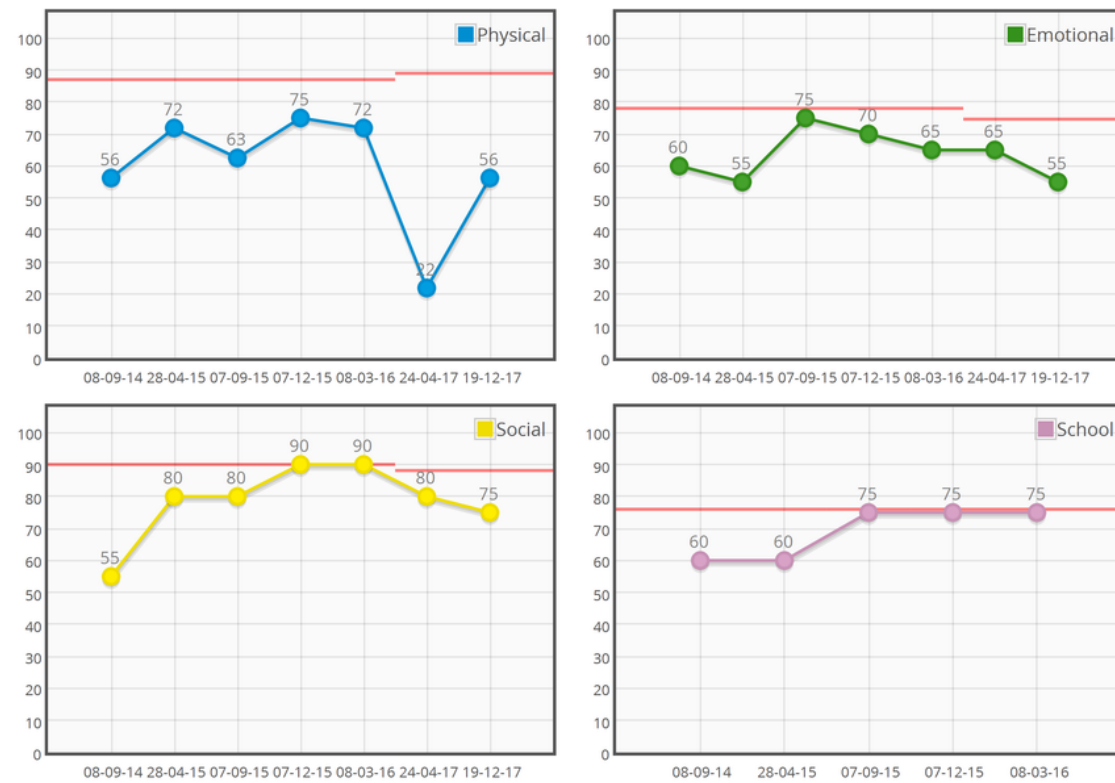
It is hard to keep up when I play with other kids

Never

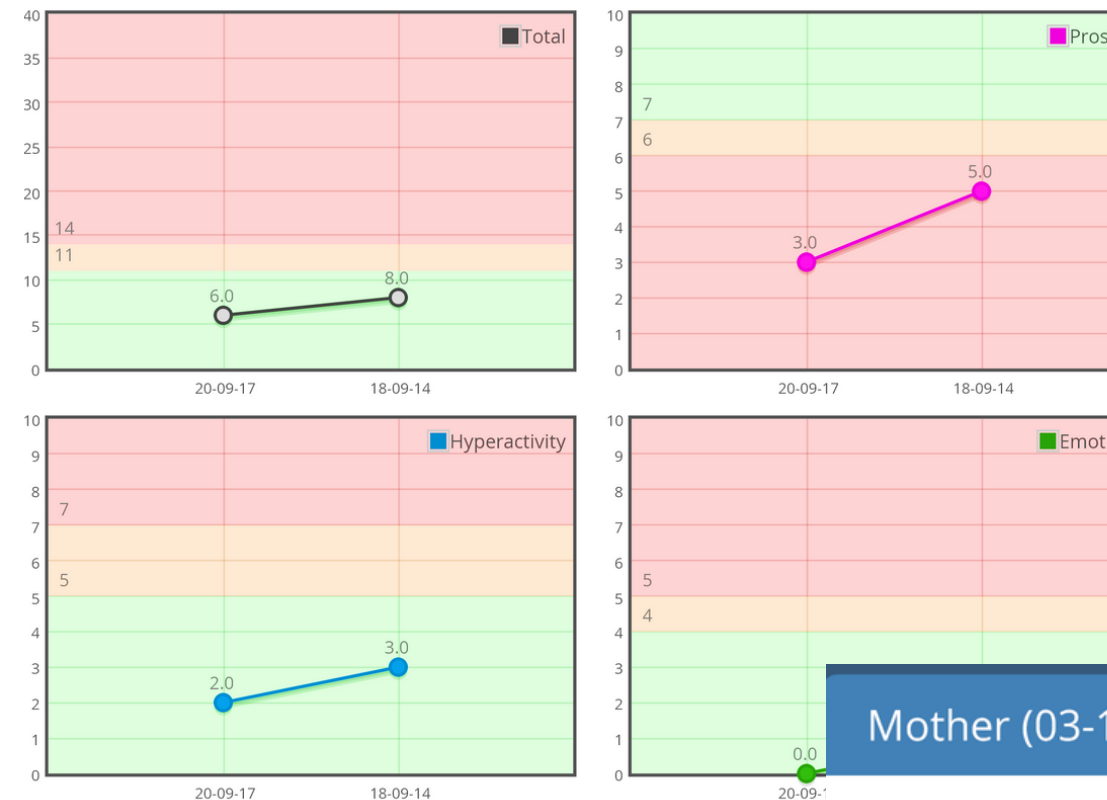


Domain score feedback options

Child



Parent(s)/Guardian(s)



Mother (03-12-1980)

Father (03-12-1982)

✓ 20-02-2017 ✓ 30-11-2017

Scores	20-02-2017	30-11-2017
Anxiety score	5 ●	11 ●
Depression score	8 ●	10 ●
Clinical	Yes ●	Yes ●



Quality of Life Research (2021) 30:3267–3277
https://doi.org/10.1007/s11136-020-02522-5

SPECIAL SECTION: FEEDBACK TOOLS

Clinicians' perspective on the implemented KLIK PROM portal in clinical practice

Lorynn Teela¹ · Maud M. van Muilekom¹ · Lieke H. Kooij¹ · Anouk W. Gathier¹ · Johannes B. van Goudoever² · Martha A. Grootenhuys³ · Lotte Haverman¹ · Hedy A. van Oers¹

Accepted: 5 May 2020 / Published online: 28 May 2020
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Quality of Life Research (2021) 30:3015–3033
https://doi.org/10.1007/s11136-020-02564-9

SPECIAL SECTION: FEEDBACK TOOLS

Using an implementation science approach to implement and evaluate patient-reported outcome measures (PROM) initiatives in routine care settings

Angela M. Stover^{1,2} · Lotte Haverman³ · Hedy A. van Oers³ · Joanne Greenhalgh⁴ · Caroline M. Potter⁵ · On behalf of the ISOQOL PROMs/PREMs in Clinical Practice Implementation Science Work Group

Accepted: 16 June 2020 / Published online: 10 July 2020
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Abstract

Purpose Patient-reported outcome and experience measures (PROMs/PREMs) are well established in research for many health conditions, but barriers persist for implementing them in routine care. Implementation science (IS) offers a potential way forward, but its application has been limited for PROMs/PREMs.

Methods We compare similarities and differences for widely used IS frameworks and their applicability for implementing PROMs/PREMs through case studies. Three case studies implemented PROMs: (1) pain clinics in Canada; (2) oncology clinics in Australia; and (3) pediatric/adult clinics for chronic conditions in the Netherlands. The fourth case study is planning

Quality of Life Research (2021) 30:3049–3058
https://doi.org/10.1007/s11136-020-02564-9

SPECIAL SECTION: FEEDBACK TOOLS

A retrospective assessment of the KLIK PROM portal implementation using the Consolidated Framework for Implementation Research (CFIR)

Hedy A. van Oers¹ · Lorynn Teela¹ · Sasja A. Schepers² · Martha A. Grootenhuys² · Lotte Haverman¹ on behalf of the ISOQOL PROMs and PREMs in Clinical Practice Implementation Science Group

Accepted: 10 July 2020 / Published online: 15 August 2020
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Quality of Life Research (2022) 31:241–254
https://doi.org/10.1007/s11136-021-02950-x

Patients' and parents' perspective on the implementation of Patient Reported Outcome Measures in pediatric clinical practice using the KLIK PROM portal

Maud M. van Muilekom¹ · Lorynn Teela¹ · Hedy A. van Oers¹ · Johannes B. van Goudoever² · Martha A. Grootenhuys³ · Lotte Haverman^{1,4}

Accepted: 10 July 2021 / Published online: 29 July 2021
© The Author(s) 2021, corrected publication 2022

Abstract

Introduction The KLIK Patient Reported Outcome Measures (PROM) portal (www.hetkligt.nu) has been implemented since 2011 in clinical practice in over 20 Dutch hospitals. Patients and/or parents complete PROMs before the outpatient



International Journal of
Environmental Research
and Public Health

Article

The Use of Patient-Reported Outcome Measures in the Clinical Practice of a Pediatric Nephrology

Floor Veltkamp^{1,†} · Lorynn Teela^{2,†} · Hedy A. van Oers² · Lotte Haverman²

¹ Department of Pediatric Nephrology, Emma Children's Hospital, Amsterdam, Meibergdreef 9, 1105 AZ Amsterdam, The Netherlands; f.veltkamp@amsterdamumc.nl (F.V.); l.teela@amsterdamumc.nl (L.T.); h.vanoers@amsterdamumc.nl (H.A.v.O.); l.haverman@amsterdamumc.nl (L.H.)
² Child and Adolescent Psychiatry & Psychosocial Care, Amsterdam Public Health, Emma Children's Hospital, Amsterdam, Meibergdreef 9, 1105 AZ Amsterdam, The Netherlands; l.h.vanoers@amsterdamumc.nl (H.A.v.O.); l.haverman@amsterdamumc.nl (L.H.)

* Correspondence: a.h.bouts@amsterdamumc.nl
† These authors contributed equally to this study.

Abstract: (1) Background: Health-related quality of life (HRQL) is lower in patients with chronic

Determinants for PROM implementation



Determinants for PROM implementation



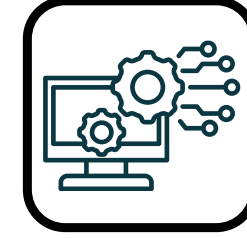
Government



Hospital



Health care professionals



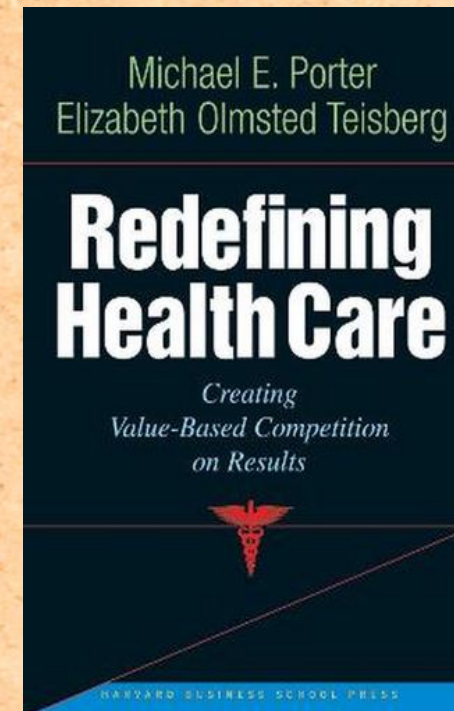
Technology



Patient & family



PROMs





The hospital; VBHC in the Amsterdam UMC



Clinical Outcomes



Experienced Health (PROMs)



Patient Experiences (PREMs)

OUTCOMES

Value =

COSTS AND EFFORTS



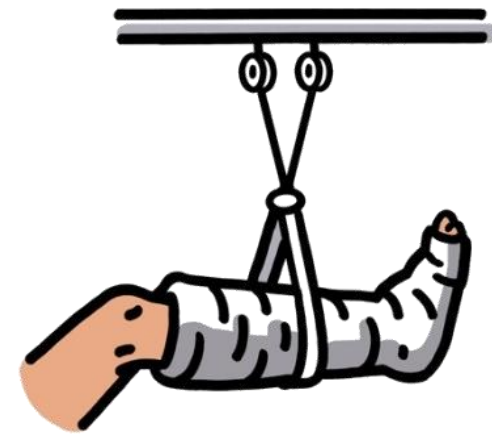
Cost bearers



Team effort



The hospital; VBHC in the Amsterdam UMC



Clinical Outcomes



Experienced Health (PROMs)



Patient Experiences (PREMs)

OUTCOMES

Value =

COSTS AND EFFORTS



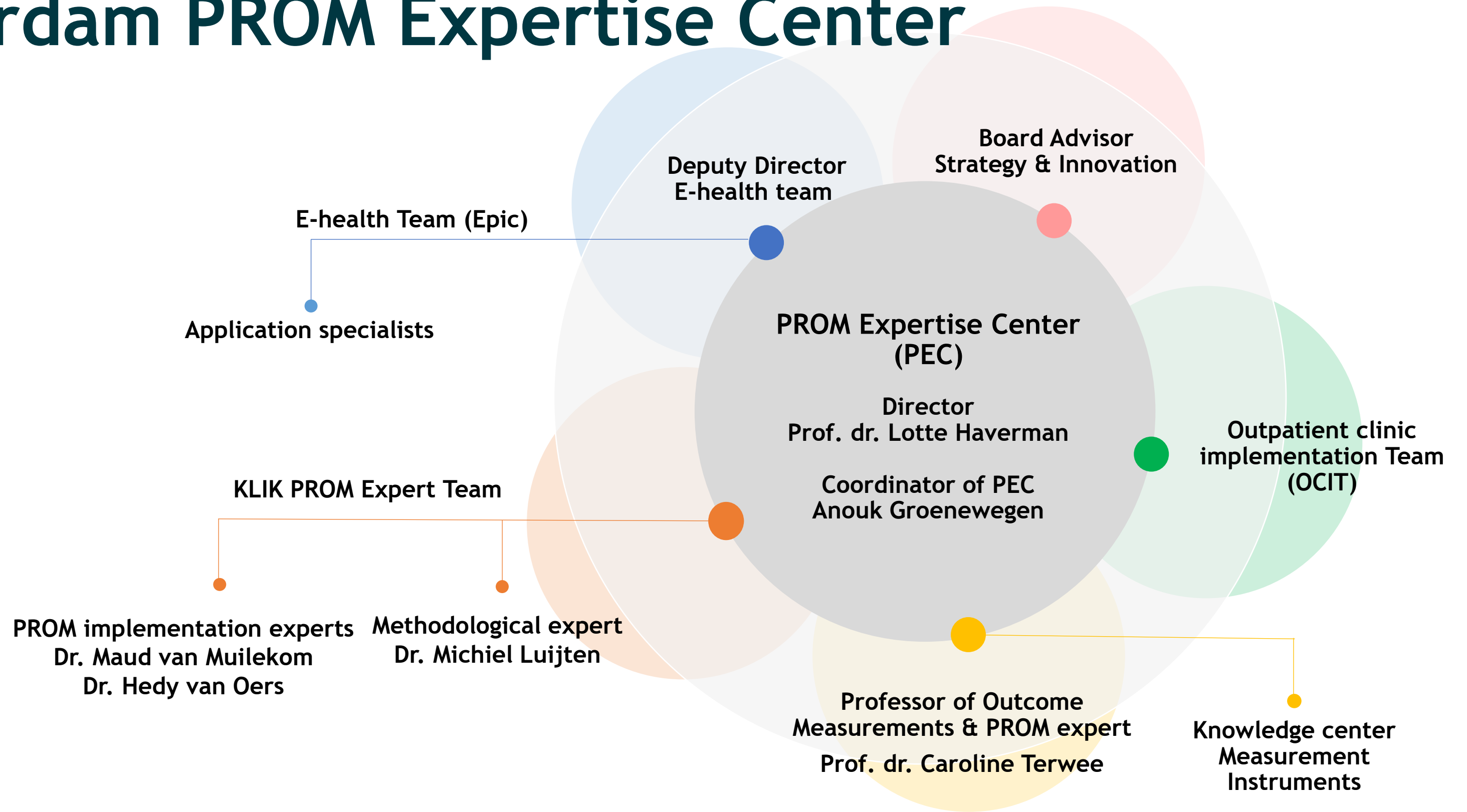
Cost bearers



Team effort



The Amsterdam PROM Expertise Center





The Amsterdam PROM Expertise Center

Development & Scope

Started in 2019

Focusing on adult patients

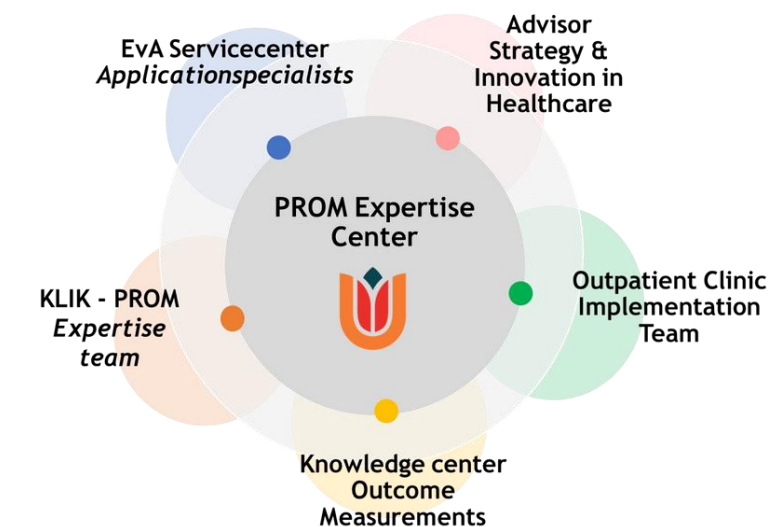
> 6 years of research on implementation and effectiveness

Hospital based (EHR EPIC)

Reach & Adoption

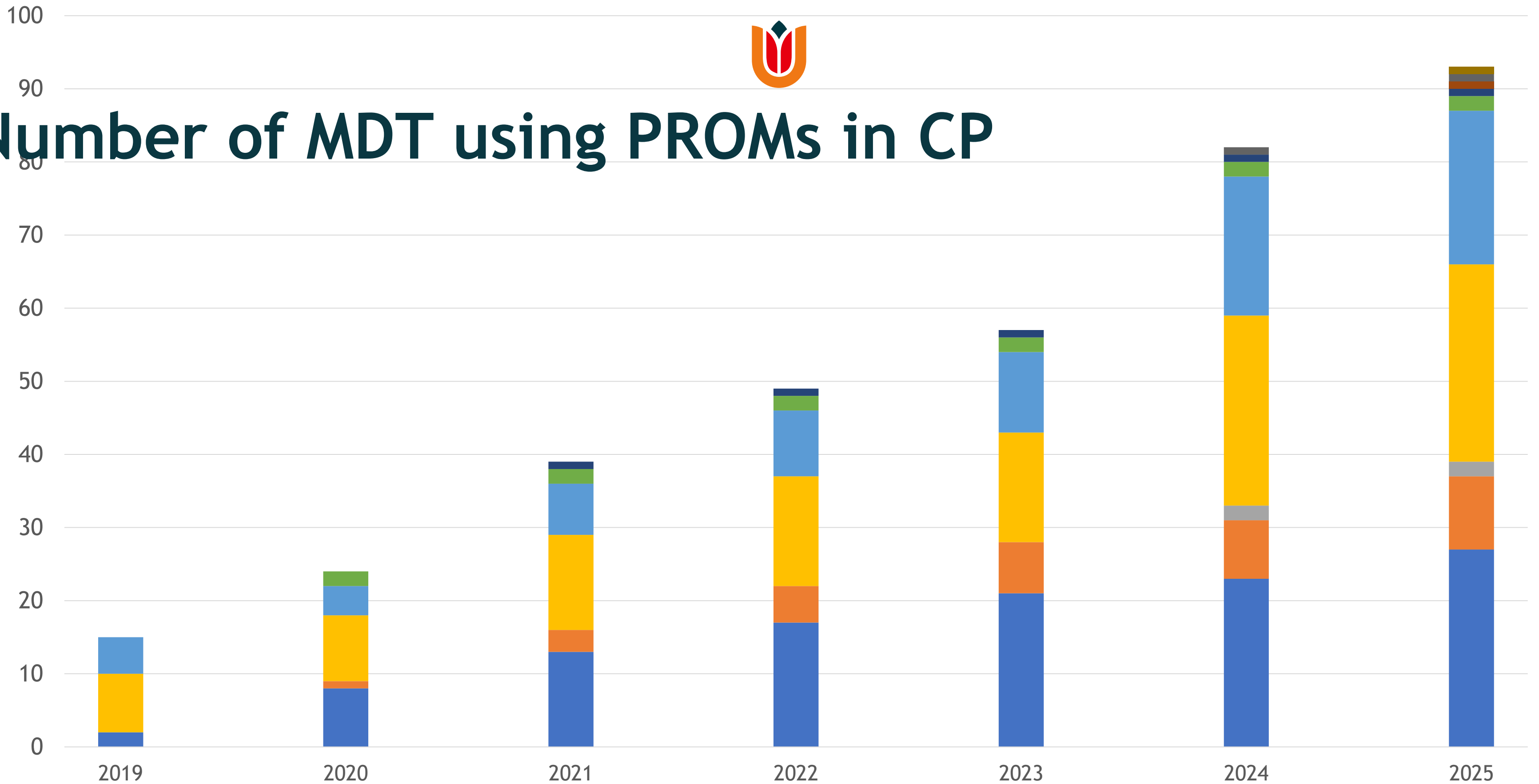
Implemented in >90 condition in Amsterdam UMC

> 500 healthcare professionals trained in daily use





Number of MDT using PROMs in CP



Internal Medicine
Neurology/Head-Neck
Laboratoria

Surgical Specialisms
Intensive Care/Surgery
Primary Care

Cardiology
Imaging

Women/Child
Outpatient clinic

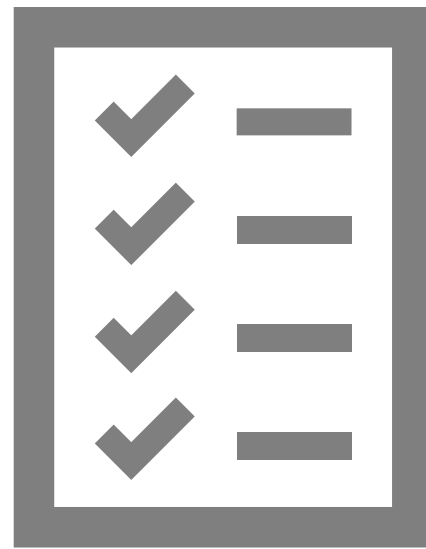
Oncology groups



Patient population	PROMs
Allogeneic stem cell therapy	PROMIS CAT: overall quality of life, anxiety, depression, fatigue, physical and social functioning, pain interference, sleep disorder + Graf vs Host disease
Benign gynaecology	PROMIS CAT: overall quality of life, anxiety, depression, fatigue, physical functioning, pain intensity + items about satisfaction with sex life
Bladder cancer	PROMIS CAT: overall quality of life, anxiety, depression, fatigue, physical functioning, pain intensity + PRO-CTCAE urinary incontinence + items about satisfaction with sex life, forgetfulness, concentration; impact on relatives;
Breast clinic	EORTC-QLQ-C30; EORTC-QLQ-B23: body image; side effects + BREAST-Q: sexual wellbeing; breast satisfaction
Glioma	PROMIS CAT: anxiety, depression, fatigue, physical functioning, pain intensity, PROMIS SF Cognitive functioning
Head and neck cancer	EORTC-QLQ-C3 + EORTC-QLQ-HN43 + HADS + NRS pain
Lung cancer	EORTC-QLQ-C30 + PRO-CTCAE-Lung
Multiple myeloma	EORTC-QLQ-C30 + EORTC-QLQ-MY20 + EQ5D-5L + PROMIS overall quality of life
Oncological gynecology	EORTC-QLQ-C30 + EORTC-QLQ-CX/EN/VU/OV + LARS + SNAQ
Oncological orthopedics	PROMIS CAT: overall quality of life, anxiety, depression, fatigue, physical functioning, pain interference, upper extremity + EQ5D5L + NRS pain + FAOS
Pituitary cancer	PROMIS CAT: overall quality of life, anxiety, depression, fatigue, physical and social functioning, pain interference + CushingQOL/AcroQOL + SNOT-22
Retinoblastoma	PROMIS CAT: anxiety, depression, fatigue, social functioning, pain interference, sleep disorder + satisfaction appearance + heredity + PAI-YA
Thyroid cancer	PROMIS CAT: anxiety, depression, fatigue, physical and social functioning, pain interference, cognitive functioning, NRS pain + EORTC-QLQ: impact on relatives + ThyPRO: work + VHI



The PROM Expertise Center



Policy



Pathway



NJEM catalyst

NEJM
Catalyst | Innovations in Care Delivery

CASE STUDY

The Amsterdam PROM Implementation Strategy: Policy and Pathway

Anouk Groenewegen, MSc, Maud M. van Muilekom, PhD, Cenne H.A.M. Sieben, MSc, Michiel A.J. Luijten, PhD, Sharon L. Janssen, MSc, Nynke Venema-Taats, MSc, Mira Korte, MSc, Caroline B. Terwee, PhD, Piet M. ter Wee, MD, PhD, Hedy A. van Oers, PhD, Lotte Haverman, PhD

Vol. 5 No. 7 | July 2024

DOI: 10.1056/CAT.23.0414

Patient-reported outcome measures (PROMs) are an essential tool in practicing value-based health care and patient-centered care. When used in clinical care, PROMs have

The Amsterdam PROM policy



1. **Individual** care



2. Select PROs and PROMs with **input from patients**.



3. Use generic PROMs, **PROMIS CATs**, add when necessary disease-specific PROMs.



4. **Limit** the **burden** for patients to ~30 questions/10 minutes.



5. Visualize outcomes on **comprehensible/attractive dashboards** for patients and clinicians.



6. Emphasize the importance to **always discuss** PROMs with patients during consultation.



7. **Educate** both clinicians and patients in the use and administration of PROMs.



8. **Evaluate** the PROM implementation periodically.





The Amsterdam PROM pathway

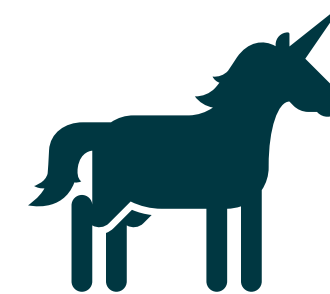
1. Design





PRO problem

1. Multidimensional outcomes
2. Unclear definition/operationalization



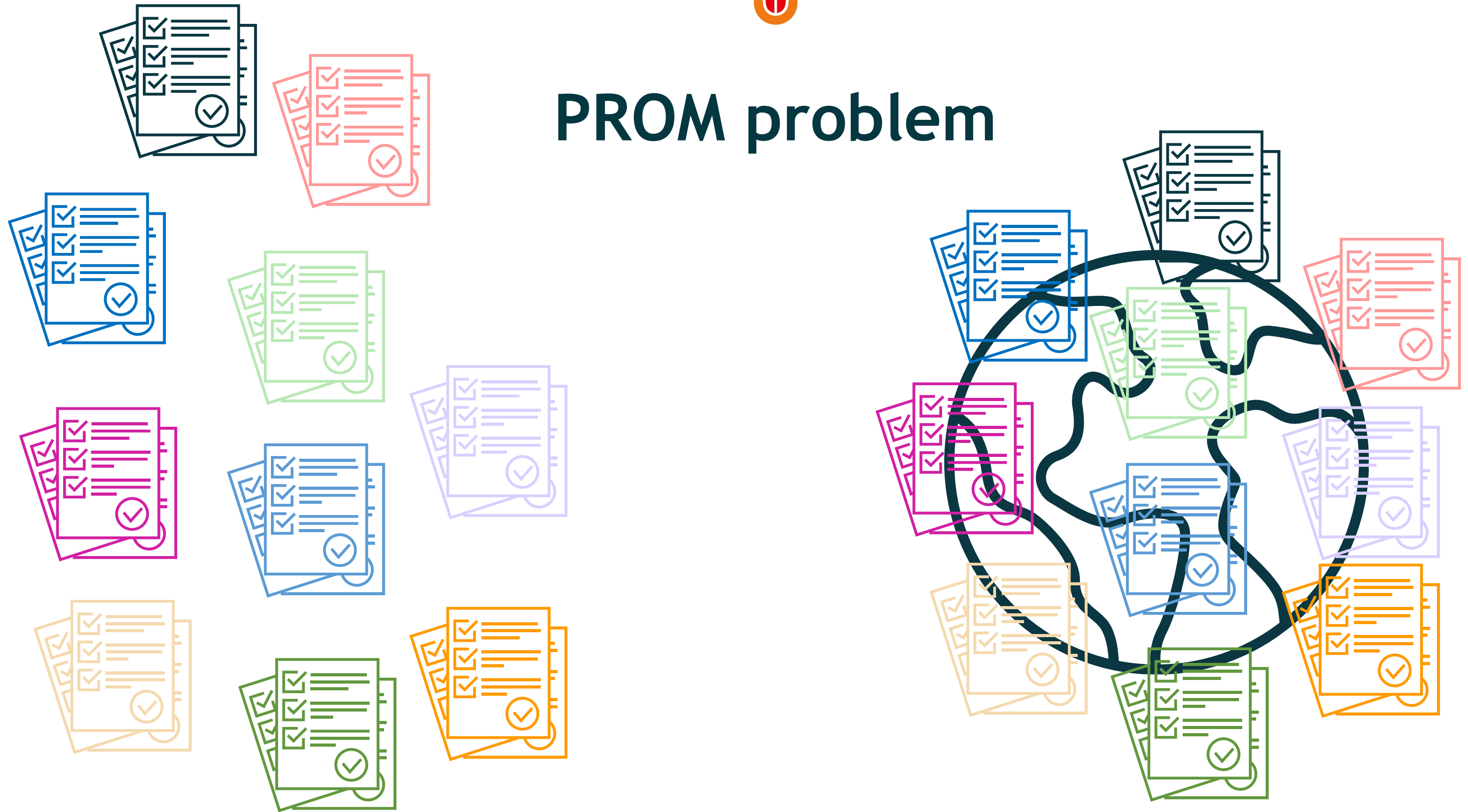


PROM problem



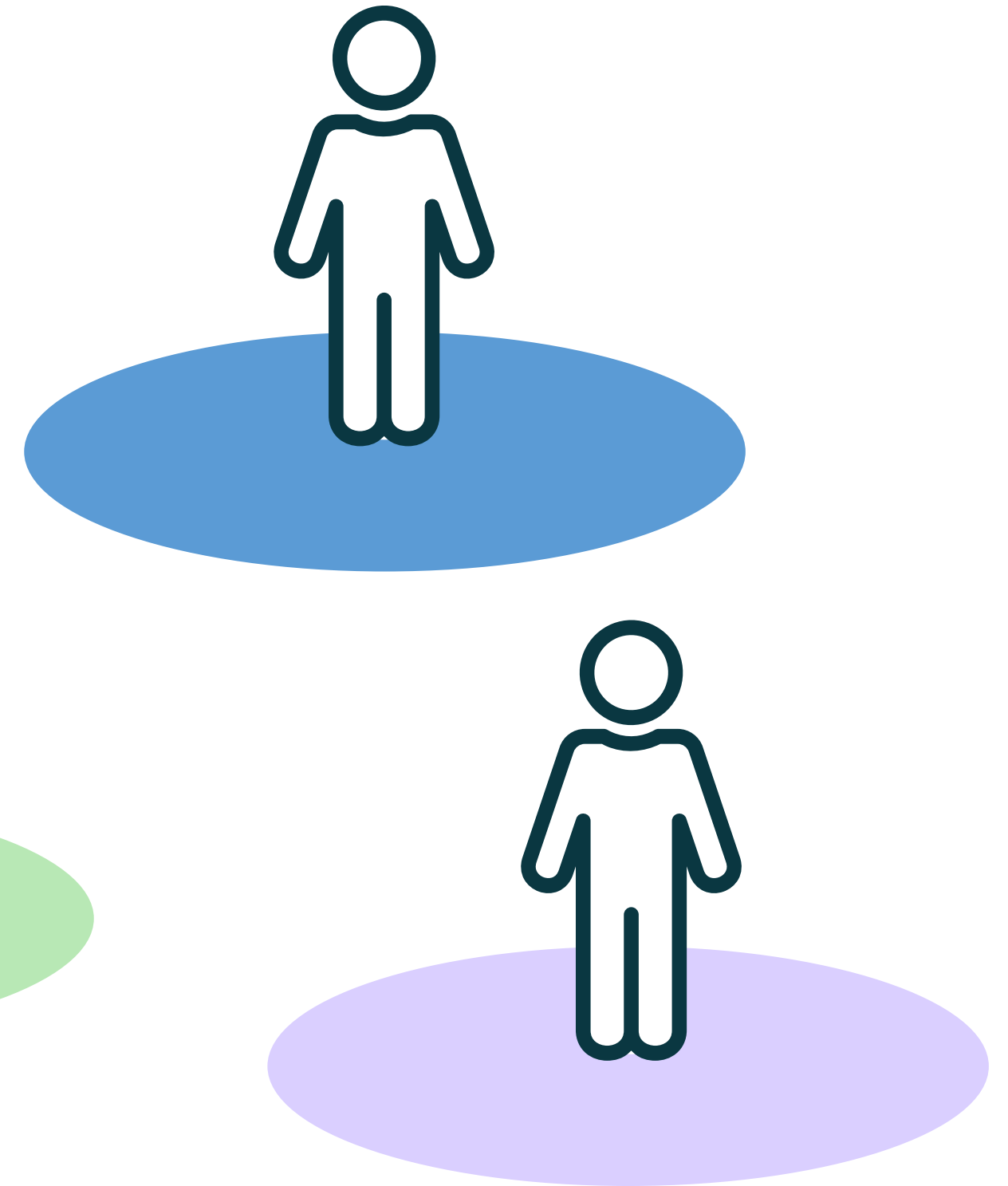
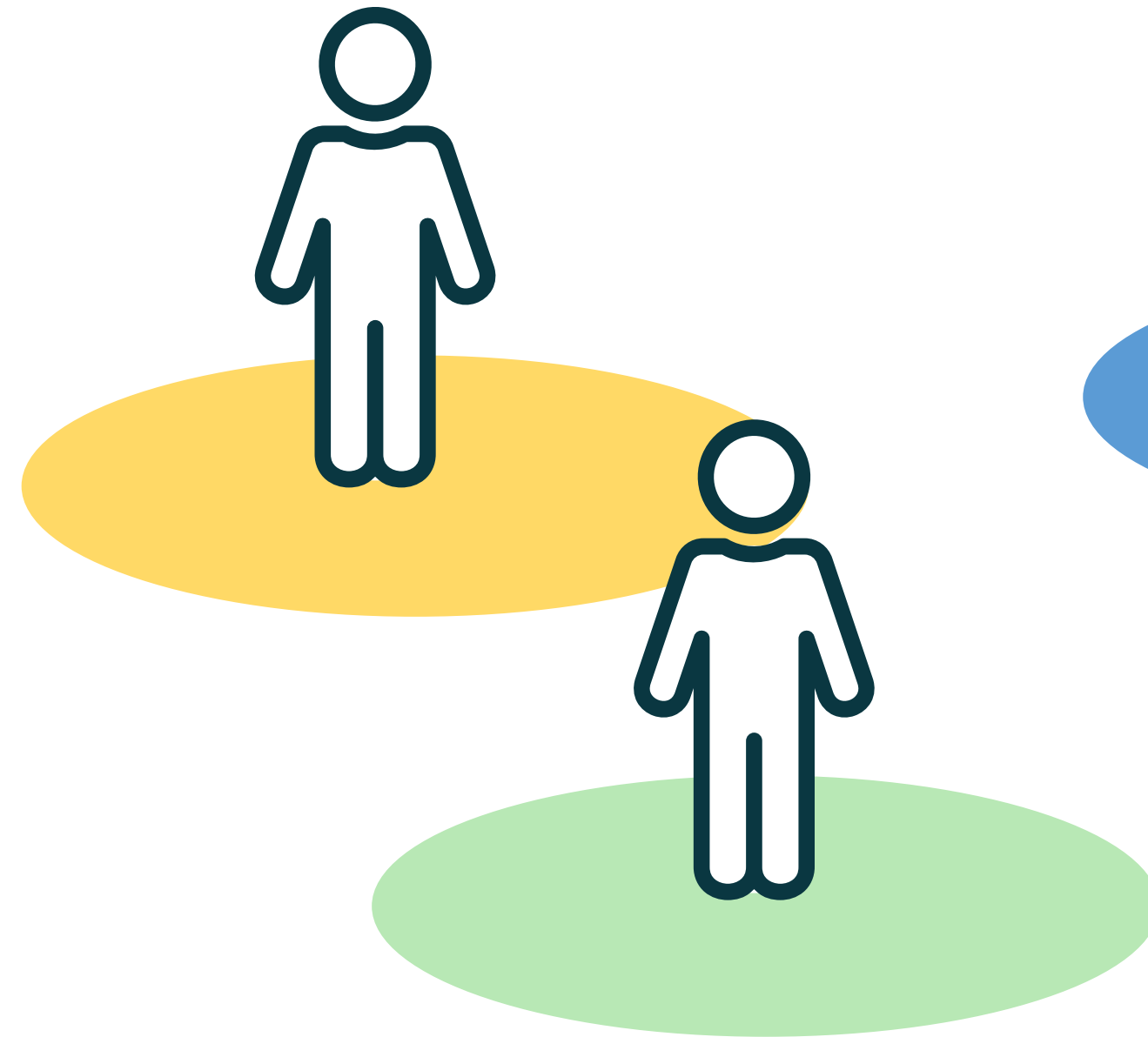
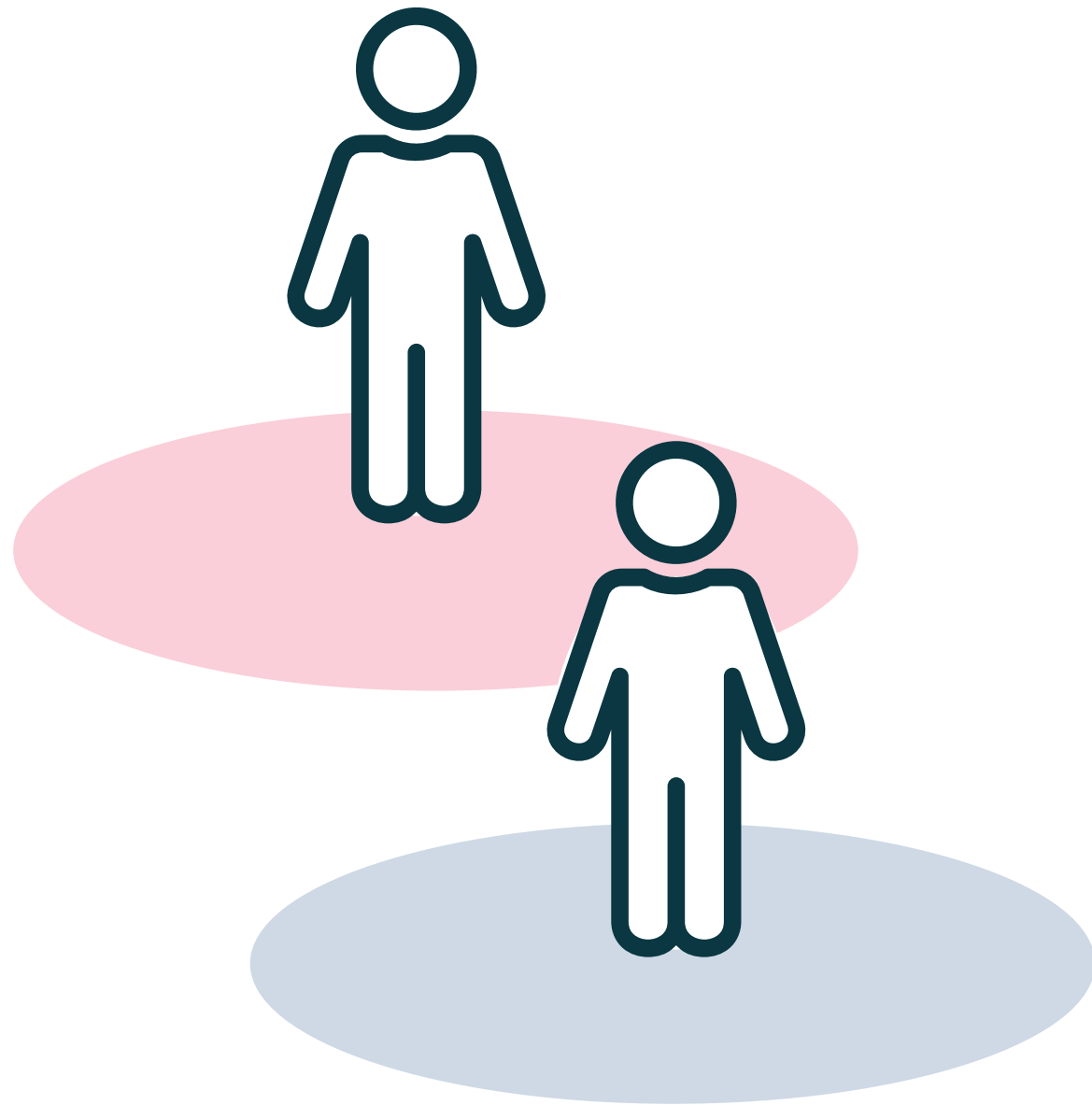


PROM problem



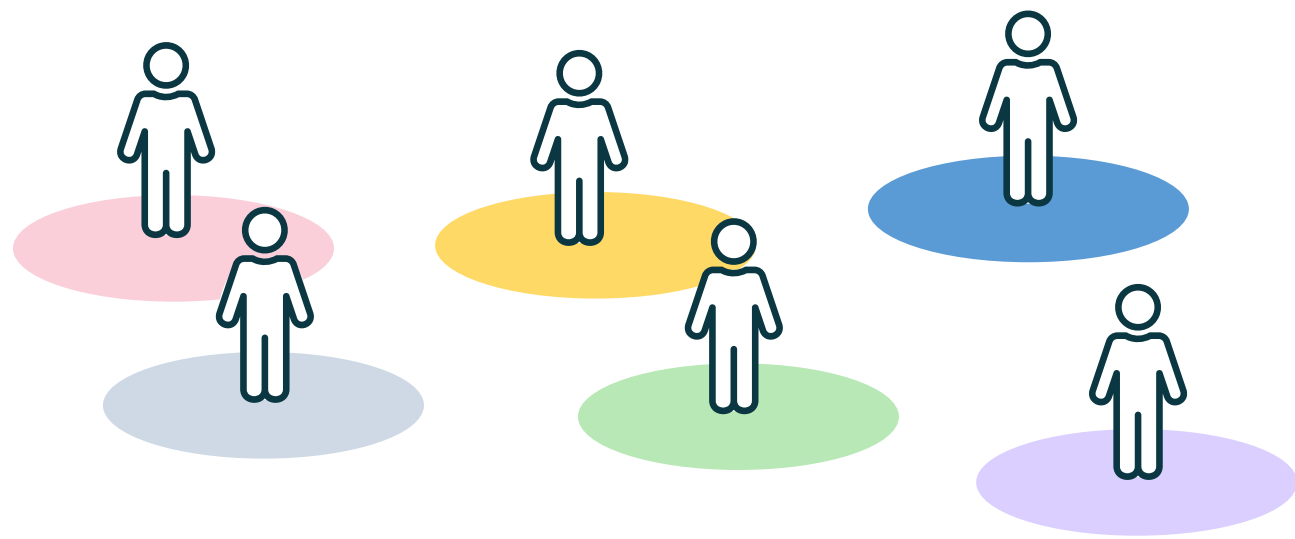


PROM problem





PROM problem



Validation needed over and over again



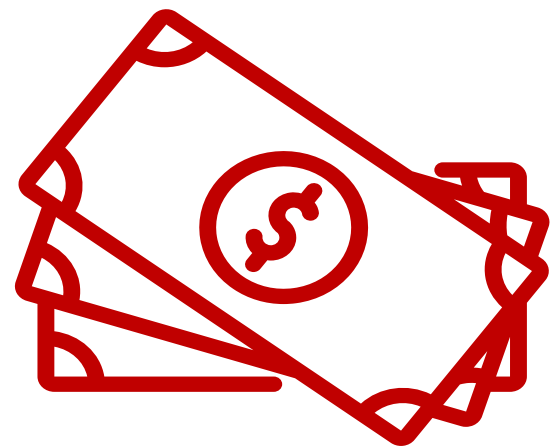
Low reliability



Hard to interpreted scores



Hard to compare outcomes



Hard to sustain and keep systems updated



The outcome maze

316 studies reporting on 91 different outcomes measured with > 457 instruments

288 instruments used in 1 single clinical trial

THERAPEUTIC ADVANCES in
Rare Disease

Original Research

Navigating the outcome maze: a scoping review of outcomes and instruments in clinical trials in genetic neurodevelopmental disorders and intellectual disability

Ther Adv Rare Dis
2024, Vol. 5: 1–19
DOI: 10.1177/
26330040241245721
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Annelieke R. Müller , Nadia Y. van Silfhout, Bibiche den Hollander, Dick H. C. Kampman, Lianne Bakkum, Marion M. M. G. Brands, Lotte Haverman, Caroline B. Terwee, Carlo Schuengel, Joost Daams, David Hessel, Frits A. Wijburg, Erik Boot and Agnies M. van Eeghen 

On an international level: ICHOM

Mental Health



ADDICTION AUTISM SPECTRUM DISORDERS DEPRESSION & ANXIETY DEPRESSION & ANXIETY FOR CHILDREN & YOUNG PEOPLE



NEURODEVELOPMENTAL DISORDERS PERSONALITY DISORDERS PSYCHOTIC DISORDERS

Musculoskeletal



HAND AND WRIST CONDITIONS HIP & KNEE OSTEOARTHRITIS INFLAMMATORY ARTHRITIS LOW BACK PAIN

Neurology



✓ Completed

The ICHOM Set of Patient-Centered Outcome Measures for Neurodevelopmental Disorders is the result of hard work by a group of leading clinicians, researchers, and patients. It is our recommendation of the outcomes that matter most to patients with neurodevelopmental disorders. We urge all providers around the world to start measuring these outcomes to better understand how to improve the lives of their patients.

1. Includes ADHD symptoms.
2. Includes Language Difficulties, Social (Pragmatic) Communication Difficulties, Fluency Difficulties, and Speech Sound Difficulties.
3. Includes Vocal and Motor Tic Frequency and Severity, Fine Motor Skills, Gross Motor Skills, and Coordination.
4. Includes Reading Accuracy, Reading



ICHOM

39 ICHOM standard sets include **307 PROs**

- Turned out to be **22 unique PRO-concepts**

These 22 PROs were measured with **114 different PROMs**



ICHOM



39 ICHOM standard sets include 307 PROs

- Turned out to be 22 unique PRO-concepts

These 22 PROs were measured with 114 different PROMs

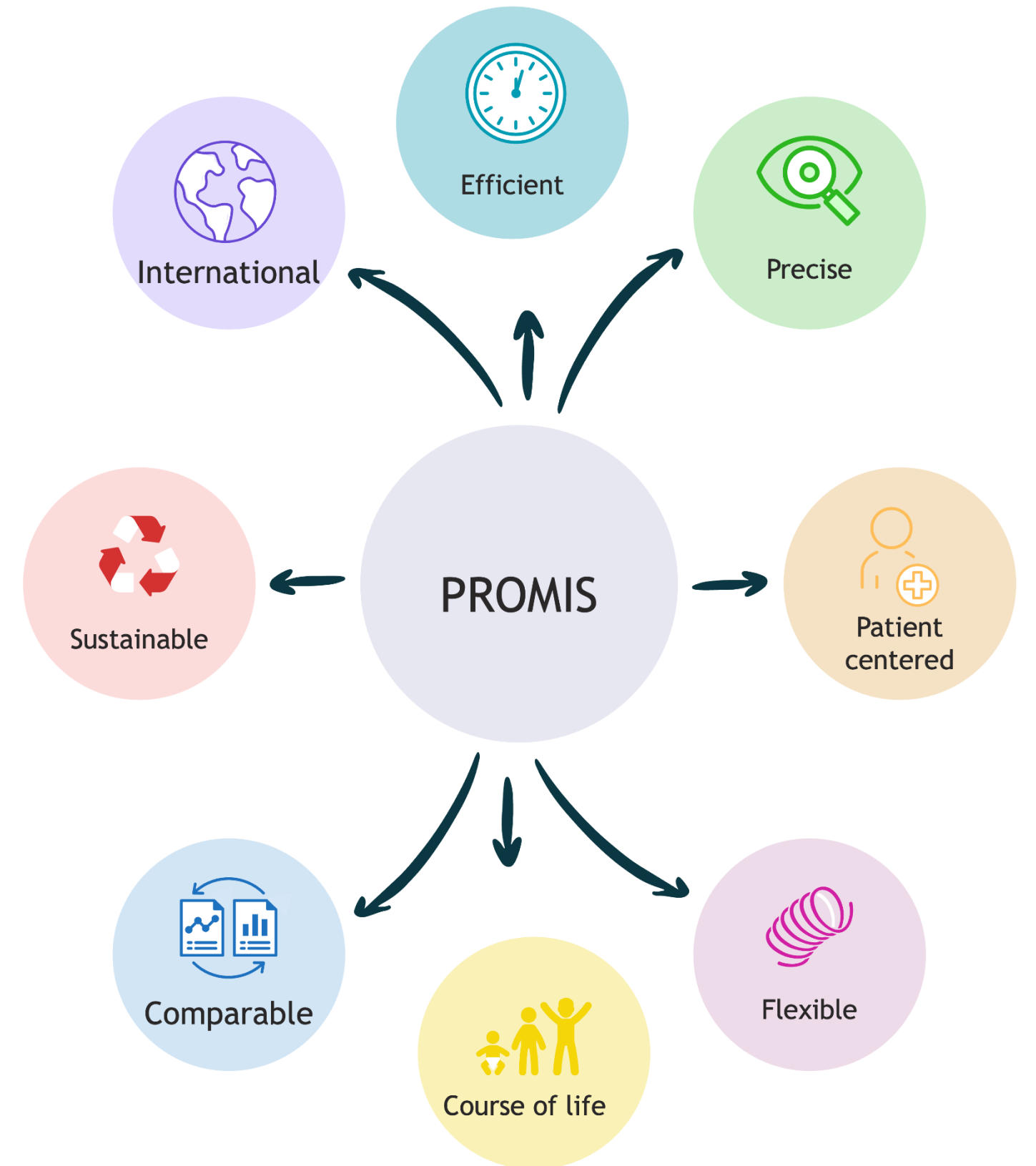
39 ICHOM standard sets:

- Physical functioning (27/39)
- Ability to participate in social roles (20/39)
- Anxiety and depression (26/39)
- Pain intensity (17/39)
- Fatigue (10/39)

PROMIS

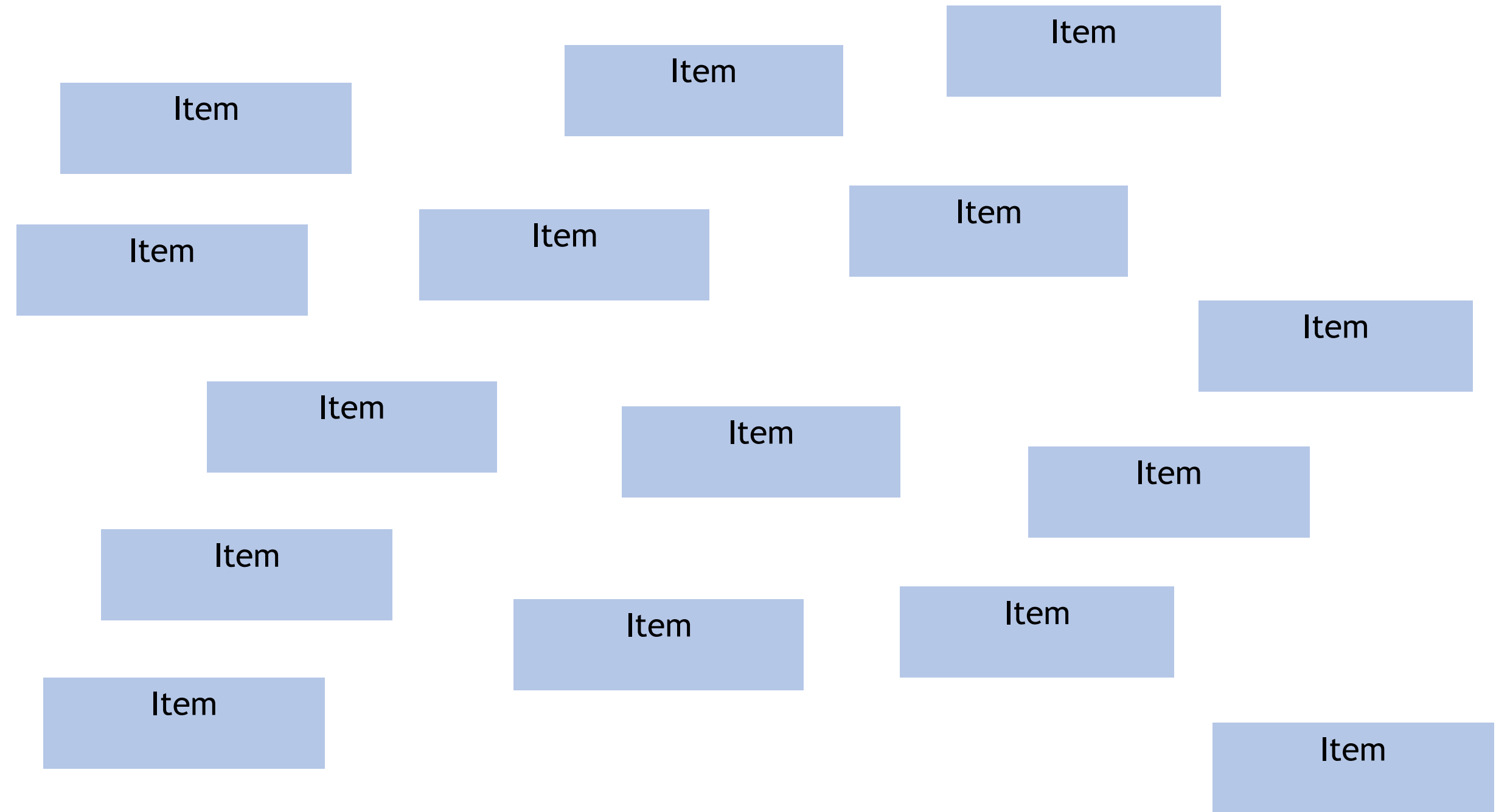
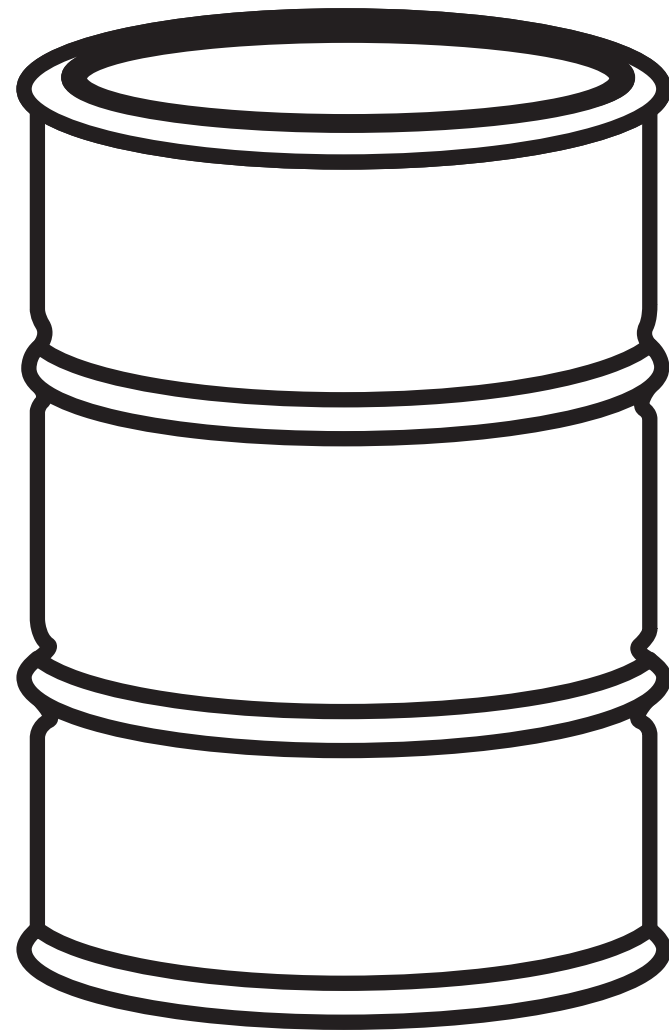
Potential solution due to

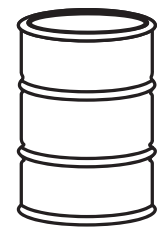
Item Response Theory





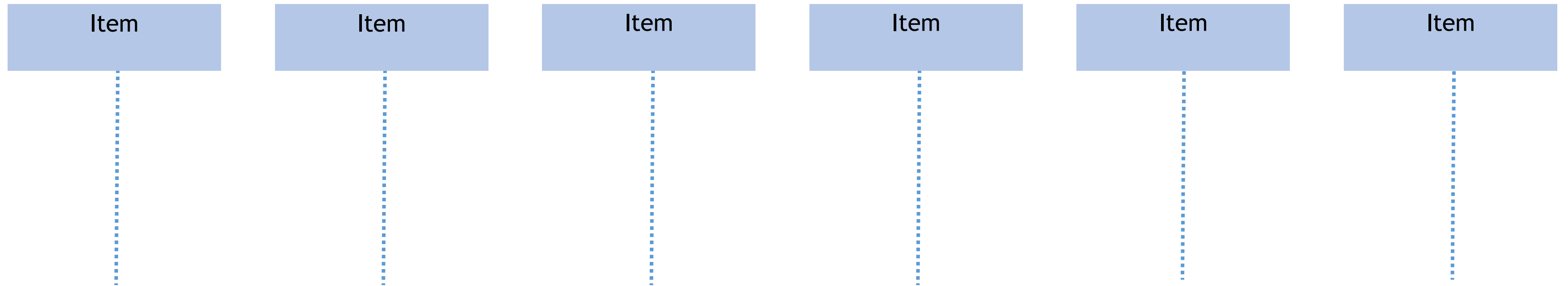
PROMIS Physical functioning item bank = 165 items





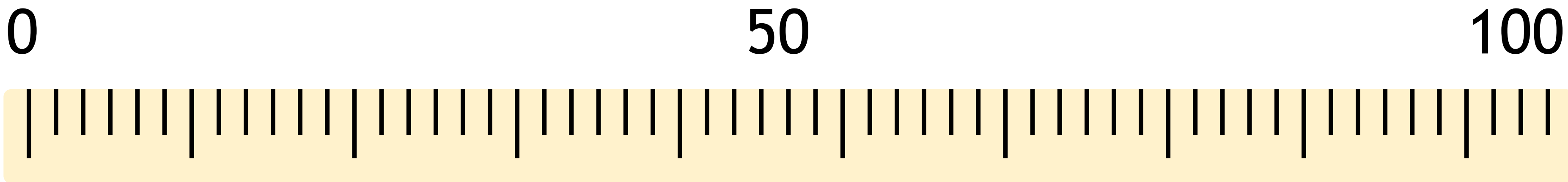
PROMIS item banks

Questions are scaled according to level of difficulty



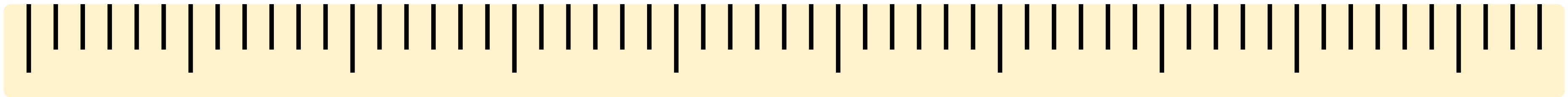
PROMIS

Scale = always t-scores 0 - 100



PROMIS

People are also scaled on this metric

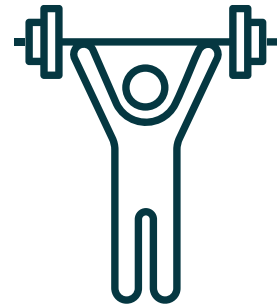
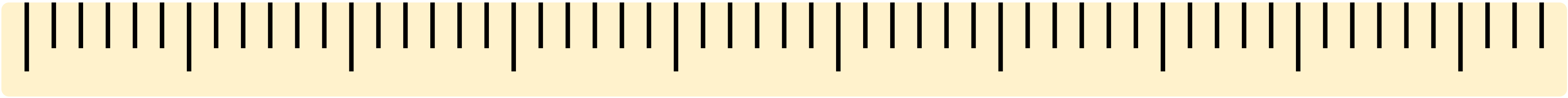


PROMIS CATs

People are also scaled on this metric



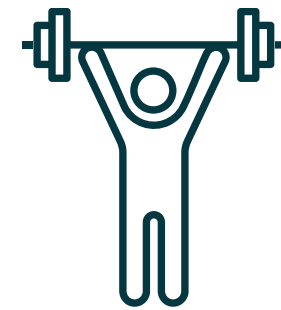
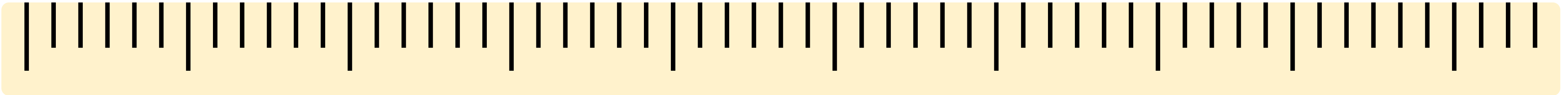
John?





PROMIS CATs

Can you walk at a normal pace?

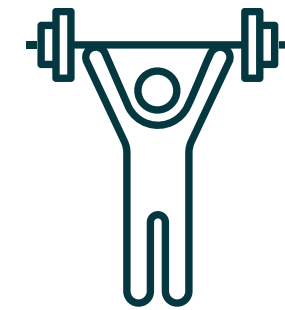
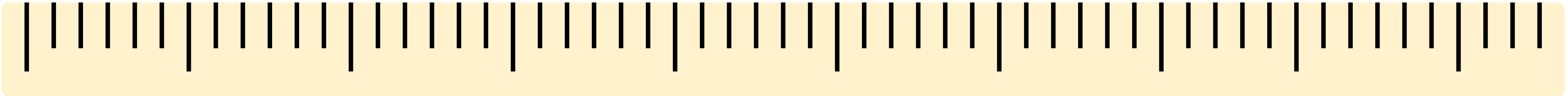




PROMIS CATs

Can you walk at a normal pace?

No



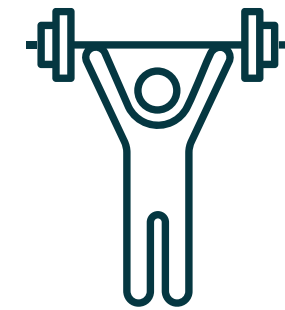
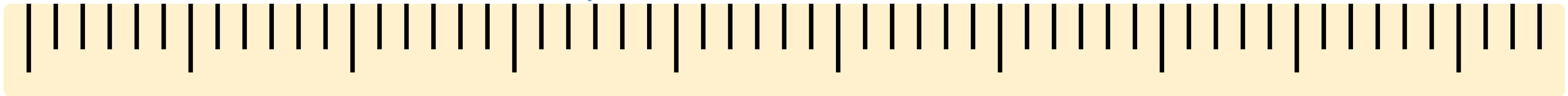


PROMIS CATs

Can you walk at a normal pace?

No

John



PROMIS CATs

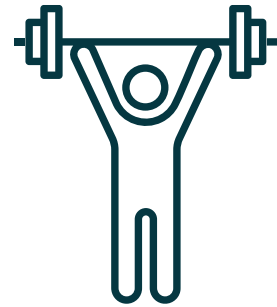
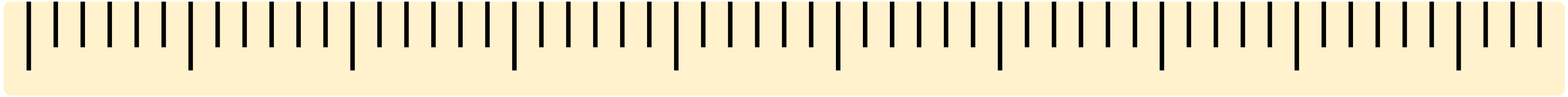


Can you walk at a normal pace?

No

Can you move a chair from one site to another?

John



PROMIS CATs



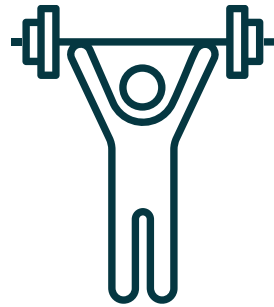
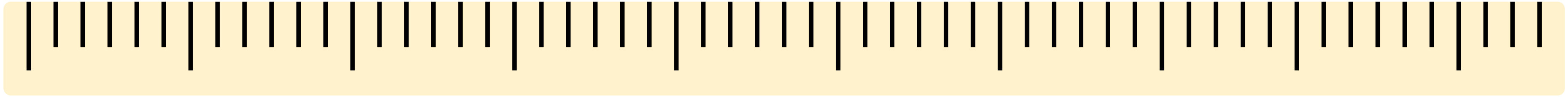
Can you walk at a normal pace?

No

Can you move a chair from one site to another?

Yes

John



PROMIS CATs



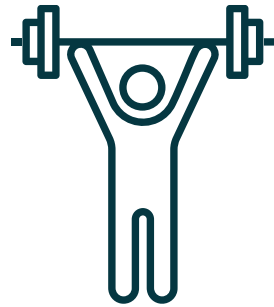
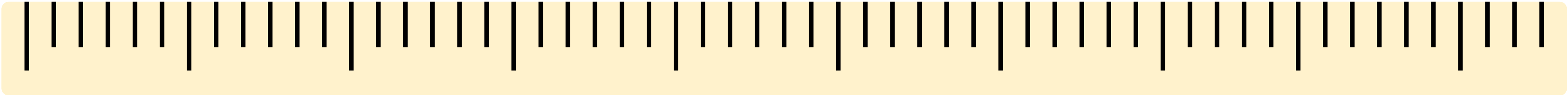
Can you walk at a normal pace?

No

Can you move a chair from one site to another?

Yes

John



PROMIS CATs



Can you walk at a normal pace?

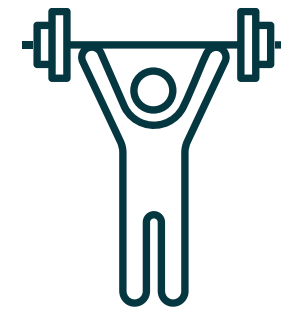
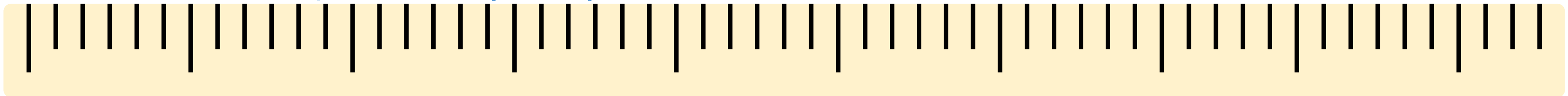
No

Can you move a chair from one site to another?

Yes

Can you stand on your tiptoes?

John



PROMIS CATs



Can you walk at a normal pace?

No

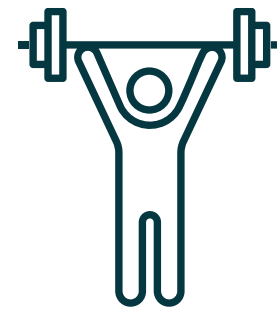
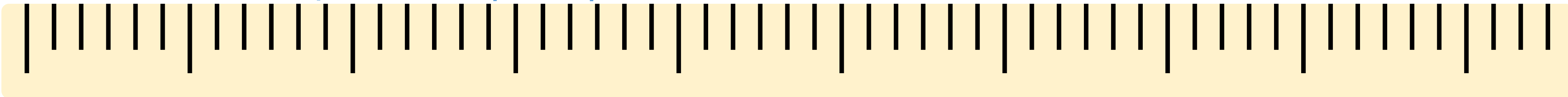
Can you move a chair from one site to another?

Yes

Can you stand on your tiptoes?

No

John





PROMIS CATs

Can you walk at a normal pace?

No

Can you move a chair from one site to another?

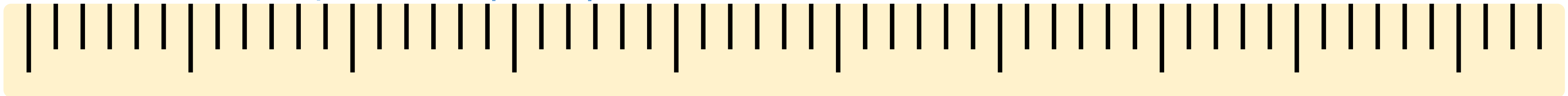
Yes

Can you stand on your tiptoes?

No

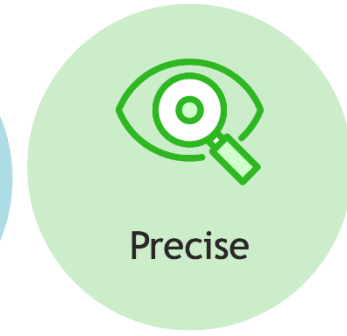
John

John t-score is 35





PROMIS CATs



Can you walk at a normal pace?

No

Can you move a chair from one site to another?

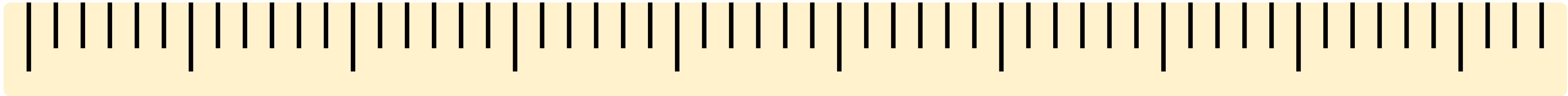
Yes

Can you stand on your tiptoes?

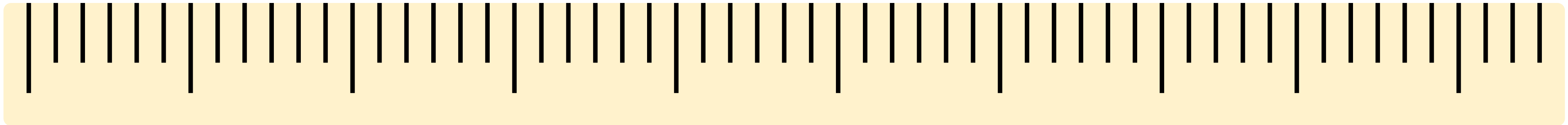
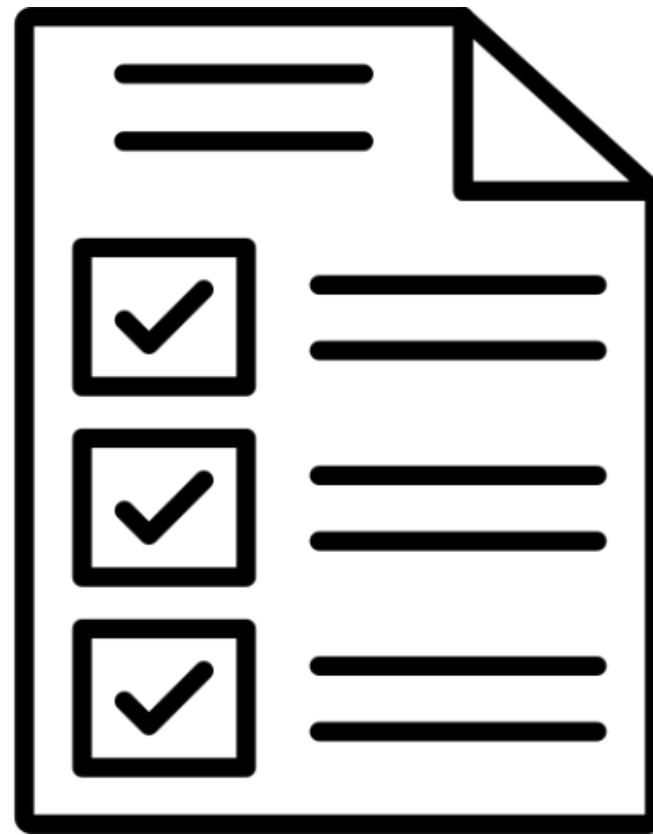
No

John

John t-score is 35



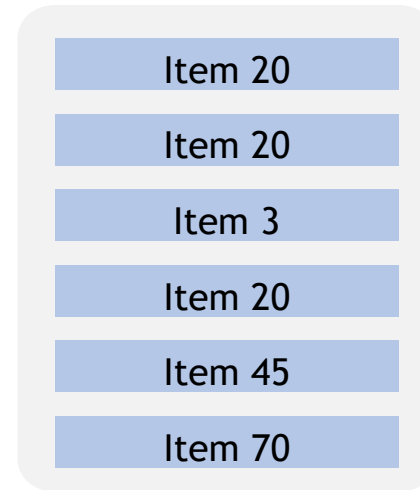
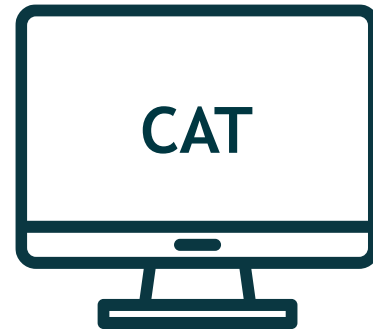
PROMIS Fixed Short Forms



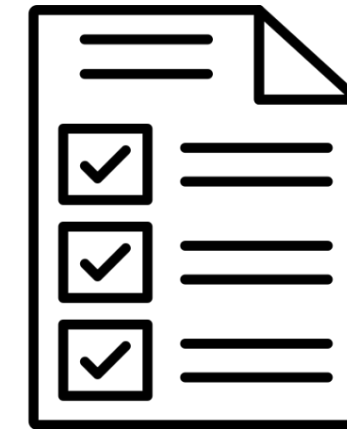
All on the same metric



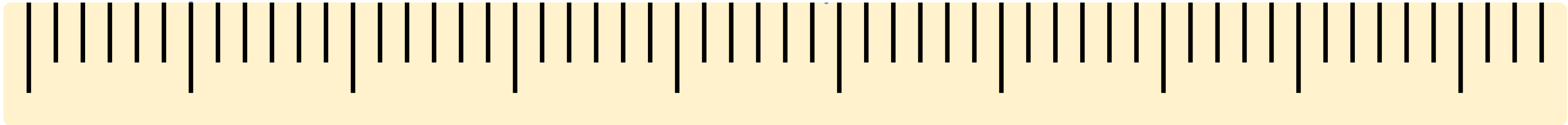
PROMIS
Fixed Short
form 4



Custom
short form



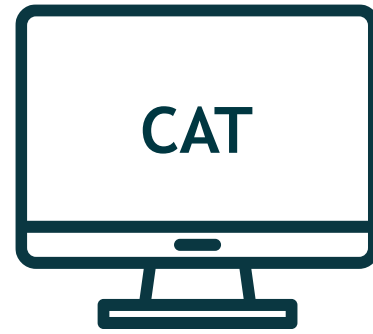
PROMIS
fixed Short
form 8



Cross walks



EORTC-30

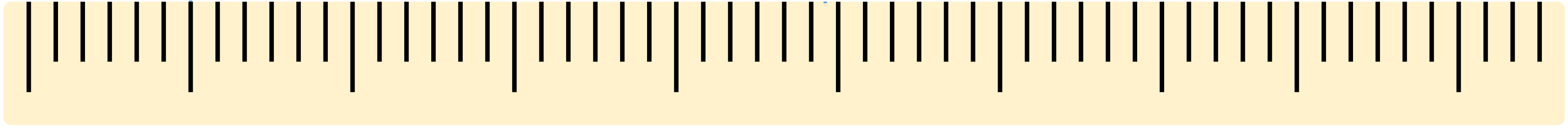


- Item 20
- Item 20
- Item 3
- Item 20
- Item 45
- Item 70

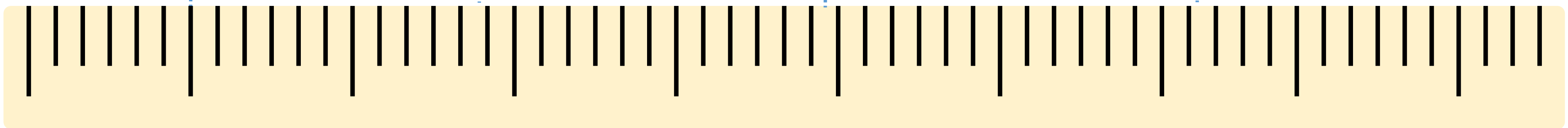
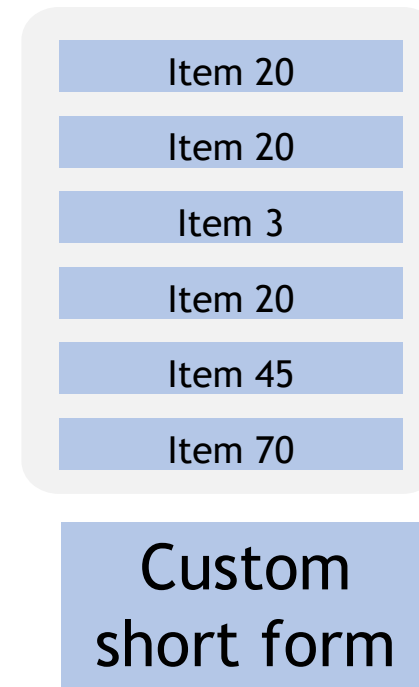
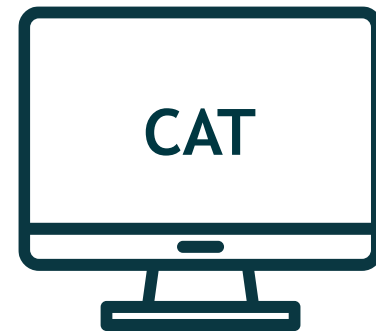
Custom short form



PedsQL

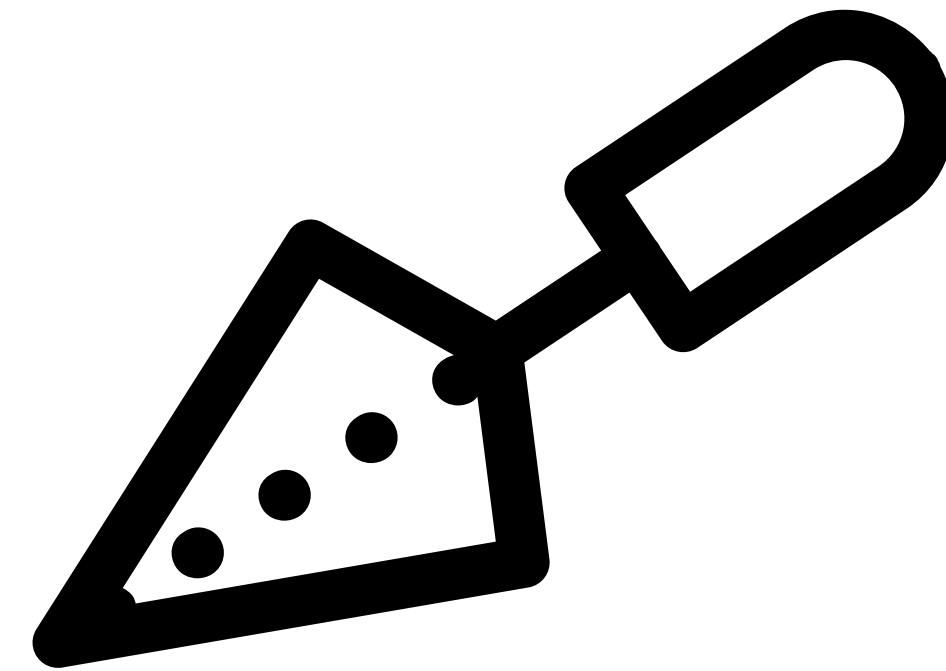


Over a lifespan





Policy PROMs



Generic: preferable PROMIS
(e.g. Anxiety, Pain, Fatigue)





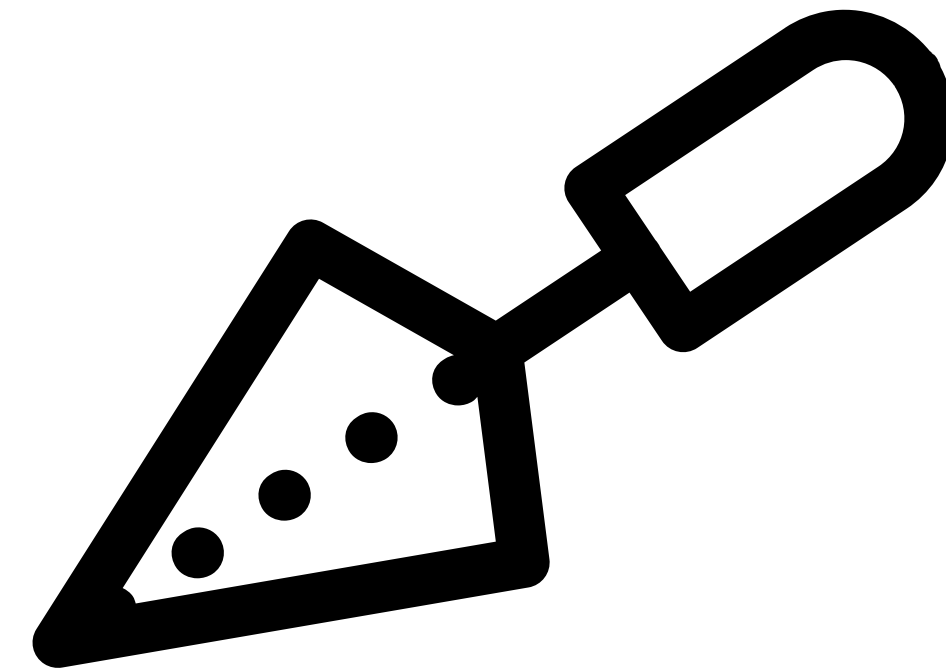
Policy PROMs

Symptom specific

(e.g. Itch)

Generic: preferable PROMIS

(e.g. Anxiety, Pain, Fatigue)





Policy PROMs

Syndrome/disease specific

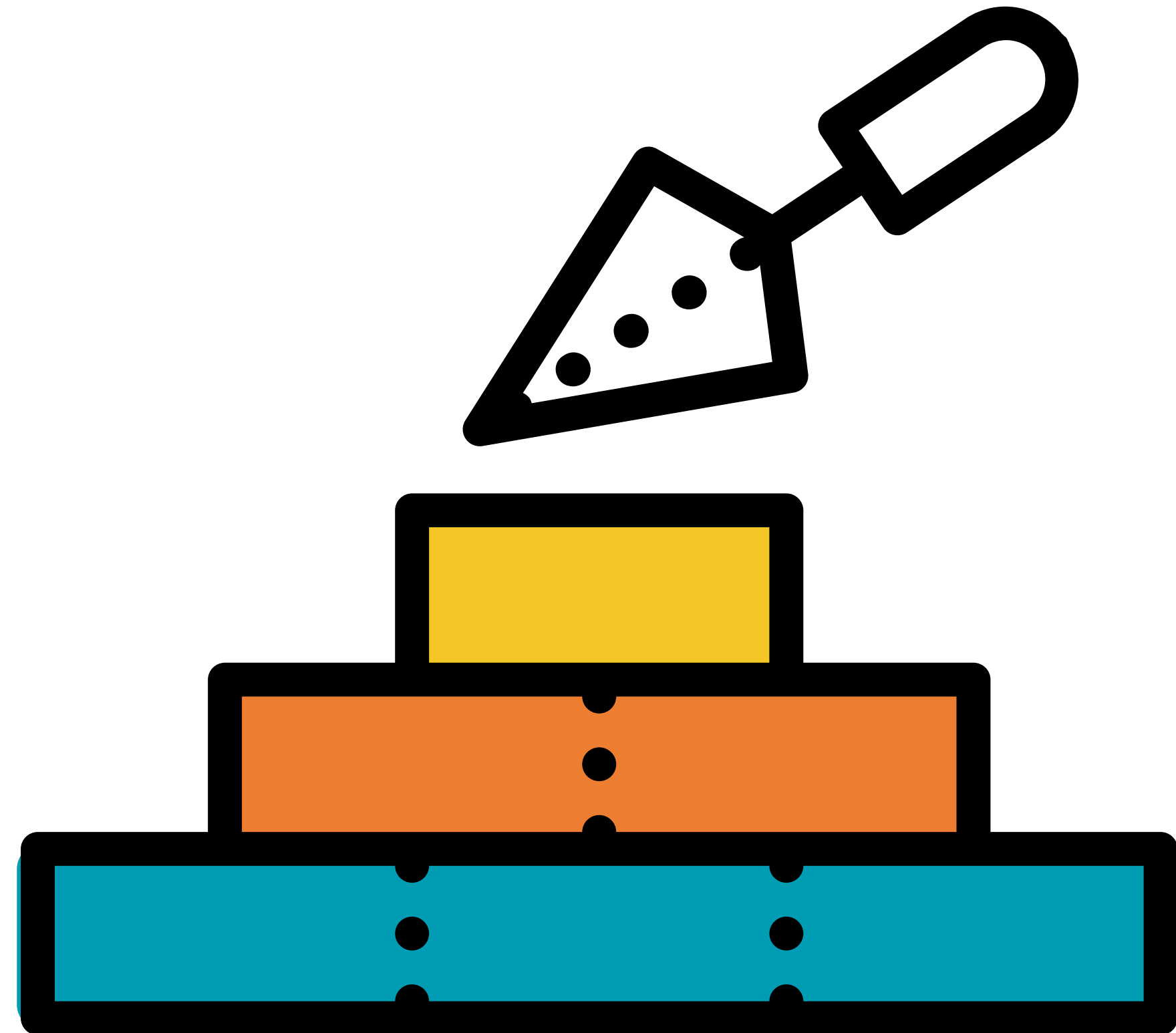
(e.g. bleedings)

Symptom specific

(e.g. Itch)

Generic: preferable PROMIS

(e.g. Anxiety, Pain, Fatigue)





The core set generic PRO(M)s

Core set generic PROs

Quality of Life

Health perception

Physical functioning

*Mental functioning
(anxiety & depression)*

Social functioning

Fatigue

Pain

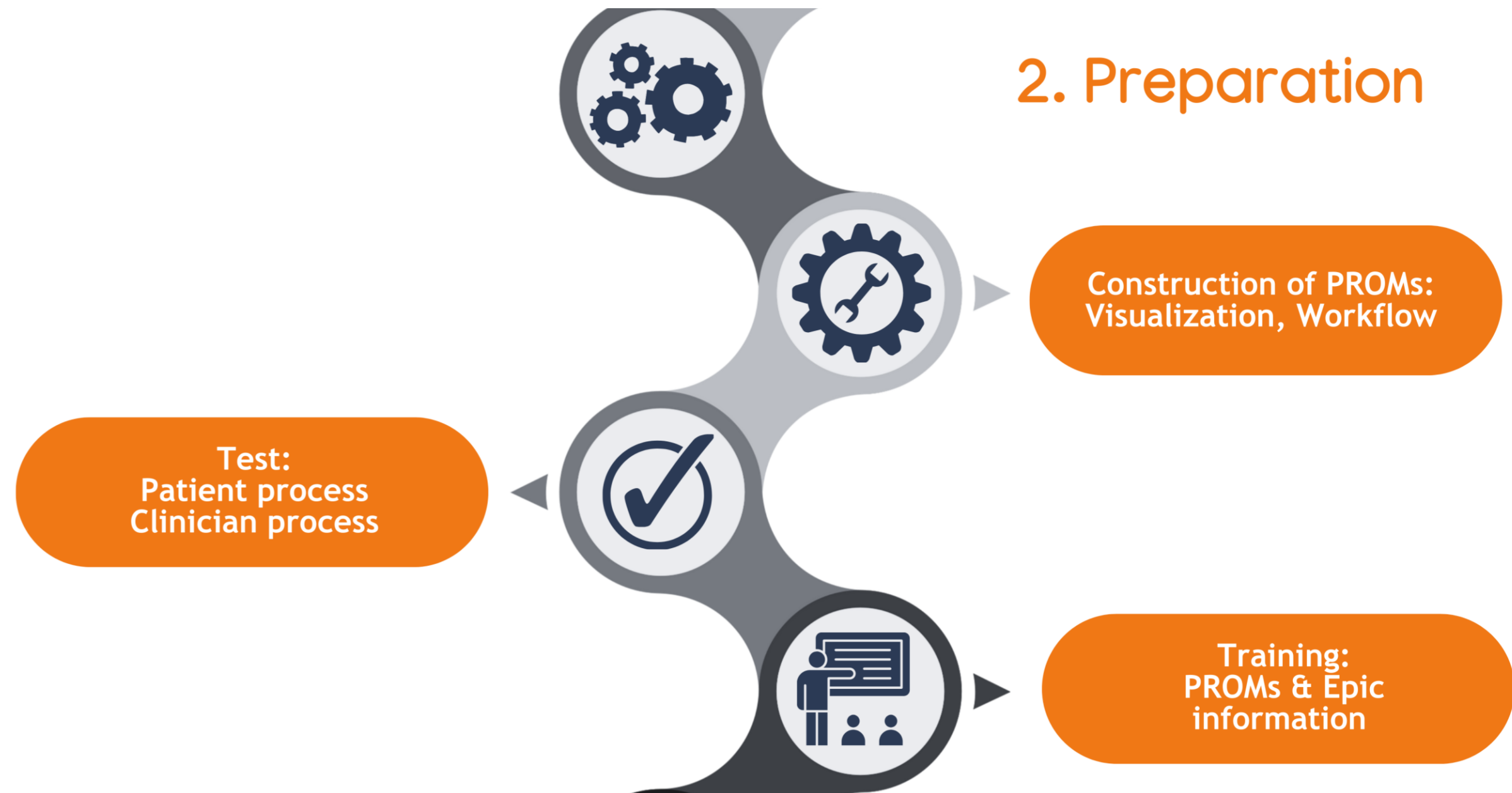
Core set Generic PROMs

PROMIS

Programma
Uitkomstgerichte
Zorg



The Amsterdam PROM pathway





ICT: Visualization PROMIS

Muilekom et al. *Journal of Patient-Reported Outcomes* (2021) 5:55
<https://doi.org/10.1186/s41687-021-00324-y>

Journal of Patient-Reported Outcomes

RESEARCH Open Access

From statistics to clinics: the visual feedback of PROMIS® CATs

Maud M. van Muilekom¹, Michiel A. J. Luijten^{1,2}, Hedy A. van Oers¹, Caroline B. Terwee², Raphaële R. L. van Litsenburg^{3,4}, Leo D. Roorda⁵, Martha A. Grootenhuys³ and Lotte Haverman^{1*}

Abstract
Background: To reduce the burden of completing Patient-Reported Outcome Measures (PROMs), PROMIS® Computerized Adaptive Tests (CATs) are being implemented in pediatric clinical practice. We aimed to develop

METHODS USED BY PRO SYSTEMS

Options for the Interpretation of and Recommendations for Acting on Different PROMs in Daily Clinical Practice Using KLIK

Lotte Haverman, PhD,* Hedy A. van Oers, MSc,* Maud M. van Muilekom, MSc,* and Martha A. Grootenhuys, PhD*†

Introduction: This paper describes the different ways in which information is being fed back to health care providers (HCPs) using the Dutch evidence-based KLIK Patient-Reported Outcome Mea-

PROM scores. The main aid is the KLIK training, which includes a theoretical and a practical part. In the training, 2 tools—a decision tree and a summary of information about the KLIK eProfile—are given to the HCPs to assist them in using KLIK.

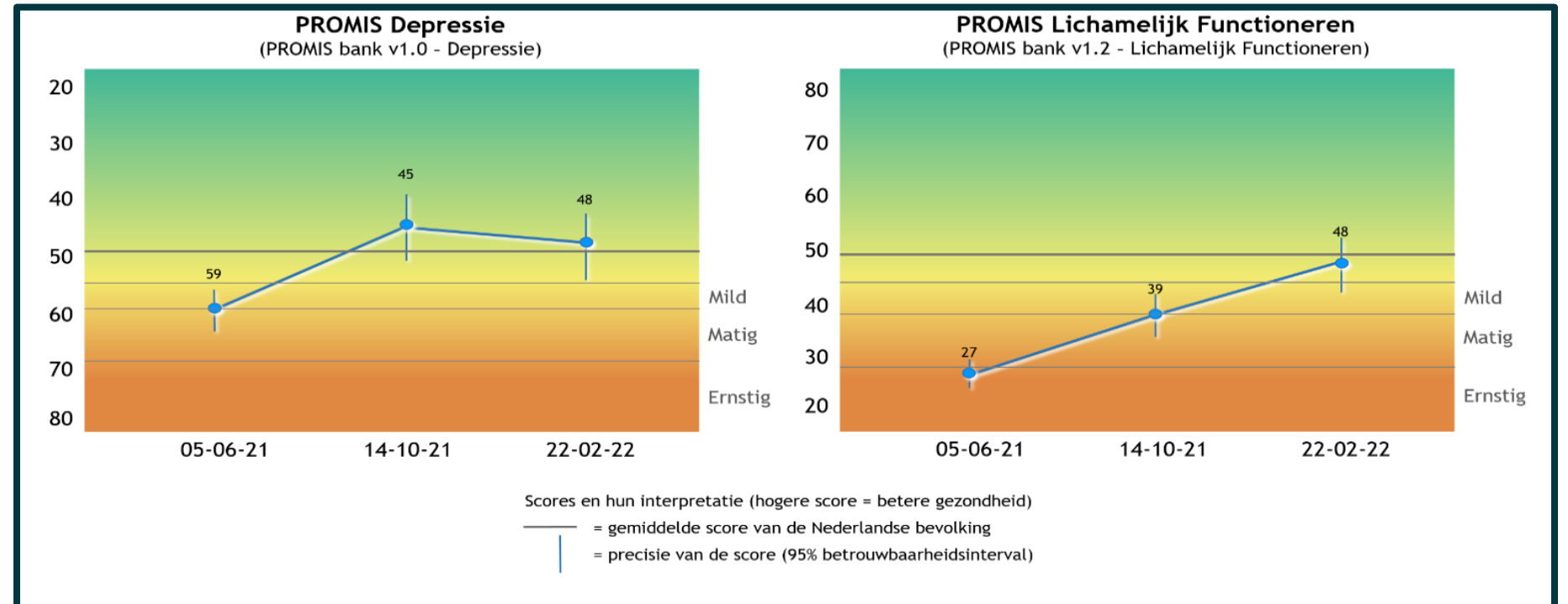
Quality of Life Research (2026) 35:66
<https://doi.org/10.1007/s11136-026-04172-5>

Making sense of PROM outcomes: a mixed method study to optimize graphical visualization formats for children

Selina Limmen^{1,2,3,4}, Maud M. van Muilekom^{1,2,3,4}, Dorinde L. Korteling^{1,2,3,5}, Lorynn Teela^{1,2,3,6}, Maarten Boers⁷, Caroline B. Terwee^{5,7}, Hedy A. van Oers^{1,2,3,8}, Lotte Haverman^{1,2,3,6}, Michiel A. J. Luijten^{1,2,3,5,7}

Received: 7 October 2025 / Accepted: 14 January 2026
© The Author(s) 2026

Abstract





Clinicians



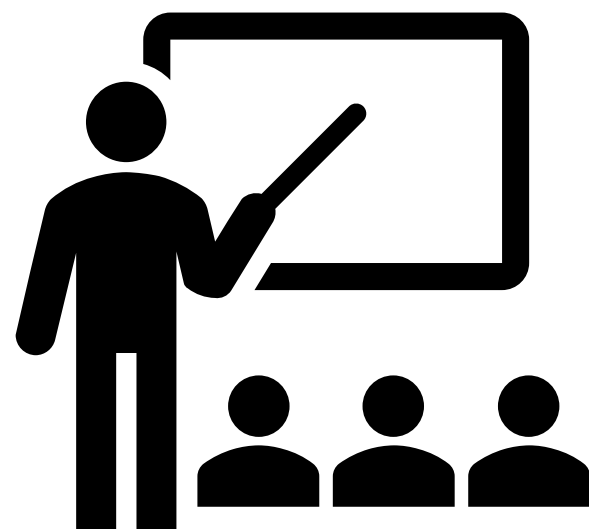


Clinicians





Clinicians



Qual Life Res (2015) 24:1707–1718
DOI 10.1007/s11136-014-0903-5



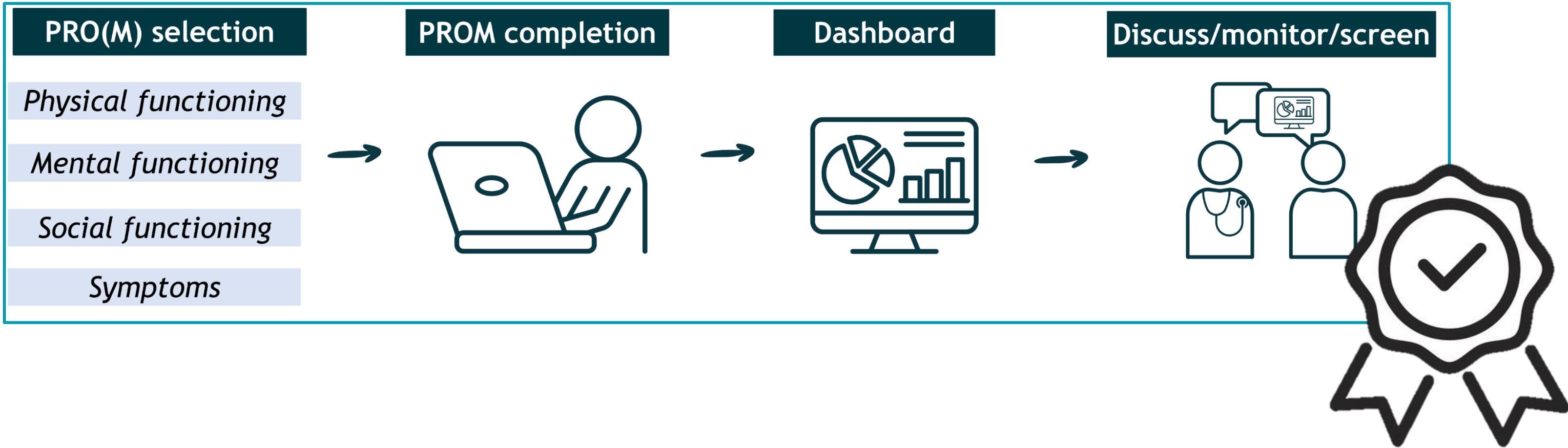
Training clinicians in how to use patient-reported outcome measures in routine clinical practice

Maria J. Santana · Lotte Haverman ·
Kate Absolom · Elena Takeuchi · David Feeny ·
Martha Grootenhuis · Galina Velikova

Accepted: 17 December 2014 / Published online: 15 January 2015
© Springer International Publishing Switzerland 2015



Clinicians





The Amsterdam PROM pathway

3. Implementation



The Amsterdam PROM pathway



1. Design

Content intake:
Desired PRO(M)s are discussed



If needed identify PROs:
Literature review and focus groups

Technical intake:
Determine workflow with Epic



Construction of PROMs:
Visualization, Workflow

Test:
Patient process
Clinician process



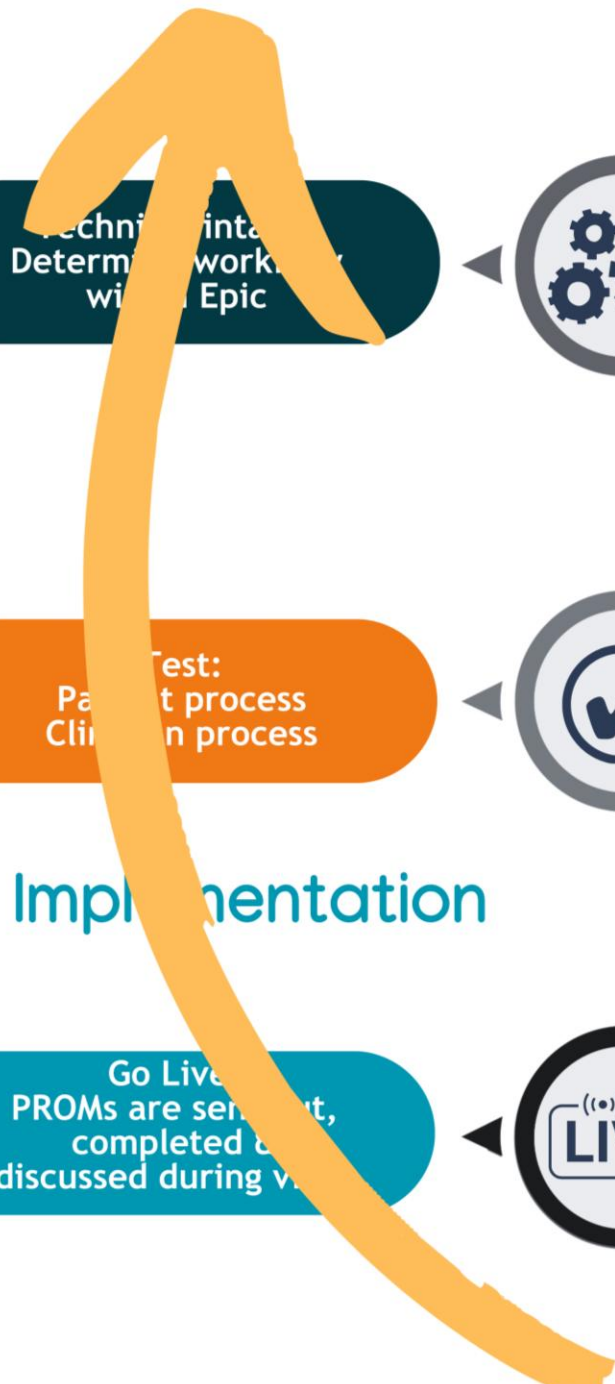
Training:
PROMs & Epic information

3. Implementation

Go Live:
PROMs are sent out,
completed & discussed during visit

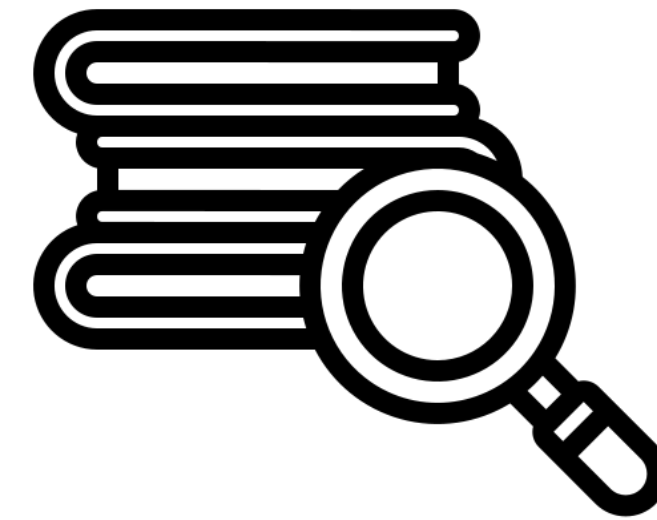


Evaluations:
Short term & Annualy





Patients and family



Unni et al. *Journal of Patient-Reported Outcomes* (2024) 8:113
<https://doi.org/10.1186/s41687-024-00745-5>

Journal of Patient-Reported
Outcomes

COMMENTARY

Open Access



Educating patients about patient-reported outcomes—are we there yet?

Elizabeth Unni^{1*}, Maud M. van Muilekom^{2,3,4}, Kate Absolom⁵, Bishnu Bajgain⁶, Lotte Haverman^{2,3,7} and Maria Santana⁸

Abstract

Background Using Patient Reported Outcome Measures (PROMs) in c

Groenewegen et al. *Journal of Patient-Reported Outcomes* (2026) 10:37
<https://doi.org/10.1186/s41687-026-01015-2>

Journal of Patient-Reported
Outcomes

REVIEW

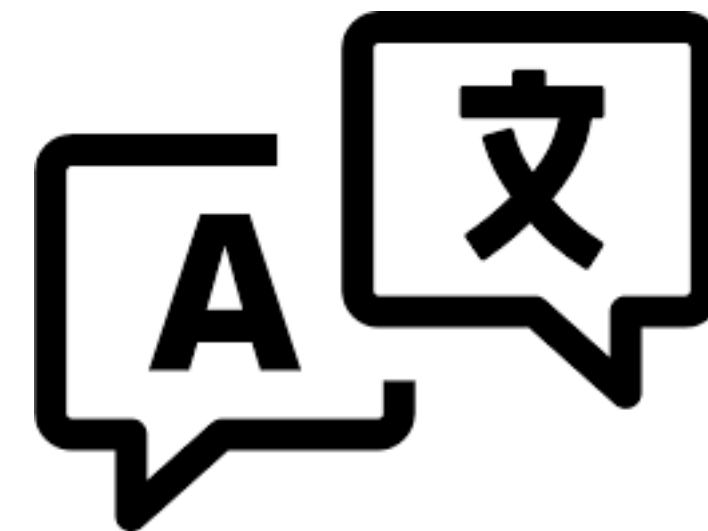
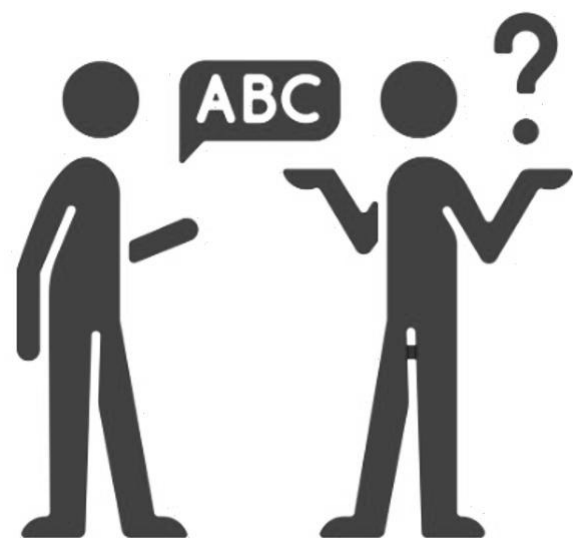
Open Access



Patient education on PROM completion in clinical care settings: a scoping review

A. Groenewegen^{1,2,3}, O. M. Biller⁴, J. Greenhalgh⁵, A. Joseph⁶, C. Lindström Egholm^{7,8}, J. Daams⁹, M. Santana^{10,11}, L. Haverman^{1,3,12}, M. M. van Muilekom^{1,2,3*} and Elizabeth Unni^{13*}

Inclusive PROMs





Item 3

Item 20

Item 45

Item 70





Item 3

~~Item 20~~

Item 45

~~Item 70~~

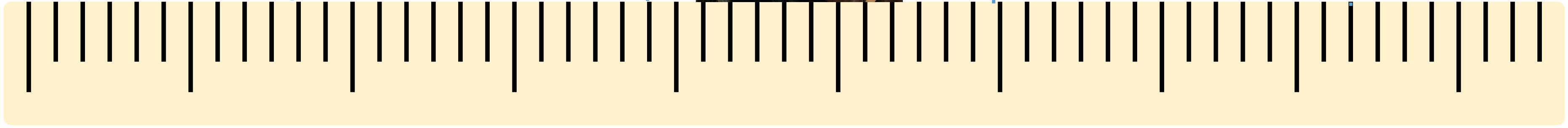
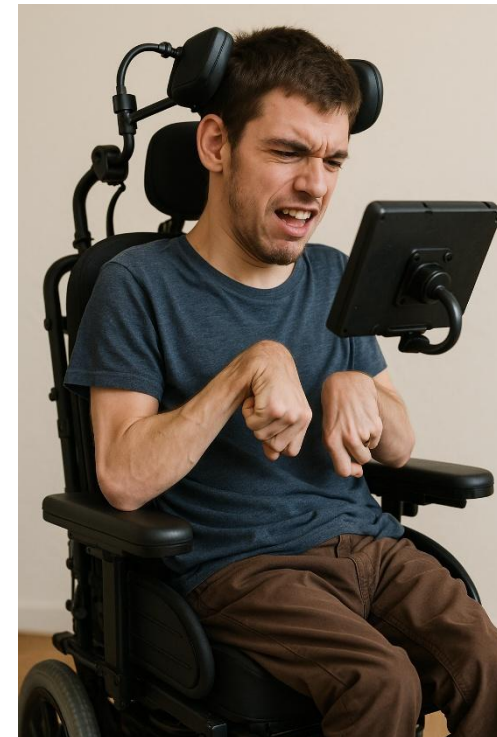


Item 3

Item 20

Item 45

Item 70

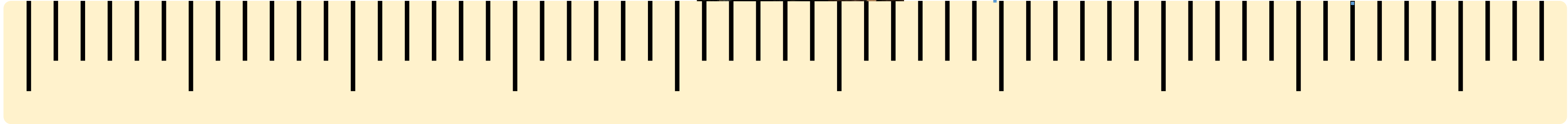


~~Item 3~~

~~Item 20~~

Item 45

Item 70



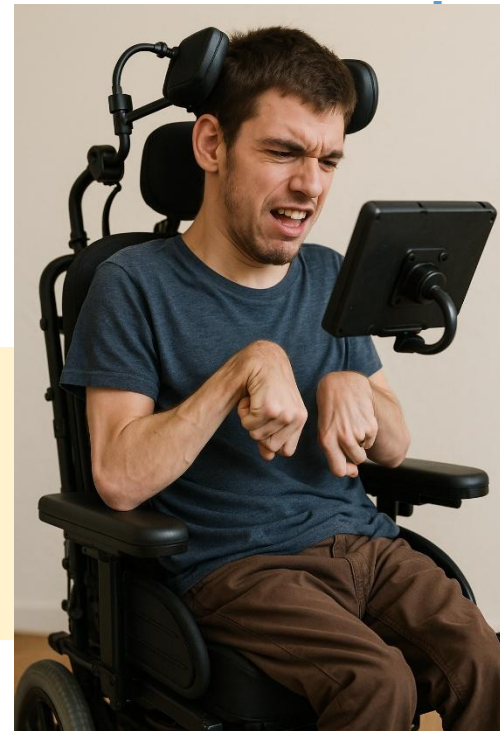


~~Item 3~~

~~Item 20~~

Item 45

Item 70





Dr. Hedy van Oers



Dr. Lorynn Teela



Dr. Maud van Muilekom



Dr. Michiel Luijten



Dr. Ellen Elsman



Dorinde Korteling



Nadia van Silfhout



Mana Nasori



Mariana Nery



Selina Limmen



Tom Steenbergen



Tessa van Gastel



Kirsten Muller



Lisa Stikvoort



Esmée Vesseur



Carmen Voorrips



Anouk Groenewegen



Franka Roest



Esmée van Zon



Juliet Hondtong



Floortje Hosman



Alannah Hijlkema



Anne Westerweel



Alessandra Viola



Heleen Haspels



Dr. Linde Scholten



Dr. Corneliëke Aarnoudse - Moens



Zorginstituut Nederland

