





**How to incorporate PROMs into everyday dialysis care: The Dutch Experience**

**Alferso C. Abrahams**  
Internist-nephrologist




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**Background**

- The burden of dialysis is high
- Dialysis patients experience numerous symptoms and have a poor health-related quality of life (HRQoL)
- HRQoL should be the most important outcome parameter in dialysis patients

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**Patient-Reported Outcome (PRO)**

- Outcomes on aspects of patients' perceived health, reported from the patient's perspective
  - HRQoL
  - functional status
  - symptom burden

3

**Patient-Reported Outcome Measure (PROM)**

- Questionnaire to measure PROs
  - generic PROM
  - specific PROM (for a disease or treatment)

4

**Patient-Reported Outcome Measure Score**

- Score for a PRO as measured by a PROM
- Interpretation
  - discussion between patient and HC professional
  - comparison with general and reference population
  - comparison with clinical and biochemical measures

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**PROMs in the Netherlands**

- 2015-2016: selection of PROMs






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Willik et al. BMC Nephrology (2019) 20:344  
<https://doi.org/10.1186/s12882-019-1521-9>

BMC Nephrology

RESEARCH ARTICLE Open Access

Check for updates

**Patient-reported outcome measures: selection of a valid questionnaire for routine symptom assessment in patients with advanced chronic kidney disease – a four-phase mixed methods study**

Esmee M. van der Willik<sup>1\*</sup>, Yvette Meuleman<sup>1</sup>, Karen Prandt<sup>2</sup>, Giel van Rijn<sup>1</sup>, Willem Jan W. Bos<sup>3,4</sup>, Frans J. van Ittersum<sup>5</sup>, Hans A. J. Bart<sup>6</sup>, Marc H. Hemmelder<sup>6,7</sup> and Friedo W. Dekker<sup>1</sup>

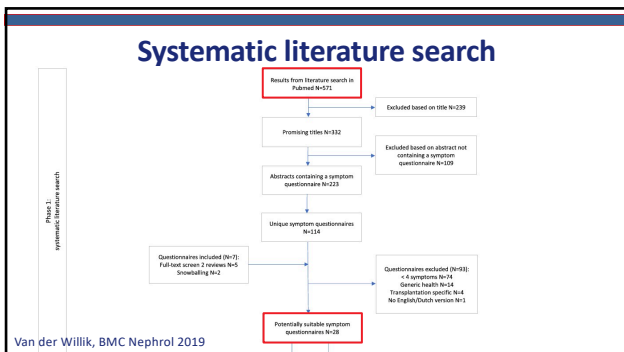
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### Selection of PROMs

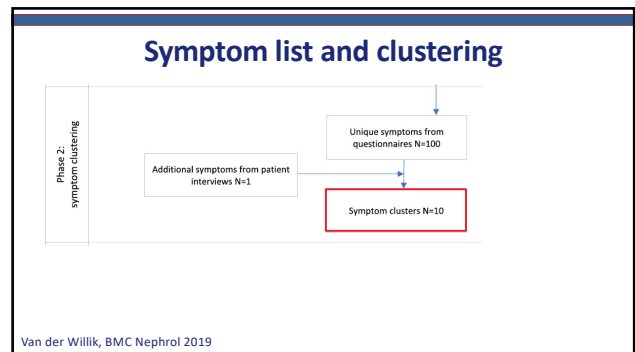
- Four-phase mixed method
  - 1) Perform a systematic literature search
  - 2) Create a complete list of unique symptoms and clustering in symptoms groups
  - 3) Preliminary selection of symptom questionnaire
  - 4) Evaluate questionnaires with panel of patients and experts

Van der Willik, BMC Nephrol 2019

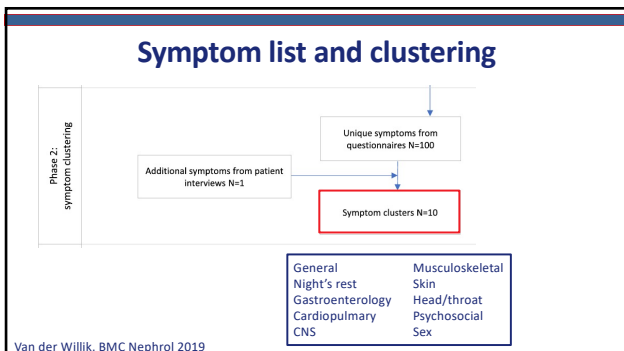
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### Preliminary selection of questionnaires

- Criteria
  - > 90% of the clusters is covered by the questionnaire
  - maximum length of 90 items / 15 minutes to complete
  - applicable and validated in patients with advanced CKD
  - suitable for use in routine care

**26 of 28 questionnaires excluded leaving DSI and IPOS-Renal**

Van der Willik, BMC Nephrol 2019

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### Feedback patient panel

**Table 3** Comparison of two CKD-specific symptom questionnaires based on feedback of the patient panel (n = 151)

	DSI (n = 78)	POS-Renal (n = 75)	p-value
Age (years)	60.6 (12.5)	62.2 (16.4)	0.8
Treatment modality			0.5
Pre-dialysis	6 (7.9)	13 (17.3)	
Hemodialysis	8 (10.5)	9 (12.0)	
Peritoneal dialysis	6 (7.9)	4 (5.3)	
Transplant	53 (69.7)	47 (62.7)	
Other	3 (3.9)	2 (2.7)	
Objective time to complete* (minutes)	5.4 (1.6)	7.5 (1.8)	<0.001
Subjective time to complete* (minutes)	3.2 (1.8)	4.8 (1.6)	<0.001
Number of symptoms reported*	12.0 (6.5)	8.0 (4.1)	<0.001
Additional 1-3 symptoms reported*	21 (27.8)	25 (33.3)	0.5
Burdensome of questionnaire (yes)	4 (5.3)	2 (2.7)	0.4
Appropriate frequency of submission (times per year)	2.7 (1.8)	2.9 (2.2)	0.6

Van der Willik, BMC Nephrol 2019

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### Dialysis Symptom Index

1. Constipation	16. Chest pain
2. Nausea	17. Headache
3. Vomiting	18. Muscle soreness
4. Diarrhoea	19. Difficulty concentrating
5. Decreased appetite	20. Dry skin
6. Muscle cramps	21. Itching
7. Swelling in legs	22. Worrying
8. Shortness of breath	23. Feeling nervous
9. Lightheadedness or dizziness	24. Trouble falling asleep
10. Restless legs or difficulty keeping legs still	25. Trouble staying asleep
11. Numbness or tingling in feet	26. Feeling irritable
12. Feeling tired or lack of energy	27. Feeling sad
13. Cough	28. Feeling anxious
14. Dry mouth	29. Decreased interest in sex
15. Bone or joint pain	30. Difficulty becoming sexually aroused

Weisbord, J Pain Sympt Manag 2004

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### 12-item Short Form

Item number	Description of Item (abridged)
1	In general, would you say your health is: excellent, very good, good, fair, poor
2	Does your health now limit you in moderate activities?
3	Does your health now limit you in climbing several flights of stairs?
4	During the past 4 weeks, have you as a result of your physical health accomplished less than you would like?
5	During the past 4 weeks, were you as a result of your physical health limited in the kind of work or other activities?
6	During the past 4 weeks, have you as a result of emotional problems, accomplished less than you would like?
7	During the past 4 weeks, have you as a result of emotional problems, not done work or other activities as carefully as usual?
8	During the past 4 weeks, how much did pain interfere with your normal work?
9	How much of the time during the past 4 weeks have you felt calm and peaceful?
10	How much of the time during the past 4 weeks did you have a lot of energy?
11	How much of the time during the past 4 weeks have you felt downhearted and blue?
12	During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities?

Ware, Med Care 1996

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### PROMs in the Netherlands

- 2015-2016: selection of PROMs
- 2016-2017: pilot study with PROMs

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Clinical Kidney Journal, 2020, 1-10  
doi: 10.1093/ckj/sfz192  
Original Article

ORIGINAL ARTICLE


## Routinely measuring symptom burden and health-related quality of life in dialysis patients: first results from the Dutch registry of patient-reported outcome measures

Esmee M. van der Willik <sup>1</sup>, Marc H. Hemmeldeir<sup>2,3</sup>, Hans A. J. Bart<sup>4</sup>, Frans J. van Ittersum<sup>5</sup>, Judith M. Hoogendijk-van den Akker<sup>6</sup>, Willem Jan W. Bos<sup>7,8</sup>, Friedo W. Dekker<sup>1</sup> and Yvette Meuleman<sup>1</sup>

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### RENINE

- Dutch registry on chronic RRT
- Collects, stores, analyses, and reports information about kidney disease and clinical outcomes
- All dialysis centres provide data → coverage rate > 95%
- Is perfectly suited to collect, process, and report PROMs

  
 Richtlijnen • Registratie • Visitatie

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### Research questions in Dutch pilot study

- What is the response rate? Centre variation?
- What is HRQoL and symptom burden? Centre variation?
- What are patients' experiences and preferences?

Van der Willik, CKJ 2020

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### Design of Dutch pilot study

- Sept 2016 – April 2017
- 16 centres (treating 26% of all Dutch dialysis patients)
- Baseline, 3 and 6 months

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### Response rate

- 1440 prevalent patients were invited
- 36% responded at least once
- 24% completed 3 questionnaires
- Response rate was higher at baseline (28% vs 21%)
- Responders were more frequently male, older, had higher SES, and started RRT more recently

Van der Willik, CKJ 2020

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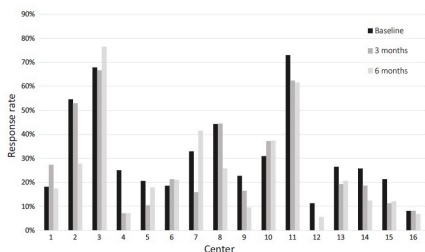
### Response rate

- Average time to complete the PROMs  $12.2 \pm 6.1$  min
- 41% needed support to complete the PROMs
  - reading questions aloud (81%)
  - filling in patients' answers (79%)
  - translating questions
  - completing questionnaire on behalf of patient
  - assistance using electronic device
  - discussing questions with relatives to remember their experiences

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### Centre variation in response rate



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### Top 10 most frequent symptoms

Rank	Symptom frequency	n (%)
1	Feeling tired or lack of energy	366 (76.4)
2	Dry skin	283 (58.7)
3	Trouble staying asleep	260 (54.3)
4	Muscle cramps	246 (51.0)
5	Itching	240 (50.0)
6	Bone or joint pain	225 (47.0)
7	Dry mouth	223 (46.8)
8	Trouble falling asleep	206 (43.2)
9	Shortness of breath	207 (43.1)
10	Decreased interest in sex	193 (41.8)

Van der Willik, CKJ 2020

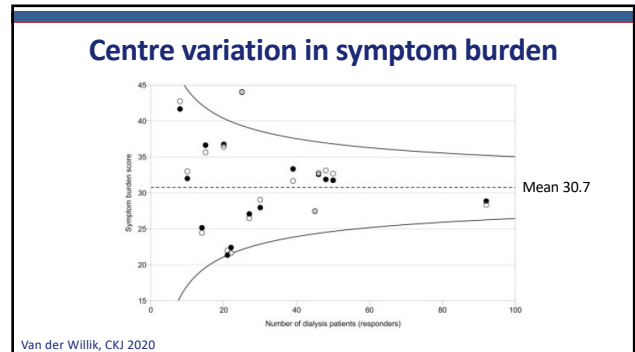
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### Top 10 most burdensome symptoms

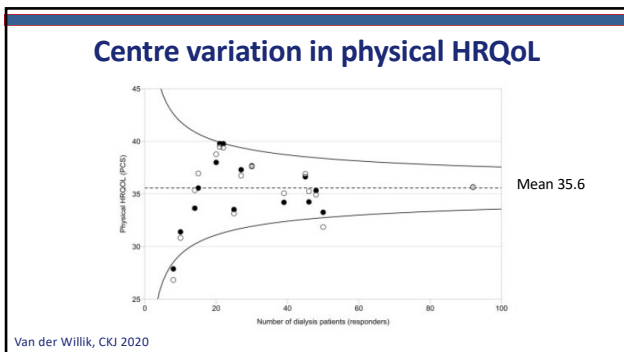
Rank	Symptom burden <sup>b</sup>	Mean (SD)
1	Difficulty becoming sexually aroused	3.42 (1.4)
2	Trouble falling asleep	3.26 (1.1)
3	Decreased interest in sex	3.25 (1.5)
4	Feeling tired of lack of energy	3.24 (1.0)
5	Bone or joint pain	3.23 (1.1)
6	Trouble staying asleep	3.18 (1.1)
7	Dry skin	3.04 (1.2)
8	Numbness or tingling in feet	2.99 (1.0)
9	Restless legs or difficulty keeping legs still	2.94 (1.0)
10	Itching	2.88 (1.0)

Van der Willik, CKJ 2020

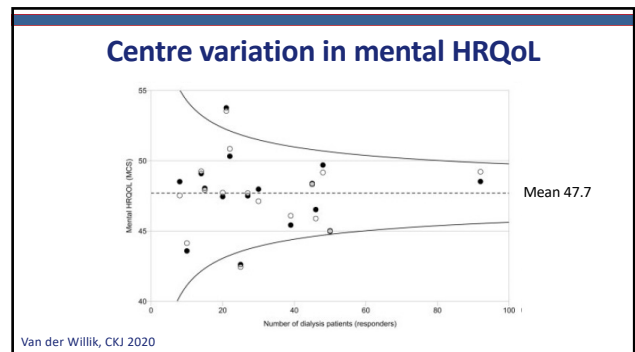
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- ### Patient experiences and preferences
- 79% wanted to share and discuss their results with clinician
  - Patients discussed the results with a nephrologist, a nurse and/or social worker → mean score 3.8 (on a scale of 1-5)
  - Professionals also appreciated discussing PROMs
- Van der Willik, CKJ 2020

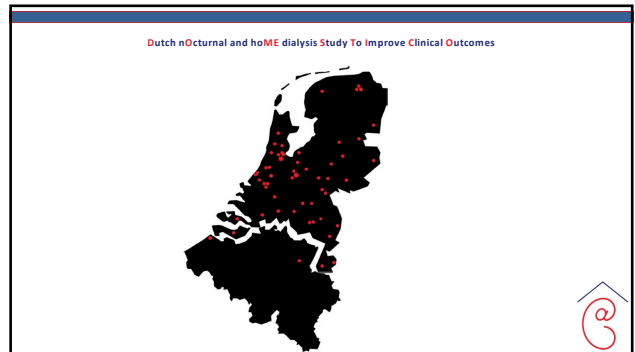
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- ### PROMs in the Netherlands
- 2015-2016: selection of PROMs
  - 2016-2017: pilot study with PROMs
  - Since 2017: **use of PROMs in DOMESTICO**

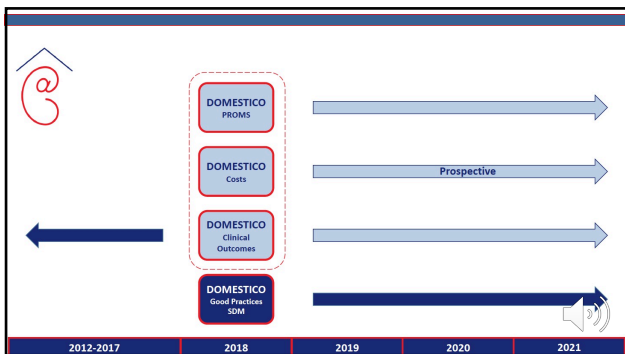
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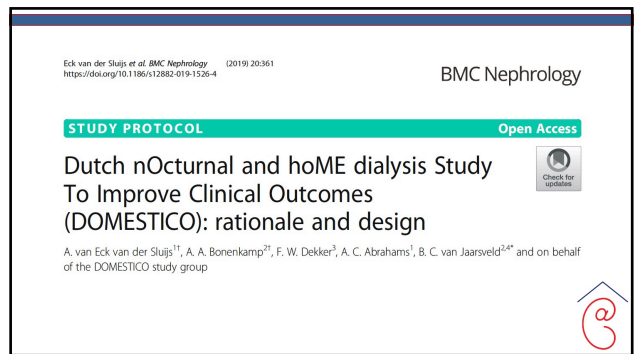
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### DOMESTICO Prospective

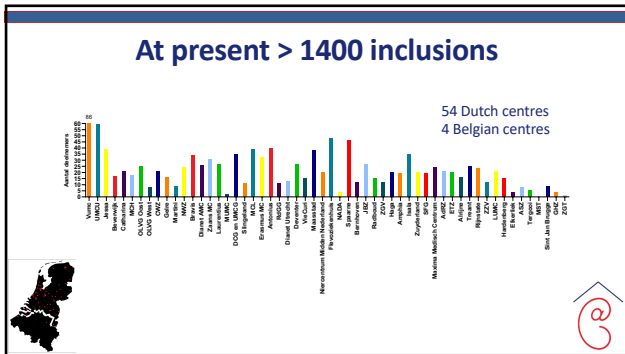
- Aim: investigate the effect of home dialysis on HRQoL, clinical outcomes, and costs
- Nationwide, prospective, observational cohort study
- **Incident** dialysis patients
  - 800 home dialysis patients
  - 800 in-centre HD patients

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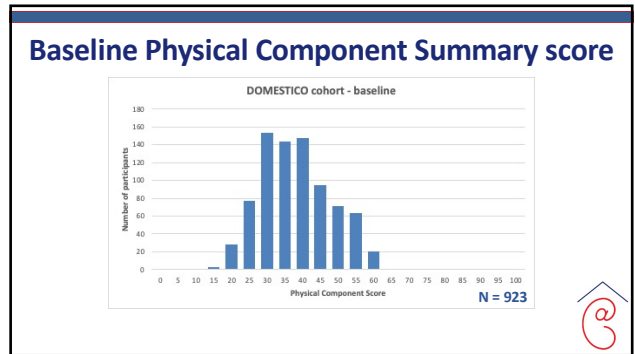
### DOMESTICO Prospective

- Primary outcome
  - HRQoL → PROMs
- Secondary outcomes
  - clinical outcomes (hospitalization, mortality)
  - costs
  - technique failure

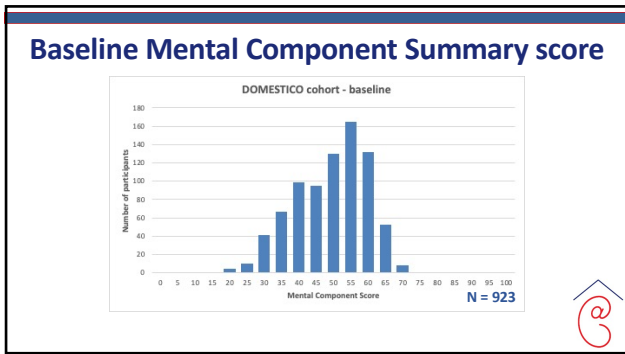
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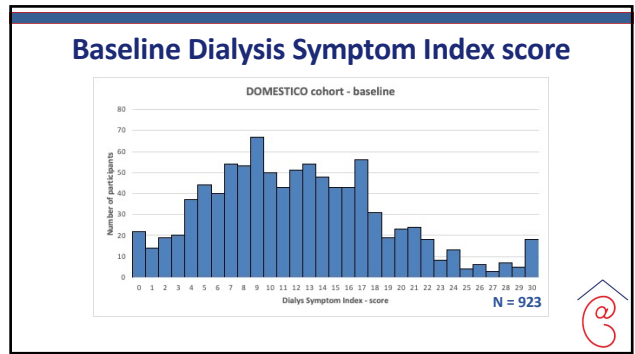
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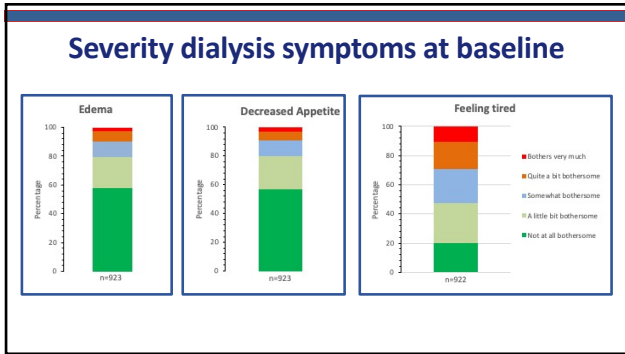
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Journal of Nephrology  
<https://doi.org/10.1007/s40620-021-01005-1>

ORIGINAL ARTICLE

### The Impact of COVID-19 on the mental health of dialysis patients

Anna A. Bonenkamp<sup>1</sup>, Theresia A. Druiventak<sup>2</sup>, Anita van Eck van der Sluijs<sup>2</sup>, Frans J. van Ittersum<sup>1</sup>, Brigit C. van Jaarsveld<sup>1,3</sup>, Alfresco C. Abrahams<sup>2</sup> on behalf of the DOMESTICO study group

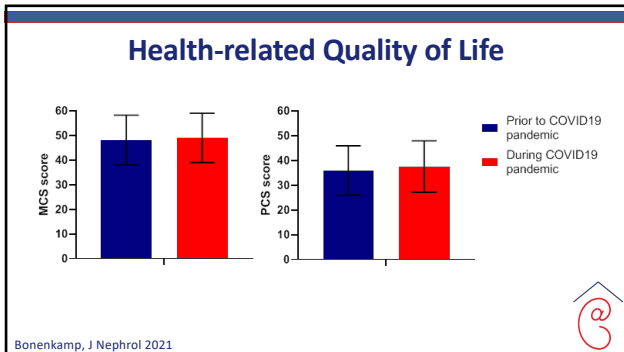
**Methods**

- Data from nationwide cohort study
- Quality of life questionnaires during pandemic and 9-6 months prior
- February 27th and July 1st 2020

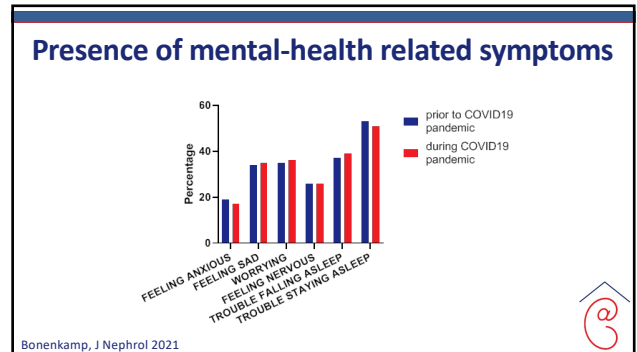
**Cohort**

- n = 177
- Age 64.9 ± 11.5
- 75% in-center haemodialysis

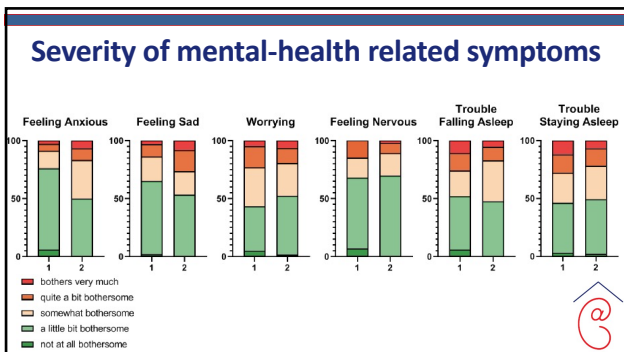
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- ### PROMs in the Netherlands
- 2015-2016: selection of PROMs
  - 2016-2017: pilot study with PROMs
  - Since 2017: use of PROMs in DOMESTICO
  - Since 2018: implementation of PROMs in daily care

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- ### Implementation of PROMs in daily care
- Frequency: at least annually, more often on indication
  - Online collection

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### Nefrodata generates invitations for PROMs ...

The screenshot shows the Nefrodata web interface. At the top, it says 'Nefrodata generates invitations for PROMs ...'. Below this, there are navigation tabs: 'Patiëntgegevens', 'Therapiegegevens', 'Klinische gegevens', and 'PROMs'. Under the 'PROMs' tab, there is a text prompt: 'Hier kunt u de uitnodiging PROMs voor de patiënt 503891 downloaden.' followed by a red-bordered 'Download' button. A red arrow points to this button. At the bottom right, there is a 'Download PROMs rapport' button. The Nefrodata logo is in the bottom right corner.

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... and collect and report results

# Nefrodata

Terug naar patiëntoverzicht

Patiëntgegevens Therapiegegevens Klinische gegevens PROMs

Hier kunt u de uitnodiging PROMs voor de patiënt 503881 downloaden: [Download](#)

12-02-2020 Centrum Universitair Medisch Centrum Utrecht

[Download PROMs rapport](#)

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### Kwaliteit van leven

Uw antwoord
1 Hoe zou u over het algemeen uw gezondheid noemen? <b>Goed</b>
2 Wordt u door uw gezondheid beperkt bij matige inspanning, zoals een tasje verplaatsen, afdozen, zwermen of fietsen? <b>Ja, een beetje beperkt</b>
3 Wordt u door uw gezondheid beperkt als u een paar trappen moet oplopen? <b>Ja, een beetje beperkt</b>
4 Lichamelijke gezondheid: u heeft minder bereikt dan u zou willen <b>Ja</b>
5 Lichamelijke gezondheid: u was beperkt in het soort werk of het soort bezigheden <b>Ja</b>
6 Emotionele problemen: u heeft minder bereikt dan u zou willen <b>Ja</b>
7 Emotionele problemen: u deed uw werk of andere bezigheden niet zo zorgvuldig als gewoonlijk <b>Nee</b>
8 In welke mate bent u de afgelopen 4 weken door pijn gehinderd in uw normale werk (zowel werk buitenshuis als huishoudelijk werk)? <b>Een klein beetje</b>
9 Hoe vaak gedurende de afgelopen 4 weken voelde u zich rustig en tevreden? <b>Vaak</b>
10 Hoe vaak gedurende de afgelopen 4 weken had u veel energie? <b>Zelden</b>
11 Hoe vaak gedurende de afgelopen 4 weken voelde u zich somber en neerslachtig? <b>Soms</b>
12 Hoe vaak hebben uw lichamelijke gezondheid of emotionele problemen u gehinderd bij uw sociale activiteiten (zoals vrienden of familie bezoeken, etc.)? <b>Meestal</b>

SF-12

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### Dialysis Symptom Index

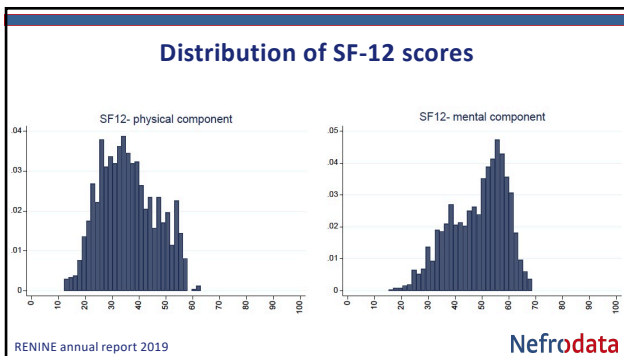
Ervaren symptomen in de afgelopen week	Ervaren in hoeveelheid last
1 Vermoeidheid	Nee
2 Maalstijvast	Nee
3 Braken	Nee
4 Diarree	Nee
5 Verminderde eetlust	Nee
6 Spierkrampen	Nee
7 Opgelaten benen	Nee
8 Duizeligheid	Nee
9 Kortademigheid	Nee
10 Ruisende oren	Nee
11 Tintelingen in de vingers	Nee
12 Vermoeidheid	Ja, een beetje last
13 Hoofdpijn	Ja, veel last
14 Droogmond	Nee
15 Pijnen buiten of gewrichten	Nee
16 Pijn op de been	Ja, heel veel last
17 Hoofdpijn	Nee
18 Spierpijn	Nee
19 Concentratieproblemen	Ja, een beetje last
20 Droogheid	Nee
21 Juk	Nee
22 Pijnreuzen	Nee
23 Nervositeit	Ja, een beetje last
24 Moeite om in slaap te vallen	Ja, een beetje last
25 Moeite doorlopen	Nee
26 Gebrekkig gevoel	Ja, veel last
27 Verlaten	Ja, veel last
28 Angstig gevoel	Nee
29 Verminderde interesse in seks	Ja, een beetje last
30 Problemen om te komen opgevoerd te raken	Ja, veel last

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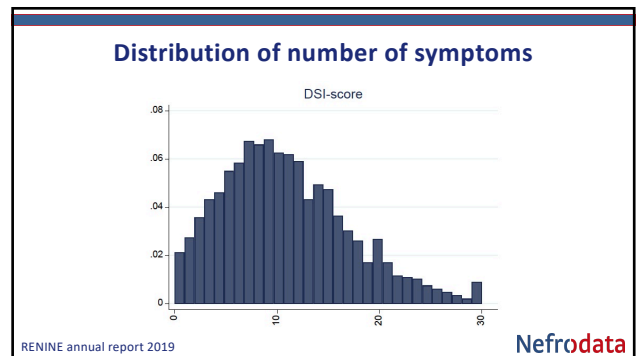
### Implementation of PROMs in daily care

- Discuss results during multidisciplinary team meeting
- And with the patient

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### Top 10 most frequent symptoms

Table 5.2. Top 10 most frequent symptoms separately for men and women

Men	Women
Feeling tired/lack of energy 73%	Feeling tired/lack of energy 77%
Dry skin 52%	Dry skin 68%
Trouble staying asleep 51%	Muscle cramps 56%
Muscle cramps 51%	Trouble staying asleep 52%
Itching 49%	Dry mouth 50%
Dry mouth 45%	Bone or joint pain 49%
Shortness of breath 44%	Itching 47%
Trouble falling asleep 43%	Trouble falling asleep 44%
Bone or joint pain 41%	Coughing 43%
Decreased interest in sex 41%	Restless legs 43%

RENINE annual report 2019 Nefrodata

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### Top 10 most burdensome symptoms

Table 5.3. Top 10 most burdensome symptoms

Men	Mean score	Women	Mean score
Difficulty becoming sexually aroused	3.27	Trouble falling asleep	3.24
Decreased interest in sex	3.14	Difficulty becoming sexually aroused	3.19
Trouble falling asleep	3.07	Trouble staying asleep	3.17
Feeling tired/lack of energy	3.06	Feeling tired/lack of energy	3.13
Trouble staying asleep	3.06	Bone or joint pain	3.13
Itching	3.01	Decreased interest in sex	3.05
Bone or joint pain	2.95	Dry skin	3.04
Dry skin	2.89	Numbness or tingling in feet	3.02
Restless legs	2.87	Restless legs	3.01
Numbness or tingling in feet	2.83	Itching	2.91

Average burden score (1-5) reported when the symptom was present.

RENINE annual report 2019 Nefrodata

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- ### PROMs in the Netherlands
- 2015-2016: selection of PROMs
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  - Since 2017: use of PROMs in DOMESTICO
  - Since 2018: implementation of PROMs in daily care
  - Since 2019: **use of PROMs in other studies**

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DIALOGICA DOMESTICO

**Nefrovisie**  
Zicht op nierzorg

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Oevelen et al. *BMC Nephrology* (2021) 22:39  
<https://doi.org/10.1186/s12882-021-02235-y> BMC Nephrology

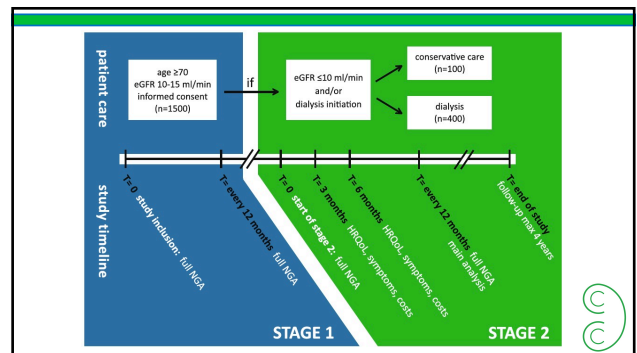
**STUDY PROTOCOL** Open Access

### DIALysis or not: Outcomes in older kidney patients with Geriatric Assessment (DIALOGICA): rationale and design

Mathijs van Oevelen<sup>1\*</sup>, Alfiero C. Abrahams<sup>2</sup>, Willem Jan W. Bos<sup>1,3</sup>, Mariëtte H. Emmelot-Vonk<sup>4</sup>, Simon P. Mooijaart<sup>5</sup>, Merel van Diepen<sup>6</sup>, Brigit C. van Jaarsveld<sup>7</sup>, Anita van Eck van der Sluijs<sup>2</sup>, Carlijn G. N. Voorend<sup>1</sup>, Marjolijn van Buren<sup>1,8</sup> and on behalf of the DIALOGICA study group

[Check for updates](#)

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### PROMs in the Netherlands

- 2015-2016: selection of PROMs
- 2016-2017: pilot study with PROMs
- Since 2017: use of PROMs in DOMESTICO
- Since 2018: implementation of PROMs in daily care
- Since 2019: use of PROMs in other studies
- **2021: key success factors and challenges**

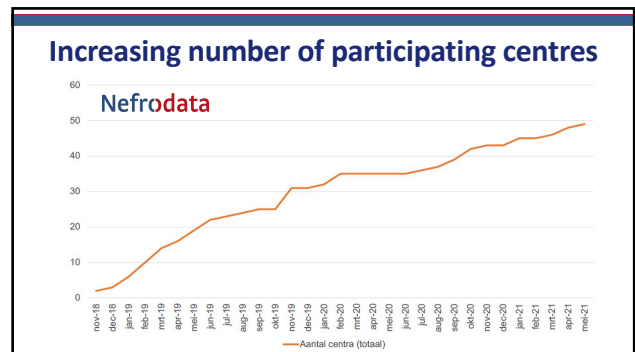
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ckj OXFORD Cera Clinical Kidney Journal, 2020, 1-10  
doi: 10.1093/ckj/nfz192  
Original Article

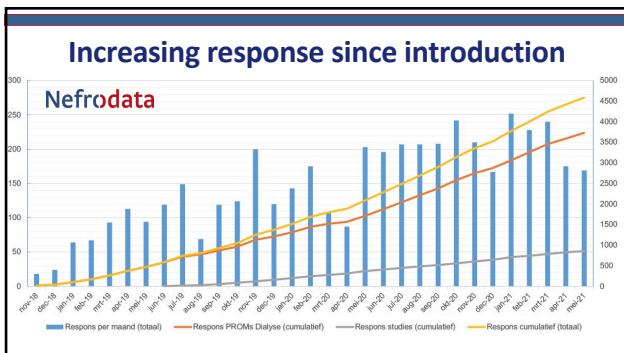
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Pilot in 16 centres  
 Sept 2016 - April 2017

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### Key success factors for implementation PROMs

- Collaboration
  - on a national level
  - on a centre level
- Appropriate infrastructure
  - on a national level → support by RENINE
  - on a centre level → integration in daily clinical care

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### Key success factors for implementation PROMs

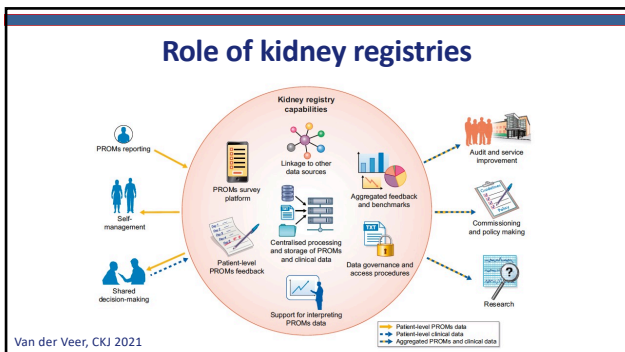
- Motivating health care professionals
- Online collection of PROMs, but also on paper
- Incorporation of PROMs in studies
- Providing individual feedback on PROMs results to patients

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### Challenges for the implementation of PROMs

- Large-scale infrastructure for collecting, storing, analysing, and reporting PROMs data is required → role for kidney registries

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### Challenges for the implementation of PROMs

- Large-scale infrastructure for collecting, storing, analysing, and reporting PROMs data is required → role for kidney registries
- Patient and staff engagement
- Support patients to complete PROMs
- Prevent survey fatigue
- Integration in electronic health records
- Attention for patients with low (e-)health literacy

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### Conclusions

- Incorporating PROMs into everyday dialysis care is feasible
- Collaboration and motivating professionals are key success factors
- Use of PROMs has a positive effect on quality of life of dialysis patients
- Use of PROMs improves quality of kidney care

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