

How to help researchers in palliative care improve responsiveness to migrants and other underrepresented populations: Developing and testing a self-assessment instrument

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Palliatieve zorg
Noord-Holland
& Flevoland



Show of hands

During the set-up of our project, we determined which groups were at risk of being underrepresented and needed consideration.

In our project, we test whether the patient information materials we use are appropriate in terms of language, (health) literacy level, and culture sensitivity.





Palliantie. Meer dan Zorg

“Palliantie is designed to achieve noticeable improvements in palliative care for patients and their families.”



ZonMw



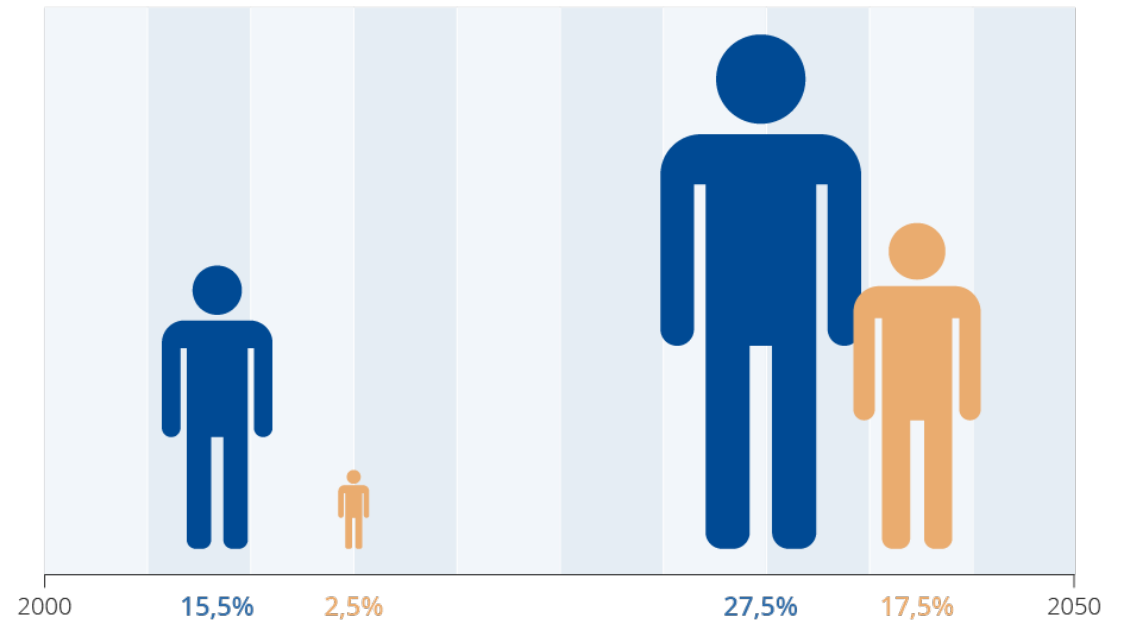
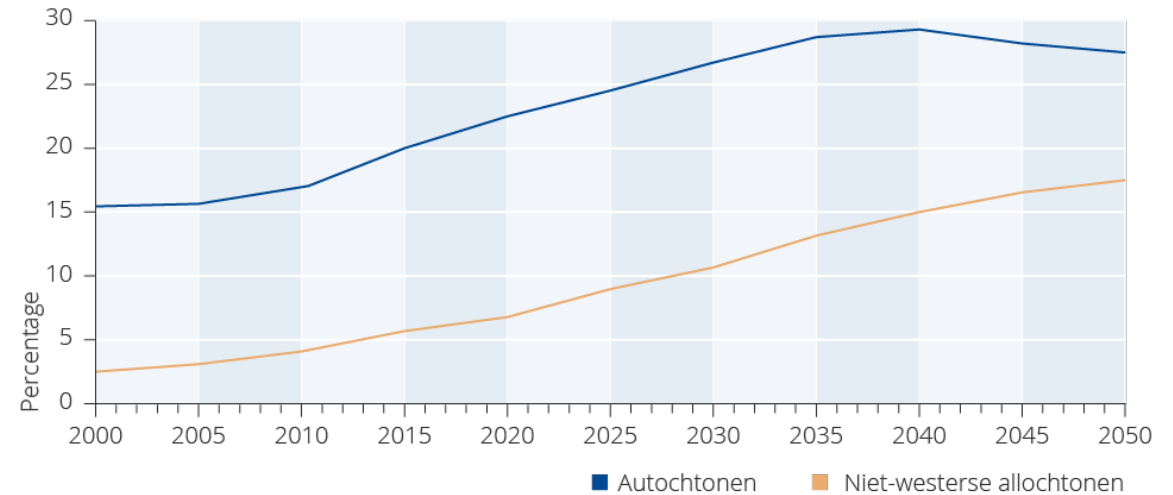


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Prognosis 2000 - 2050

Share of people with a Dutch background & people with a non-western migration background aged ≤ 65 in the total population.



Garssen, J. & Van Duin, C. 2009



	Non-western migration background Total n=605	Dutch & western migration background Total n=4722		
	%	%	Adjusted OR*	CI (95%)
Hospital death	39.1	20.1	1.96	1.39 - 2.78
Hospital admission in the last month	51.6	33.9	1.74	1.26 - 2.41
Morphine in the last 24h	72.8	80.1	0.62	0.43 - 0.89
Continuous deep sedation	16.8	25.2	0.52	0.34 - 0.80
Artificial nutrition or hydration during sedation	29.6	8.6	3.20	1.23 - 8.33

*Adjusted for age, sex and cause of death

Torensma, M. et al., 2019. Care and decision-making at the end of life for patients with a non-western migration background living in the Netherlands: A mortality follow back study. *Manuscript submitted for publication.*



Objective

To develop a self-assessment instrument to help researchers assess and find ways to improve their palliative care projects' responsiveness to diversity, in light of the aging migrant population.





HPH Task Force MFH
Migrant
Friendly
Hospitals and Health Services



International Network of
HHealth
Promoting
Hospitals & Health Services

Five main standards to ensure equity in health care

1. EQUITY IN POLICY

- *To define how the organisation should develop policies, governance and performance monitoring systems, which promote equity*

2. EQUITABLE ACCESS AND UTILISATION

- *To encourage the health organisation to address barriers which prevent or limit people accessing and benefiting from health care services*

3. EQUITABLE QUALITY OF CARE

- *To support the organisation in developing services that are responsive to the diverse needs of patients and families along the whole care pathway*

4. EQUITY IN PARTICIPATION

- *To support the organisation in developing equitable participatory processes that respond to the needs and preferences of all users*

5. PROMOTING EQUITY

- *To support the organisation in promoting equity in its wider environment through cooperation, advocacy and capacity building.*



“I can imagine that the theme ‘quality of care’ within a project is only relevant when you actually influence the care given within your project. Because actually it [our project] is about healthcare providers doing their work and us [researchers] supporting them on one particular aspect. Or even just observing what happens, when it isn’t an intervention project.”

(2018.04 Researcher)



Self-assessment instrument

- General introduction and instructions
- 20 diversity responsiveness measures
- Project stages:
 - Set-up; Execution; Follow-up
- Areas for improvement
- Tips and recommendations





Research Questions

1. What should be included in a self-assessment instrument evaluating the diversity responsiveness of palliative care projects?
2. On which groups should a self-assessment instrument evaluating the diversity responsiveness of palliative care projects focus; should other groups, in addition to migrants, be included?
3. How do users evaluate the usability of this self-assessment instrument for improving the diversity responsiveness of palliative care projects?



Delphi study



- Consensus methods
- Purposive sample of 22 | 16 experts
- Questionnaire of 30 + 3 items with a 5-point Likert scale
- Consensus rate of 75%

Usability study



- Think aloud methods
- Convenience sample of 7 research projects
- Observation & interviews
- Thematic analysis



Research Questions

1. What should be included in a self-assessment instrument evaluating the diversity responsiveness of palliative care projects?

Project set up



We describe the implications for the outcome of the project when we choose not to make the project responsive to diversity **82%**

We work to establish a representative research team **81%**

We set up monitoring of engagement of underrepresented groups **77%**

Project execution

We identify and overcome barriers for patient participation by underrepresented groups **95%**

We consider (health) literacy levels, language ability, and culture when asking for informed consent **90,5%**

We identify and overcome gatekeeper bias for inclusion of underrepresented patients **85%**

Project follow-up

We consult patient organisations for interpretation of results **90,5%**

We work to raise awareness on the growing diversity of the patient population within palliative care amongst other researchers **95%**

We share findings concerning underrepresented groups with these groups in an understandable, appropriate manner. **95,5%**



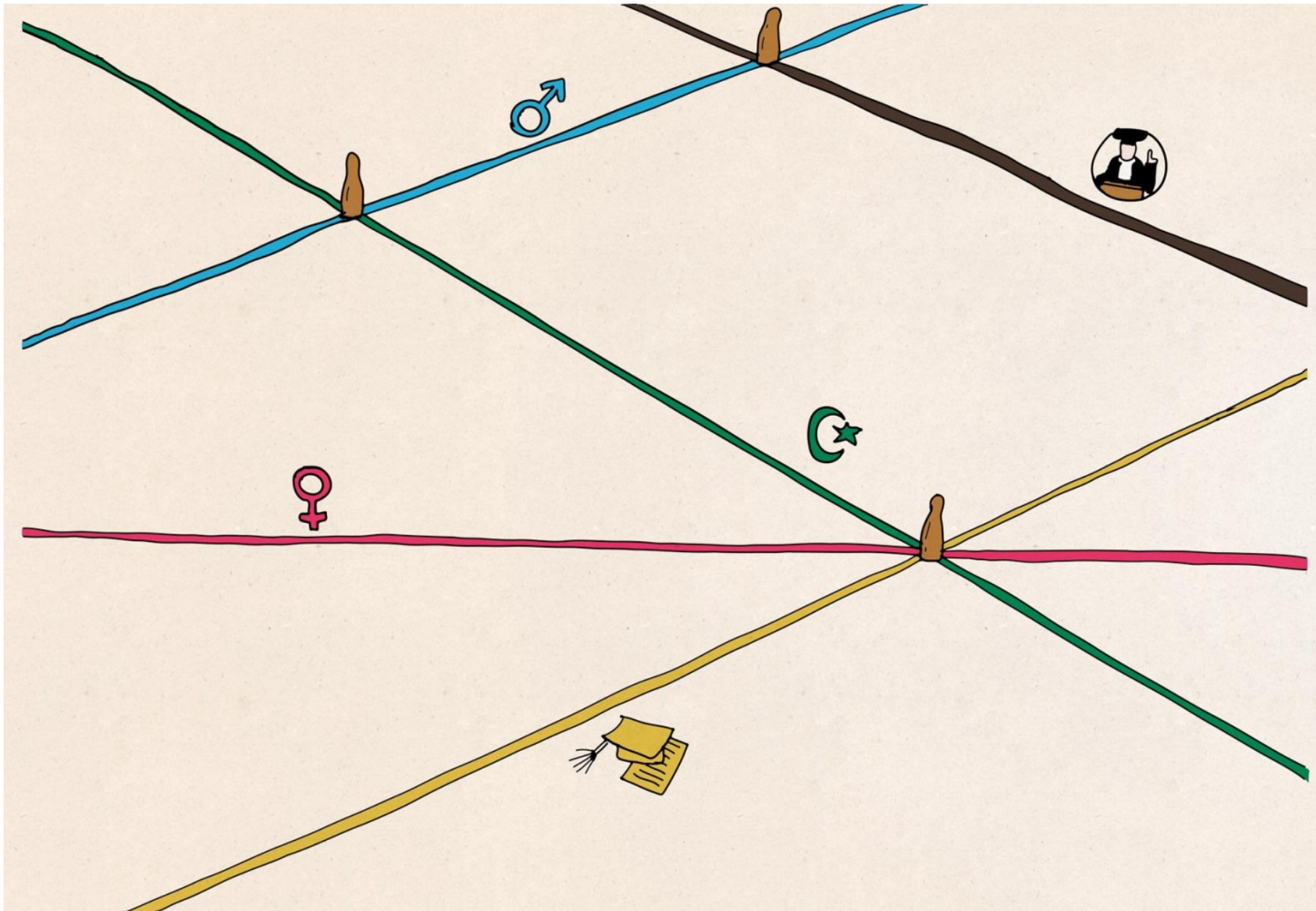
Results

Item	Relevance			
	Round 1 Mean (SD)	Round 1 Consensus rate %	Round 2 Mean (SD)	Round 2 Consensus rate %
22 To offer healthcare organizations and healthcare professionals engaged in the project training in diversity responsive care practice.	4.2 (1.2)	70	4.3 (0.9)	87



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Diversity responsiveness

Diversity responsiveness of palliative care projects entails deliberation of all intersecting factors that may cause patients to be underrepresented in palliative care research and underserved by palliative care services . . . These include factors such as educational background, socioeconomic status, physical or mental disability, age, sex, gender, sexual orientation, language, religion, culture, ethnicity and migration history. We ask special consideration of factors at play for patients with a non-western migration background.



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Usability

- Learnability
how well can users complete self-assessment when they use the instrument for the first time?
- Error-rate
how many errors do users make, how severe are these errors?
- Satisfaction
how pleasant is it to use the instrument?
- Applicability
how do users prefer to apply the self-assessment?





Satisfaction

“Yes, indeed, I found that to be very nice! ... The actions are supported by the group. Especially because it is so confronting, in a certain way, that you see ‘we don’t do any of this’. And there was no one, not anyone that said ‘we don’t have to do it’ and is completely ... I don’t think you will convince those. But in this group I really liked that it resulted in supported actions.”

(2018.05 Researcher)



Applicability

“I think that the need for this instrument especially exists when writing proposals. That people’s attention is drawn to the instrument when they are writing proposals. ... I think it would be useful for people. Because, usually, you merely do something based on your own vision and what you know as a team. But usually there is a lot more, and this [the instrument] can help you with that.”

(2018.02 Researcher)



Applicability ctd.

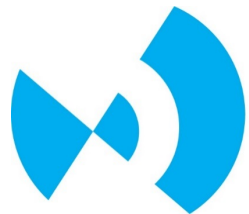
“You’re not going to do all of them. It’s as simple as that. ... If you target this towards low literacy, I’m just picking something, and not specifically towards cultural diversity. Which is indeed very important, and can be an aspect of it, but if it is not only targeted towards that... I am not going to use one tool for patients with a non-western background, another for... The broader the applicability of a tool...”

(2018.05 Researcher)



Torensma, M.* et al., (in press). How to help researchers in palliative care improve responsiveness to migrants and other underrepresented populations: Developing and testing a self-assessment instrument. *BMC Palliative Care*.

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