

## Palliativ indsats til patienter med livstruende sygdom fra ikke-vestlige lande

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# Indhold

**Palliativ indsats - ikke-vestlige lande**

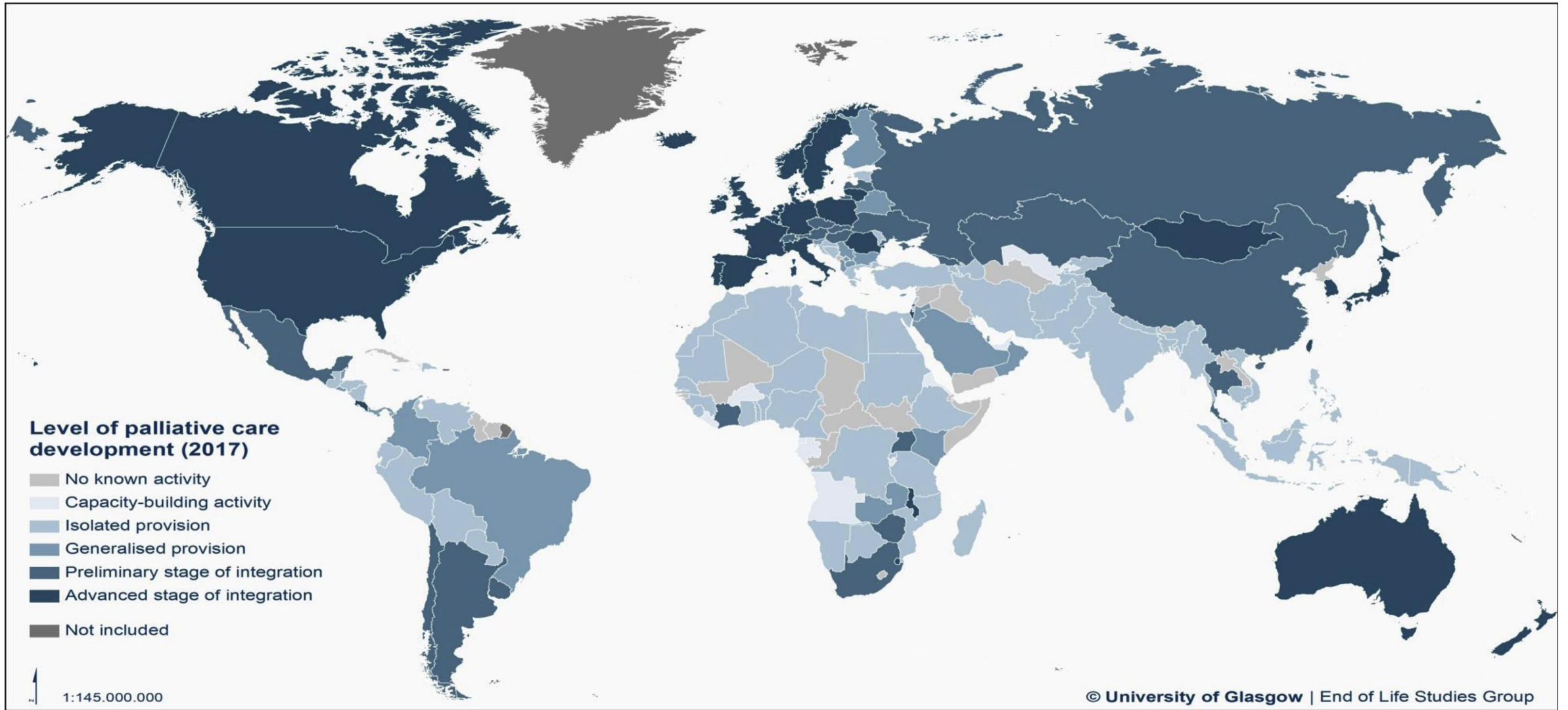
**Sundhedskompetencer**

**Etiske overvejelser**

**Øvelse**

The screenshot shows a web browser displaying the REHPA website. The address bar shows the URL <https://www.rehpa.dk/palliation/om-palliation/#/>. The page has a dark blue header with the REHPA logo and navigation links: FORLØB, REHABILITERING, PALLIATION, KRP, VI TILBYDER, PROJEKTER, UDGIVELSER, and OM REHPA. Below the header, there are two tabs: 'Palliativ indsats: Børn og unge' and 'Palliativ indsats: Specialiseret'. A search bar with the text 'Presse | Nyheder | Kalender | Kontakt | Søg' is visible. The main content area has a dark blue background with the title 'Definitioner af palliation' in large white text. Below the title is a quote in white text: "Den palliative indsats har til formål at fremme livskvaliteten hos patienter og familier, som står over for de problemer, der er forbundet med livstruende sygdom, ved at forebygge og lindre lidelse gennem tidlig diagnosticering og umiddelbar vurdering og behandling af smerter og andre problemer af både fysisk, psykisk, psykosocial og åndelig art." followed by 'Sundhedsstyrelsens oversættelse af WHO's definition fra 2002.' A small white arrow icon is in the bottom right corner of the page content.

# REHPA



### Alleviating the access abyss in palliative care and pain relief— an imperative of universal health coverage: the Lancet Commission report



Felicia Marie Knaul, Paul E Farmer\*, Eric L Krakauer\*, Liliana De Lima, Afsan Bhadelia, Xiaoxiao Jiang Kwete, Héctor Arreola-Ornelas, Octavio Gómez-Dantés, Natalia M Rodríguez, George A O Alleyne, Stephen R Connor, David J Hunter, Diederik Lohman, Lukas Radbruch, María del Rocío Sáenz Madrigal, Rifat Atun†, Kathleen M Foley†, Julio Frenk†, Dean T Jamison†, M R Rajagopal‡, on behalf of the Lancet Commission on Palliative Care and Pain Relief Study Group‡

#### Executive Summary

In agonising, crippling pain from lung cancer, Mr S came to the palliative care service in Calicut, Kerala, from an adjoining district a couple of hours away by bus. His body language revealed the depth of the suffering.

We put Mr S on morphine, among other things. A couple of hours later, he surveyed himself with disbelief. He had neither hoped nor conceived of the possibility that this kind of relief was possible.

Mr S returned the next month. Yet, common tragedy befell patient and caregivers in the form of a stock-out of morphine.

Mr S told us with outward calm, "I shall come again next Wednesday. I will bring a piece of rope with me. If the tablets are still not here, I am going to hang myself from that tree". He pointed to the window. I believed he meant what he said.

Stock-outs are no longer a problem for palliative care in Kerala, but throughout most of the rest of India, and indeed our world, we find near total lack of access to morphine to alleviate pain and suffering.

*Dr M R Rajagopal, personal testimony*

Poor people in all parts of the world live and die with little or no palliative care or pain relief. Staring into this access abyss, one sees the depth of extreme suffering in the cruel face of poverty and inequity.

The abyss is broad and deep, mirroring relative and absolute health and social deprivation. Of the 298·5 metric tonnes of morphine-equivalent opioids distributed in the world per year (average distribution in 2010–13), only 0·1 metric tonne is distributed to low-income countries

poor or otherwise vulnerable people in high-income countries—is a medical, public health, and moral failing and a travesty of justice. Unlike so many other priorities in global health, affordability is not the greatest barrier to access, and equity-enhancing, efficiency-oriented, cost-saving interventions exist.

The global health community has the responsibility and the opportunity to close the access abyss in the relief of pain and other types of suffering at end-of-life and throughout the life course, caused by life-limiting and life-threatening health conditions. However, unlike many other essential health interventions already identified as priorities, the need for palliative care and pain relief has been largely ignored, even for the most vulnerable populations, including children with terminal illnesses and those living through humanitarian crises, and even in the Sustainable Development Goals (SDGs).<sup>2</sup> Yet palliative care and pain relief are essential elements of universal health coverage (UHC).

Several barriers explain this neglect: the focus of existing measures of health outcomes—major drivers of policy and investment—on extending life and productivity with little weight given to health interventions that alleviate pain or increase dignity at the end of life;<sup>3</sup> opiophobia, which refers to prejudice and misinformation about the appropriate medical use of opioids;<sup>4,5</sup> the focus, in medicine, on cure and extending life and a concomitant neglect of caregiving and quality of life near death;<sup>6,7</sup> limitations on patient advocacy due to the seriousness of illnesses; the focus on preventing non-medical use of internationally controlled substances without balancing the human right to access medicines to relieve pain;<sup>8-12</sup>

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This online publication has been corrected. The corrected version first appeared at [theLancet.com](http://theLancet.com) on March 9, 2018

See Comment page 1338

\*Equal contributors

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## Journal of Pain and Symptom Management

Volume 60, Issue 4, October 2020, Pages 754-764





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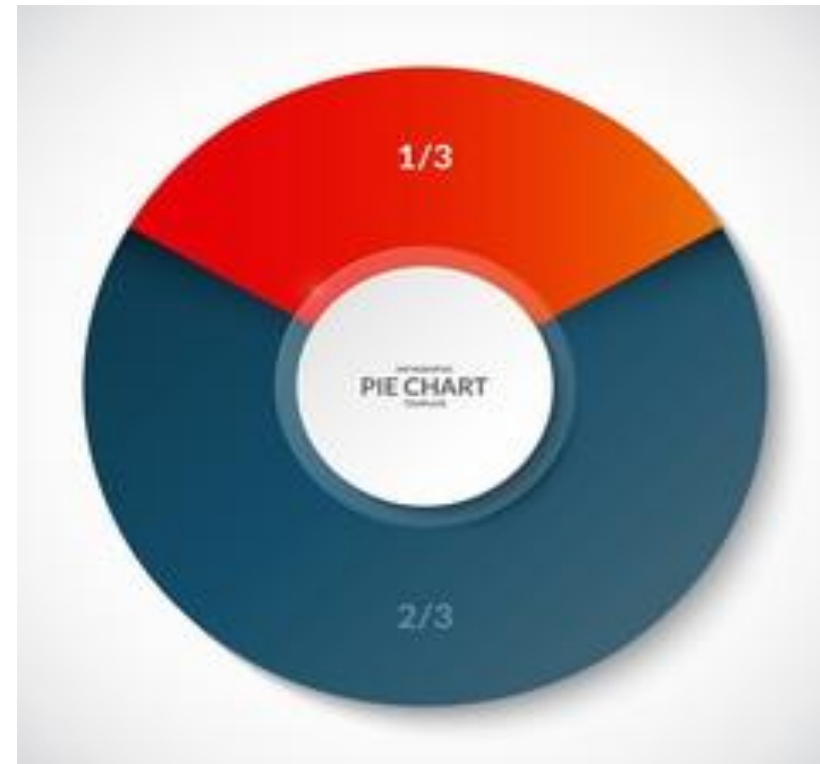
Original Article

# Redefining Palliative Care—A New Consensus-Based Definition

Lukas Radbruch MD <sup>a</sup>  , Liliana De Lima MHA <sup>b</sup>, Felicia Knaul MD <sup>c</sup>,  
Roberto Wenk MD <sup>d</sup>, Zipporah Ali MD <sup>e</sup>, Sushma Bhatnagar MD <sup>f</sup>,  
Charmaine Blanchard MD <sup>g</sup>, Eduardo Bruera MD, PhD <sup>h</sup>, Rosa Buitrago BSc, MChPh <sup>i</sup>,  
Claudia Burla MD, PhD <sup>j</sup>, Mary Callaway MME <sup>k</sup>, Esther Cege Munyoro MD <sup>l</sup>,  
Carlos Centeno MD <sup>m</sup>, Jim Cleary MD <sup>n</sup>, Stephen Connor PhD <sup>o</sup>,  
Odontuya Davaasuren MD <sup>p</sup>, Julia Downing PhD <sup>q</sup>, Kathleen Foley MD, PhD <sup>k</sup>,  
Cynthia Goh MD <sup>r</sup>, Wendy Gomez-Garcia MD <sup>s</sup>... Tania Pastrana MD, PhD <sup>ii</sup>

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# Fakta







Nørredam M. Migration and health. Danish Med J. 2015;61(4):B5068

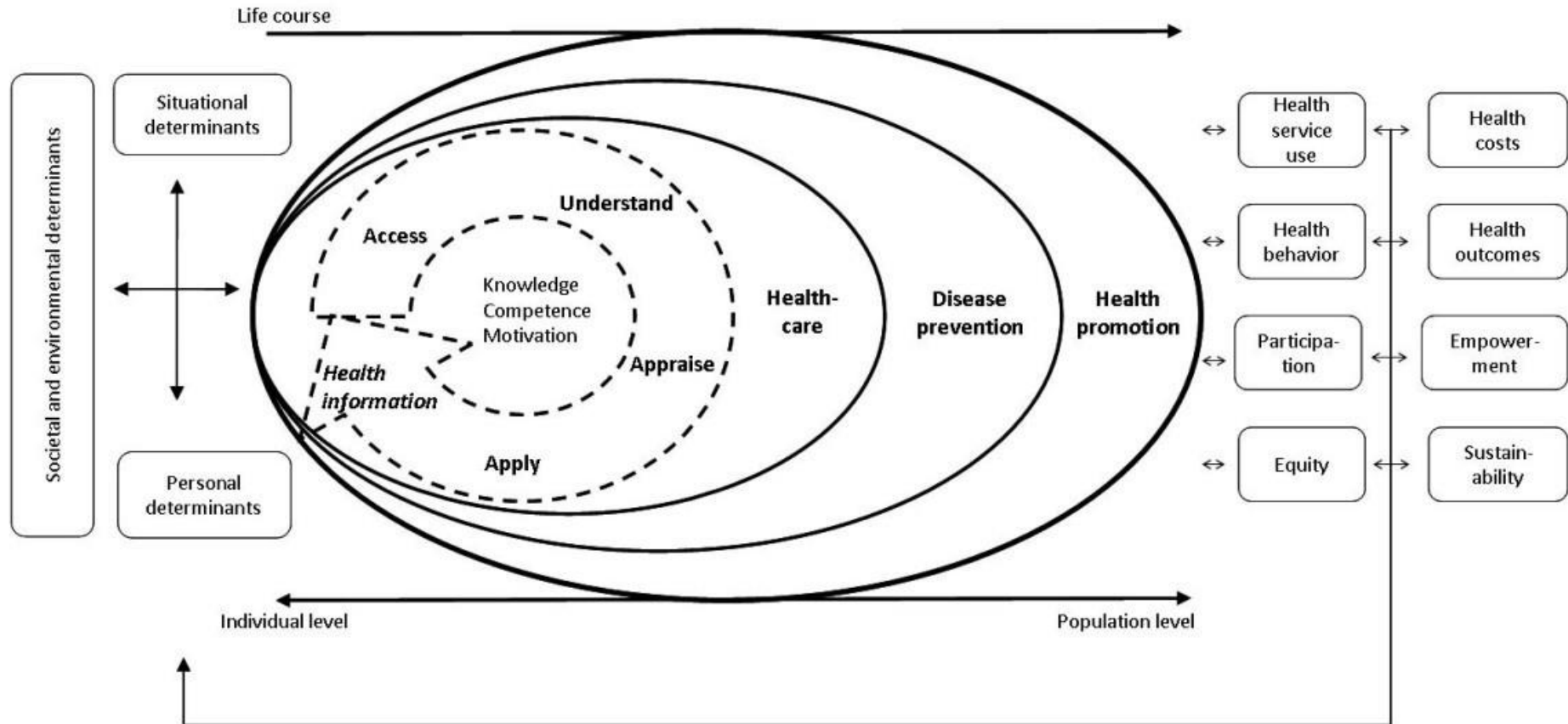
# We are all same, same...but different



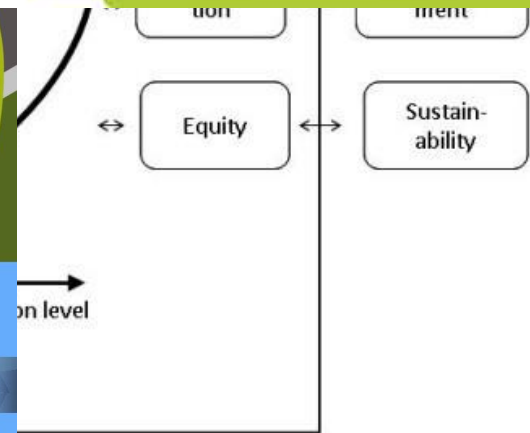
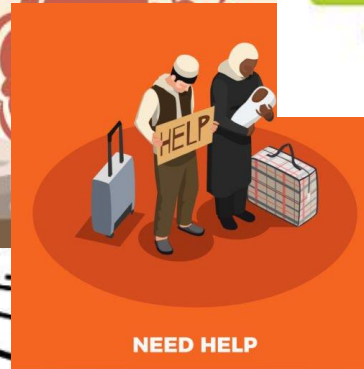
“Værdig død”

# REHPA

## Sundhedskompetencer



# REHPA Sundhedskompetencer



# Etiske Overvejelser



# Etiske Overvejelser



**Navn:** Fru Fatima Ahmed

**Alder:** 67 år

**Oprindelse:** Oprindeligt fra Pakistan, Fru Ahmed har boet i Danmark i 15 år. Hun taler lidt dansk, men er mere komfortabel med urdu.

**Familie:** Fru Ahmed bor sammen med sin søn og svigerdatter, som begge arbejder fuld tid. Hendes mand døde for flere år siden. Hun har også to yngre døtre, men de bor i andre dele af Danmark.

**Sundhedstilstand:** Fru Ahmed har fremskreden lungekræft, og hendes helbred forværres hurtigt. Sundhedsteamet har anbefalet palliativ behandling for at lindre symptomerne og forbedre hendes livskvalitet.

**Religiøs overbevisning:** Fru Ahmed er praktiserende muslim, og hendes tro spiller en vigtig rolle i hendes liv. Familien insisterer på, at religiøse praksisser, såsom daglige bønner, bliver overholdt, og de mener, at det er vigtigt at respektere kulturelle traditioner, især i livets sidste fase.





**Udfordringer**

**Fatima  
Ahmed**



**Løsninger**



**Plan**





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# Klinisk Praksis

<b>1.</b>
<b>2.</b>
<b>3.</b>
<b>4.</b>

# Forskning

**1. ?**

**2. ?**

**3. ?**

**4. ?**

## **Klinisk Praksis**

**1.**

**2.**

**3.**

**4.**

## **Forskning**

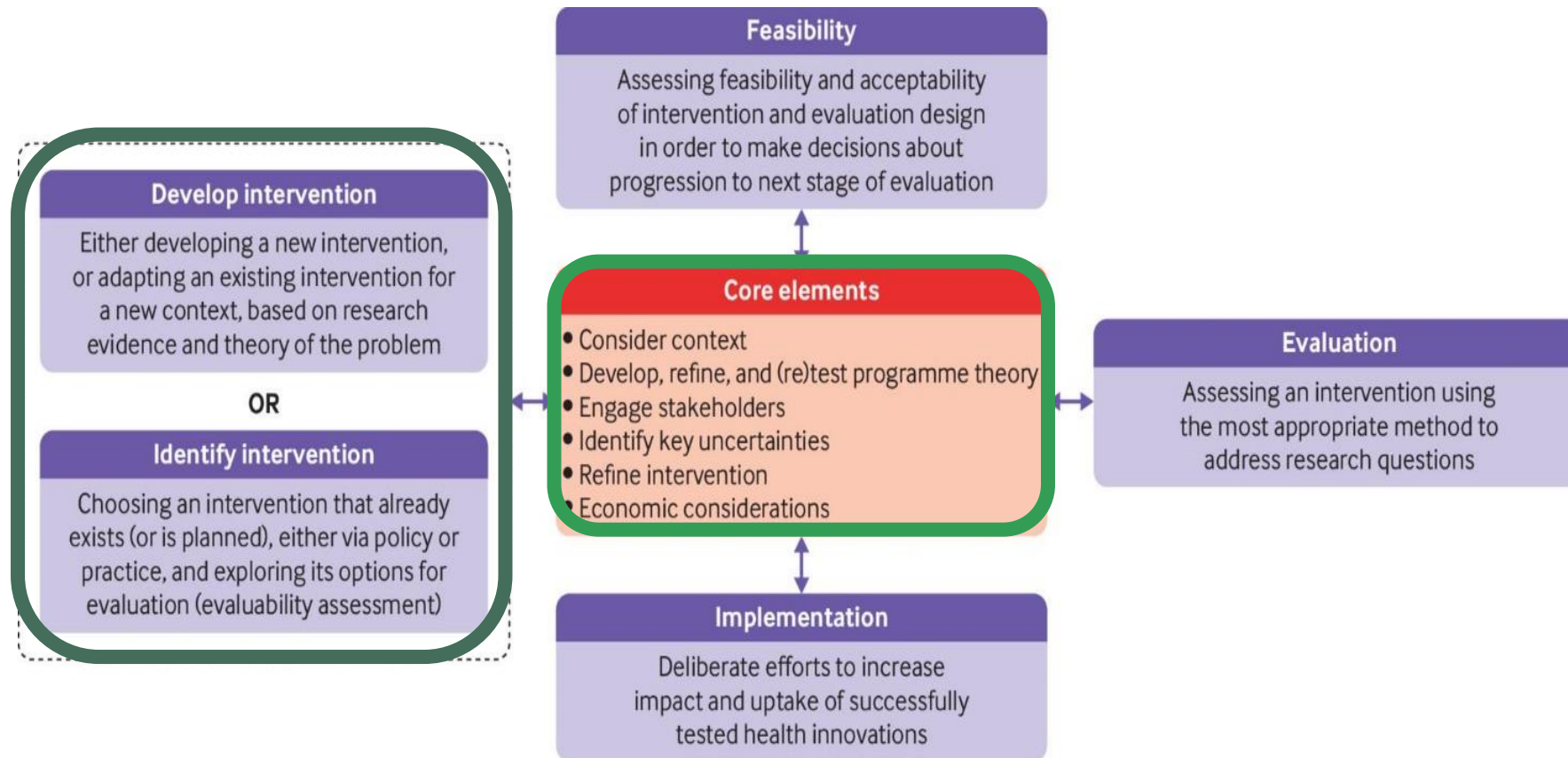
**1. Kommunikation**

**2. Navigation**

**3. Præferencer**

**4. Ressource**

# Det britiske medicinske forskningsråds (MRC) anbefalinger om udvikle og evaluere komplekse interventioner

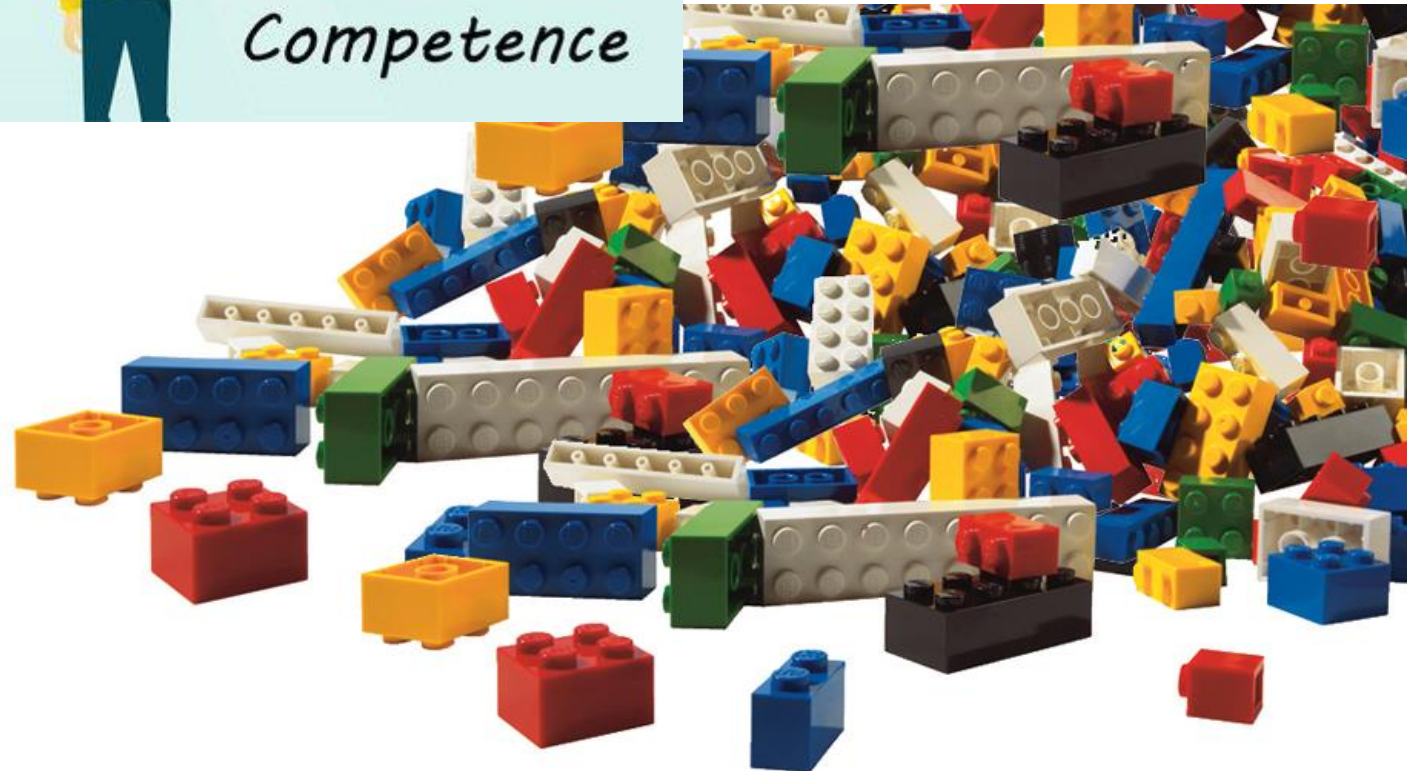


Skirvington, Kathryn, et al. "A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance." *bmj* 374 (2021).

## Metode



## Implikationer



# Final Intervention



**Kursus- og træningssession til  
sundhedspersonale**

**Konsultationer med  
sundhedspersonalet**

**Koordinering af omsorg og pleje  
mellem primær, sekundær og  
frivillig sektor**





# Publikationer

Journal of Immigrant and Minority Health  
<https://doi.org/10.1007/s12284-020-00500-0>

REVIEW PAPER

Original Manuscript

Palliative  
A Systemic

Jahan Shabnam

Accepted: 22 October 2020  
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**Abstract**

The paper aims to explore the experiences of ethnic minority patients with palliative care and their family caregivers in June 2020, seen through the lens of a thematic analysis. The main themes were:

## Palliative Care Experiences of Ethnic Minority Patients and Family Caregivers in Denmark: A Systemic Approach



ELSEVIER

Contents lists

European Journal of Palliative Care

journal homepage:

Development of a complex intervention for ethnic minority patients with palliative care needs: A qualitative study

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ARTICLE INFO

**Keywords:**  
Palliative care  
Transients and migrants  
Non-western  
Health services  
Denmark

ABSTRACT

**Purpose:** International research on palliative care services is often underdeveloped. The purpose of this study was to explore the experiences of ethnic minority patients with a life-threatening illness and their family caregivers in Denmark. **Methods:** The overall aim was to explore the experiences of ethnic minority patients and their family caregivers with palliative care services in Denmark. **Results:** The study identified four main themes: (1) Lack of knowledge about palliative care services, (2) Language barriers, (3) Cultural differences, and (4) Stigma. **Conclusion:** The study highlights the need for more research on palliative care services for ethnic minority patients and their family caregivers in Denmark.

Jahan Shabnam og Hanne Bess Boelsbjerg

## Hard to reach – easy to ignore – Manglende forskning blandt etniske minoriteter

palliative care, ethnic minority, research, language, religion

En stigende andel af den ældre befolkning i Danmark har en etnisk baggrund. Der er derfor et stigende pleje- og behandlingsbehov blandt mennesker, hvor modersmålet ikke er dansk. Til trods herfor er det sjældent, at etniske minoritetspatienter og deres pårørende inddrages i forskning, der vedrører deres behov for palliation. Med udgangspunkt i flere danske forskningsprojekter afsløres barrierer for denne forskning. Visse barrierer kan betragtes som generelle for den sundhedsfaglige forskning. Alligevel er det noget, som forskere og sundhedsprofessionelle inden for det palliative felt helst undlader at forholde sig til. Artiklen eksemplificerer tiltag, der kan medvirke til at sikre, at patienter og pårørende med etnisk minoritetsbaggrund inddrages i forskning.

**Jahan Shabnam**  
Ph.D., MSc, MPH, Ph.D.-studerende, REHPA, Videncenter for Rehabilitering og Palliation, Syddansk Universitet. Hun arbejder særligt i relation til palliation, etniske minoritetspatienter, ulighed i sundhed og intervention.  
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An increasing number of the elderly population in Denmark has an ethnic minority background. Thus, there is a growing need for care and treatment among people with a first language other than Danish. Despite this, ethnic minority patients with palliative care needs and their relatives rarely participate in research about palliation. Based on several Danish studies the barriers to participation is revealed. Some of these barriers can be received as general within health care research. Nevertheless, researchers and health professionals in palliative care prefer to avoid recognizing this. The article exemplifies measures that can contribute to ensuring that patients and relatives with an ethnic minority background are involved in research.

**Hanne Bess Boelsbjerg**  
cand.mag. i religionsvidenskab, ph.d. IST, Syddansk Universitet. Post doc. på Interacting Minds Centre, Aarhus Universitet i projektet «Borderlands of living». I sin forskning fokuserer hun på bestemmelse af bevidsthed, medicinsk kultur, etniske minoritetspatienter, kærlighed, eksistentielle overvejelser og spirituelle behov blandt døende.  
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I sin forskning fokuserer hun  
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minoritetspatienter, kærlighed,  
eksistentielle overvejelser og spirituelle  
behov blandt døende.  
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# Refleksivitet



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