



# EU PACE project

## Comparing and improving palliative care in long term care facilities



prof Lieve Van den Block

[lvdblock@vub.be](mailto:lvdblock@vub.be)  
[www.eupace.eu](http://www.eupace.eu)

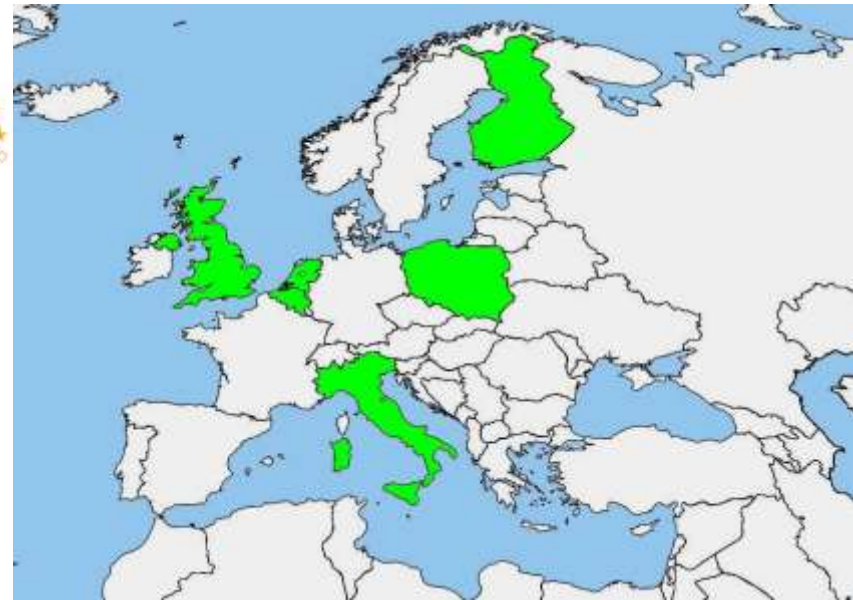


# Aging and Palliative Care Research Programme



# EU funded project 2014-2019

## Describe and improve palliative care in long-term care facilities i.e. nursing or care homes



[www.eupace.eu](http://www.eupace.eu)

Current  
state of the art

# Large variations in long-term care facilities across 29 EU countries





# Large variations in long-term care facilities across 29 EU countries

- Financial and regulatory mechanisms
  - Public, private, profit
- Staffing
- Populations and length of stay
- Palliative care development

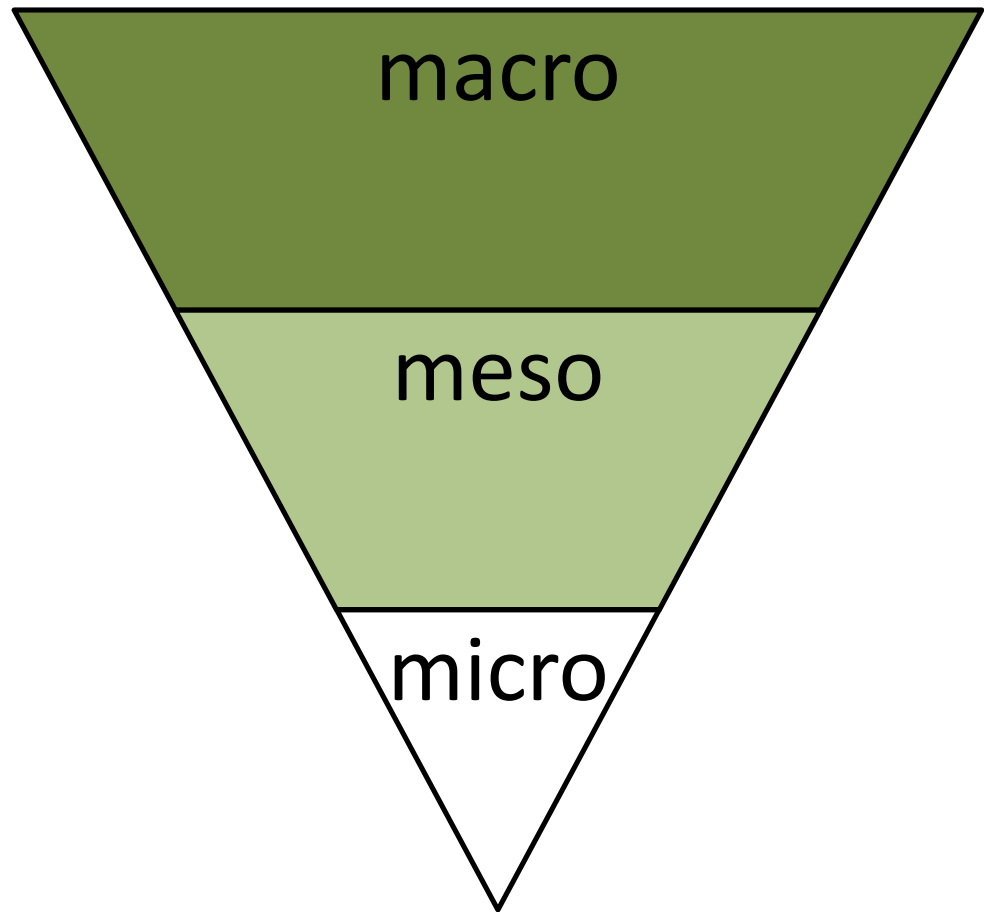


# Variations in PC activity on three levels

national/regional policy,  
legislation, ...

implementation  
activities (education,  
service models,  
frameworks, ...)

proportion of LTCFs  
where there is evidence  
of PC delivery



# Variety of approaches

## Inspirational for each other



JAMDA

journal homepage: [www.jamda.com](http://www.jamda.com)

Original Study

### Palliative Care Development in European Care Homes and Nursing Homes: Application of a Typology of Implementation

Katherine Froggatt PhD<sup>a,\*</sup>, Sheila Payne PhD<sup>a</sup>, Hazel Morbey PhD<sup>b</sup>,  
Michaela Edwards PhD<sup>b</sup>, Harriet Finne-Soveri PhD<sup>c</sup>, Giovanni Gambassi PhD<sup>d</sup>,  
H. Roeline Pasman PhD<sup>e</sup>, Katarzyna Szczerbińska MD, PhD<sup>f</sup>, Lieve Van den Block PhD<sup>g</sup>  
on behalf of PACE

#### Palliative care systems and current practices in long term care facilities in Europe

Report of the

European Association of Palliative Care Taskforce on  
*Mapping Palliative Care Systems in Long Term Care Facilities in Europe*

January 2017 (amended March 2017)

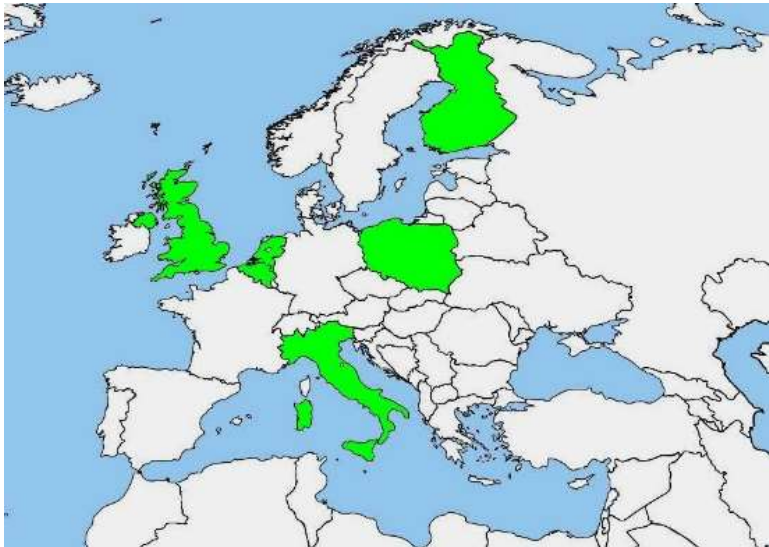


PACE - comparing the effectiveness of Palliative Care for older people in long-term care facilities in Europe



# Variations but same challenges

PACE study in 6 countries



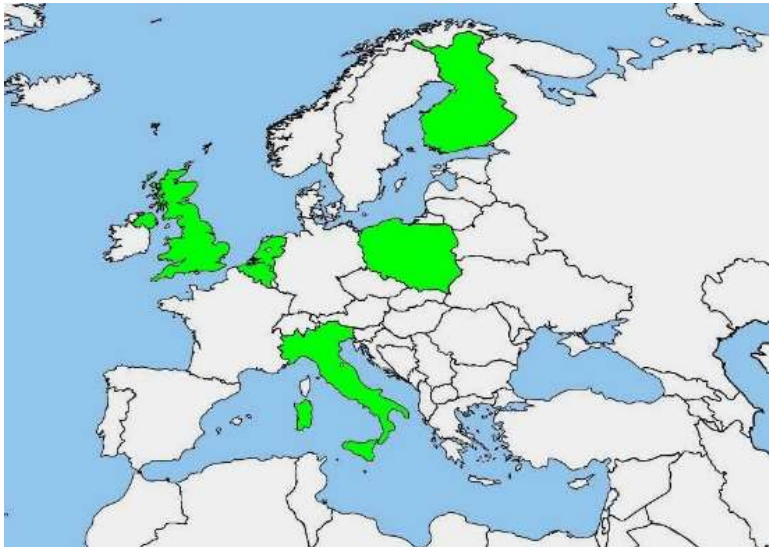
Complex populations

Room for improvement

- staff PC competences
- quality of end-of-life care and quality of dying

# Variations but same challenges

PACE study in 6 countries



Complex populations

- Room for improvement
- staff PC competences
  - quality of end-of-life care and quality of dying

# PACE descriptive studies 2015



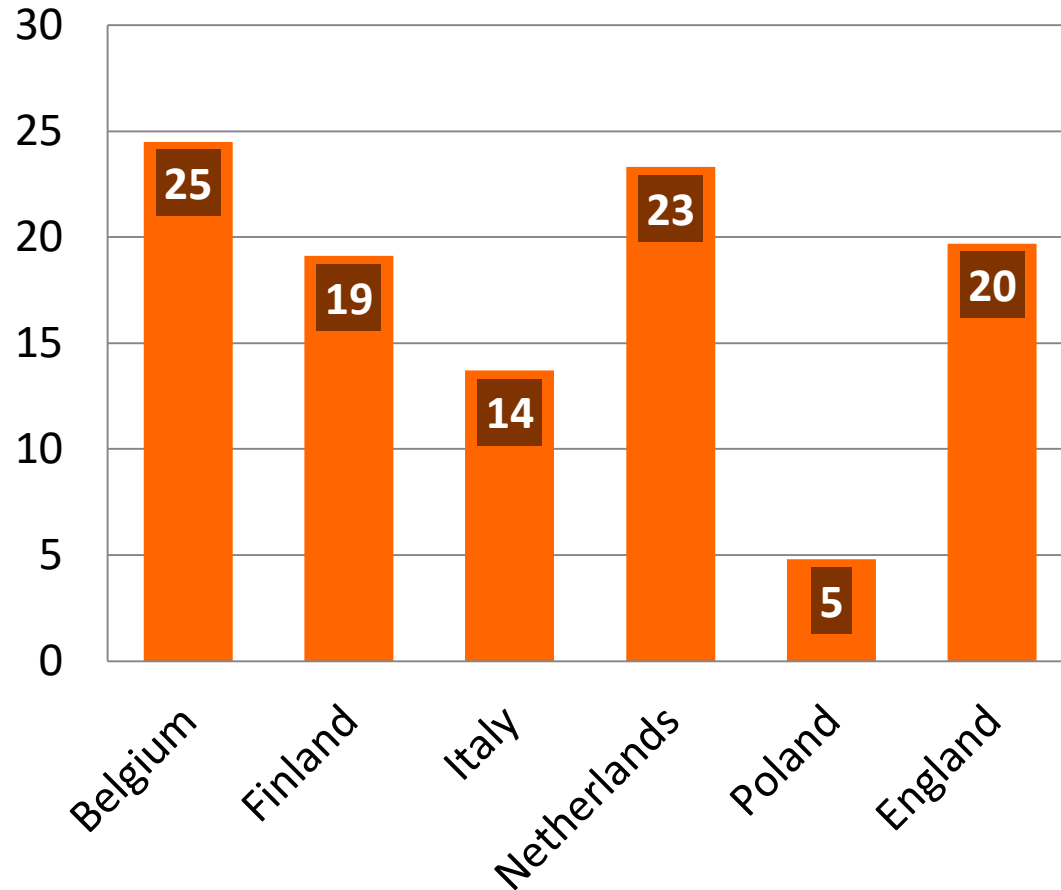
representative samples of facilities  
in 6 countries: **322 facilities** covering all types  
and regions

**1701** deceased residents

**2275** staff members: nurse, care/nurse assistant

structured surveys from staff, relatives, GPs,  
management: response rates from 58% to 95%

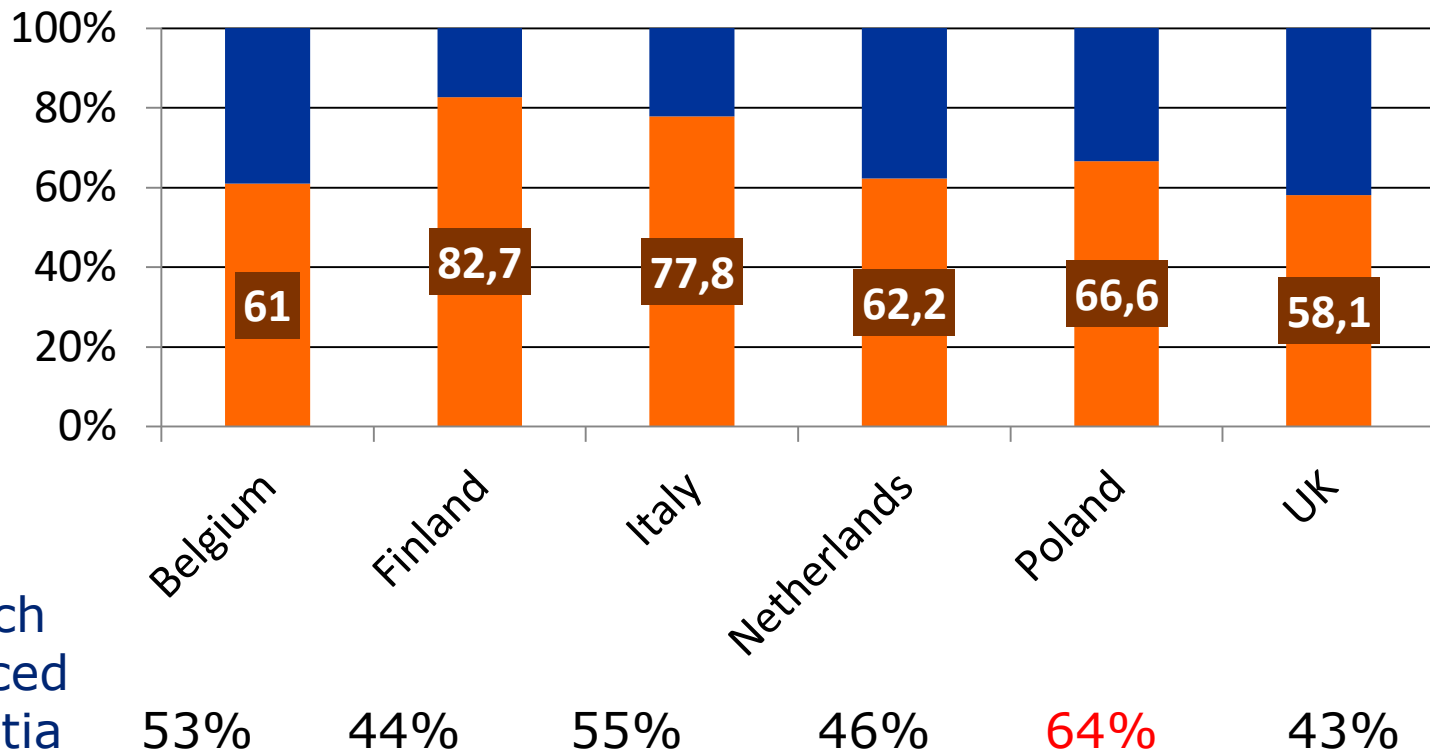
# Median length of staf in months: overall short



*Averages across different types of LTCFs*

# Dementia?

yes no

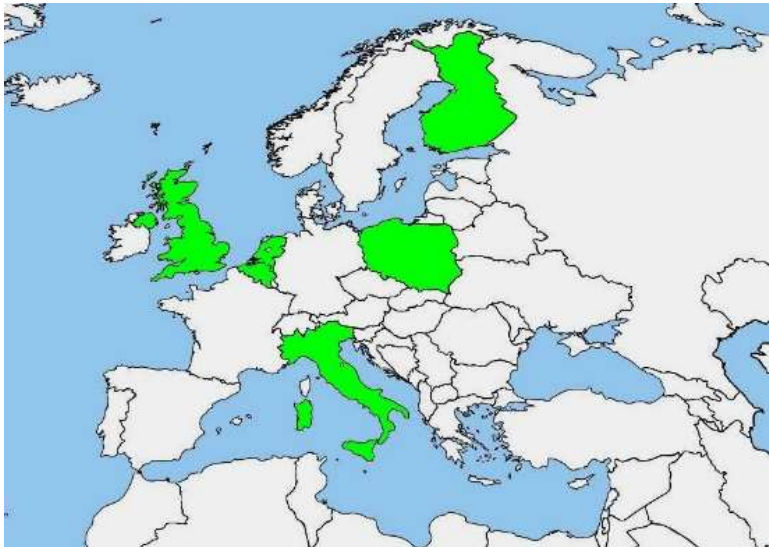


*Averages across different types of LTCFs*

*Clinical judgment of GP or nurse*

# Variations but same challenges

PACE study in 6 countries



Complex populations

**Room for improvement**

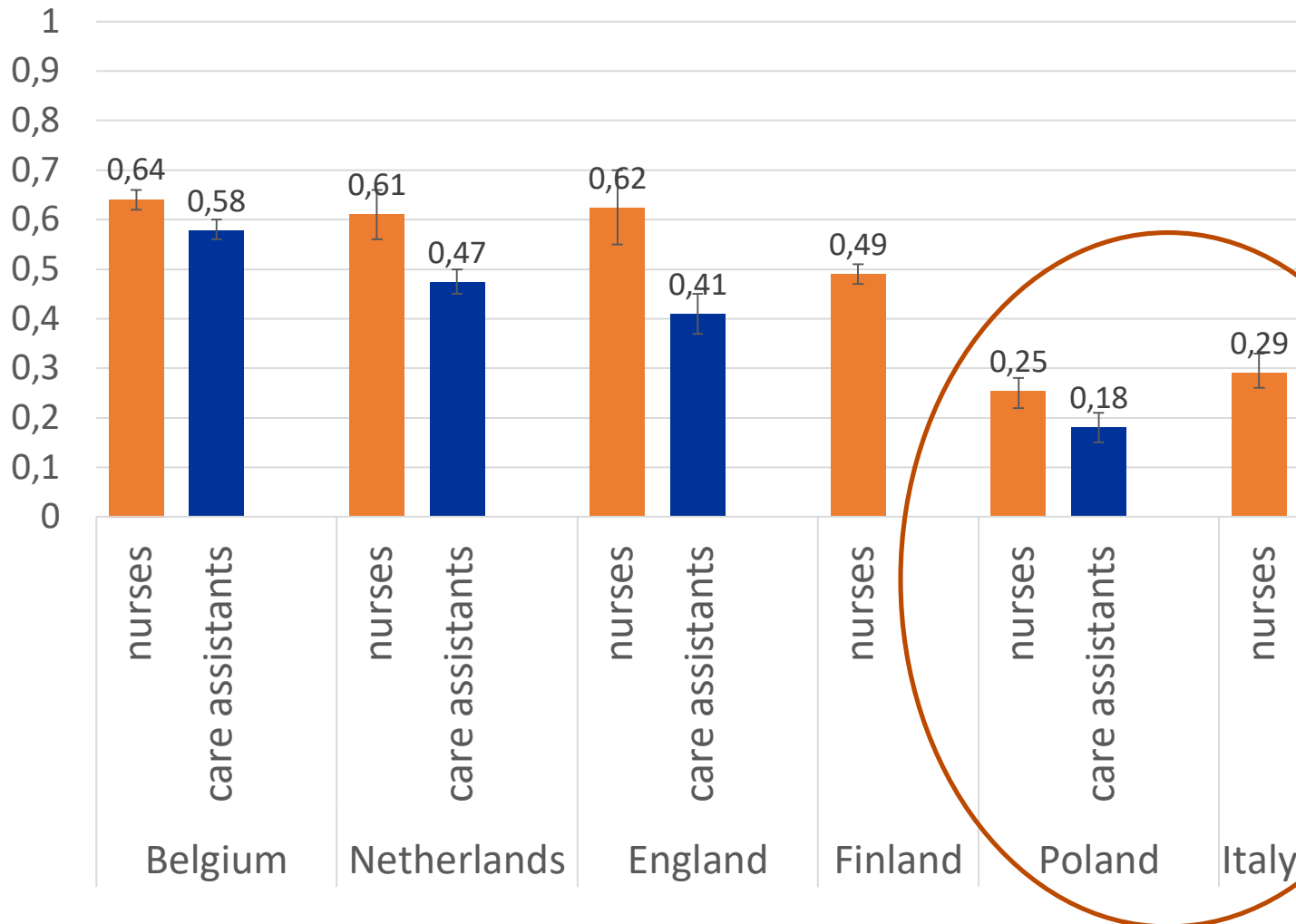
- staff PC competences
- quality of end-of-life care and quality of dying



# Staff knowledge of palliative care

## Palliative Care Survey

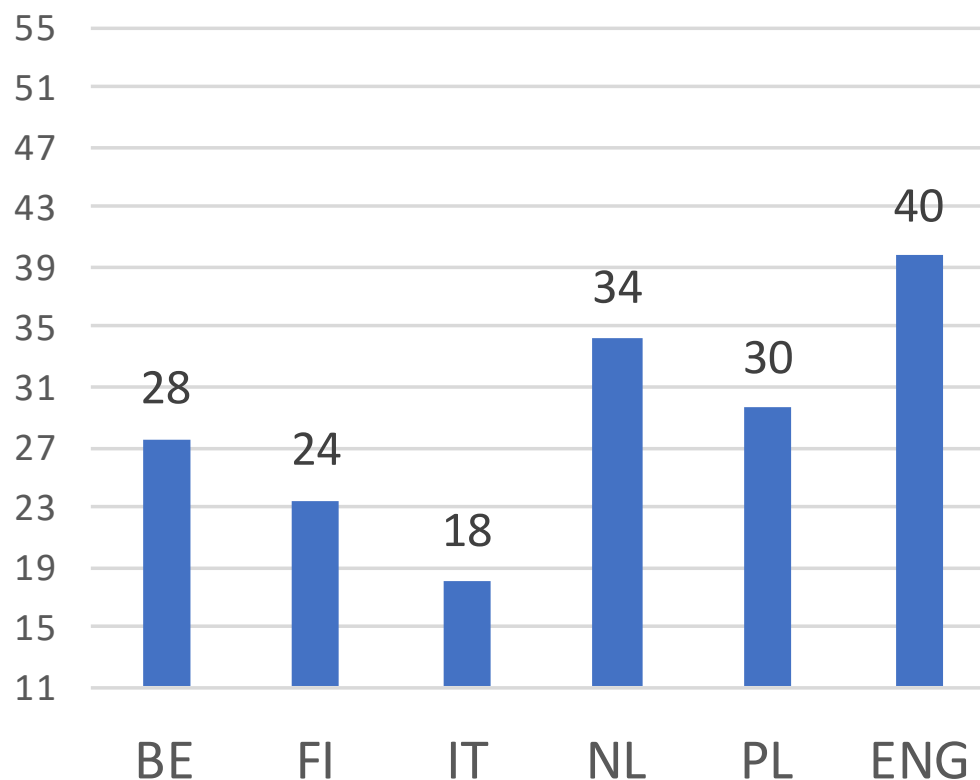
higher mean scores (0 to 1) = better knowledge



Quality of care in **last month of life** as  
judged by **staff** (QOD-LTC)

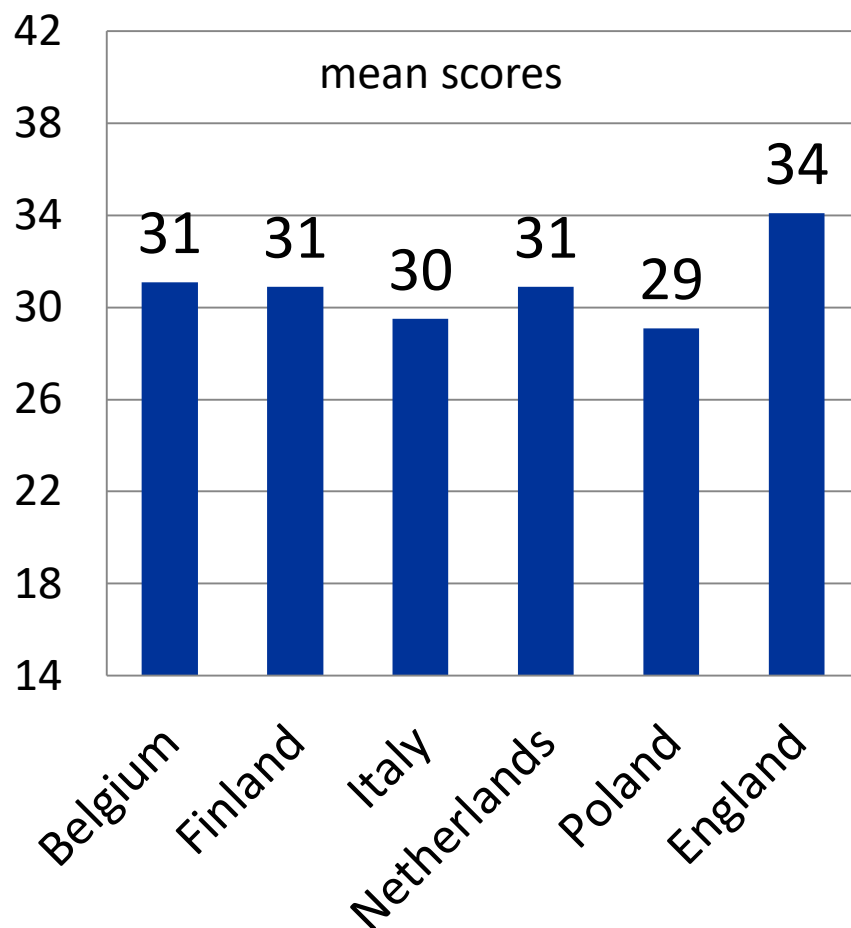
subscale: **preparatory tasks**

Higher mean scores = better quality



# Symptoms of residents in the **last week of life** as judged by **staff**

## CAD-EOLD

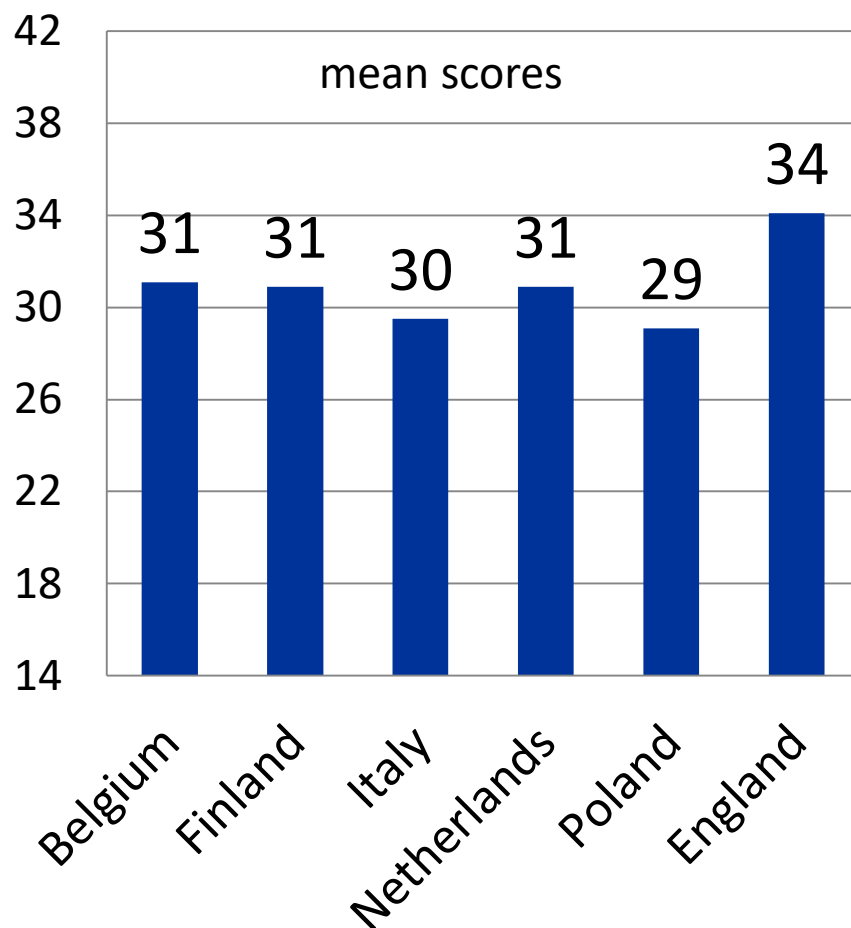


scale items:  
discomfort, pain,  
shortness of breath,  
choking, difficulty  
swallowing, anxiety,  
crying, calm etc

higher scores  
=  
better quality of dying

# Symptoms of residents in the **last week of life** as judged by **staff**

## CAD-EOLD



scale items:

**discomfort, pain,**  
shortness of breath,  
choking, **difficulty**  
**swallowing,** anxiety,  
crying, **calm,** etc

higher scores

=

better quality of dying



Smets et al, 2018  
Pivodic et al,  
2018, accepted



Wichman et al,  
2018, accepted



Oosterveld et al,  
2018, accepted

on behalf of PACE

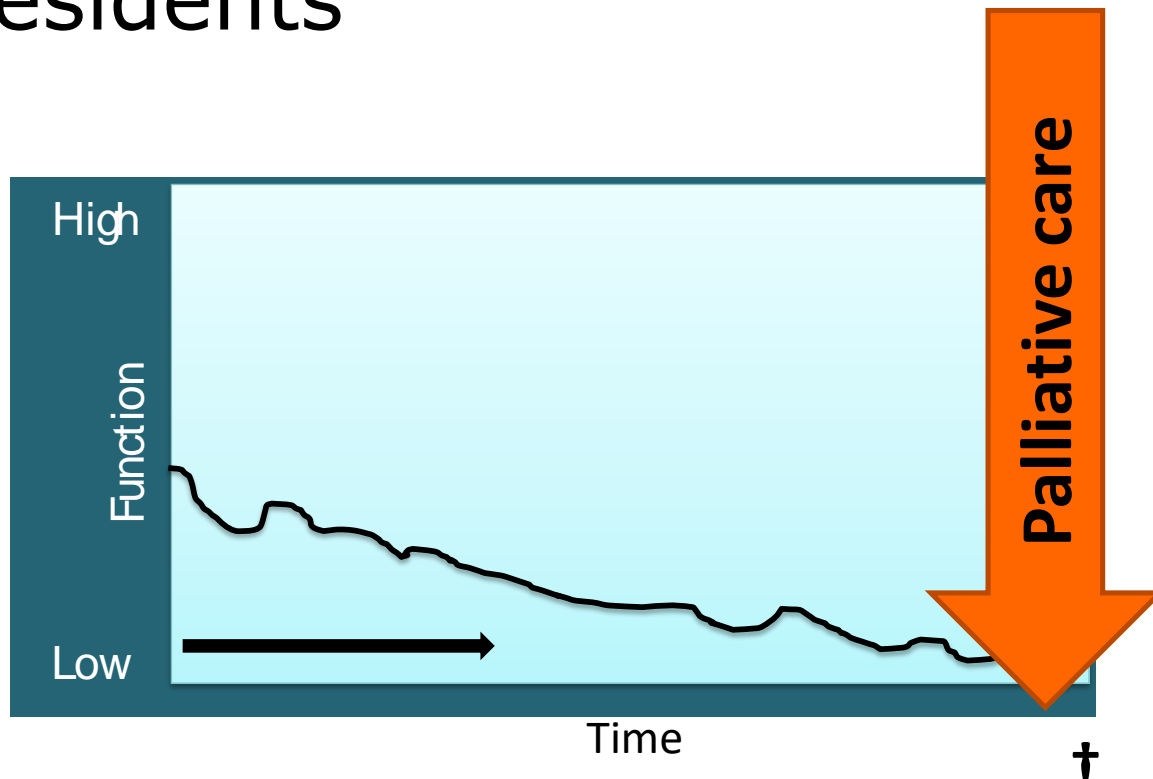
# How to improve?

## PACE Steps to Success



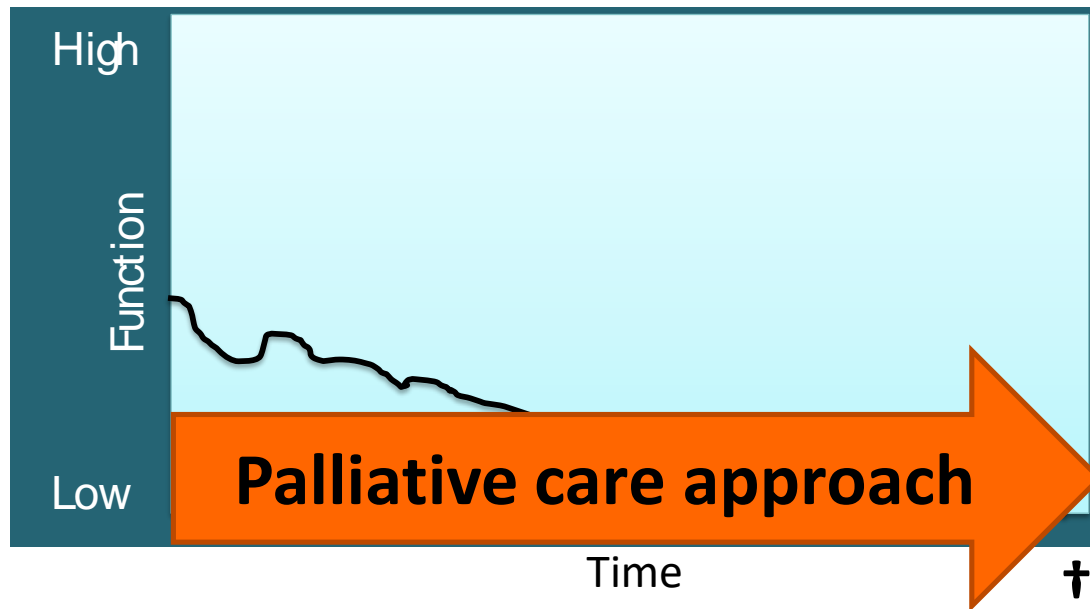
Palliative care is an approach to improve quality of life of all people with life-threatening illness and of their families

# Old model of palliative care not suitable for population of LTCF residents



Frailty and dementia trajectory

New model of palliative care:  
Early integration, alongside  
life-prolonging treatments  
**Preferred culture in LTCFs**



# 6 steps train-the-trainer programme



External trainers

PACE  
coordinators in  
the facilities

One year  
implementation:  
6 steps with  
tools



# Involving the whole setting

## Preparation

2 months

Introduction of  
programme to LTCF  
(staff, family, GPs)  
Provide training for  
PACE Coordinator(s)

Led by:  
Country trainer

## Implementation

6 months

Introduce 6 steps

Led by:  
Country Trainer  
with PACE  
Coordinator(s)

## Consolidation

4 months

Ongoing support

Led by:  
PACE Coordinator(s)  
supported by Country  
trainer

# General palliative care in PACE Steps to success programme

1. Advance care planning
2. Mapping changes in physical condition to anticipate dying better
3. Palliative care register to be used during monthly multidisciplinary meeting, involving staff and GPs
4. Screening of pain and depression (PAIN-AD, Geriatric Depression Scale, Cornell for dementia)
5. Checklist last days of life
6. Reflective debriefing after death



# Cluster RCT in 7 countries 2016-2017

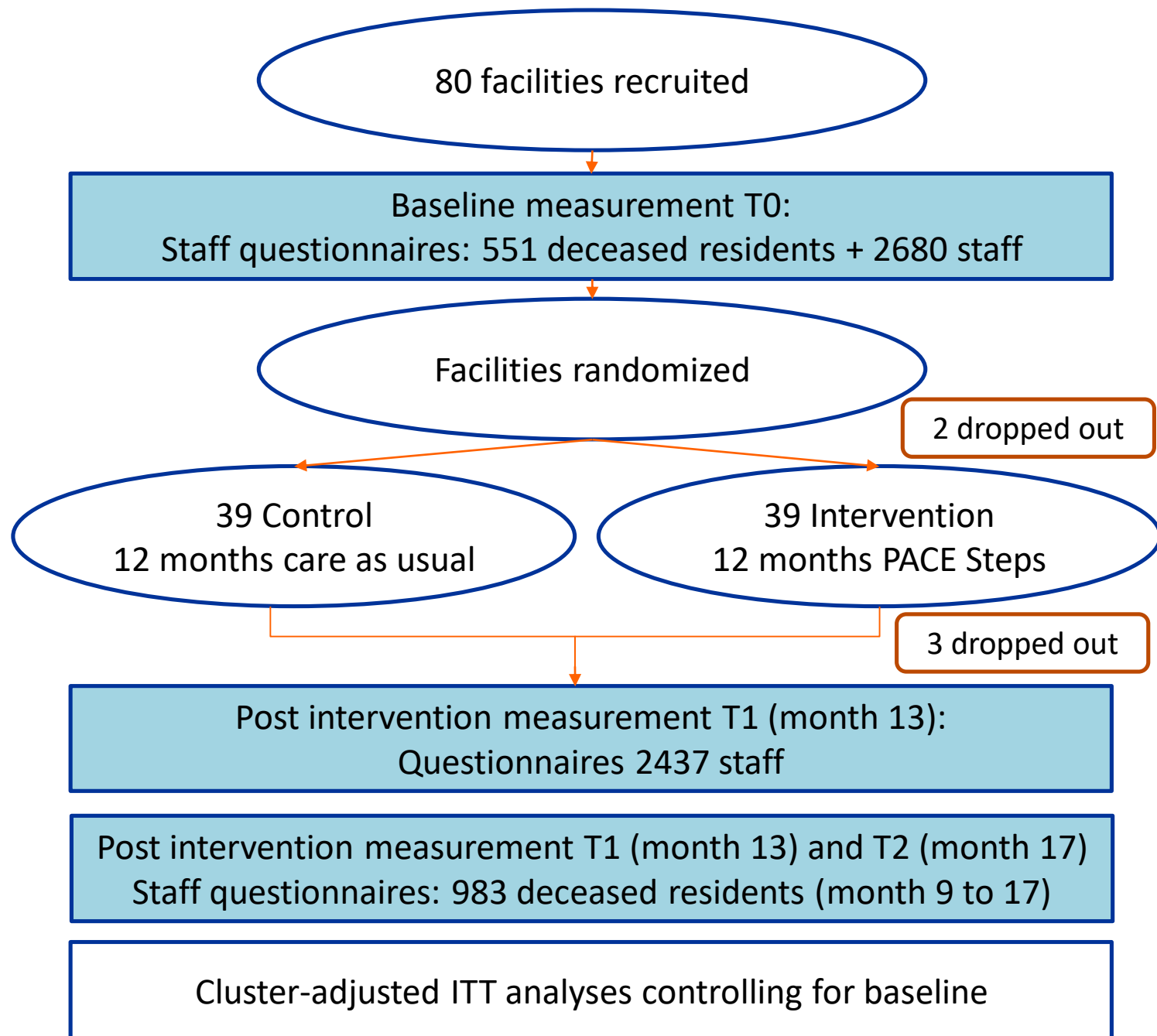
BE, NL, ENG, PL, FI, IT, Switzerland

80 facilities randomized

Outcome, process, cost evaluation

By implementing PACE Steps to Success:

- is quality of dying and quality of end-of-life care of **residents** improved?
- is **staff** knowledge of palliative care improved?  
compared to a control group

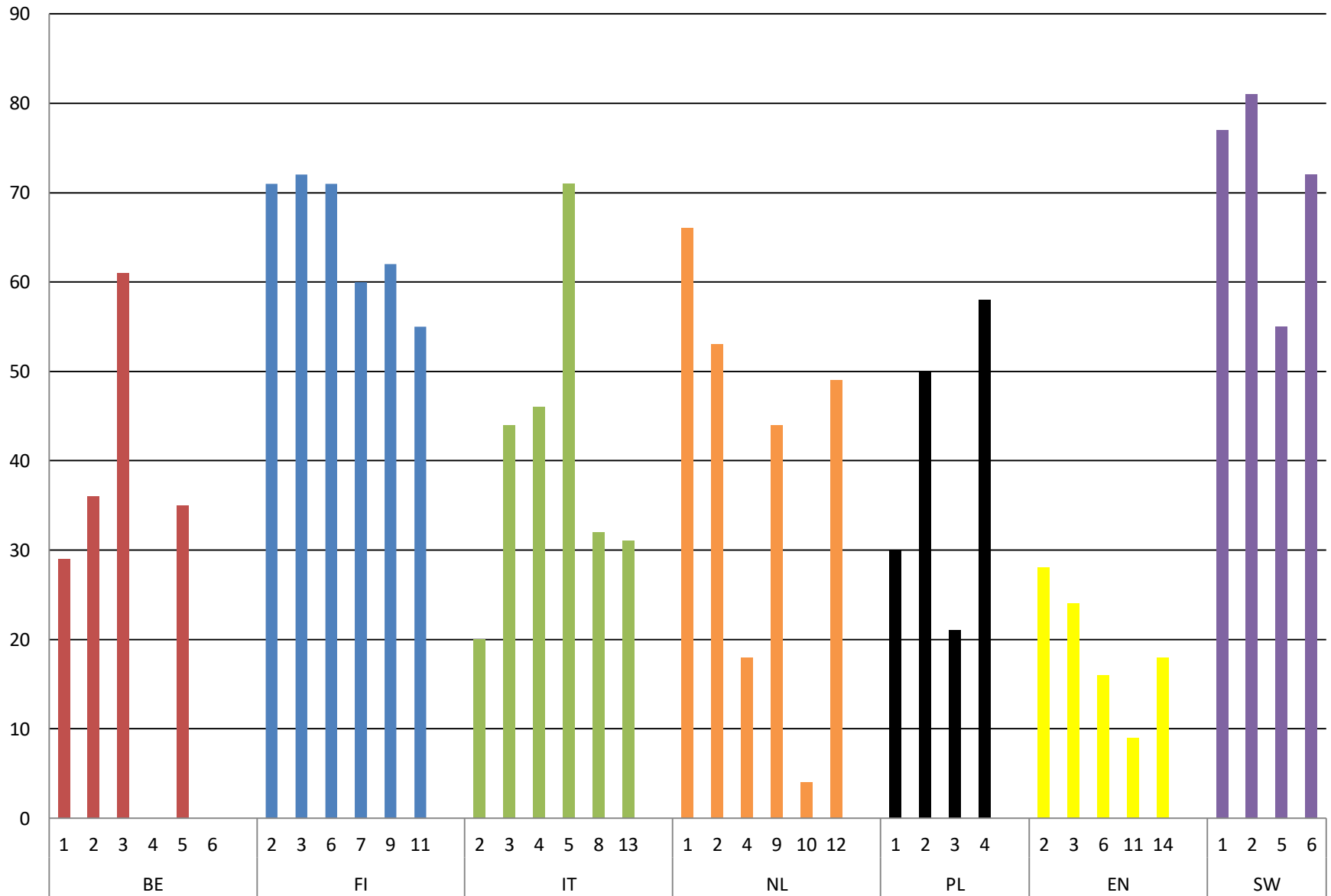


Trial ended

Results effectiveness and process evaluation  
forthcoming

7 country implementation of  
PACE Steps to Success in 80 LTCFs  
was very challenging

# Mean % of staff present at the trainings



# Key recommendations

Trainer's expertise

Active management support

Selection of key PACE coordinator within the facility

Continuous training and monitoring

Tailoring intervention to local context

Flexibility to adapt (timing/content of) intervention to changes in context

English, Dutch, Polish, Finnish, Italian, French

<http://www.eapcnet.eu/>



## **PACE Steps to Success Programme**

**Steps towards achieving high quality palliative care  
in your care home**

**Information Pack**



[www.eupace.eu](http://www.eupace.eu)

[lvdblock@vub.be](mailto:lvdblock@vub.be)

Acknowledged



This project has received funding from the European Union's Seventh Framework Programme for research, technological development and demonstration under grant agreement no. 603111.