






















Fit for the future:

International comparisons
in end-of-life care and
what we can learn from
them

Joachim Cohen

What can we learn from the FIFA
ranking?

21	 Côte d'Ivoire	912 (911.94)	917	0	◀▶	492.15	492.15	353.50	176.75	493.40	148.02	475.12	95.02	⌵
22	 Albania	888 (888.30)	722	14	▲	664.86	664.86	04.10	52.05	493.29	105.99	71.01	35.40	⌵
23	 France	882 (882.05)	882	-1	▼	288.09	288.09	773.40	386.70	361.23	108.37	494.47	98.89	⌵
24	 Iceland	877 (876.97)	877	-1	▼	511.49	511.49	337.64	125.73	388.33	116.50	116.25	23.25	⌵
25	 Denmark	876 (876.01)	876	-1	▼	474.54	474.54	396.00	198.00	294.08	88.22	576.24	115.25	⌵
26	 Mexico	838 (838.18)	697	14	▲	375.76	375.76	491.00	248.35	225.71	183.55	402.18	80.52	⌵
27	 Ghana	827 (827.14)	827	-2	▼	488.33	488.33	246.69	123.34	472.57	141.77	368.50	73.70	⌵
28	 Bosnia and Herzegovina	819 (818.84)	819	-2	▼	342.61	342.61	322.43	211.15	644.25	113.87	372.91	75.75	⌵
29	 USA	816 (815.57)	748	5	▲	336.44	336.44	466.52	233.26	648.60	194.58	256.45	51.29	⌵
30	 Ukraine	791 (790.85)	791	-3	▼	323.14	323.14	531.31	265.65	481.98	144.60	287.29	57.46	⌵
31	 Russia	782 (781.81)	782	-3	▼	322.79	322.79	392.16	196.18	495.97	142.79	570.25	114.05	⌵
32	 Scotland	774 (774.08)	774	-3	▼	389.89	389.89	428.42	214.21	313.25	93.98	380.00	76.00	⌵
33	 Poland	769 (768.71)	769	-3	▼	524.06	524.06	223.25	111.63	224.75	67.42	328.01	65.60	⌵
34	 Tunisia	768 (767.82)	758	-2	▼	454.98	454.98	312.96	156.48	287.01	86.10	351.32	70.26	⌵
35	 Hungary	763 (763.41)	763	-4	▼	432.75	432.75	246.50	123.25	389.88	116.96	452.25	90.45	⌵
36	 Ecuador	758 (757.57)	738	-1	▼	265.93	265.93	395.82	197.91	587.40	176.22	587.53	117.51	⌵
37	 Sweden	752 (751.88)	752	-4	▼	404.51	404.51	332.50	166.25	292.78	87.83	466.43	93.29	⌵
38	 Costa Rica	728 (727.98)	695	3	▲	210.80	210.80	690.14	345.07	433.75	130.12	209.93	41.99	⌵
39	 Senegal	722 (721.70)	715	0	◀▶	501.93	501.93	247.05	123.53	176.30	52.89	216.76	43.35	⌵
40	 Northern Ireland	721 (721.40)	721	-3	▼	556.12	556.12	198.39	99.19	157.43	47.23	94.29	18.86	⌵
41	 Iran	718 (718.19)	716	-3	▼	437.18	437.18	255.56	127.78	302.00	90.60	313.16	62.63	⌵

What does it tell us?

Is it valid?

Is it important to us?

How do we explain it? (Why?)

Are differences acceptable?

Can we learn from it / adapt?

QUALITY OF DEATH

An EIU report commissioned by Lien Foundation

What does it tell us?

Is it valid?



QUALITY OF DEATH

An EIU report commissioned by Lien Foundation

Basic end-of-life healthcare environment (20%)

Availability of end-of-life care (25%)

Cost of end-of-life care (15%)

Quality of end-of-life care (40%)

QUALITY OF DEATH

An EIU report commissioned by Lien Foundation

What does it tell us?

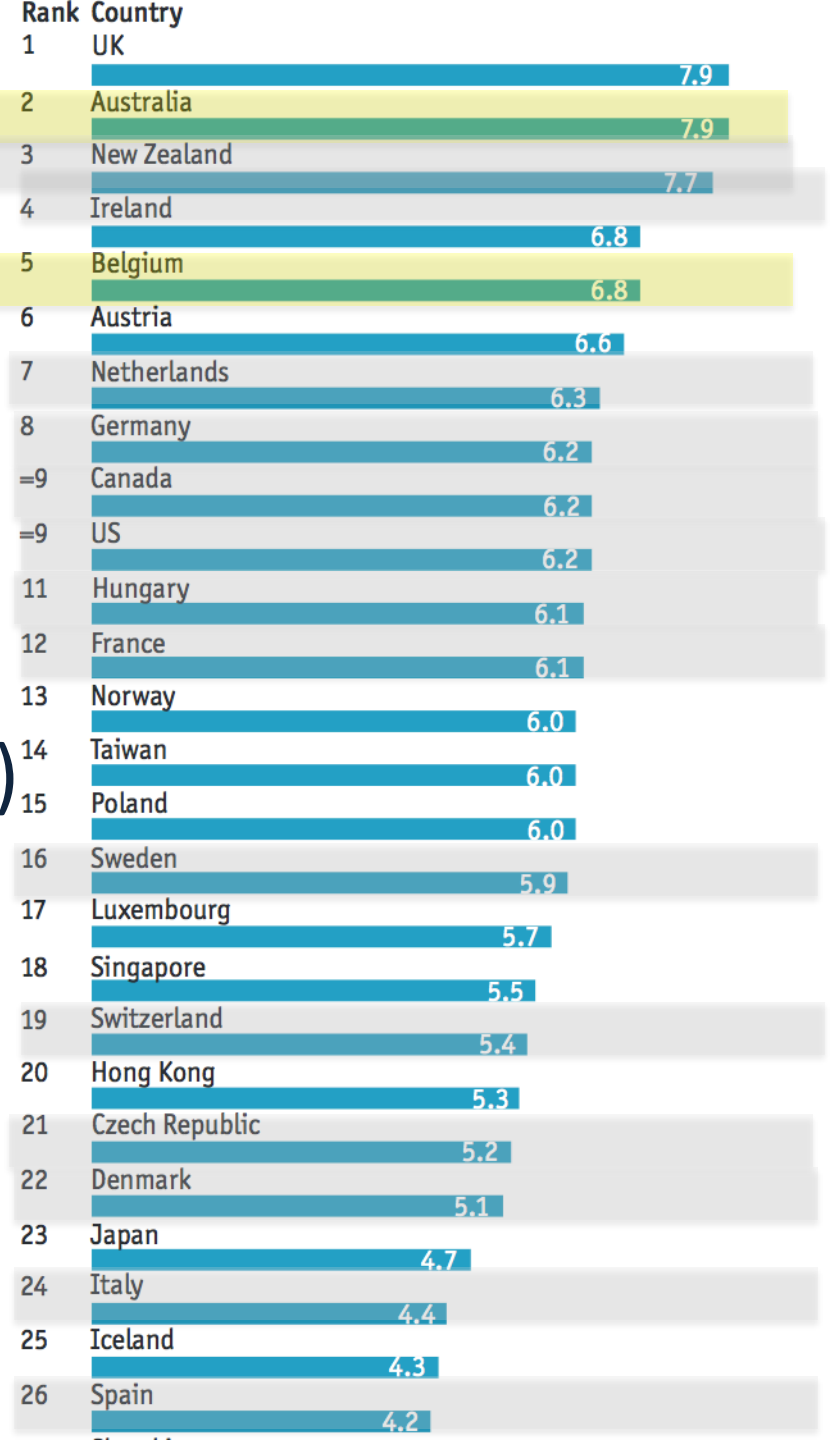
Is it valid?

Is it important to us?

How do we explain it? (Why?)

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Some essentials about international comparative research

Three principal rationales for international comparative research

1. Learning about (describing)
2. Learning why (explaining)
3. Lessons learned from (identifying best practice)

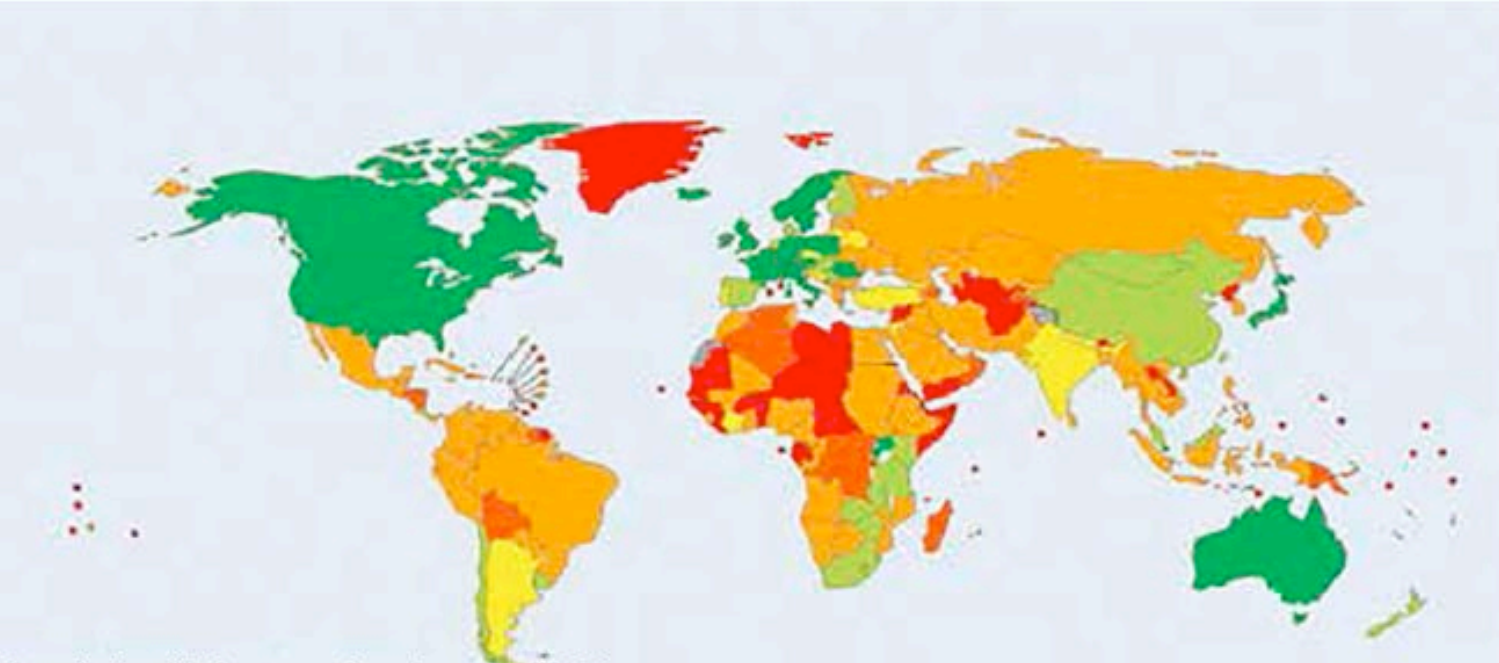
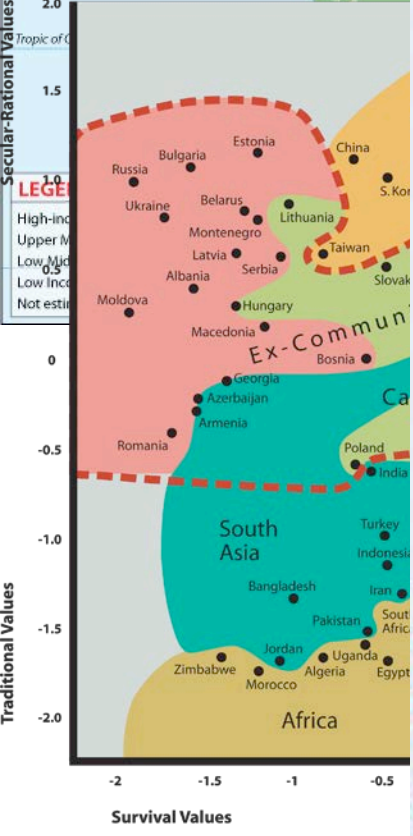
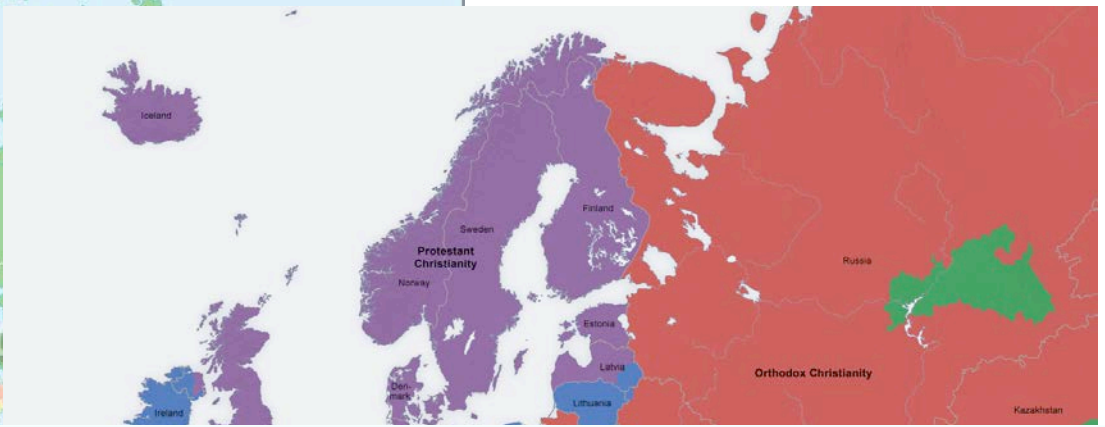
Concepts cannot be separated from context

Do concepts differ between countries in terms
of:

Conceptual, functional and semantic equivalence?

Linguistic equivalence?

Measurement equivalence



- Level of palliative care development (PCD)**
- Level 1: not known activity
 - Level 2: capacity building
 - Level 3a: isolated provision
 - Level 3b: generalized provision
 - Level 4a: preliminary integration
 - Level 4b: advanced integration
 - Not applicable

<http://www.thewpca.org/resources/global-atlas-of-palliative-care/>

Mixed methods approaches in international research provide most enriching insights

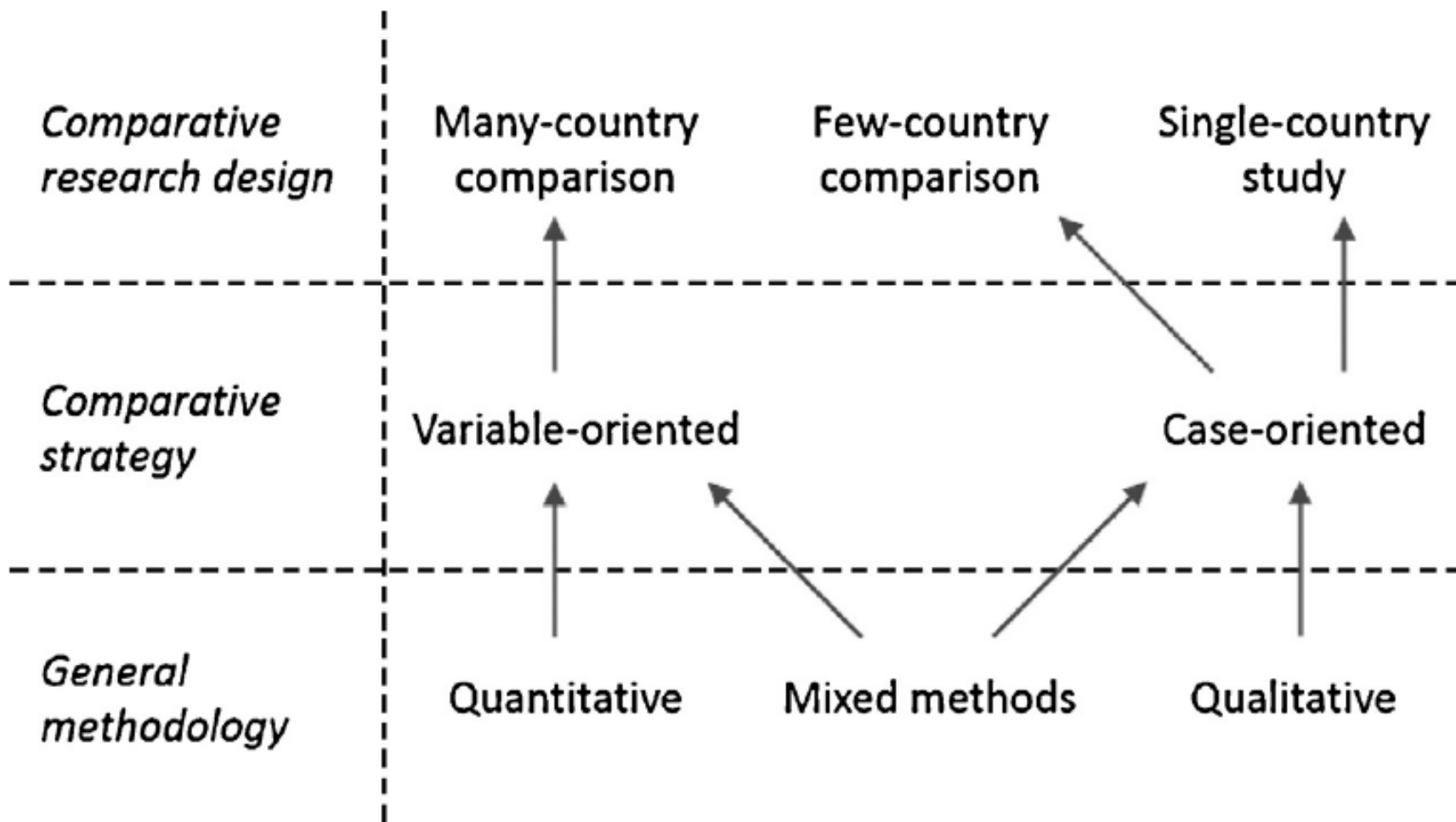


Fig. 1. Relationship of comparative research design to methods.

Key points

1. characteristics or circumstances of death and dying determined more by country than by patient characteristics

Large variations in:

place of death

place of care

Hospital expenditures

use of services

2. country-specific priorities in terms of allocation and quality assurance
3. healthcare organisational choices in terms of end-of-life care influence EOL patterns
4. An international comparative research agenda for EOLC is needed

Key points

1. characteristics or circumstances of death and dying determined more by country than by patient characteristics

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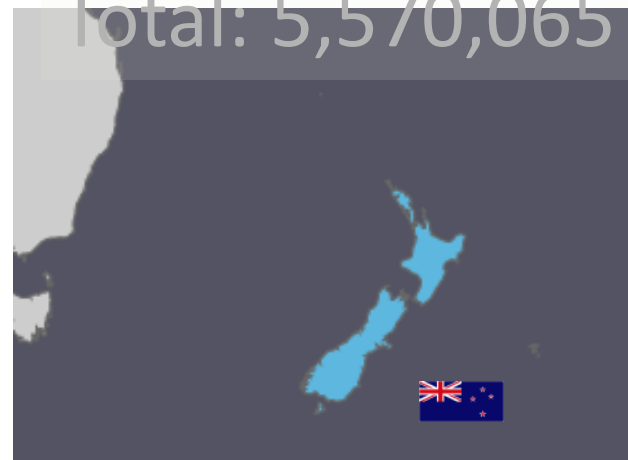
Hospital expenditures

use of services

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Variation in place of death

International Place of Death (IPoD) Study



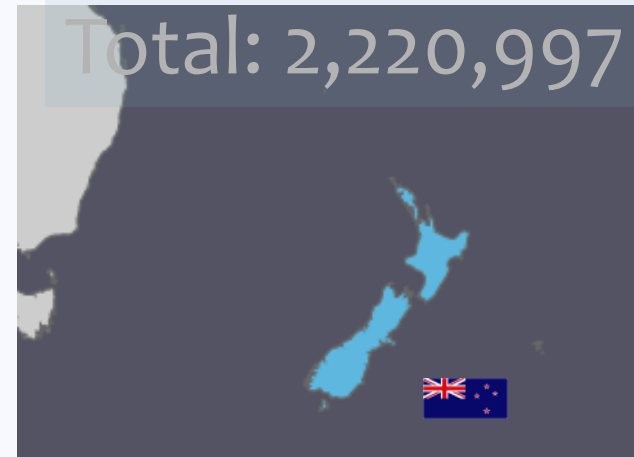
Total: 5,570,065 deaths

'population in need of palliative care' by Rosenwax, McNamara et al.

Underlying cause of death:

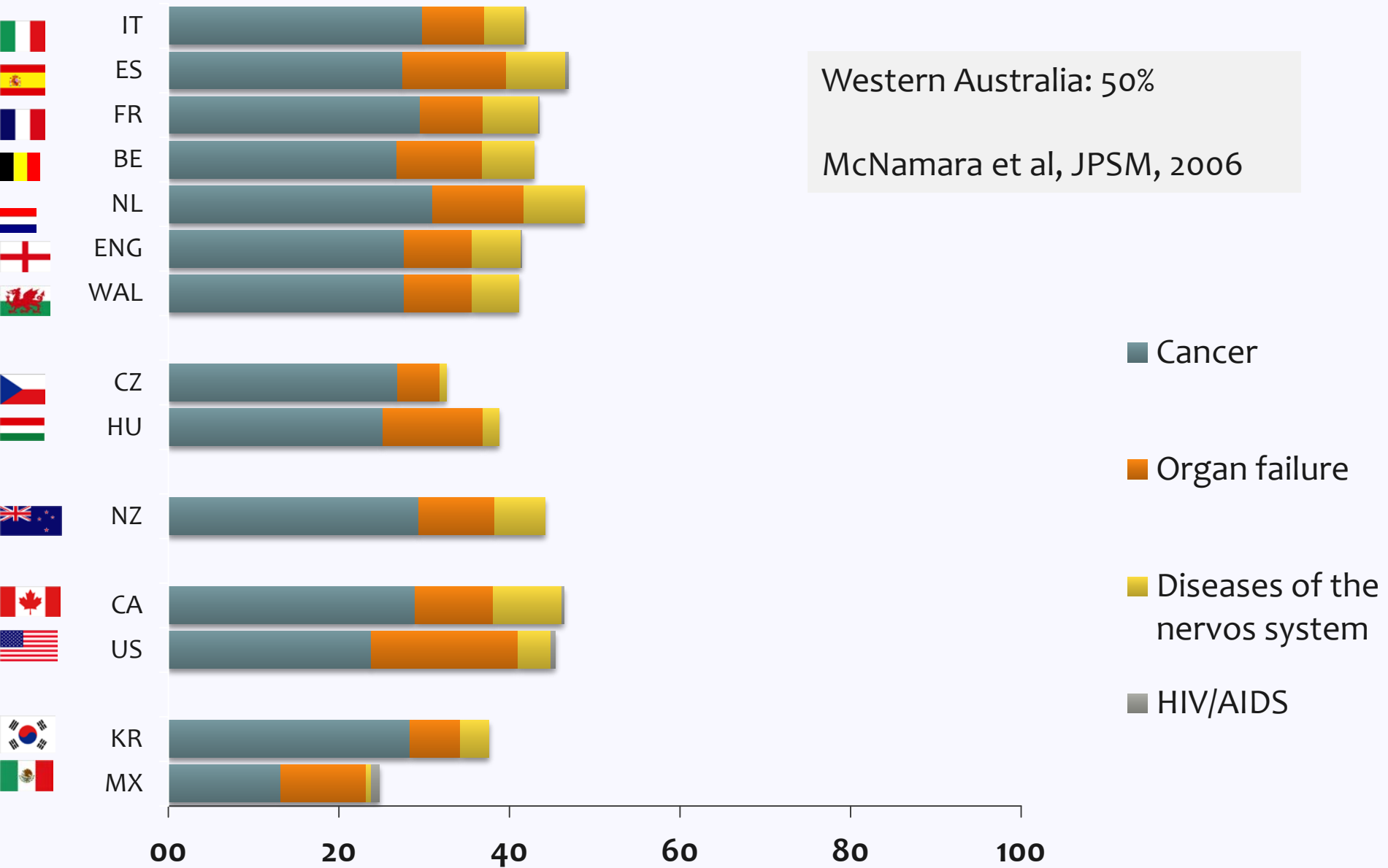
- Cancer
- Heart failure
- Renal failure
- Liver failure
- Chronic obstructive pulmonary disease
- Diseases of the nervous system
- HIV/AIDS

Population in need of palliative care

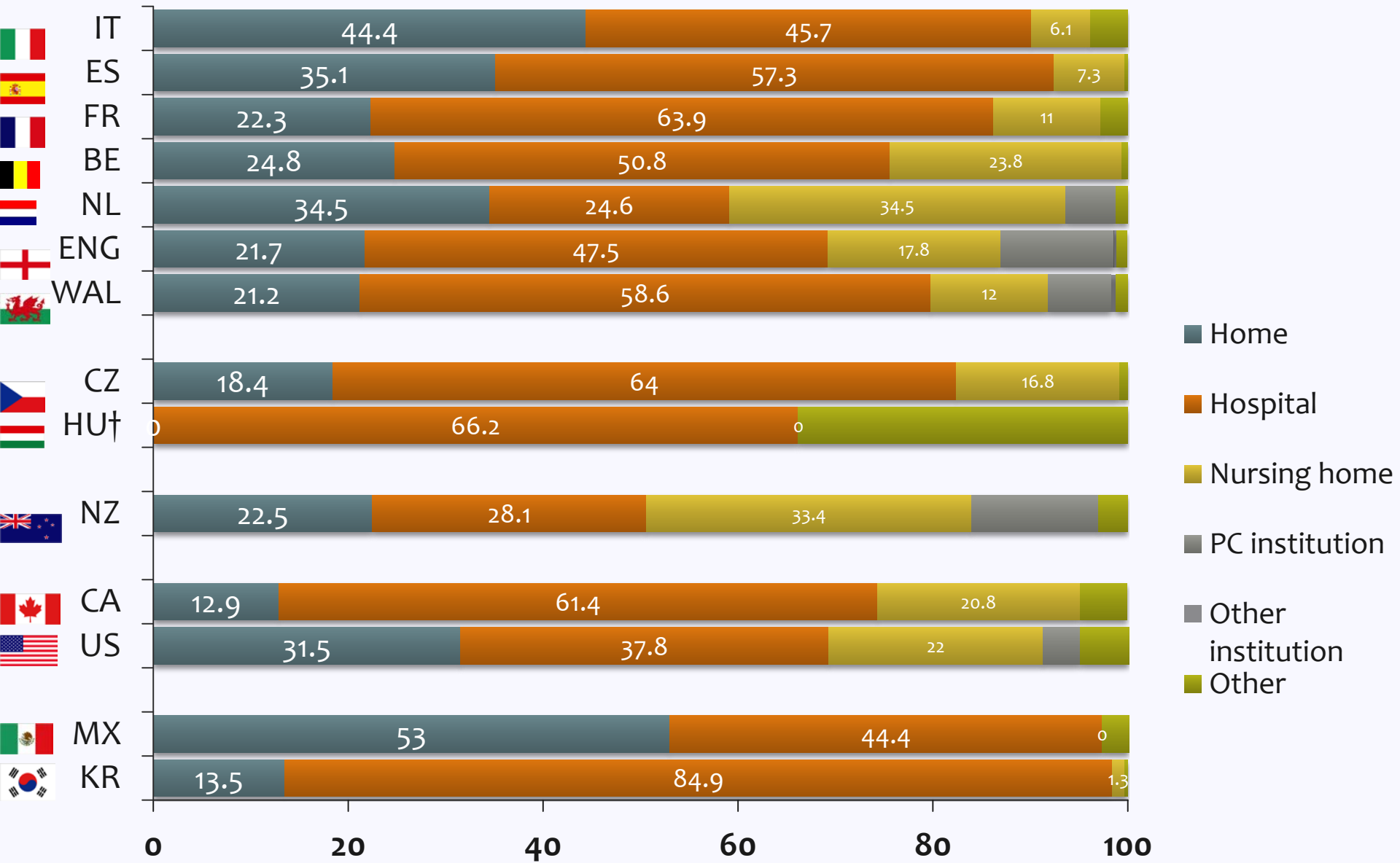


Total: 2,220,997 deaths

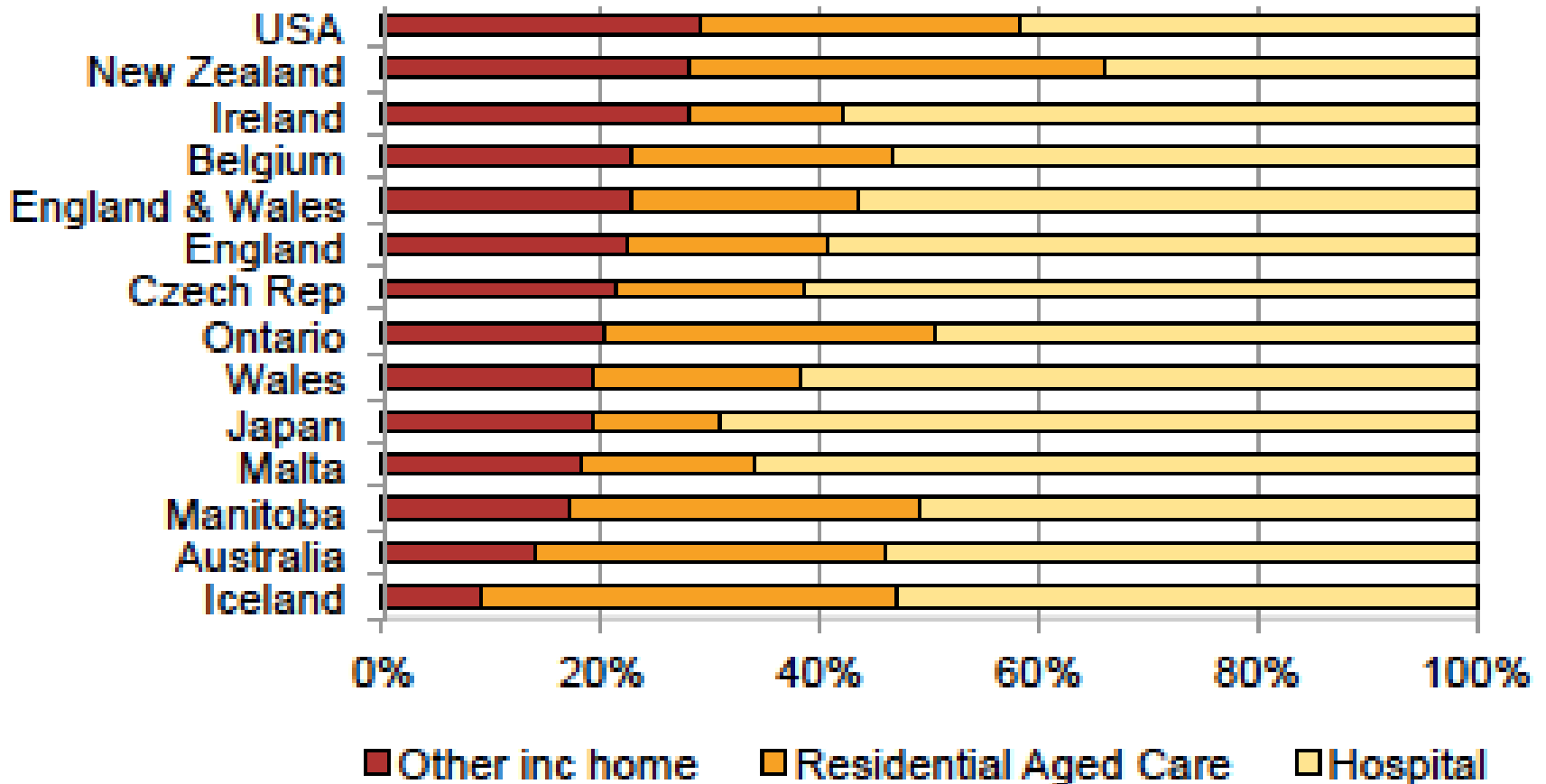
Population in need of palliative care



Large cross-national variation in place of death (N= 2,220,997)

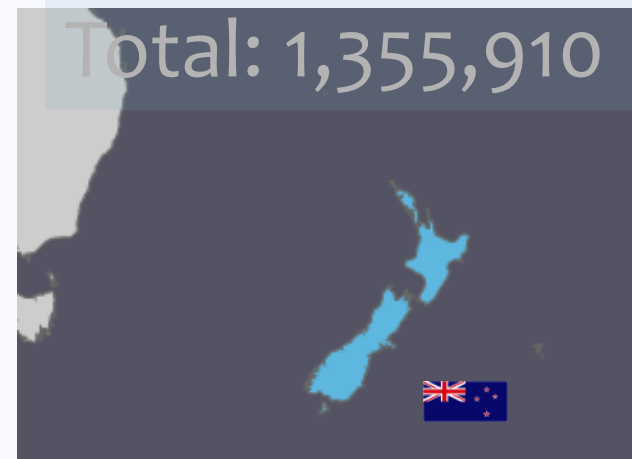


Australia: few over 65 die at home



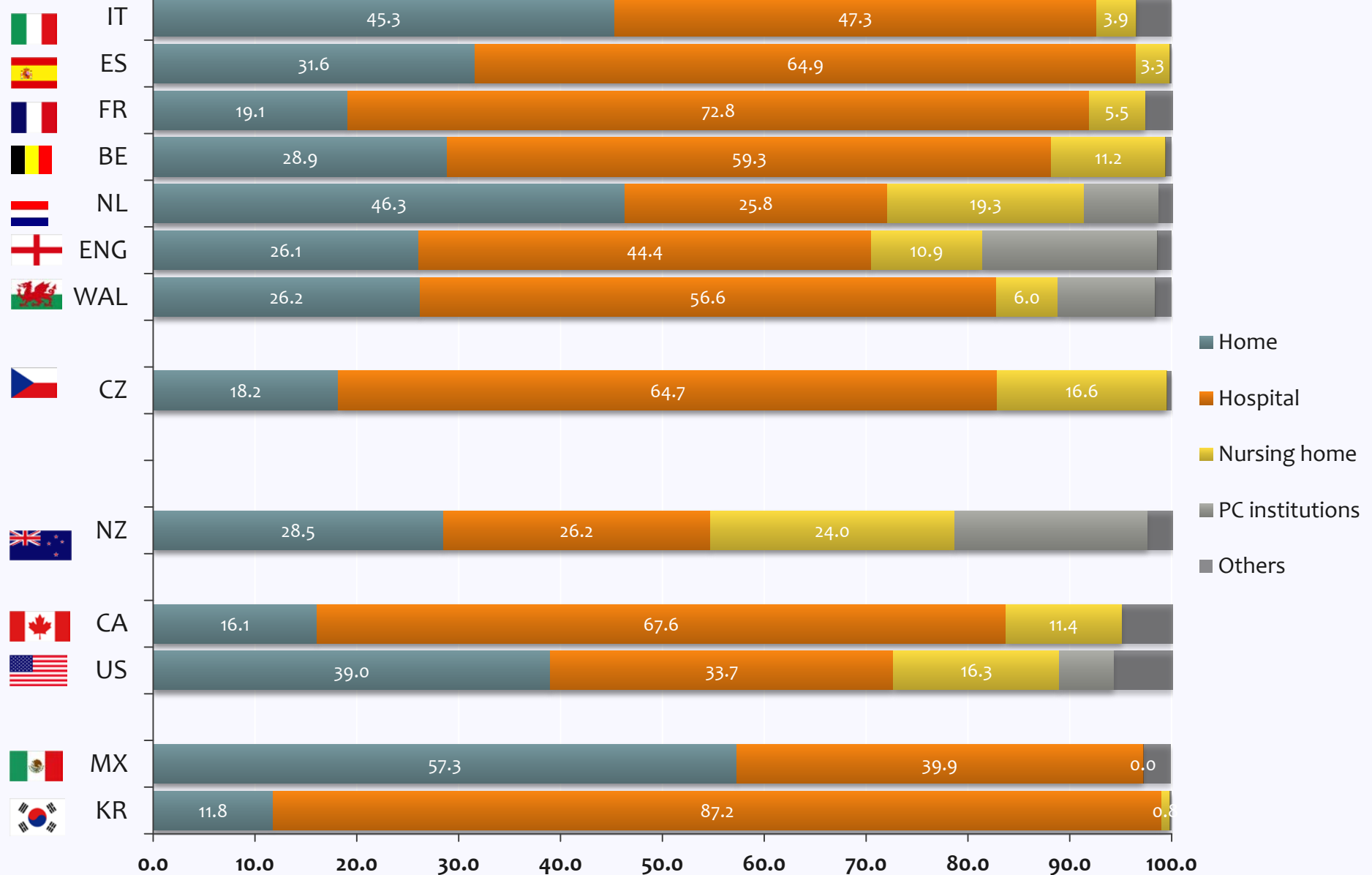
Grattan report (2014)

Population dying of cancer



Total: 1,355,910 deaths

Large cross-national variation in place of death (N= 1,355,910)



In most countries cancer patient more likely to die at home



Variation in place of care

International Consortium for End-of-Life Research Study

Claims and registry data (2010 data)

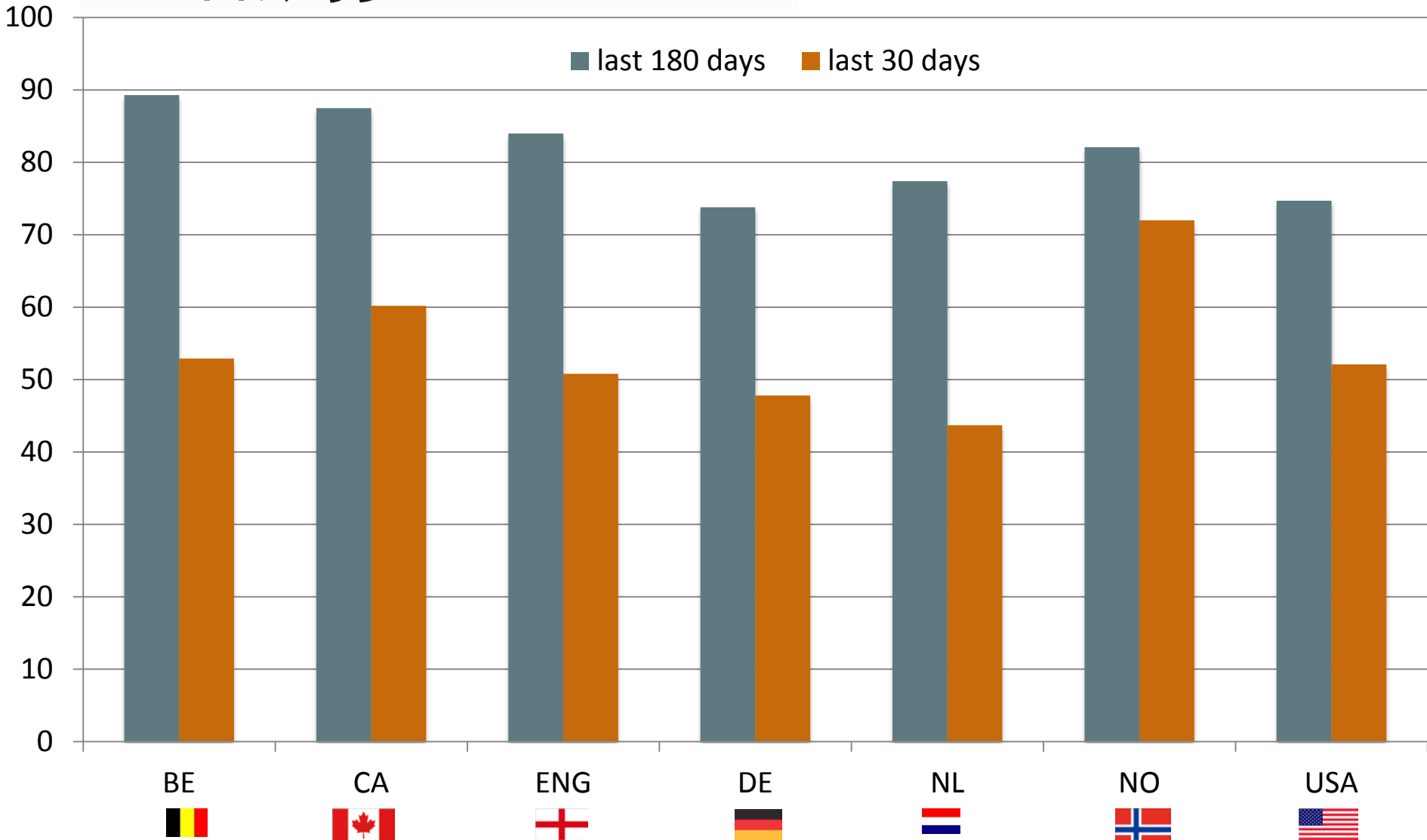


Total: 447,193 cancer deaths

Variation in hospital admission rates in last month

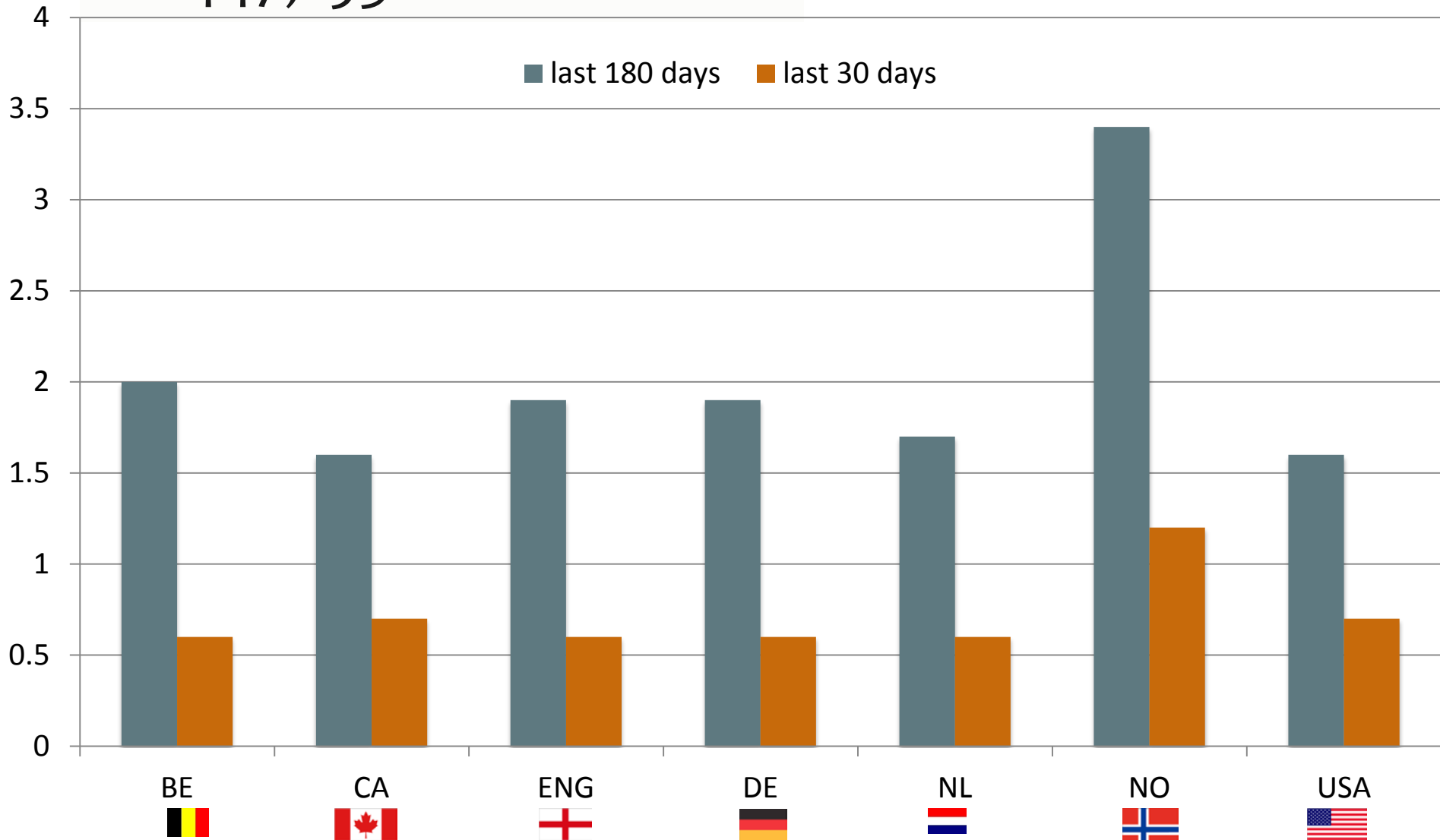
% with at least 1 admission

N= 447,193



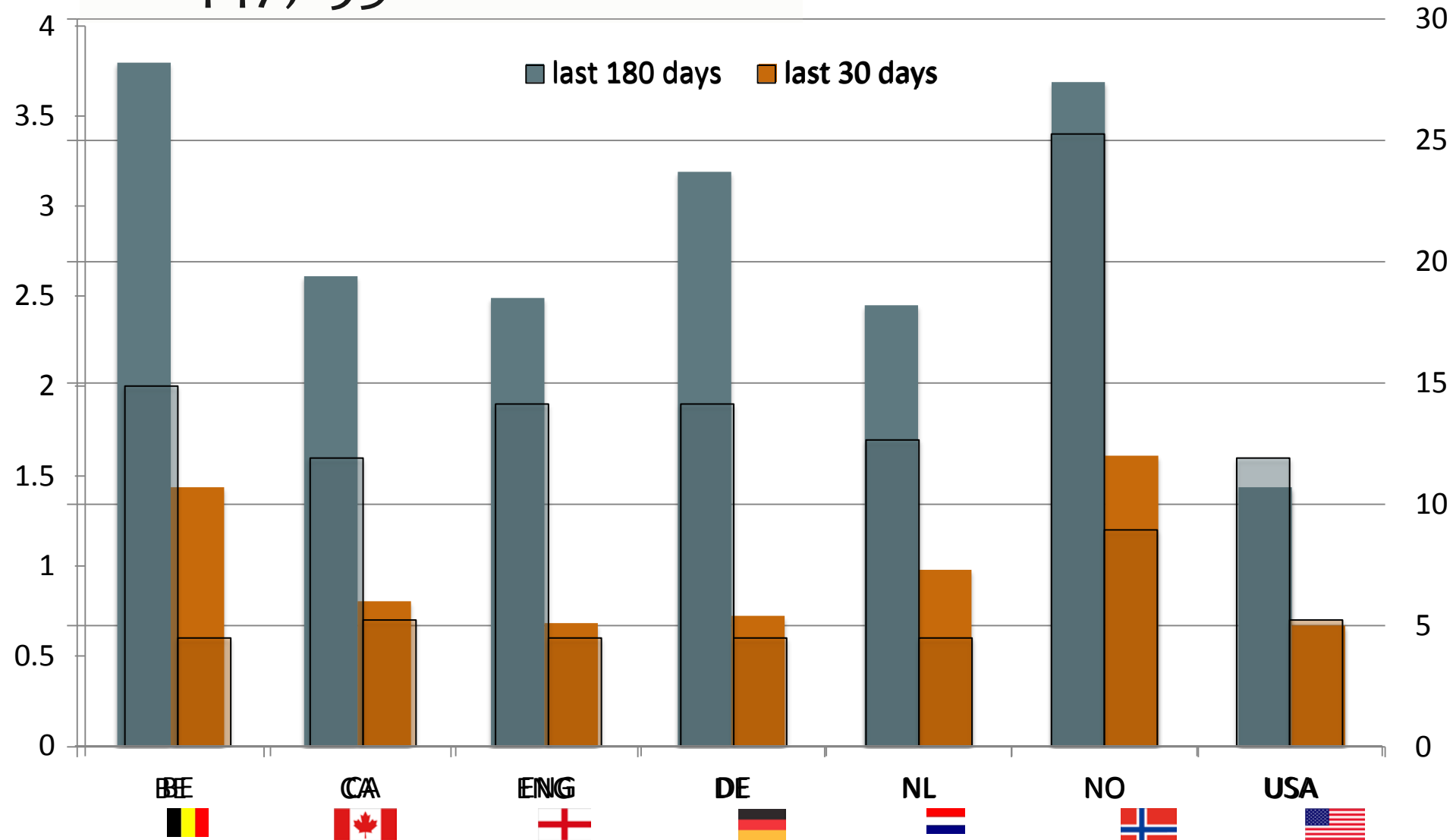
Variation in mean hospital admissions and nr days spent in hospital in last month

mean nr of admissions
N= 447,193



Variation in mean hospital admissions and nr days spent in hospital in last month

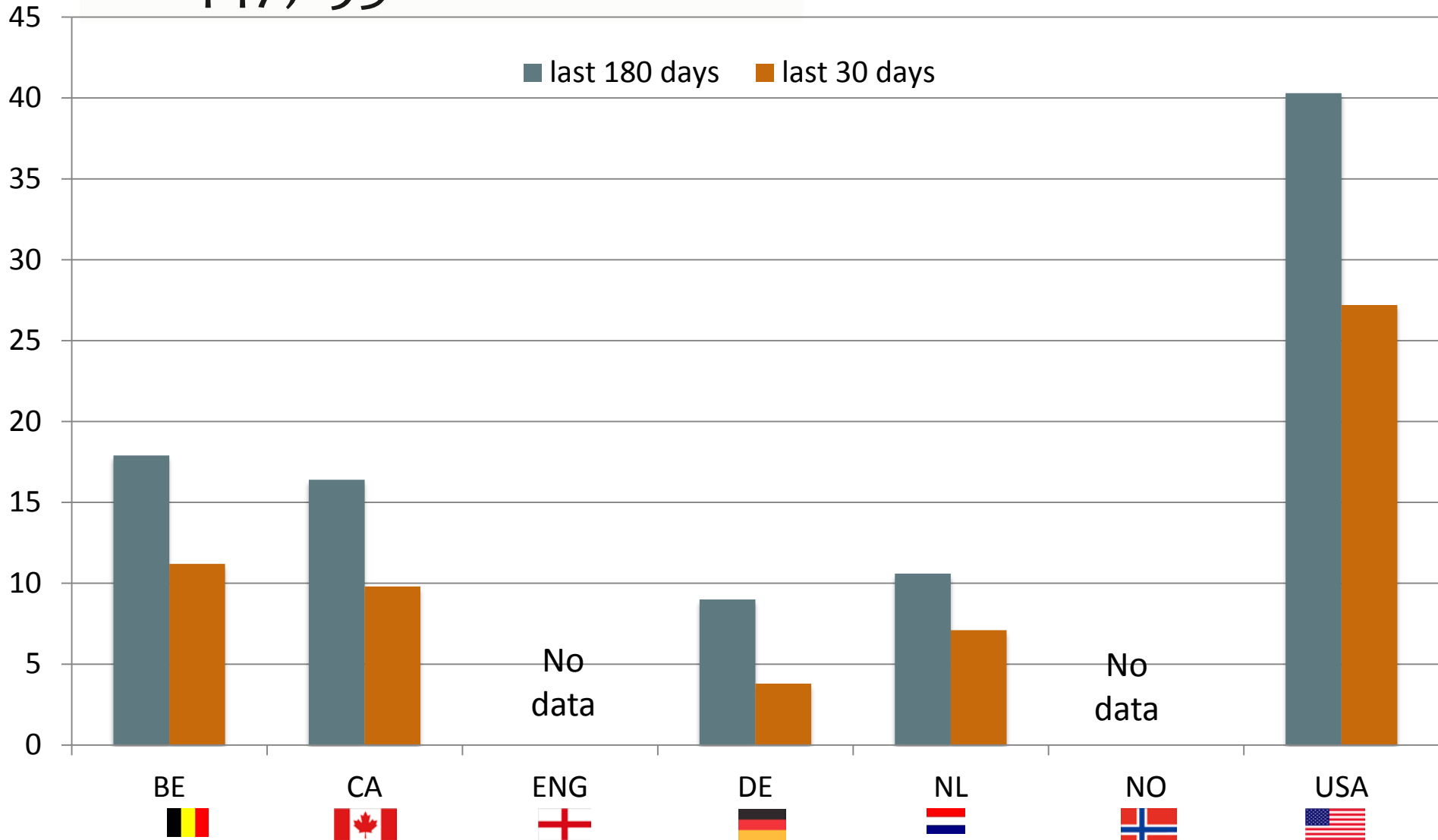
mean nr of admissions and mean nr of days
N= 447,193



Variation in ICU admissions

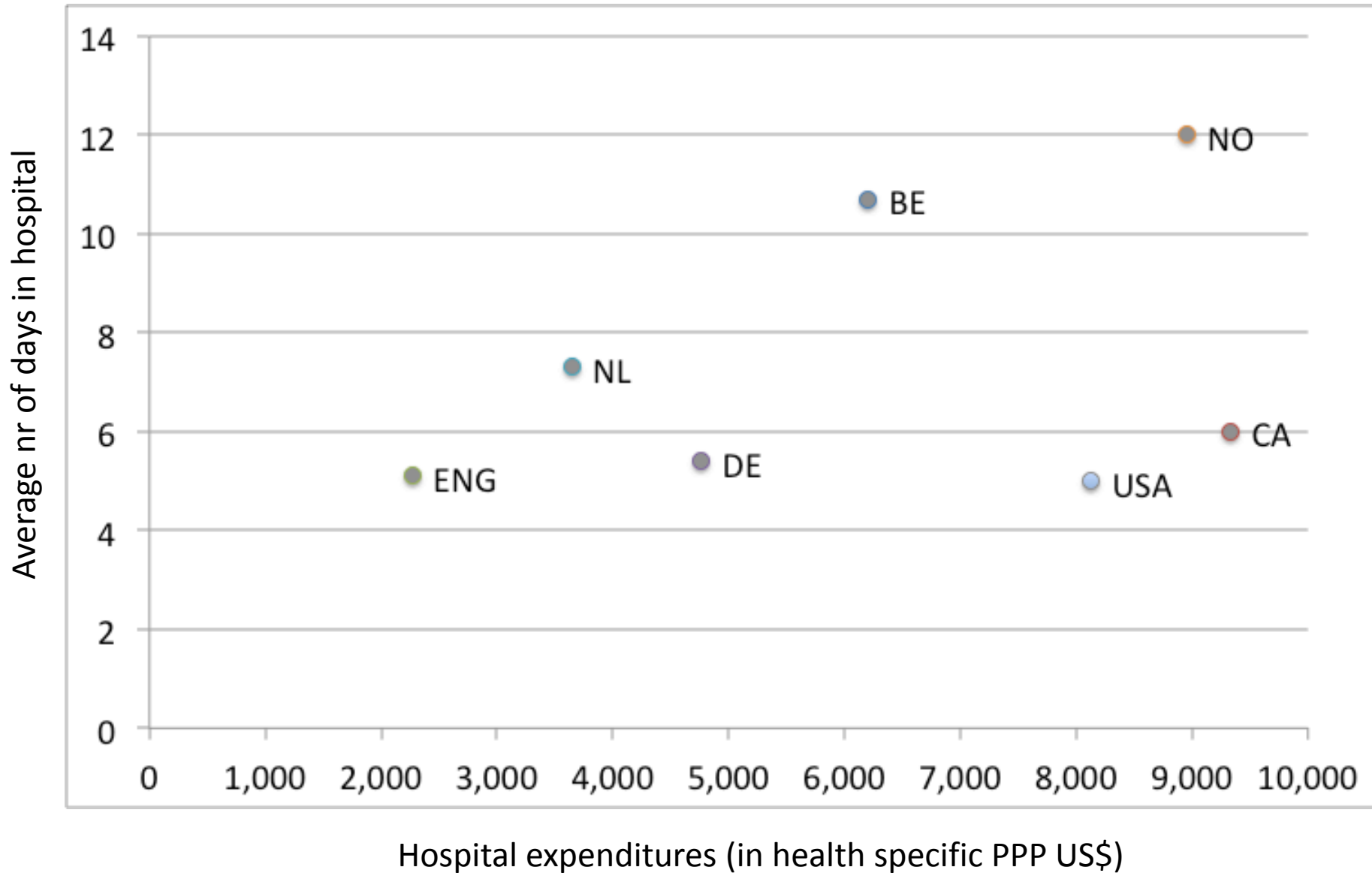
% with an admissions

N= 447,193



Variation in hospital expenditures

Resource Utilization and Hospital Expenditures in last 30-days of Life



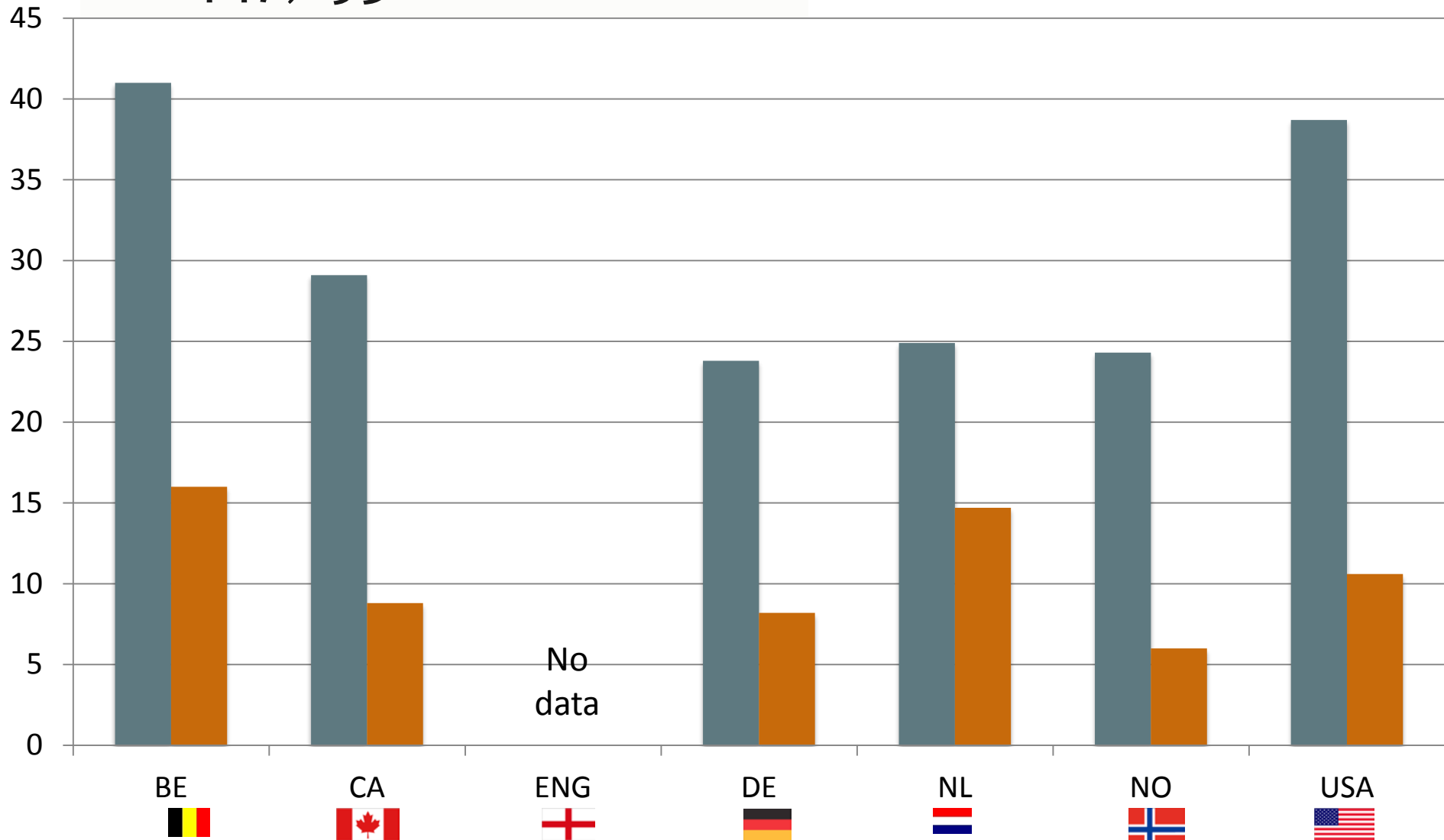
Variation in use of services

Variation in use of chemotherapy in final months

% with at least one chemotherapy episode

N= 447,193

■ last 180 days ■ last 30 days



So what?

Not useful because of the obvious differences in the health care systems, reimbursements and cultural attitudes

What does it tell us?

Differences in how countries manage end-of-life care

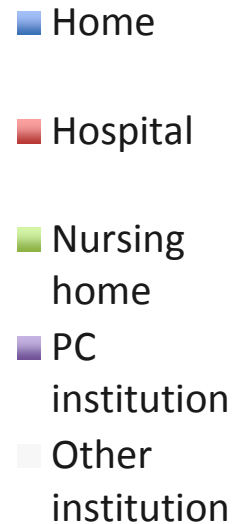
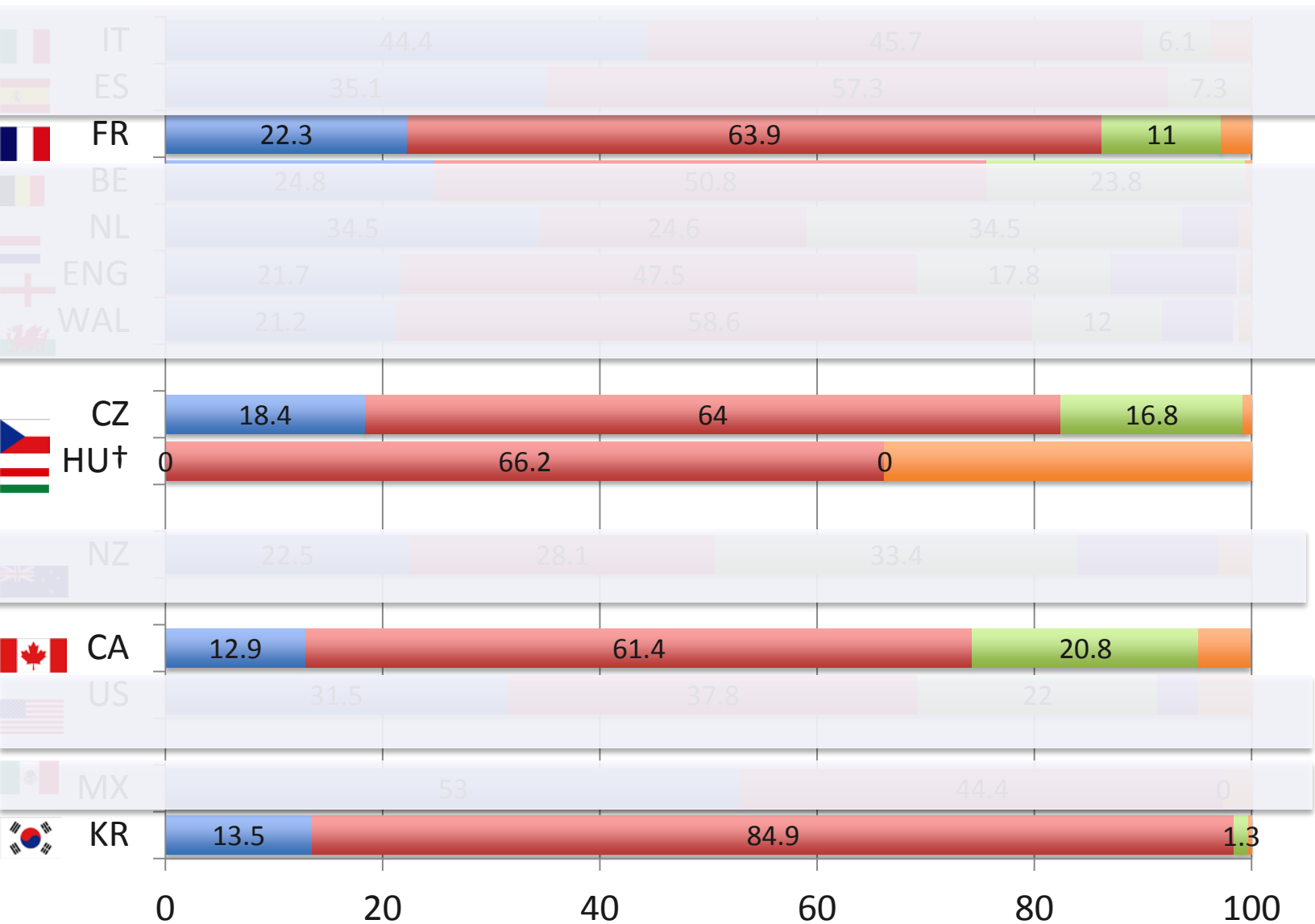
hospital-centric vs out-of hospital centric

eg in cancer

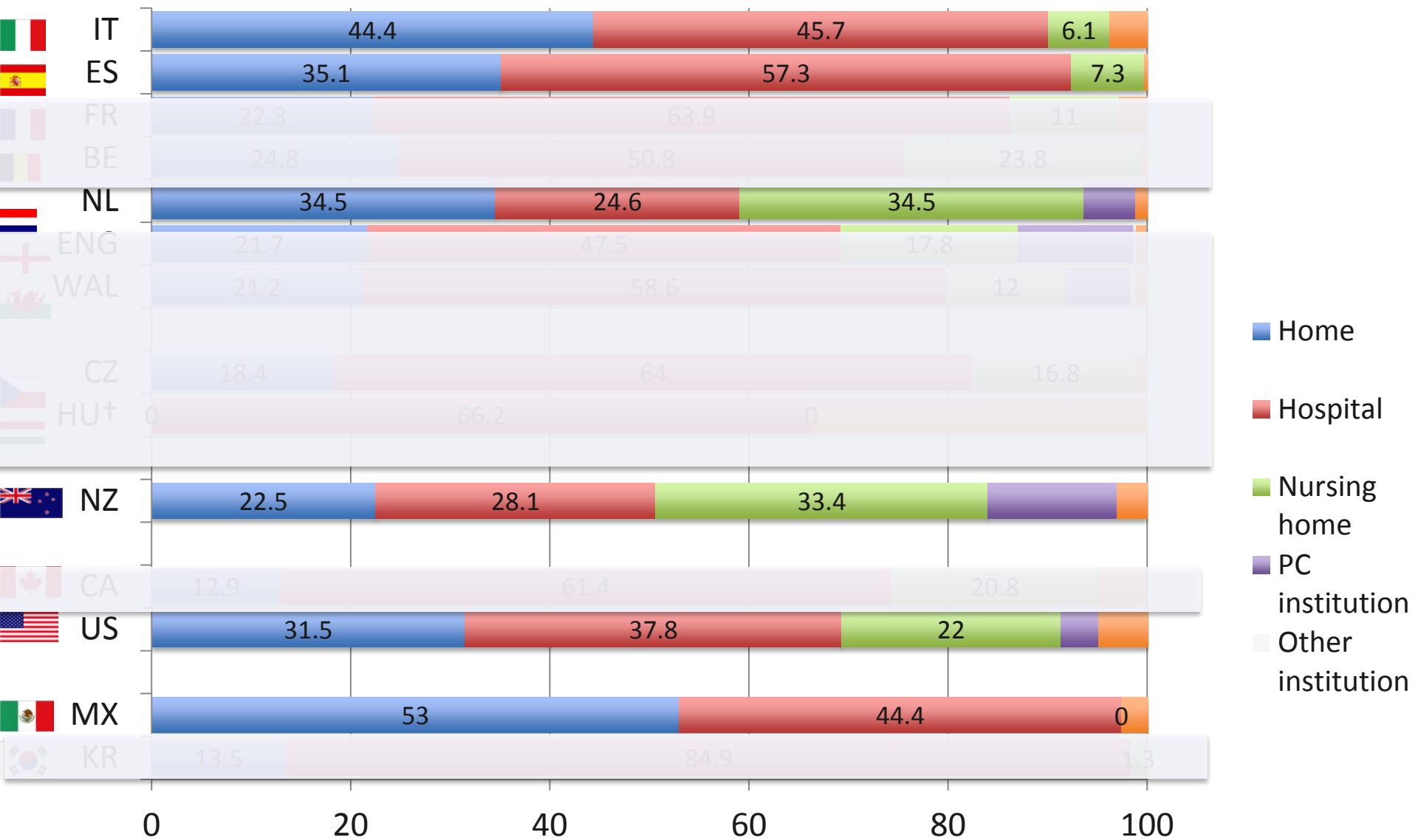
choices re: specialist palliative care services

Country-specific priorities in terms of allocation and quality assurance

Attention to end-of-life care in hospital:



Attention to home and care home as settings of end-of-life care :



What does it tell us?

Differences in how countries manage end-of-life care

hospital-centric vs out-of hospital centric

eg in cancer...

Country-specific priorities in terms of allocation of quality assurance

Differences in spending

Quality of EOLC issues → benchmarking

Is it valid to us?

Conceptual equivalence?

eg hospital vs nursing home

Comparable populations and methods

Limited information

context and contingencies

Is it important to us

Yes

quality of care

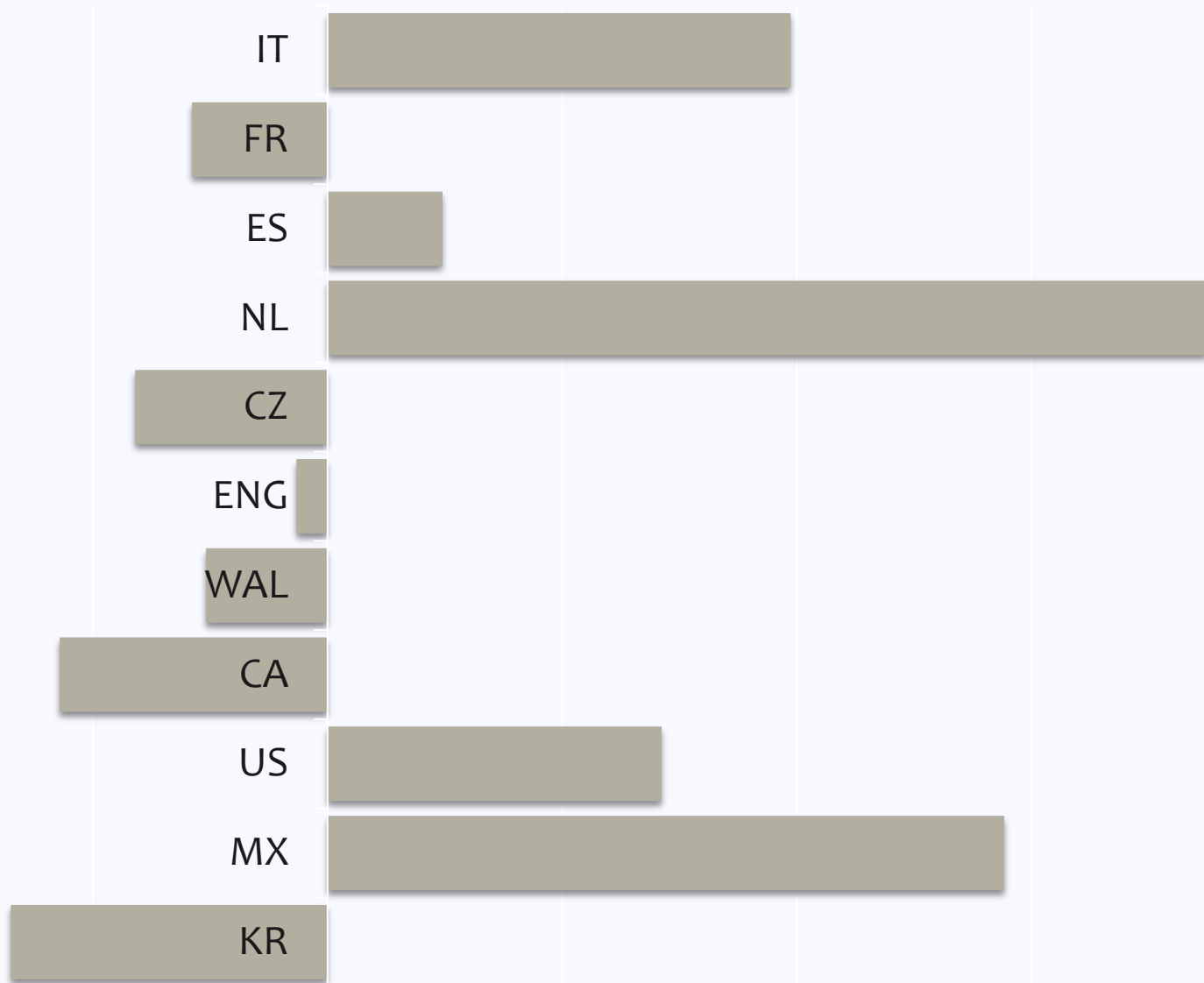
rational use of resources

planning of care (monitoring of needs and services within population)

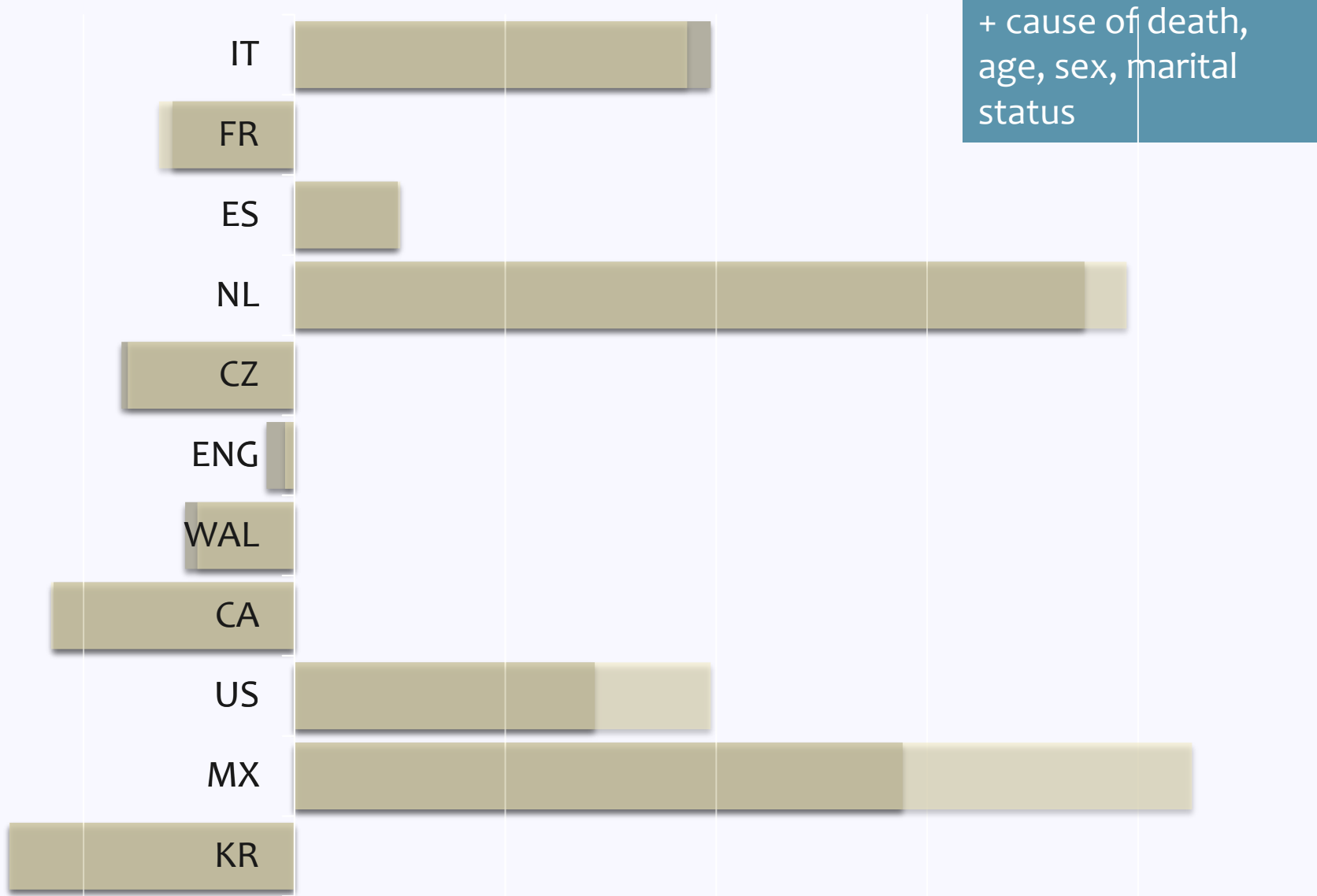
How do we explain the differences

Addressing the why question

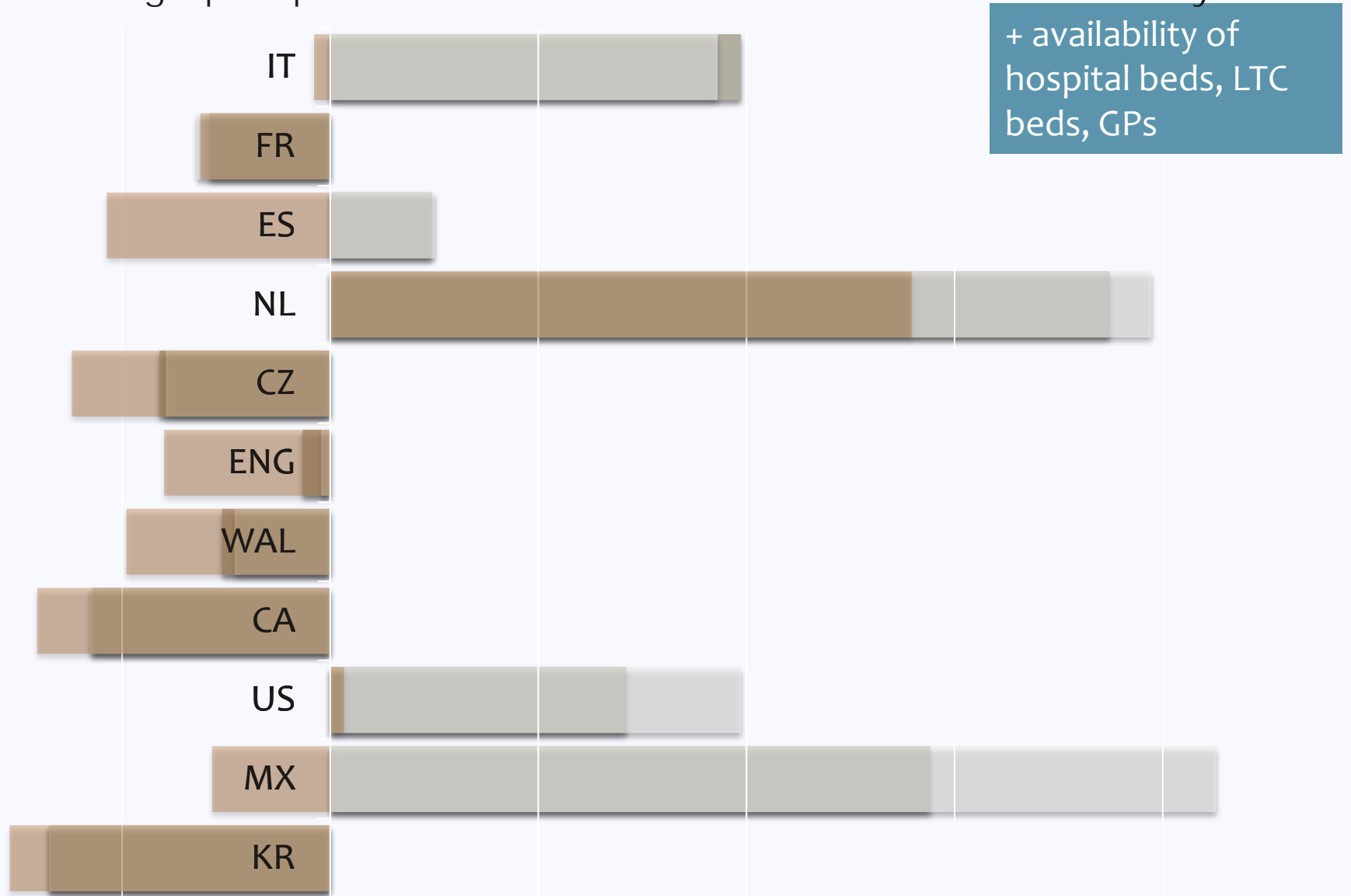
Variation in home death only partly explained by clinical and sociodemographic patient characteristics and health care availability



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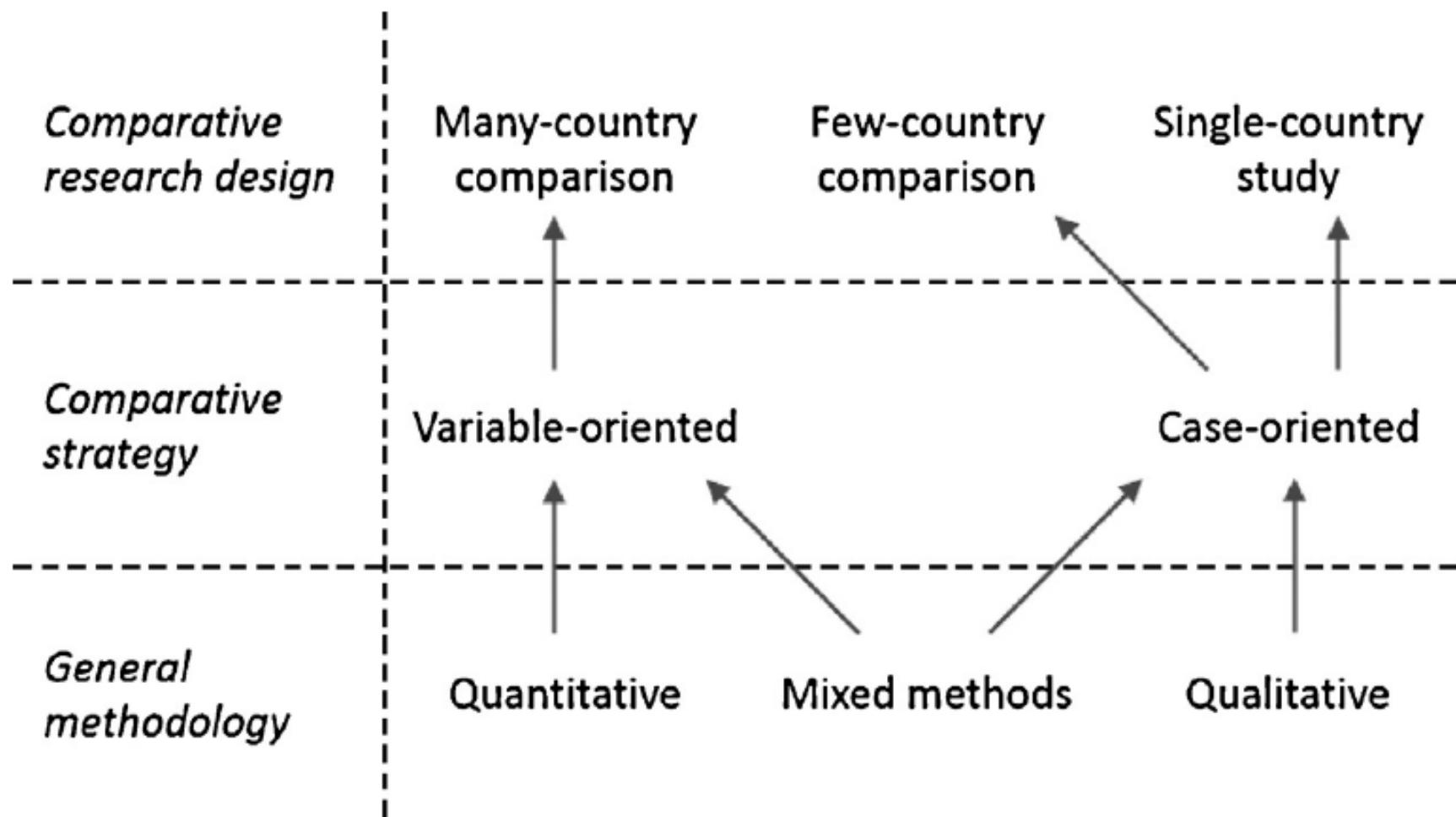
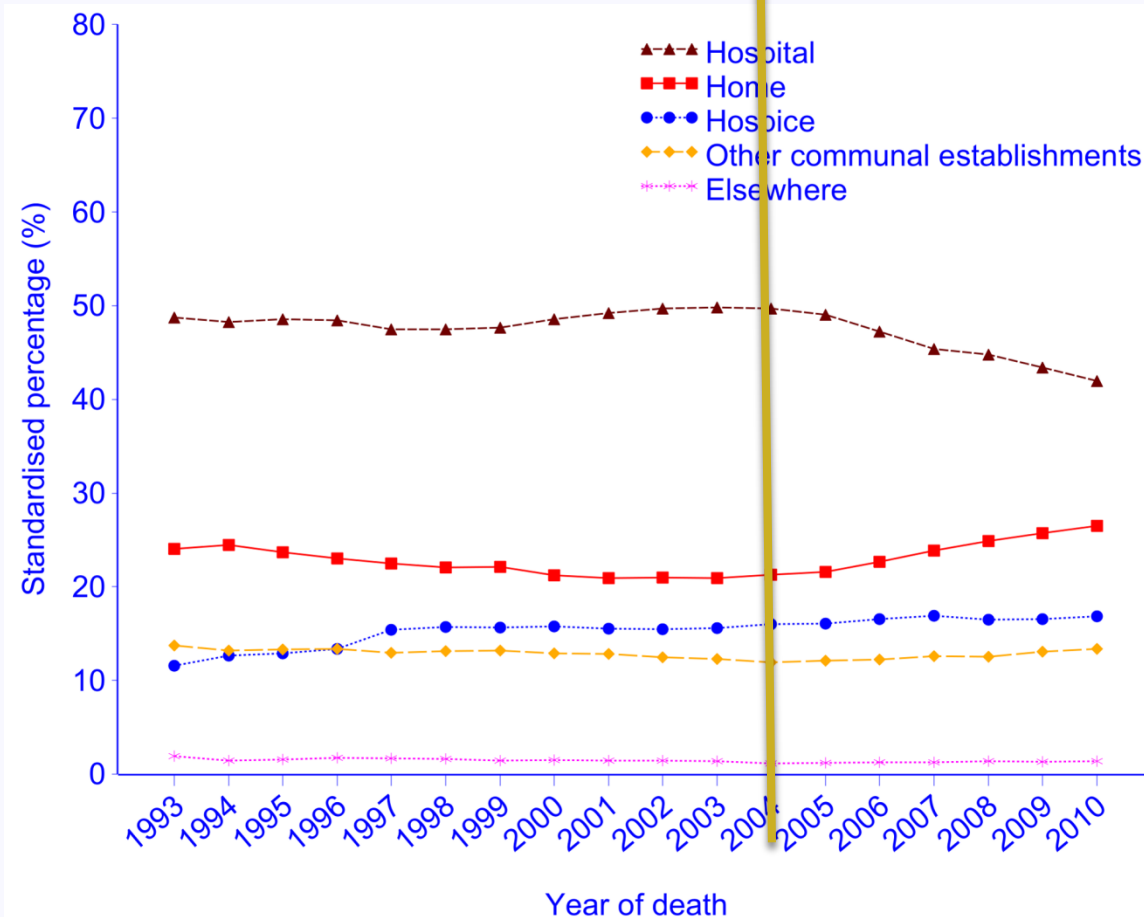


Fig. 1. Relationship of comparative research design to methods.

In England: rise in hospital deaths followed by decrease

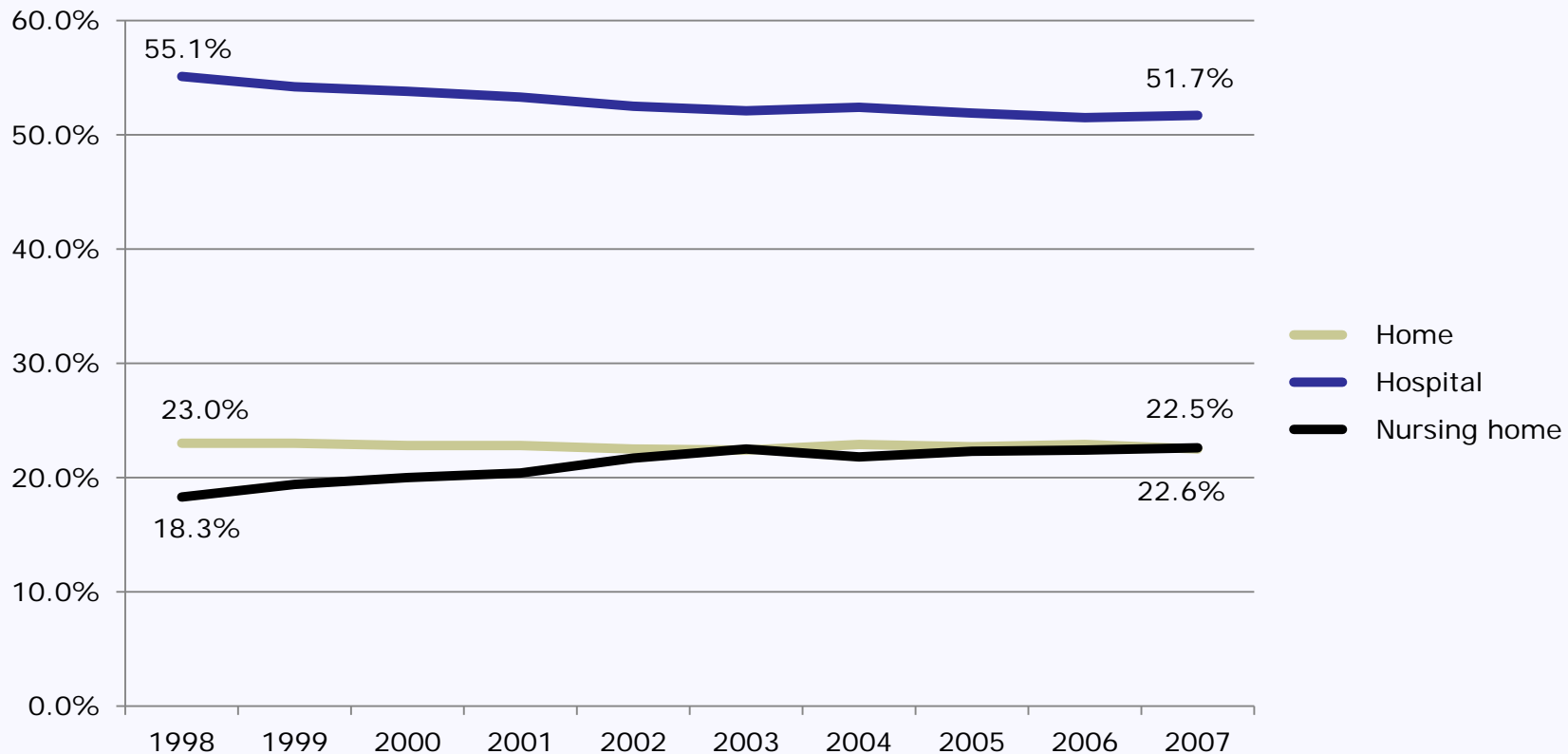
Percentage of cancer deaths by place of death in England (1993-2010)



Could this be the effect of the End of Life Care Programme?

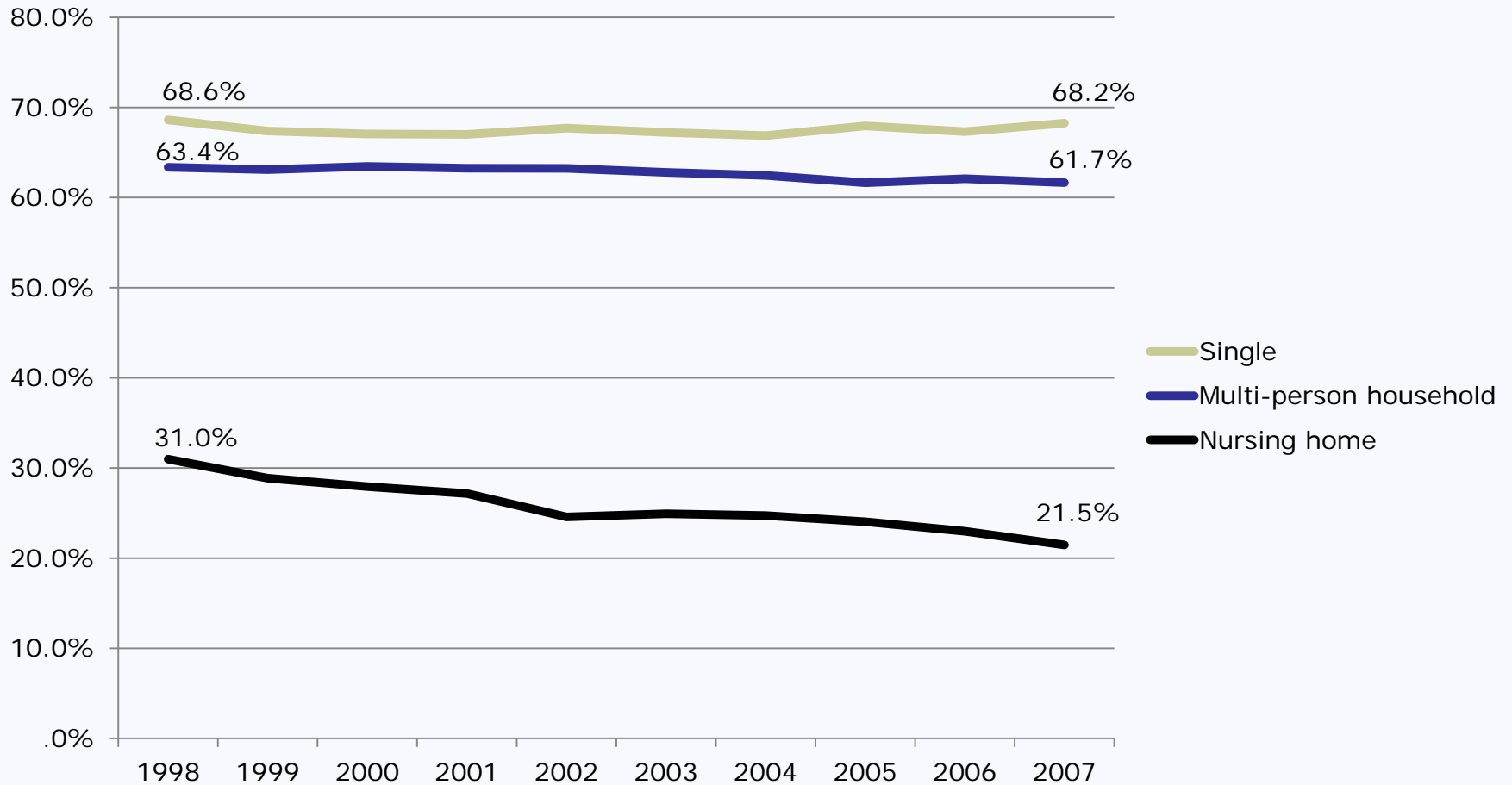
TRENDS IN PLACE OF DEATH IN BELGIUM

- *All deaths 1998-2007*



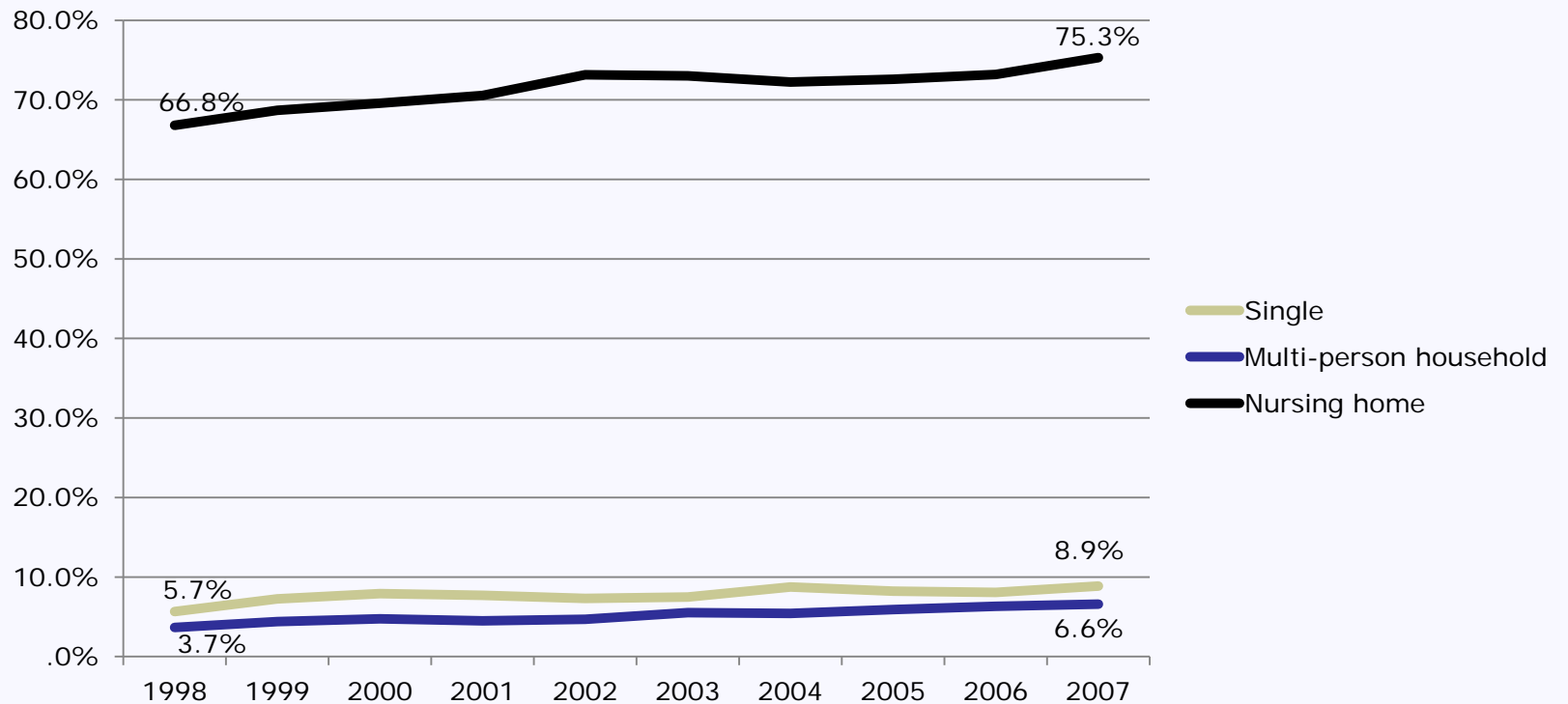
DECREASING PROPORTION DIES IN HOSPITAL IN BELGIUM

Proportion dying in hospital by living arrangement

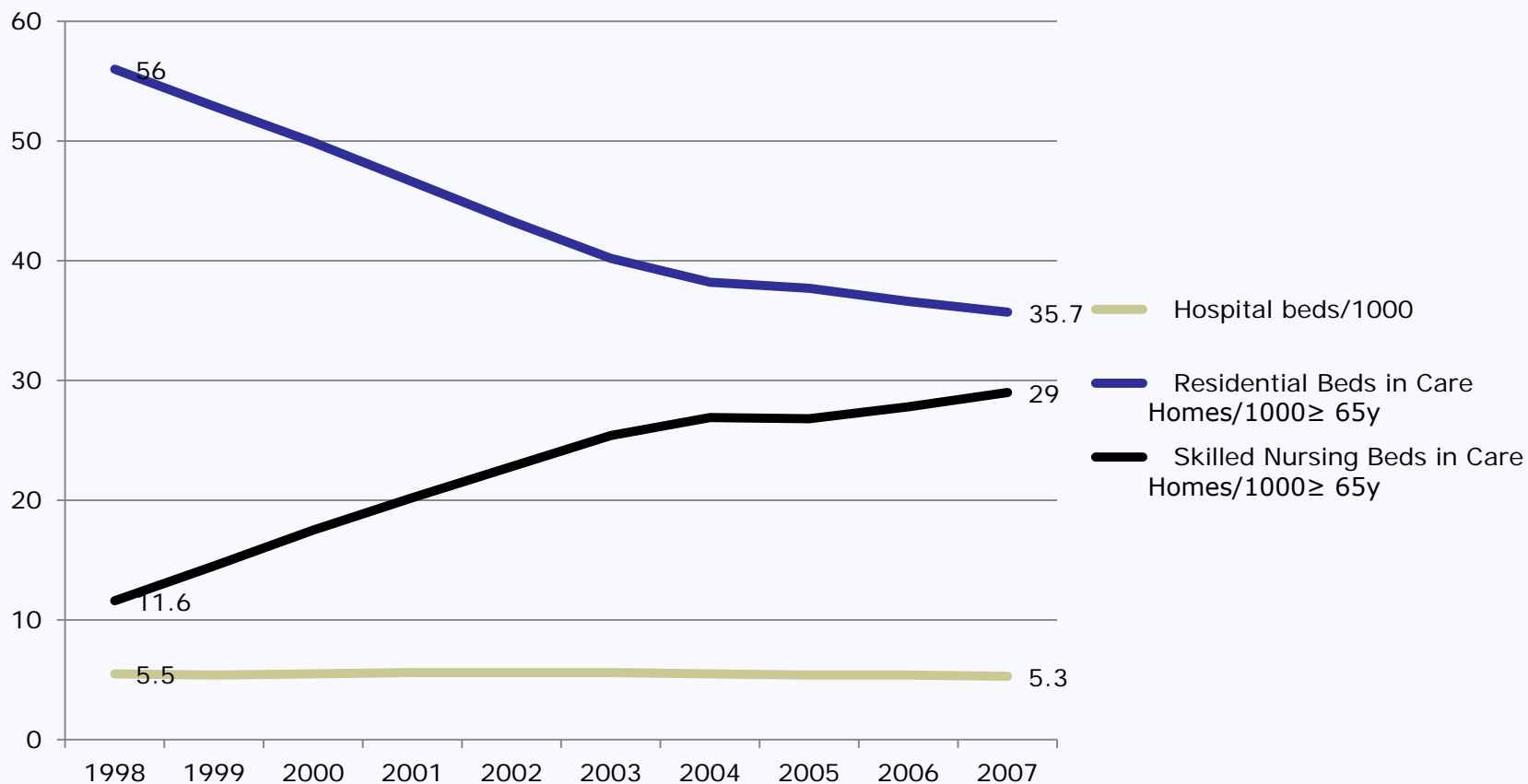


INCREASING PROPORTION DIES IN NURSING HOME IN BELGIUM

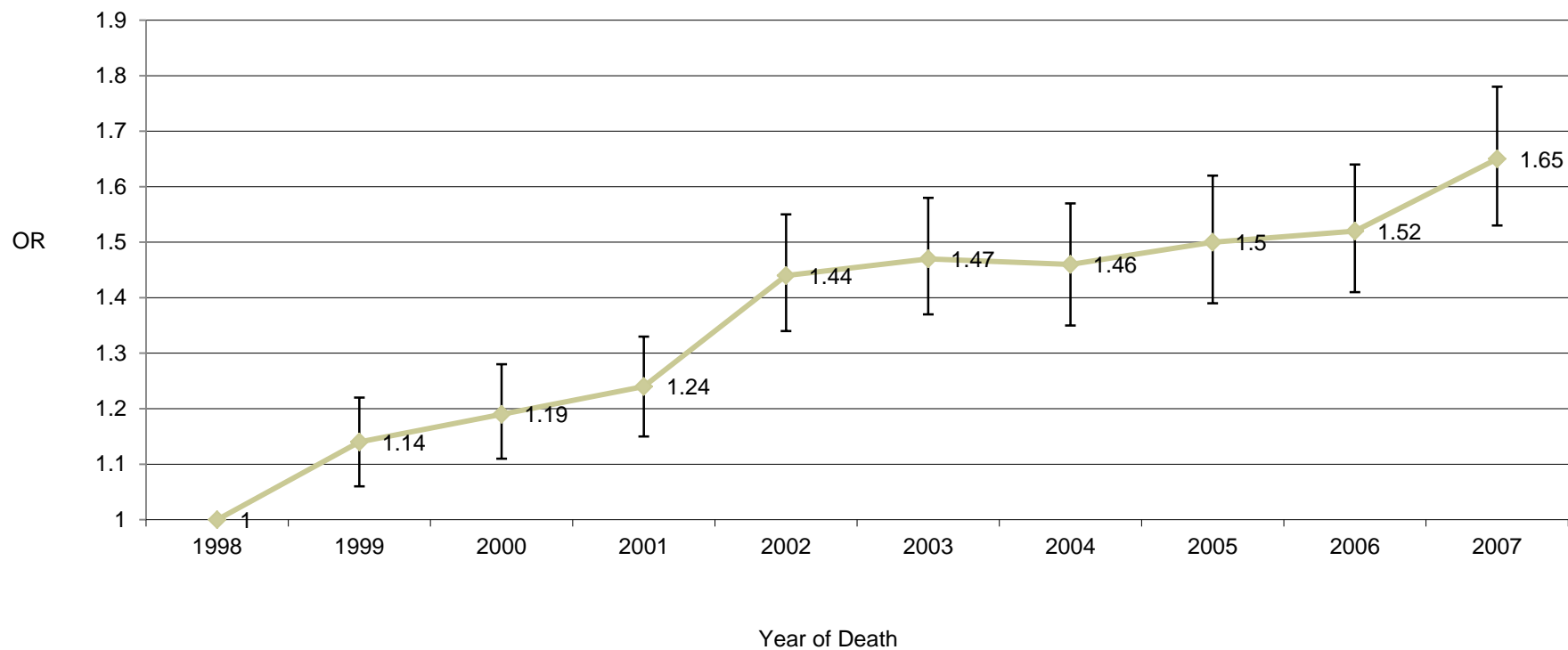
Proportion dying in nursing homes by living arrangement



BELGIUM HAD A POLICY OF CONVERSION OF RESIDENTIAL TO SKILLED NURSING BEDS IN LONG-TERM CARE SETTINGS

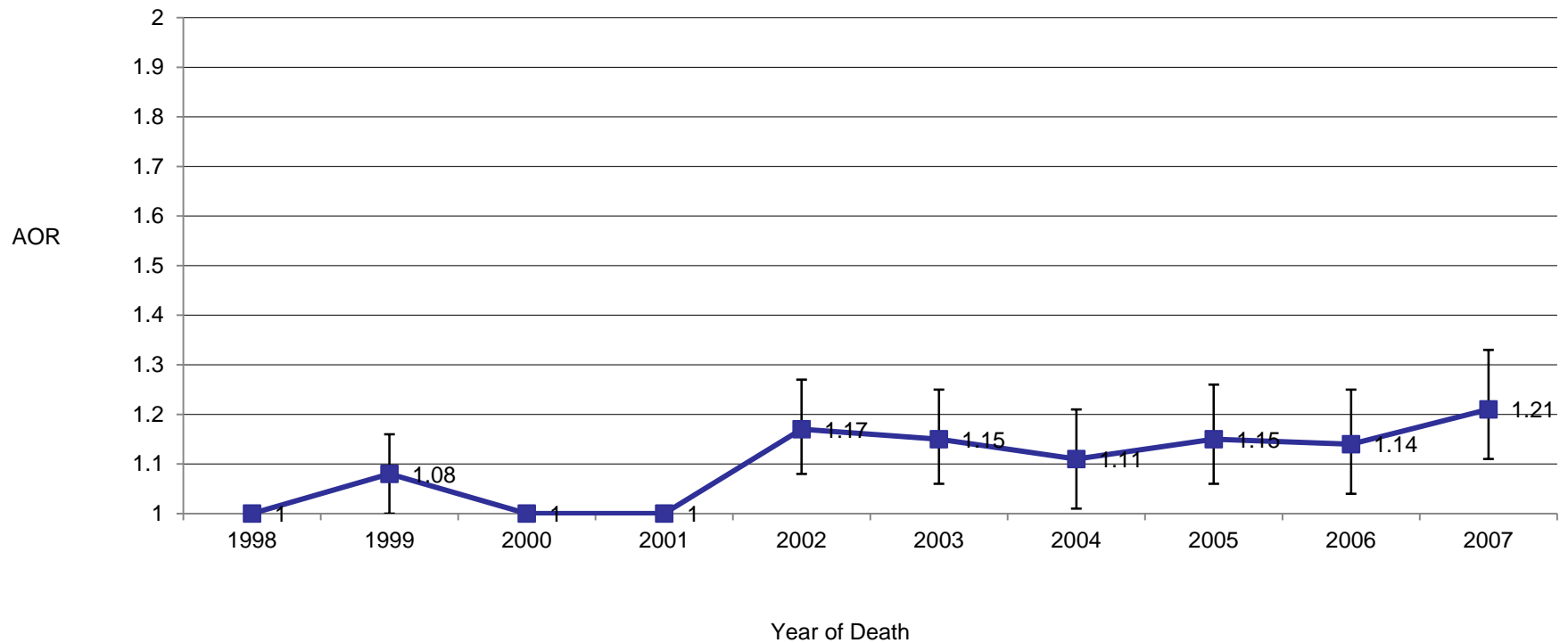


Unadjusted Odds Ratios of Nursing Home Relative to Hospital Death



TRENDS IN NURSING HOME DEATH

Adjusted Odds Ratios of Nursing Home Relative to Hospital Death

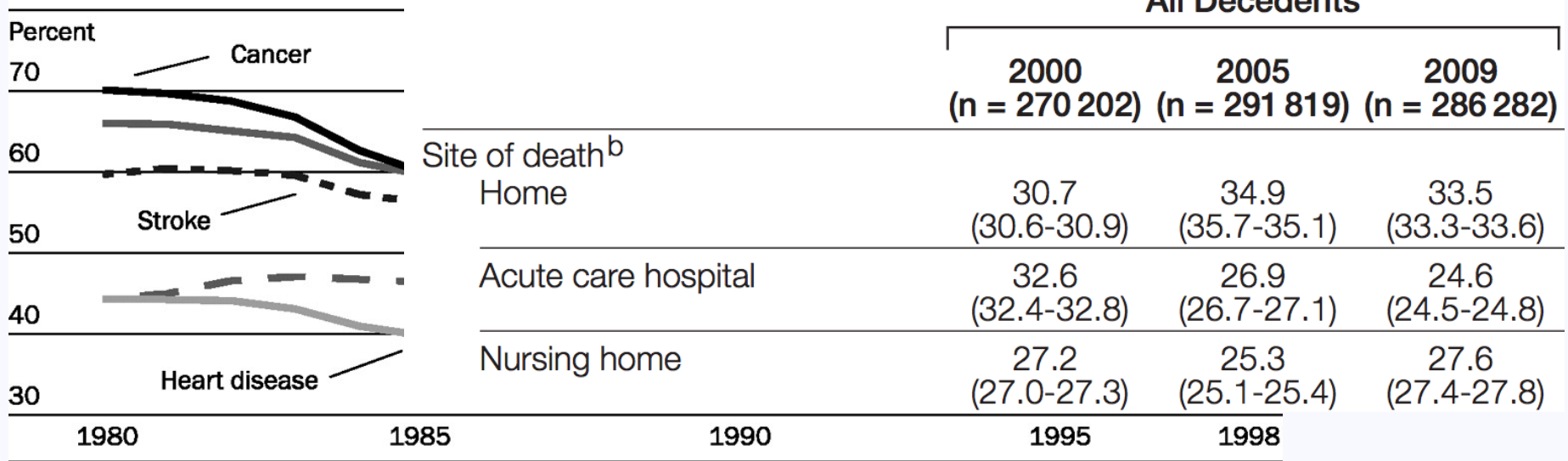


Houttekier et al *BMC Pub Health* 2011

US SAW REVERSAL OF TRENDS IN HOSPITAL DEATHS

James Flory et al. Health Aff 2004;23:194-200

EXHIBIT 3
Decline In Percentage Of Americans Dying As Inpatients, By Cause Of Death,
1980-1998



SOURCE: National Vital Statistics System Death Certificate Records.

NOTES: AMI is acute myocardial infarction. COPD is chronic obstructive pulmonary disease.

Could this be the
 effect of policy
 changes?

VARIOUS FACTORS RESPONSIBLE FOR THE COUNTRY DIFFERENCES:

- *Effects of specific end-of-life care policies*
- *Past choices regarding settings of end-of-life care (cancer vs non-cancer)*
- *Wider societal factors and historical contingencies*

Perceptions about avoidability of a 'terminal' hospitalization differ

Country	%in hospital	% avoidable
England	48%	
Belgium	51%	
New Zealand	28%	
Netherlands	25%	

Different studies

Are the differences acceptable?

Yes:

If preferences different

→ No good empirical indications

If QoL QoD is guaranteed despite differences

→ hard to tell whether that's the case

No:

Too large to be logical

Contingent but not arbitrary

Can countries learn from each other?

Yes:

Valuable insights from looking across countries

Understanding similarity or specificity of problems

Understanding policy development, ways to address problems, opportunities and constraints

BUT:

need other type of information

Benchmarking

Explain how and why policy measures or strategies are effective

Context specificity

key question: Under what circumstances and to what extent will a programme that works in country A also work in country B?

Fit for the future?

Large-scale cross national comparison is only a first step

Need for a research agenda based on learning, explaining and understanding

No too much omphaloskepsis



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