Enabling everyone to die well - what are (some of) the gaps and who is responsible for addressing these?

Professor (Dr) Julia Verne and Professor Maggie Doherty

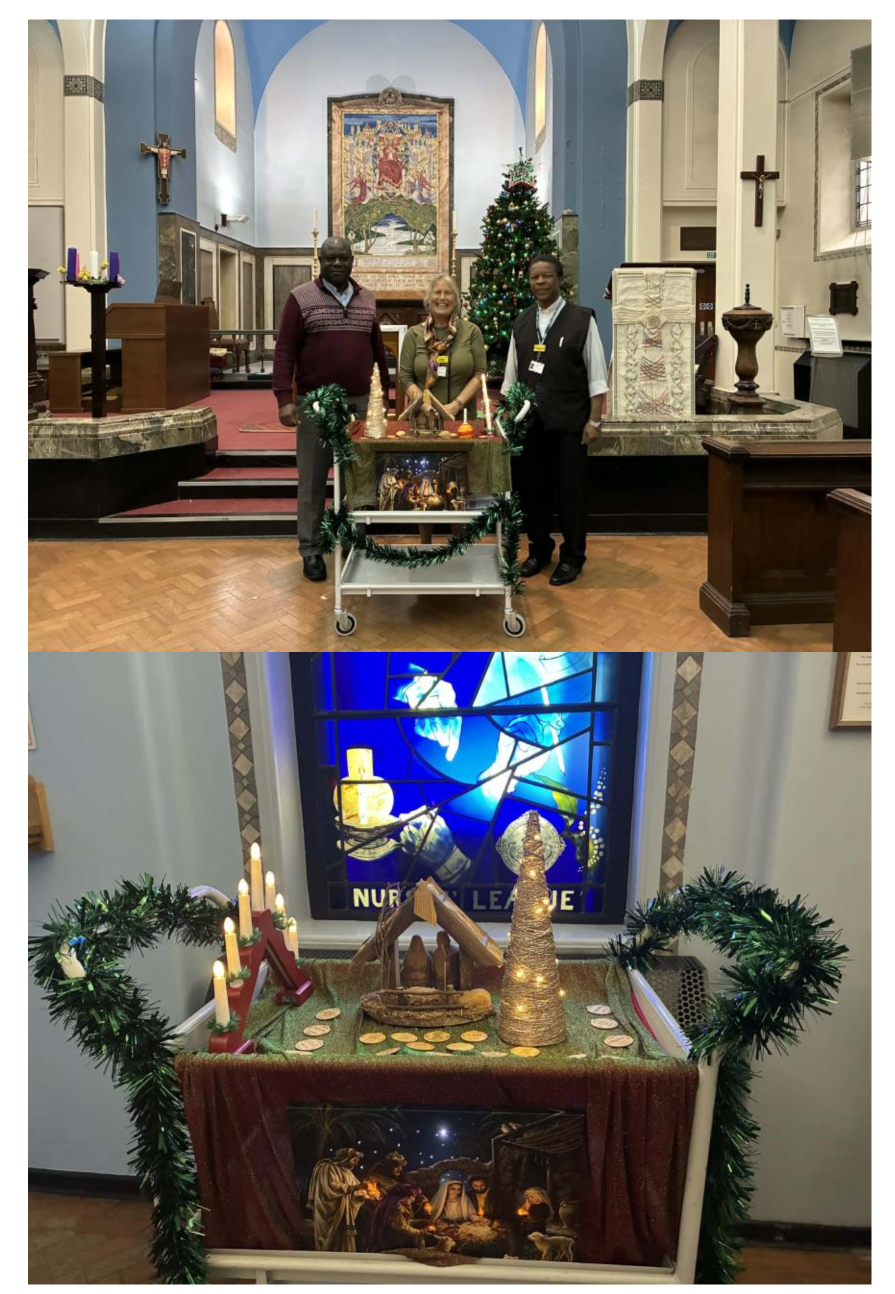
Klepsydra/hour glass
Since 1500BC Athenian Courts to time limit discourses

Professor (Dr) Julia Verne

From Doctor/Academic
Public Health Specialist with 30 years experience in improving Palliative and End of Life Care at Local, Regional and National Levels also National expertise and leadership in tackling Liver Disease and Inequalities

To Academic/Chaplain:
Visiting Professor at Dame Cicely Saunders Institute in Palliative Care and Hepatology, King’s College London

Honorary Assistant Chaplain King’s College Hospital NHS Trust



Associate Professor Margaret (Maggie) Doherty

Lead, Centre for the Art of Living and Dying Well · St Mary's University, London

MCIPR | FRSA | CAICP

Research and Academic Focus

Digital health, end-of-life care and health inequalities. MSc Digital Health (Univ. of Lancashire, 2024); certified in Strategic Communications (LSE) and AI Communication (CAICP, 2025).

Research Publications

Contributions to Social Science & Medicine, Palliative Medicine and Death Studies. Leading Research England-funded community participatory research on death literacy across Birmingham's diverse faith communities - now extending to London with The Royal Marsden.

Practice & Innovation

Developed the award-winning 'Art of Dying Well' podcast, named by The Guardian as one of the top three podcasts on death. Partnered with Lancaster University Medical School to introduce 'Deathbed Etiquette' into health and social care settings.

Background

Former Press Secretary to Cardinal Cormac Murphy-O'Connor and senior communications roles at the Catholic Bishops' Conference of England and Wales. Trustee, St Joseph's Hospice, Hackney.

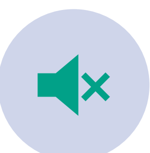
Welcome

- Everyone is welcome
- Time out of the day to connect with others
- An opportunity to share experiences
- A place to be quiet and listen
- Time for reflecting or just being present
- There are no judgements
- This is a safe space

Ground Rules

Confidentiality - personal details shared will stay within the group

Personal safety - we won't do or say anything that makes us feel uncomfortable

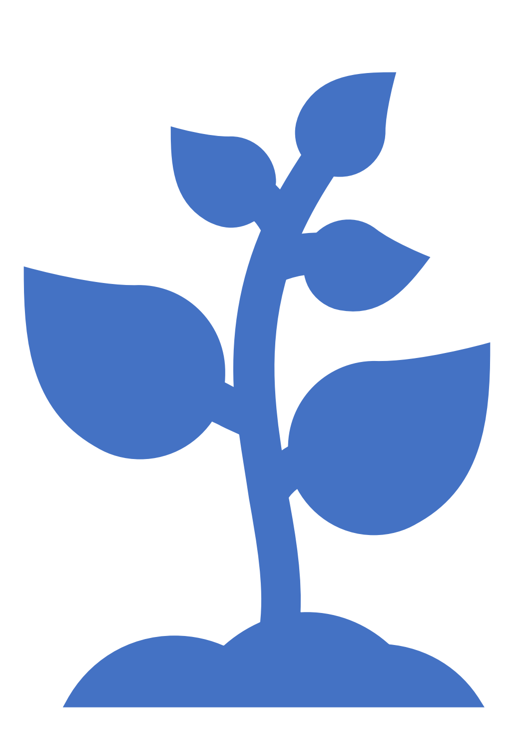


Silence can be very supportive - don't feel you have to say anything

We respect each others' views

Try to get involved if you feel comfortable

No such thing as a silly question



There is no such thing as a silly question

- Every moment and every event of every man’s life on earth plants something in his soul.

Thomas Merton

- SO……. People, their families and situations are complex
- There are as many complexities, beautiful, sad and difficult in death as there are people dying!

- Almost 1 death per minute in England!

Bereavement touches so many lives – on average 4-8 family/friends for each person who has died

Aims:

To reflect on the needs of people who are dying and the bereaved

To reflect on the roles we can play as professionals

and humans

to improve holistic care and to especially address inequalities

Caring for people well at the end of their life is a Human Rights Issue

- **Article 12 International Covenant on Economic, Social and Cultural Rights**
- **Article 7 International Covenant on Civil and Political Rights**

'all member countries of the United Nations are obliged to safeguard patients at the end of life against pain and suffering, allowing them to die with dignity'

All of us are contributing to making this happen

But…. A medical model for dignity

Journal of Pain and Symptom Management
Volume 70, Issue 5, November 2025, Pages 447-458

Original Article

First-Ever Global Ranking of Palliative Care: 2025 World Map Under the New WHO Framework

Vilma A. Tripodoro MD, PhD [1,2], Jesús Fernando López Fidalgo PhD [3], Juan José Pons PhD [4], Stephen R. Connor PhD [5], Eduardo Garralda MA [1,2], Fernanda Bastos MD [1,2], Álvaro Montero MA [1,2], Laura Monzón Llamas MSc [1,2], Ana Cristina Béjar MD [1,2], Daniela Suárez MSc [1,2], Carlos Centeno MD, PhD [1,2]

[1] ATLANTES Global Observatory of Palliative Care (V.A.T., E.G., F.B., A.M., L.M.L., A.C.B., D.S., C.C.), Institute for Culture and Society, University of Navarra, Pamplona, Spain

[2] IdiSNA – Navarre Health Research Institute (V.A.T., E.G., F.B., A.M., L.M.L., A.C.B., D.S., C.C.), Pamplona, Spain

Global Atlas of Palliative Care

2nd Edition

London, UK 2020

Global Atlas of Palliative Care *2nd Edition*

www.thewhpca.org

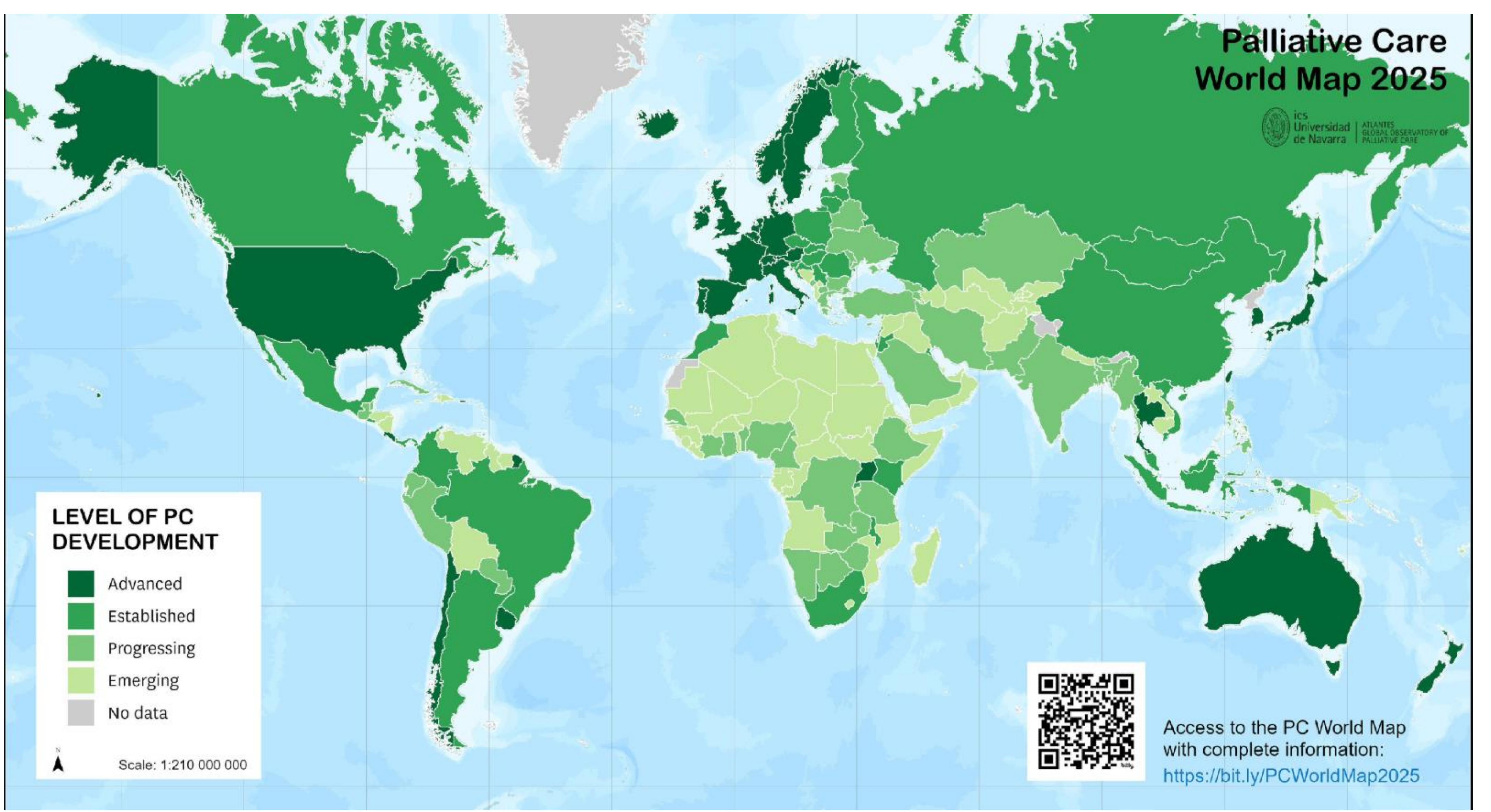
Atlas of Palliative Care in Latin America

ALCP EAPC ics Universidad de Navarra

Data and Atlases help us identify inequalities in access to Palliative Care

Relationship Between the Sets of Indicators and the Palliative Care Development Conceptual Framework (WHO, 2021)

Dimension	#	Indicators for Monitoring Palliative Care Development
Empowerment of people and communities	1	Existence of groups dedicated to promote the rights of patients in need of palliative care, their families, their caregivers and disease survivors
	2	Existence of national policy or guideline addressing advance care planning of medical decisions for the use of life-sustaining treatment or end-of-life care
Health policies	3	Existence of a current national palliative care plan, programme, policy or strategy with a defined implementation framework
	4	Inclusion of palliative care in the list of health services provided at the primary care level in the national health system
	5	Existence of a national coordinating authority for palliative care (labelled as unit, branch, department) in the Ministry of Health (or equivalent) responsible for palliative care
Research	6	Existence of congresses or scientific meetings at the national level specifically related to palliative care
	7	Palliative care research in the country estimated by peer-reviewed articles
Essential medicines	8	Reported annual opioid consumption, excluding methadone, in Defined Daily Dose for statistical purposes (S-DDD)
	9	Availability of essential medicines for pain and palliative care at all levels of care
	10	General availability of immediate-release oral morphine (liquid or tablet) at the primary level
Education and training	11	Proportion of medical and nursing schools with palliative care formal education in undergraduate curricula
	12	Specialisation in palliative medicine for physicians
Integrated palliative care services	13	Number of specialised palliative care programmes in the country per population
	14	Number of specialised palliative care programmes for the paediatric population in the country



202 countries
In Europe
1 Germany
2 Netherlands
12 UK
14 Portugal
16 Spain

World:
1 Germany
2 Netherlands
20 UK
22 Portugal
25 US
28 Spain

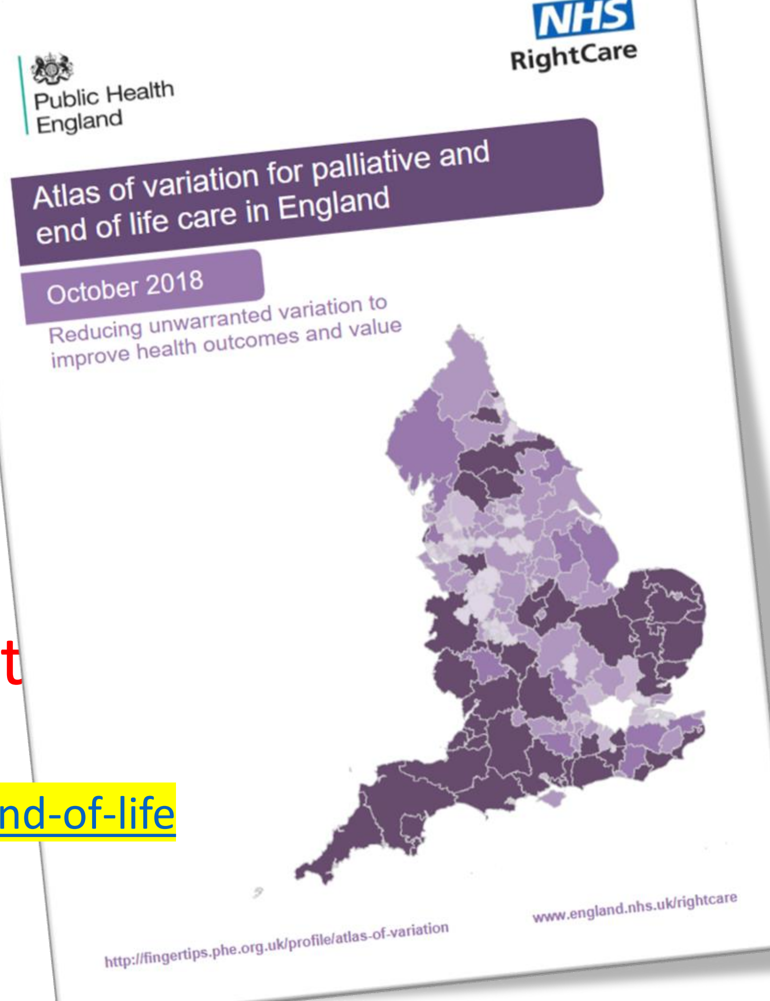
National End of Life Care Intelligence Network England (Established 2010)

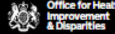
- Indicator updates

Toolkits for:

- Health Administrators
- Hospices
- Palliative Care Specialist

https://fingertips.phe.org.uk/profile/end-of-life





Office for Health Improvement & Disparities

Fingertips | Public health data

Guidance API Contact us Your data

Search for indicators

Home > Profile home

Palliative and End of Life Care Profiles

These profiles have been developed by the National End of Life Care Intelligence Network (NEoLCIN) to improve the availability and accessibility of information and intelligence around palliative and end of life care. They provide an overview across multiple geographies in England, to support commissioning and planning of local services.

The data in the profiles are grouped into topics. These include:

- needs assessment
- care homes and community
- hospital care
- place of death
- mortality
- dementia
- underlying cause of death

The Fingertips Guidance contains information on how to use the profiles.

Classification of place of death is a guide that supports the methods used for all place of death indicators on these profiles.

Factsheets

Patterns of care, England 2021

This factsheet for England describes patterns of care near the end of life related to 4 major conditions; cancer, cardiovascular disease, dementia and respiratory disease. It includes experimental statistics describing the number of people who died in 2021, their causes of death, demographic characteristics (age, sex, ethnic group, deprivation quintile), hospital admissions, length of stay in hospital and place of death.

The data behind this data factsheet is available as a spreadsheet.

The graphics and tables from the factsheet are available as slides.

Care homes

These factsheets for England and upper tier local authorities (UTLAs) include trends in care home deaths including care home residents who die elsewhere, COVID-19 deaths in care homes, dementia amongst those who died in care homes and data on care home bed availability by service speciality.

The data behind these factsheets is available as a spreadsheet.

Next update planned for January 2024

Place of death

These factsheets for Integrated Care Boards (ICBs) provide the most recent data available on trends in place of death and compares this with the pattern seen in 2019 as a baseline.

It compares ICB and England data from 2019 to 2023 for the number and percentage of deaths in hospitals (acute or community, not psychiatric); at home; in care homes; in hospices (not community), and 'other places'.

The data behind these factsheets is available as a spreadsheet.

Next update planned for January 2024

Resource directory

This directory of intelligence and guidance supports the data in these profiles. These cover the following themes:

Policy and guidance | Place of care | Conditions | Inequalities | Commissioning and contracting | Data and intelligence | Education and training

This will be updated quarterly.

START
Go to the data

Contents

— Profile home
— Factsheets
— Resource directory
— Atlas of variation for palliative and end of life care
— Contact us
— Commissioning and contracting
— Conditions
— Data and intelligence
— Education and Training
— Inequalities
— Place of care
— Policy and Guidance
— Updates more than 12 months ago

Recent updates

Subscribe to receive notifications on the latest updates.

October 2023

Palliative and End of Life Care factsheets update:

Recent trends in place of death factsheet updated to include data up to June 2023.

Recent trends of deaths in care homes and provision of care factsheet updated to included data up to June 2023

August 2023

New publication - Palliative and End of Life Care factsheet: Patterns of care, England 2021

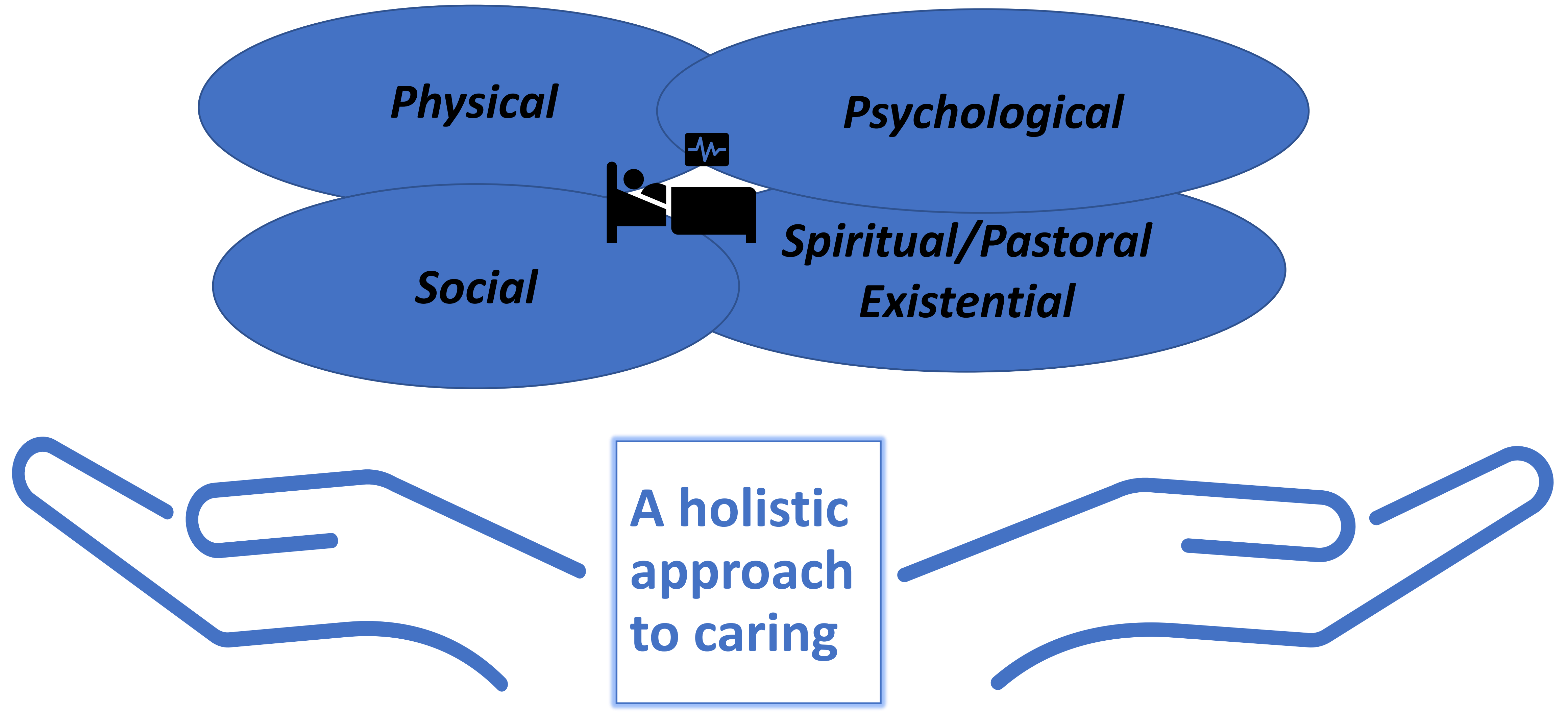
June 2023

Indicator updates

The place of death indicators have been updated with data for Integrated Care Boards (ICBs) and ICB sub-location replacing data for care commissioning groups (CCGs) and Sustainability and Transformation Partnerships (STPs).
The percentage of deaths in care homes who were temporary care home residents

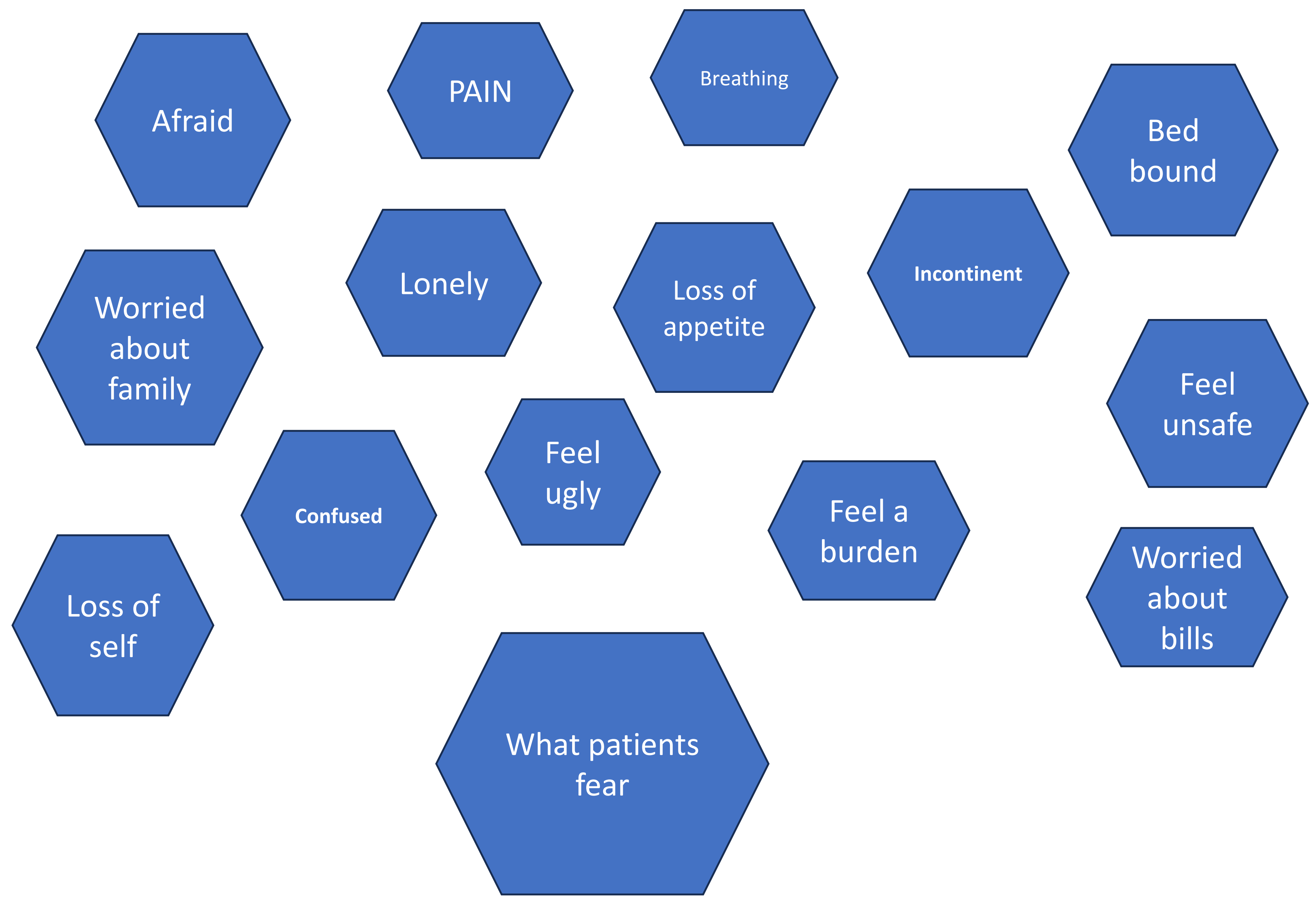
What are your experiences of death and bereavement good and bad?

The Palliative Care Approach

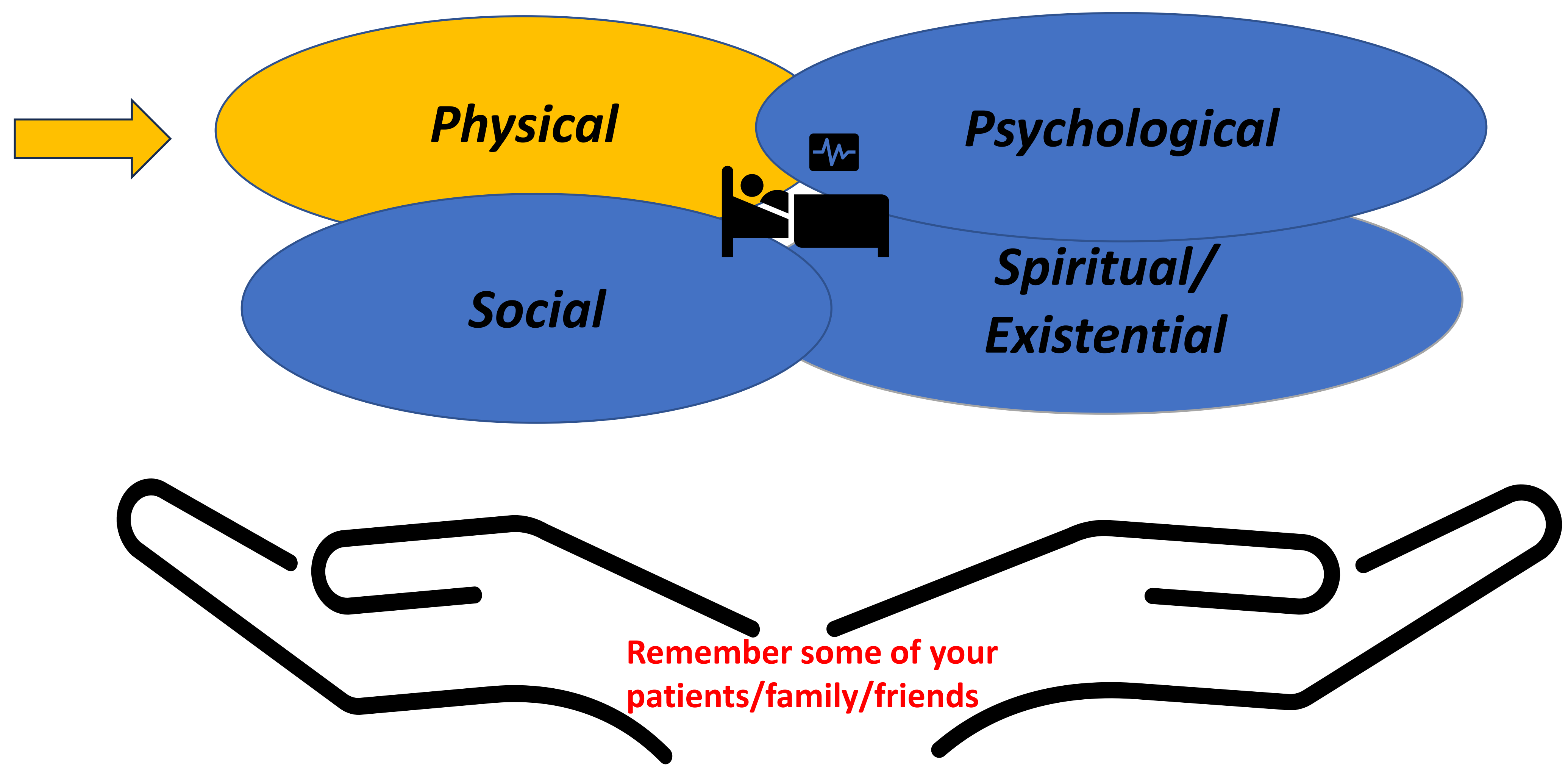


Why might a person's death not be the best it could have been ? Type of suffering in red

- Unresolved pain or physical suffering (Physical)
- Anxious/lonely (Psychological)
- Unable to pay bills (Social)
- Spiritual/existentialist suffering
- Not said last goodbyes (sorry or I love you) (Psychosocial)
- Relatives not present/family conflict (Psychological)
- Rushed to hospital when wanted to stay at home (Psychosocial)
- Poor care (All domains)
- Poor communication (All domains)


Afraid
PAIN
Breathing
Bed bound
Worried about family
Lonely
Loss of appetite
Incontinent
Feel unsafe
Confused
Feel ugly
Feel a burden
Worried about bills
Loss of self
What patients fear

A holistic approach – what can we do

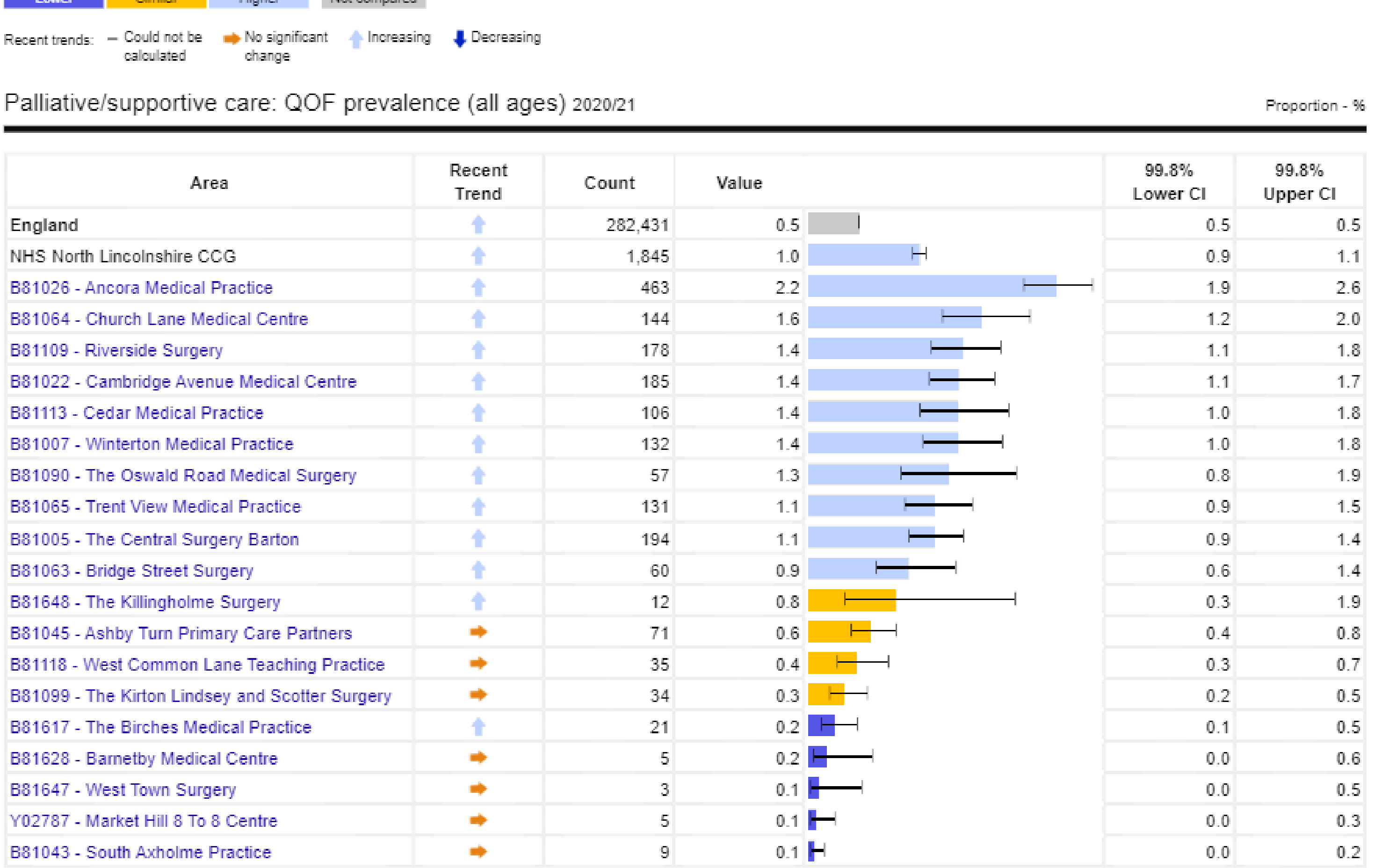


Addressing Physical Suffering

- Ensure all health service and social care personnel are trained in at least basic palliative care
- Training in symptom including pain management
- Diagnose that a person is in the final phase of life
- Assess physical symptoms
- Discuss with patient and place on Family Doctor's (GP) End of Life Register (Gateway to fast track)
- Encourage GPs to use End of Life Care Register
- Access to medications in the community
- Evidence based Guidelines
- Quality Assurance methodology
- Other ?

Cancer care includes better access to palliative care than other conditions

% of patients in need of palliative care / support, as recorded on PEoLC Registers, irrespective of age (QOF data), GP Practices, In North Lincolnshire



Lower | Similar | Higher | Not compared

Recent trends: – Could not be calculated | No significant change | Increasing | Decreasing

Palliative/supportive care: QOF prevalence (all ages) 2020/21 — Proportion - %

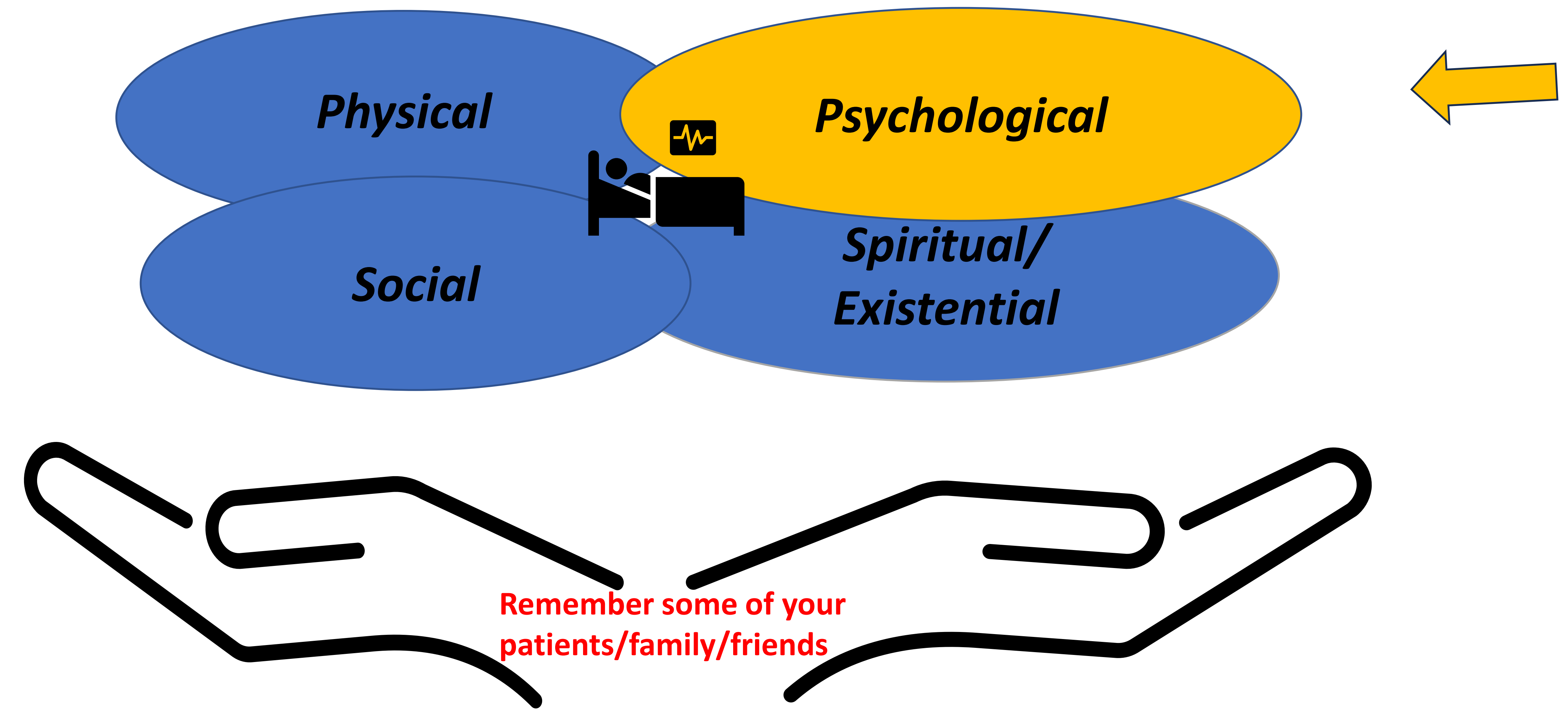
Area	Recent Trend	Count	Value	99.8% Lower CI	99.8% Upper CI
England	Increasing	282,431	0.5	0.5	0.5
NHS North Lincolnshire CCG	Increasing	1,845	1.0	0.9	1.1
B81026 - Ancora Medical Practice	Increasing	463	2.2	1.9	2.6
B81064 - Church Lane Medical Centre	Increasing	144	1.6	1.2	2.0
B81109 - Riverside Surgery	Increasing	178	1.4	1.1	1.8
B81022 - Cambridge Avenue Medical Centre	Increasing	185	1.4	1.1	1.7
B81113 - Cedar Medical Practice	Increasing	106	1.4	1.0	1.8
B81007 - Winterton Medical Practice	Increasing	132	1.4	1.0	1.8
B81090 - The Oswald Road Medical Surgery	Increasing	57	1.3	0.8	1.9
B81065 - Trent View Medical Practice	Increasing	131	1.1	0.9	1.5
B81005 - The Central Surgery Barton	Increasing	194	1.1	0.9	1.4
B81063 - Bridge Street Surgery	Increasing	60	0.9	0.6	1.4
B81648 - The Killingholme Surgery	Increasing	12	0.8	0.3	1.9
B81045 - Ashby Turn Primary Care Partners	No significant change	71	0.6	0.4	0.8
B81118 - West Common Lane Teaching Practice	No significant change	35	0.4	0.3	0.7
B81099 - The Kirton Lindsey and Scotter Surgery	No significant change	34	0.3	0.2	0.5
B81617 - The Birches Medical Practice	Increasing	21	0.2	0.1	0.5
B81628 - Barnetby Medical Centre	No significant change	5	0.2	0.0	0.6
B81647 - West Town Surgery	No significant change	3	0.1	0.0	0.5
Y02787 - Market Hill 8 To 8 Centre	No significant change	5	0.1	0.0	0.3
B81043 - South Axholme Practice	No significant change	9	0.1	0.0	0.2

1% of the population die each year

~25% not predictable

We must improve inclusion of palliative care patients on GP special registers so that they get access to priority care.

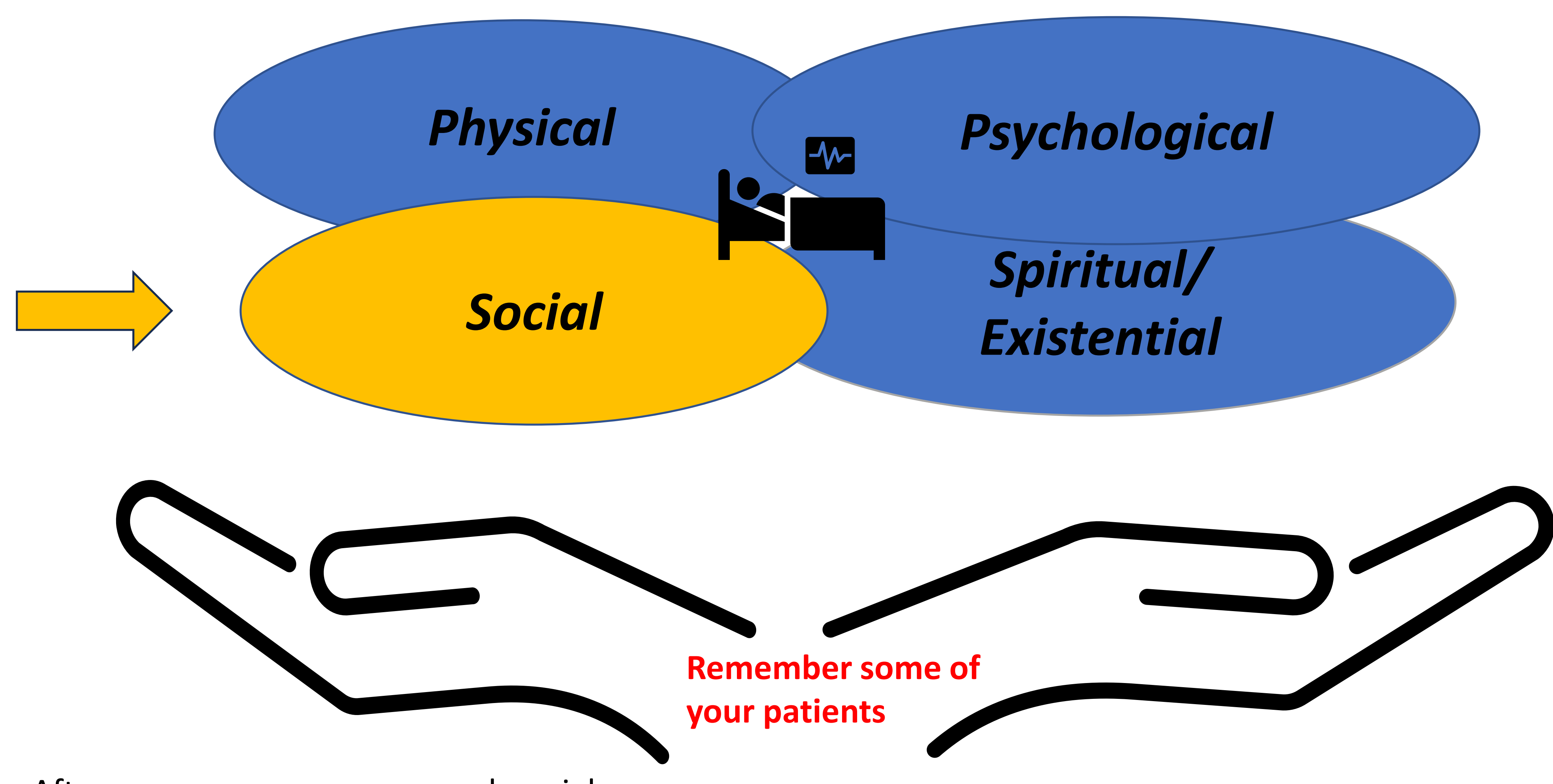
A holistic approach – what can we do



In England almost all psychological support provided by Charitable Organisations to patients and the bereaved – again almost exclusively to cancer patients and their families

Hospices

A holistic approach – what can we do



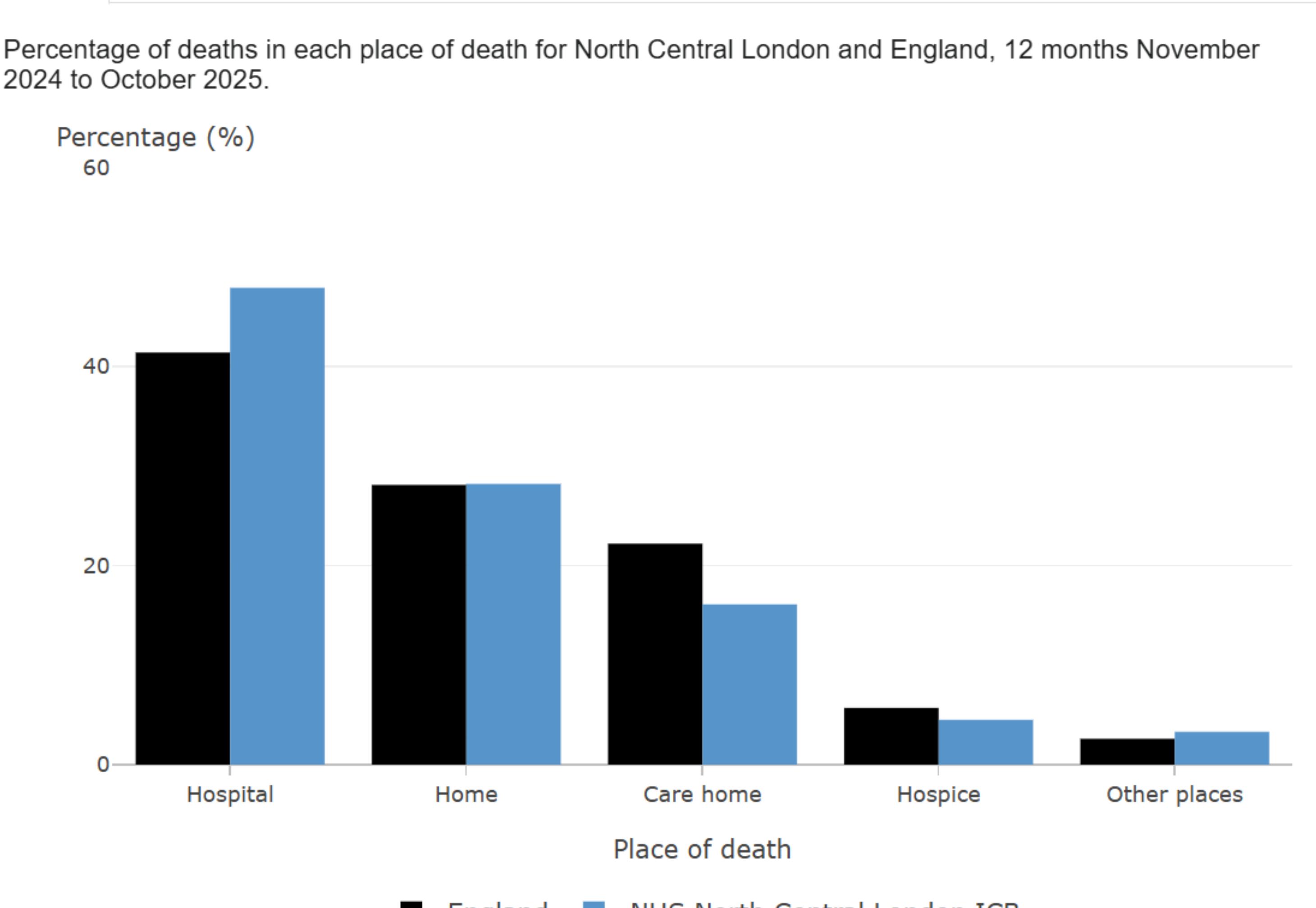
After cancer vs. non-cancer and social factors are the biggest source of injustice in access to end of life care

An example of local health administration variation in place of death from the England average

Why might this be?

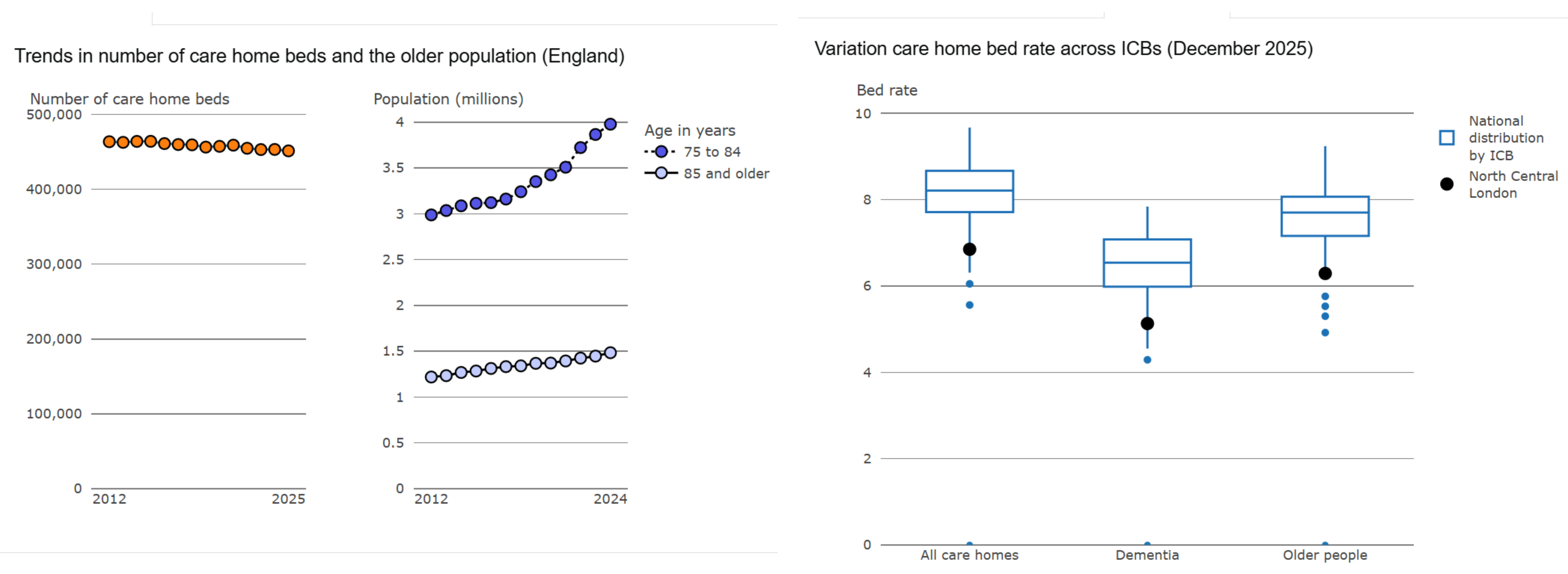
Access to care home/hospice beds?

Demographic and ethnic mix of the population?



https://fingertips.phe.org.uk/profile/end-of-life/supporting-information/factsheets

Trend in Number of care home beds and older population and local variation in provision



https://fingertips.phe.org.uk/profile/end-of-life/supporting-information/factsheets

Demographics and cultural and social change

How does this impact on the challenges in providing support

What are the challenges ?

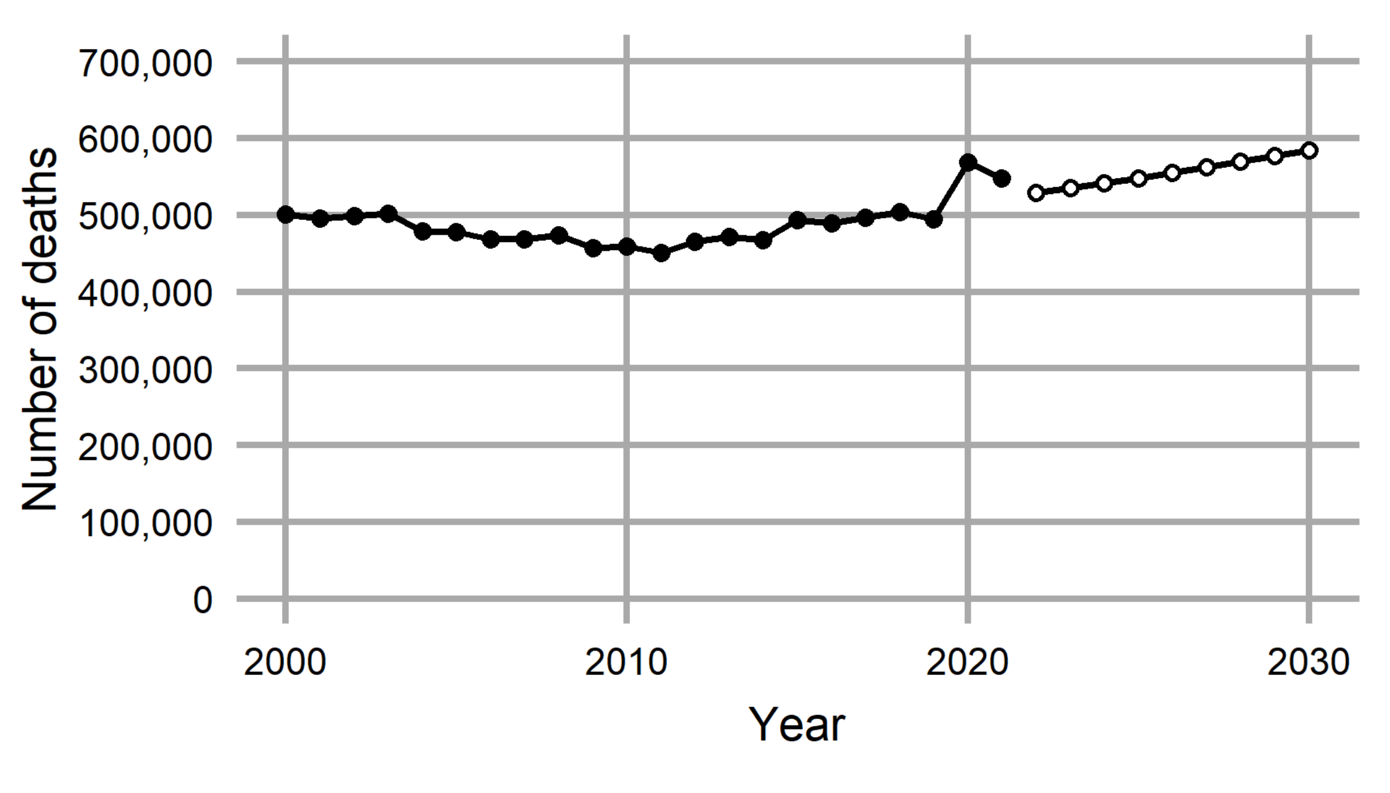
- Absolute increase in numbers of people needing palliative and end of life care
- And families needing bereavement support
- Different types of care – not just specialist palliative care
- Less predictable course with slow decline with multi-morbidity

  Dementia and loss of mental capacity
- Fewer young people to care
- More elderly living alone
- Changing ethnic composition
- More end-of-life care provided in care homes

Poverty, ethnic, gender inequalities, complex challenges for some groups

The number of people dying is increasing

Baby boomer cohort and longer life expectancy



Over half a million deaths every year

1,370 per day

Almost 1 death per minute

GENDER DIFFERENCE

Mean age at death 82 M 86 F

England trend in number of deaths (2000 to 2021) and projections (2022 to 2030)

Distribution of all deaths by Age, England 2021

	Under 75	75 to 85	85 or older
Number of deaths (any cause)	178,855	156,846	211,947
Percentage of all deaths	33%	29%	39%

2/3 deaths in people aged 75+

Number of people requiring end of life care is increasing
By 2040 an estimated 42.4% (161,842 more people/year)
Major causes cancer and dementia

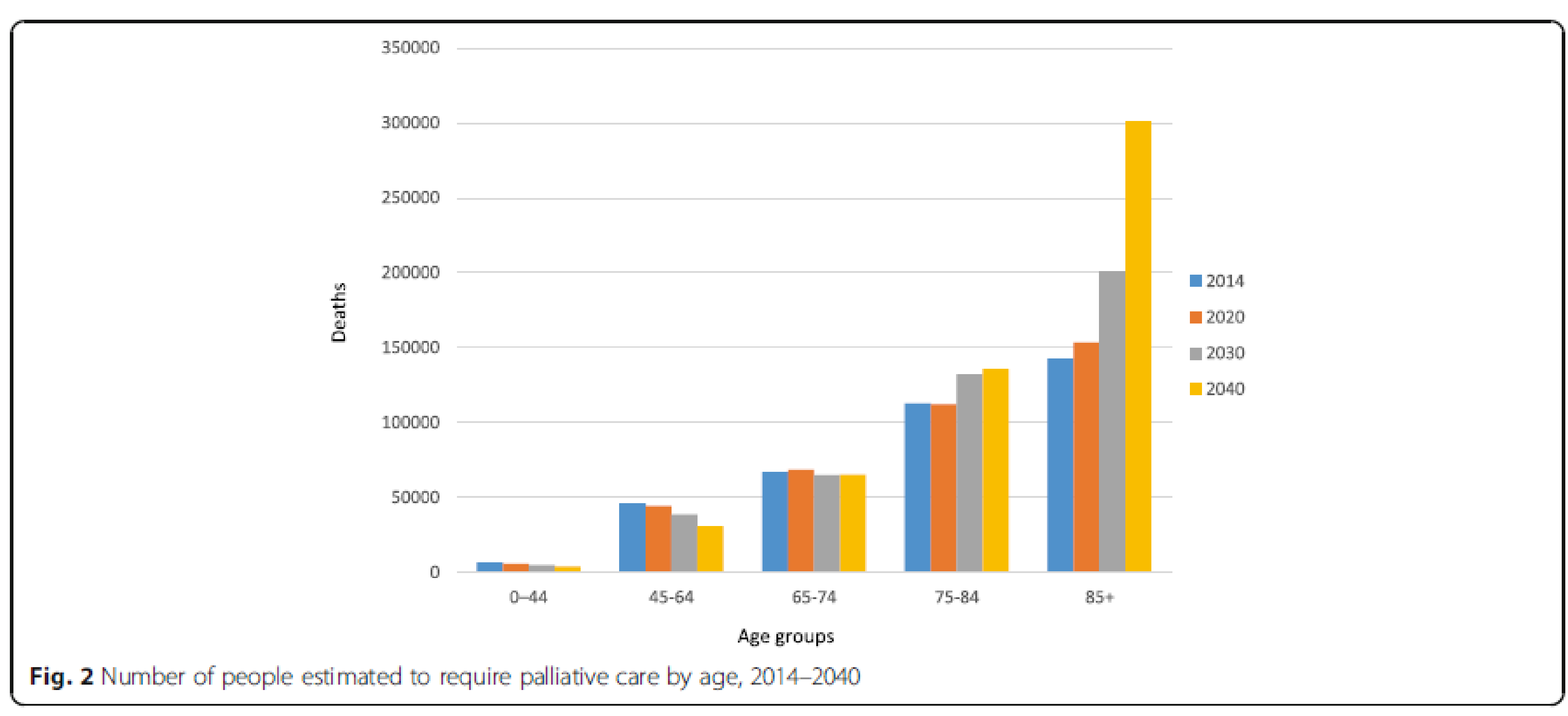
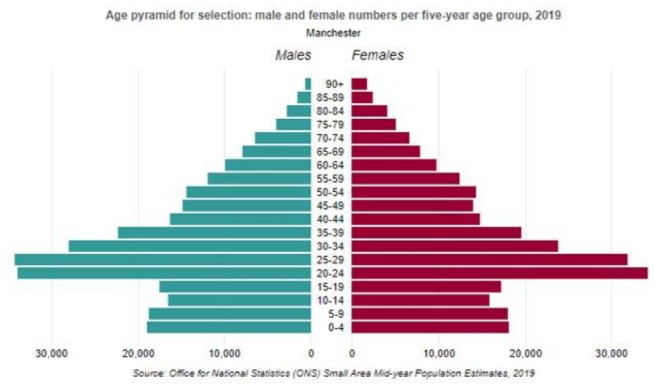


Fig. 2 Number of people estimated to require palliative care by age, 2014–2040

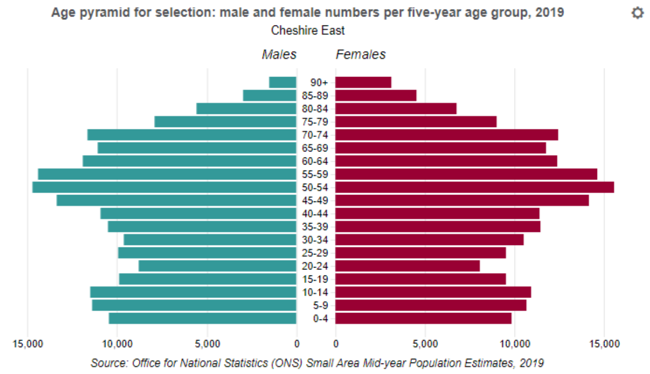
Source: Etkind SN et. al. - How many people will need palliative care in 2040? Past trends, future projections and implications for services - BMC Medicine201715:102

Age Pyramids: male and female numbers per five-year age group, 2019

Manchester

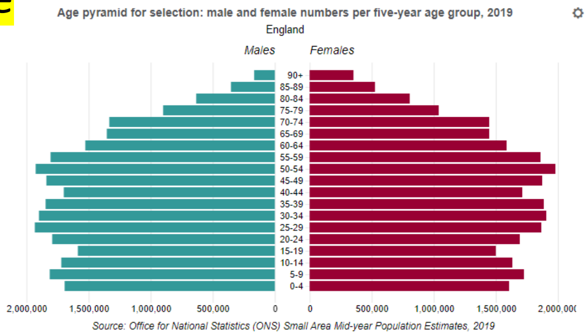


Cheshire East

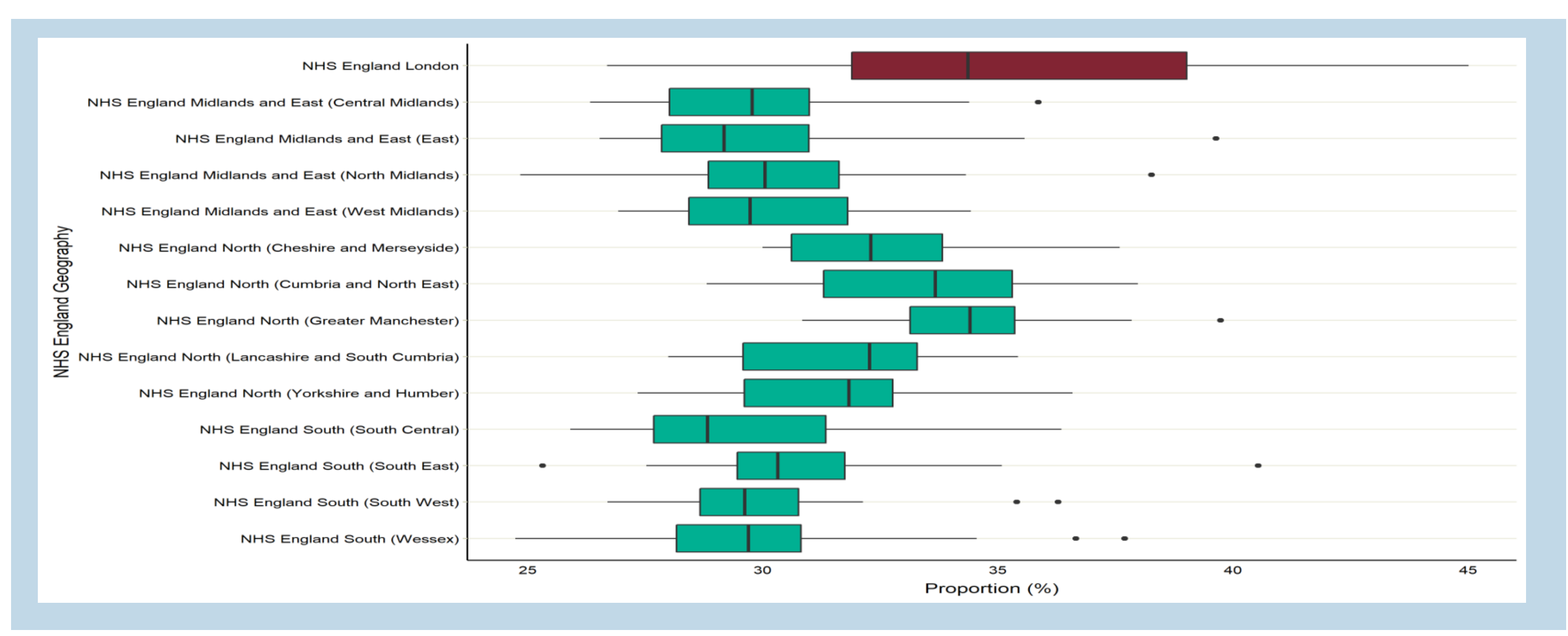


England

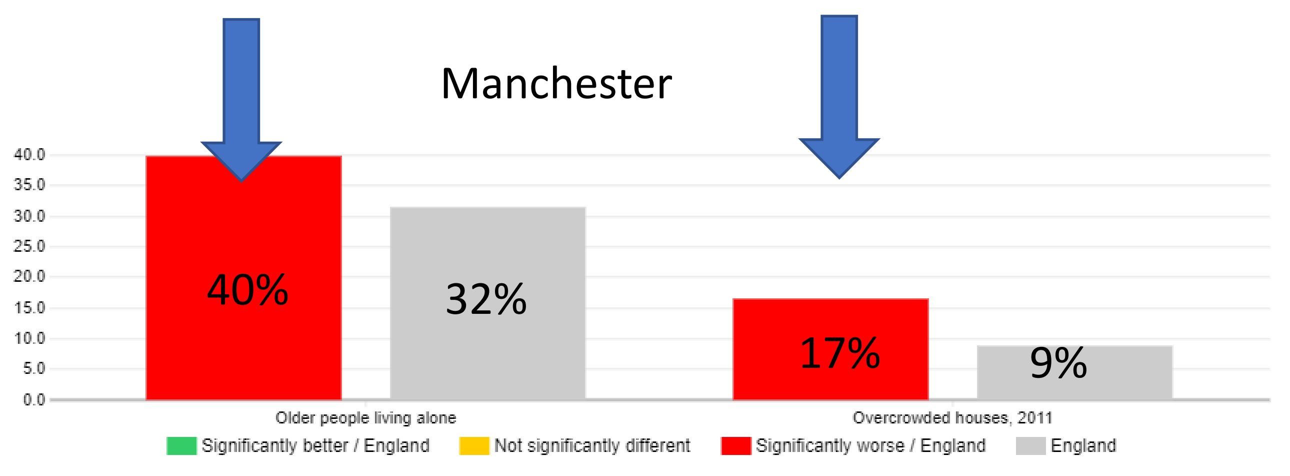
N.B. fewer younger people to care for older people

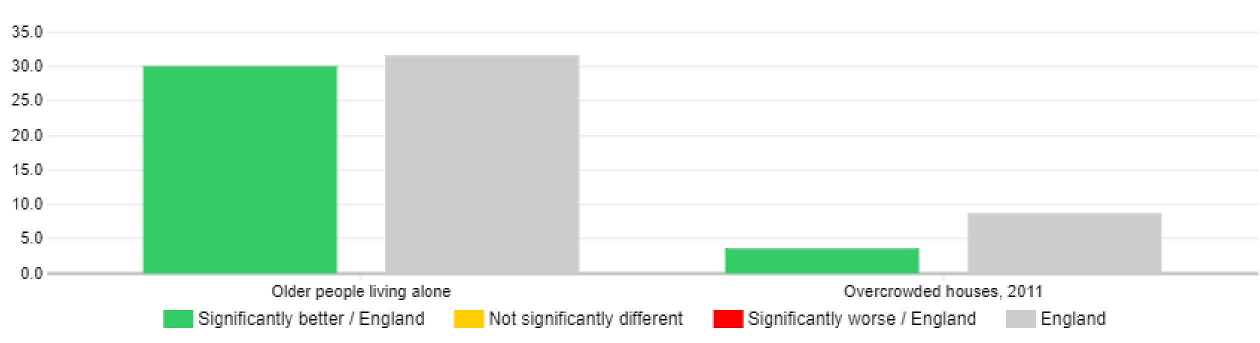


Variation of the proportion of people aged 65 and older and living alone (2011) with health regions in England by local authority Interquartile range (box), extent up to 1.5 times the box width (whiskers) and outliers



Housing and living environment – resources to die at home: lonely or overcrowded





We asked people (45+) do you have any one to count on if you were seriously ill or dying?

- 12% of those aged 45+ had no relative, friend or neighbour that they could count on for regular help if the need arose
- 19% claimed there was one person
- 37% claimed there were two to four people they thought they could count on.
- 33% thought there were five or more people

- The Reservoir of Goodwill: Conceptualising a Community Care Model for Later Life Care Yvette Morey, Sara Spear, Alan Tapp, Julia Verne, Stella Warren, Amy Beardmore **DOI: 10.31389/jltc.345**

Loneliness and poverty

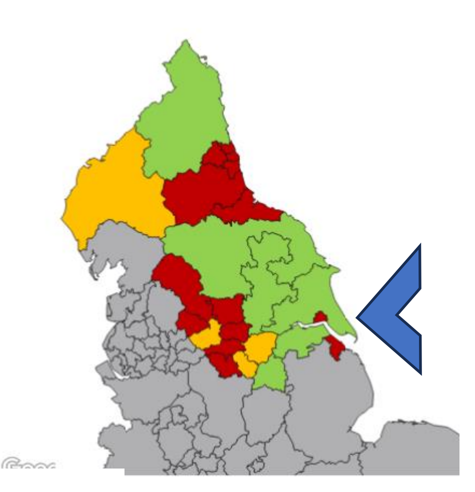
Percentage of people ≥65years living alone

High: South Tyneside, Hull

Almost 1 in 3 older people living alone

Better 95% | Similar | Worse 95% | Not compared

Map of CCGs (2021/22) in England for Older people living alone, % of people aged 65 and over who are living alone
(Proportion - % 2011)



Better 95% | Similar | Worse 95% | Not compared

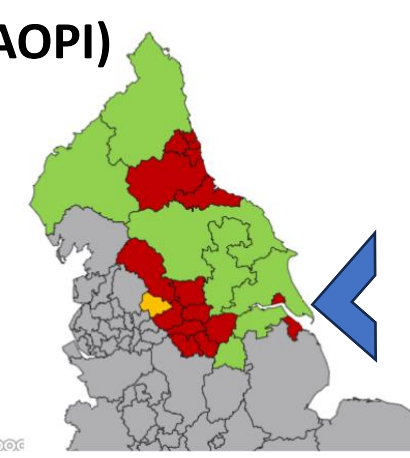
Older people living alone, % of people aged 65 and over who are living alone 2011 — Proportion - %

Area	Count	Value	95% Lower CI	95% Upper CI
England	2,725,596	31.5	31.4	31.5
North East and Yorkshire NHS Region, old due to ICB changes	-	-	-	-
NHS South Tyneside CCG	9,973	37.1	36.6	37.7
NHS Hull CCG	13,075	36.6	36.1	37.1
NHS Newcastle And Gateshead CCG	26,843	36.3	35.9	36.6
NHS North Tyneside CCG	12,641	35.8	35.3	36.3
NHS Leeds CCG	38,326	35.0	34.7	35.3
NHS Calderdale CCG	11,210	34.5	34.0	35.0
NHS Sunderland CCG	16,075	34.4	33.9	34.8
NHS Sheffield CCG	28,964	33.8	33.5	34.1
NHS Tees Valley CCG	37,165	33.5	33.2	33.8
NHS County Durham CCG	30,493	33.0	32.7	33.3
NHS Wakefield CCG	18,205	33.0	32.6	33.4
NHS Barnsley CCG	13,118	32.8	32.3	33.2
NHS Bradford District and Craven CCG	26,223	32.5	32.2	32.9
NHS North East Lincolnshire CCG	9,190	32.5	31.9	33.0
NHS Rotherham CCG	14,286	31.9	31.4	32.3
NHS Kirklees CCG	20,412	31.8	31.5	32.2
NHS Doncaster CCG	16,179	31.6	31.2	32.0
NHS North Cumbria CCG	19,669	31.3	30.9	31.6
NHS Northumberland CCG	19,407	30.7	30.3	31.0
NHS Vale Of York CCG	18,625	30.4	30.0	30.8
NHS North Yorkshire CCG	26,256	30.2	29.9	30.5
NHS North Lincolnshire CCG	8,946	29.8	29.3	30.3
NHS Bassetlaw CCG	6,189	29.6	28.9	30.2
NHS East Riding Of Yorkshire CCG	18,442	27.4	27.1	27.8

Better 95% | Similar | Worse 95% | Not compared

Map of CCGs (2021/22) in England for Older people in poverty: Income deprivation affecting older people Index (IDAOPI)
(Proportion - % 2019)

Older People in Poverty (IDAOPI)

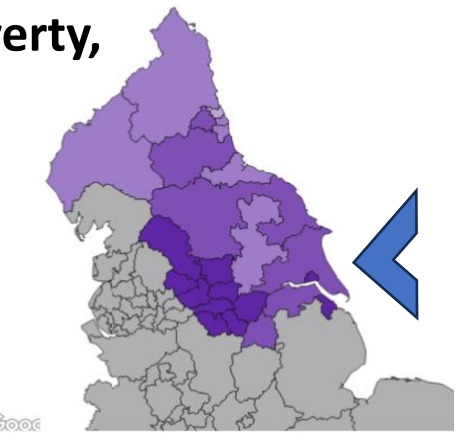


14% in Region
High: Hull, Sunderland

Quintiles: Best | | | | Worst | Not applicable

Map of CCGs (2021/22) in England for Modelled estimates of the proportion of households in fuel poverty (%)
(Proportion - % 2020)

Modelled % of households in fuel poverty,



13% in the Region
High: Hull, Barnsley

Tackling financial hardship -

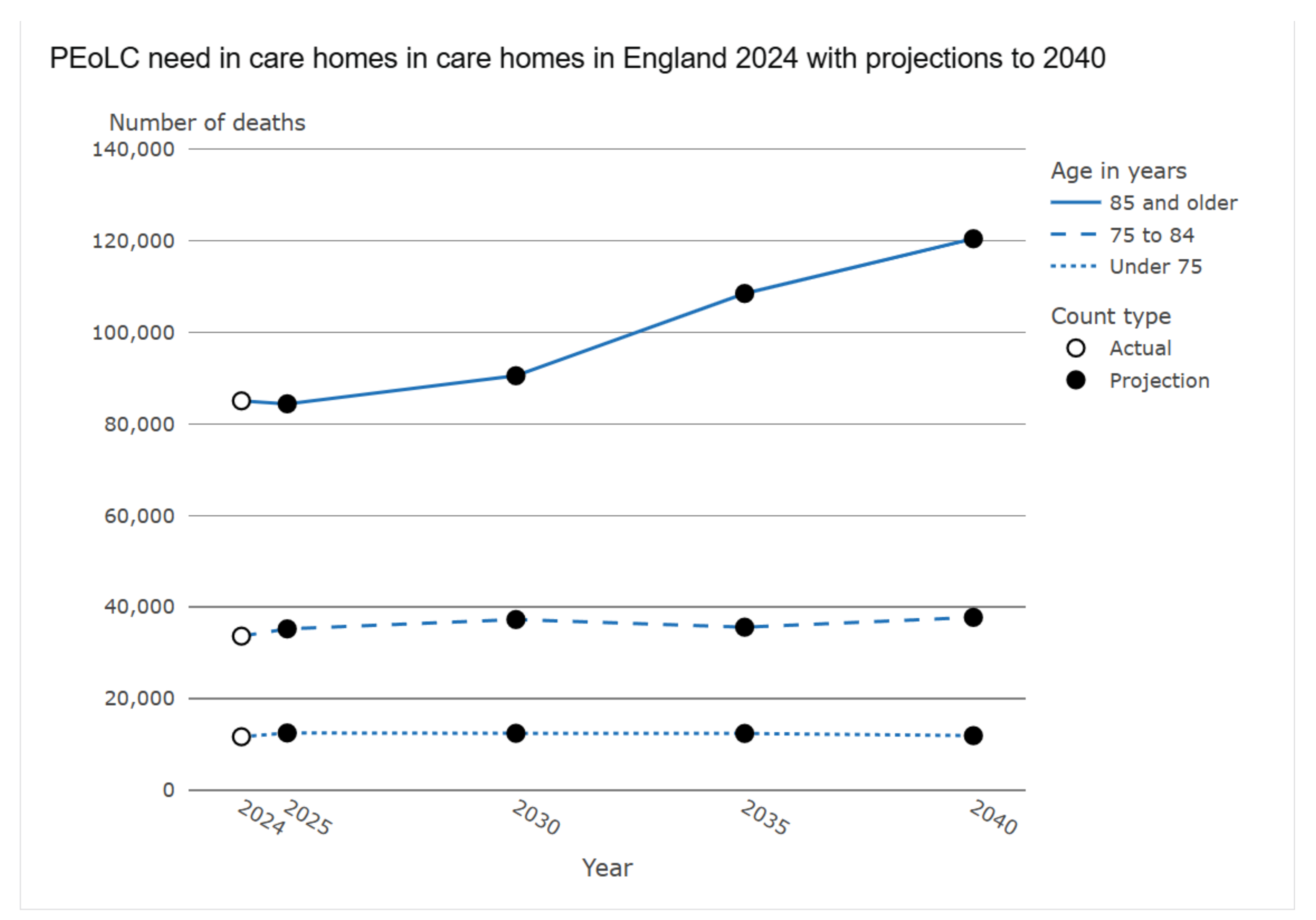
Key Financial and Care Benefits (UK)

Free Services: End-of-life care in a hospital or hospice, GP visits, and district nursing are free under the NHS, including palliative care at home
Fast tracked payment of Nursing Home Fees (otherwise means tested – depends on finances)

- **Special Rules (Fast-Tracked Access):** If a doctor or professional (GOV.UK SR1 form) confirms a life expectancy of 12 months or less, individuals get immediate (days) access to benefits.

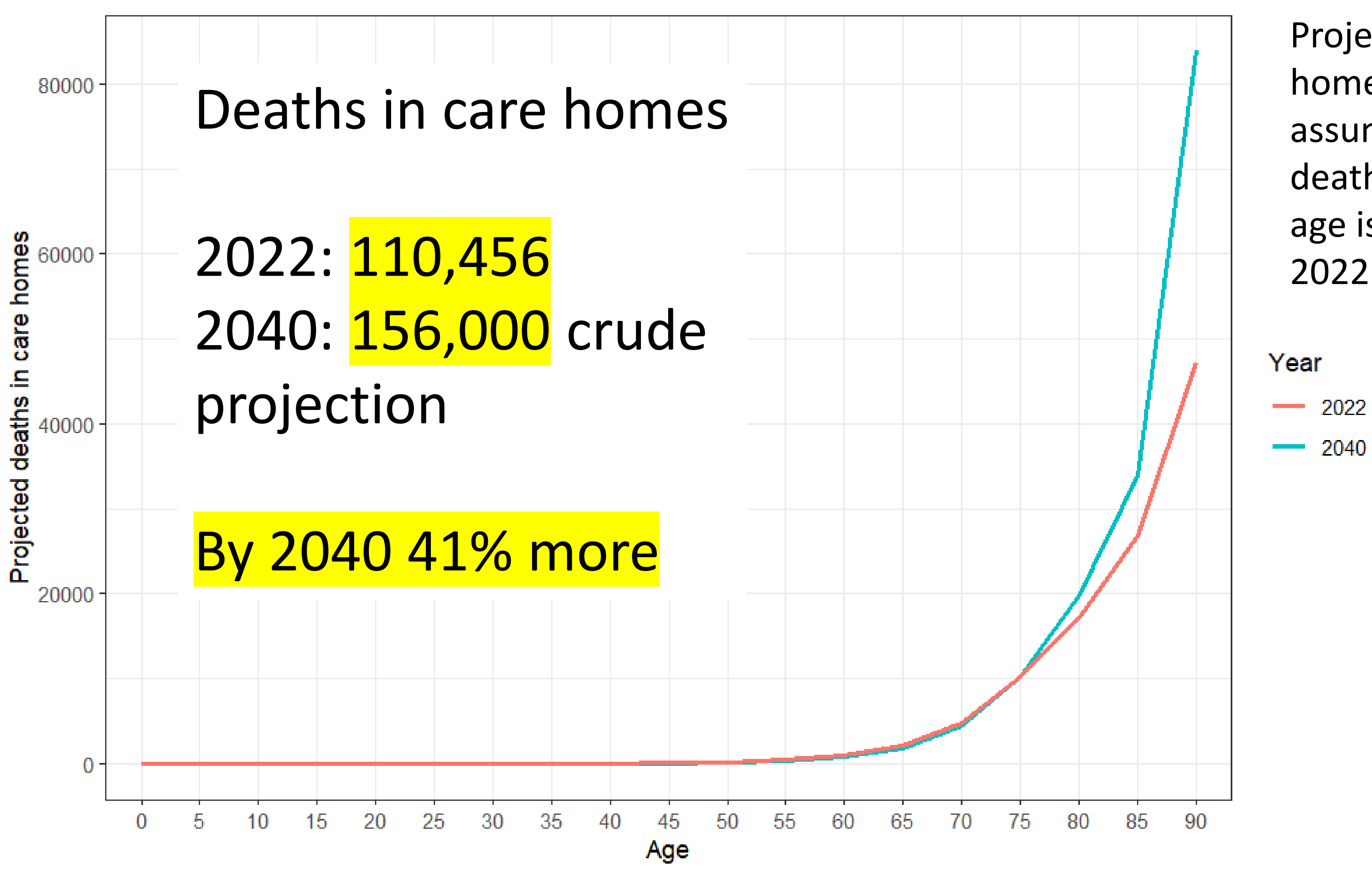
- **Personal Independence Payment (PIP):** Helps with extra living costs if under State Pension age.
- **Attendance Allowance (AA):** For those over State Pension age requiring care.
- **Employment and Support Allowance (ESA):** Financial support if unable to work.
- **Universal Credit (UC):** Supports living costs if you have a low income.
- **Disability Living Allowance (DLA) (Children):** For children under 16 with a terminal condition.
- **Carer's Allowance:** Provided to those caring for a terminally ill person.

Provide extra support to ensure access to benefits with health literacy (translated leaflets) and for marginalised groups eg for people with Severe Mental Illness or Learning Disabilities



PEoLC need in care homes in care homes in England 2024 with projections to 2040
Number of deaths
140,000
120,000
100,000
80,000
60,000
40,000
20,000
0
2024
2025
2030
2035
2040
Year
Age in years
85 and older
75 to 84
Under 75
Count type
Actual
Projection

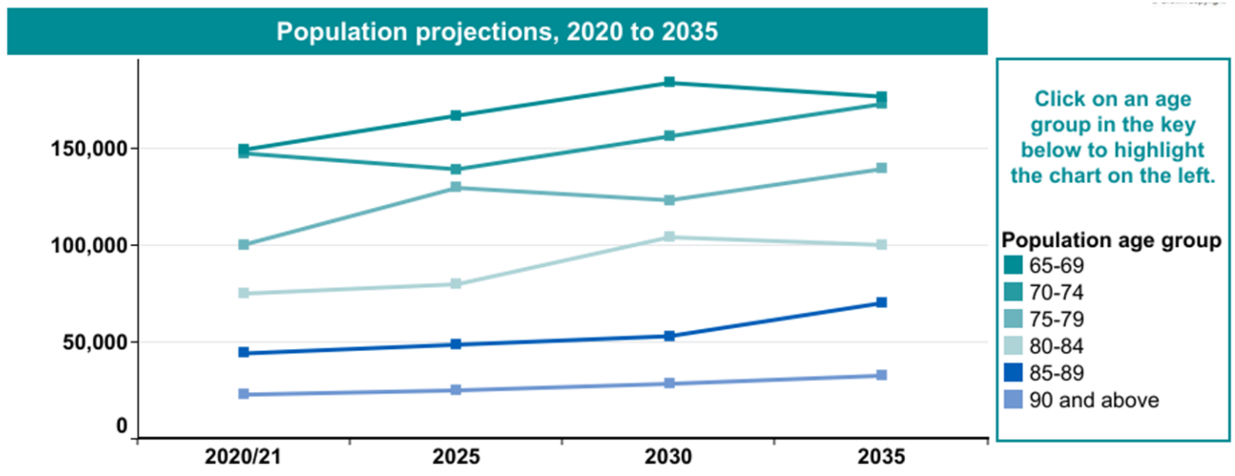
The number of people needing care and dying in care homes is increasing

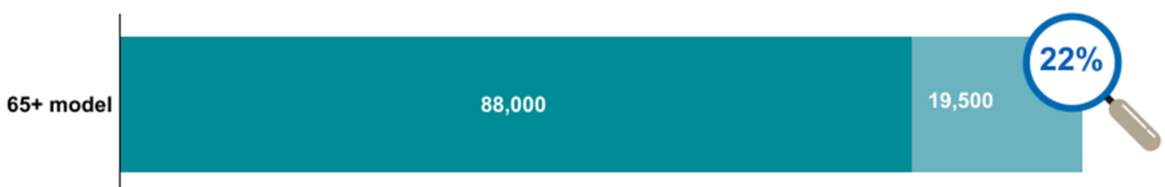


Projected deaths in care homes calculated assuming percentage of deaths in care home by age is the same in 2040 as 2022

Skills for care: Social Care workforce projections for 2035

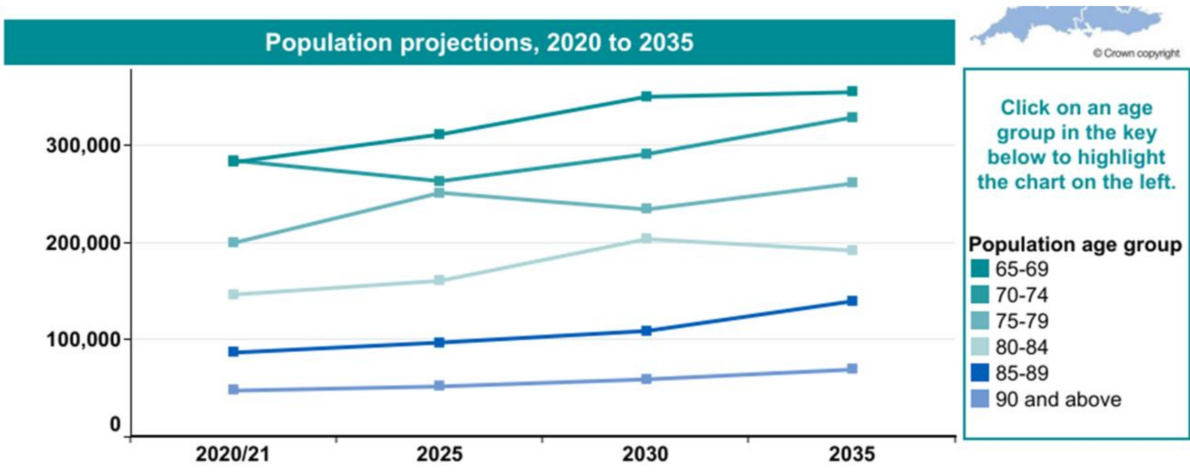
North East

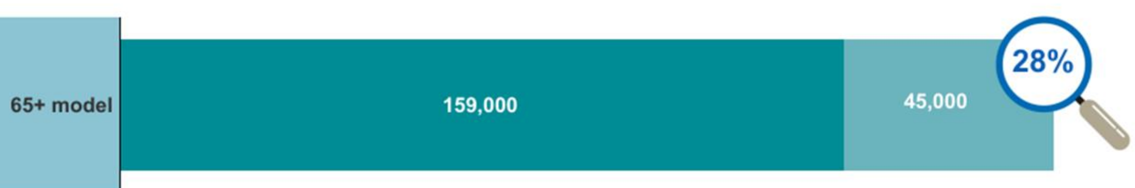




This model projects the size of the workforce if it grows proportionally to the number of people aged 65 and over in the population. This model does not account for changes in services delivered, technology, or the impact of COVID-19.

Yorkshire and Humber





This model projects the size of the workforce if it grows proportionally to the number of people aged 65 and over in the population. This model does not account for changes in services delivered, technology, or the impact of COVID-19.

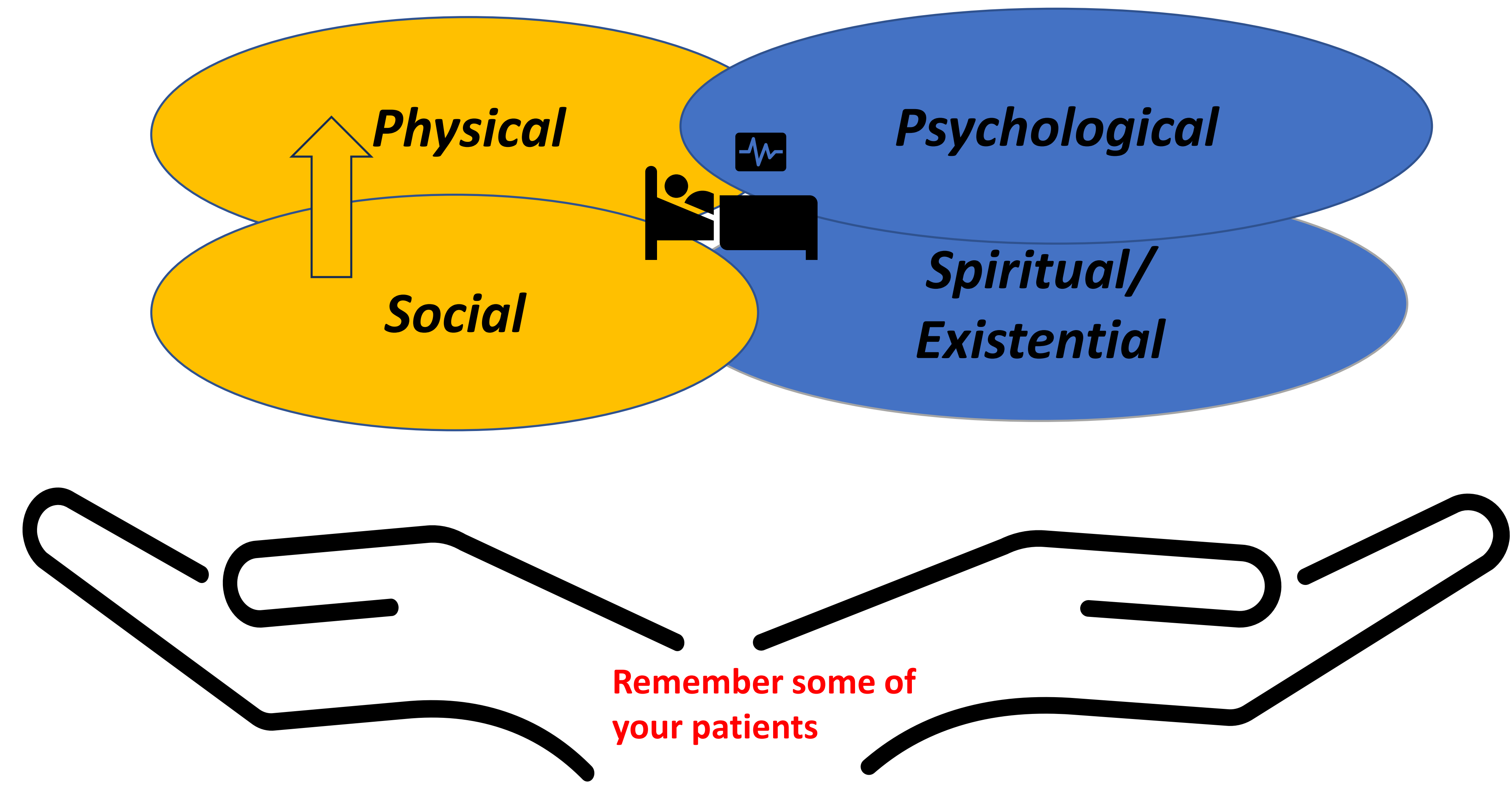
The Government need to address the shortage of care workers (many come from other countries)

Maybe consider incentives for family carers

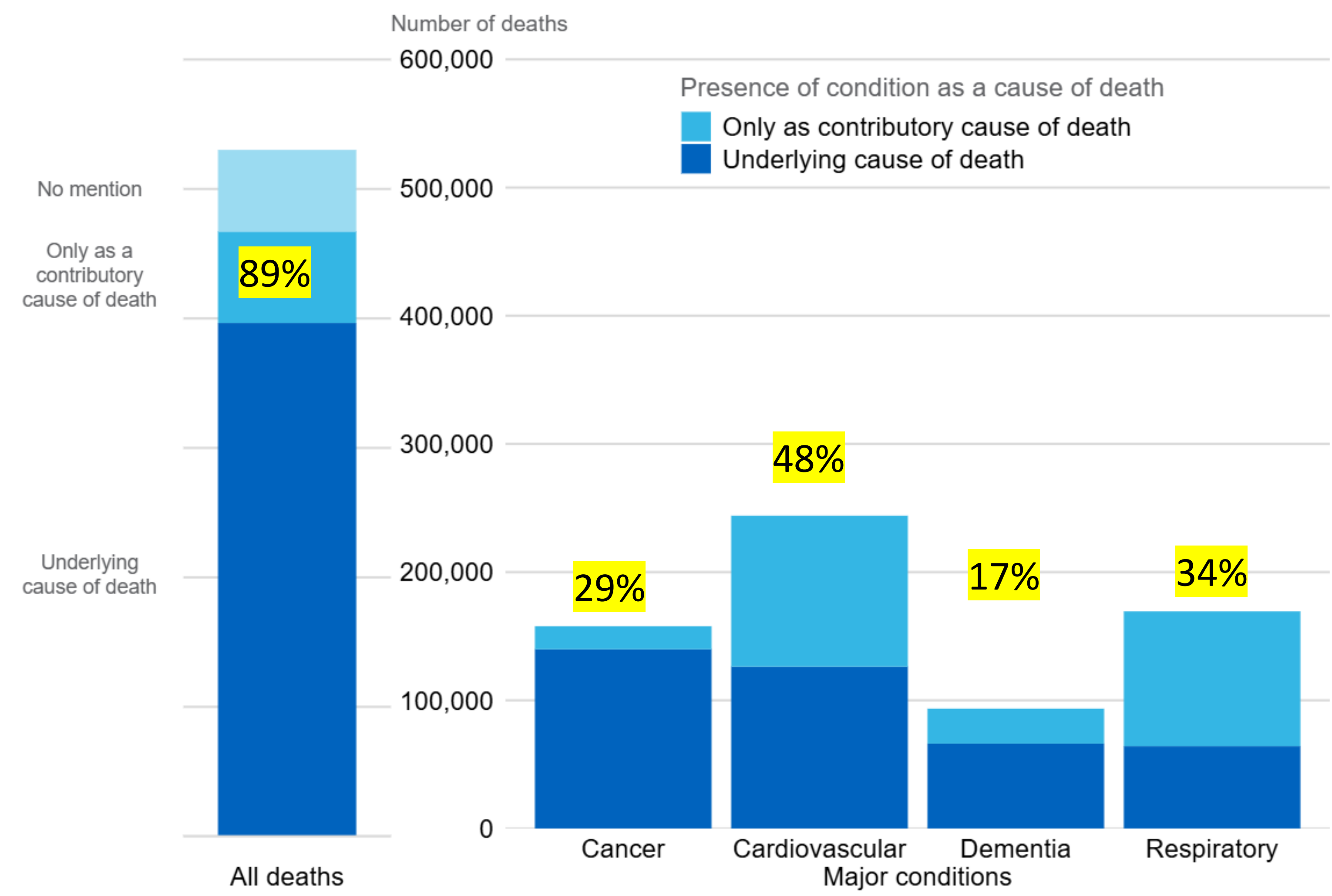
Most common nationalities of NHS staff, June 2022

Nationality	Staff	Nationality	Staff
UK/British	1,122,927	Pakistani	5,833
Indian	44,785	Romanian	5,519
Filipino	30,356	Zimbabwean	5,460
Nigerian	15,439	Spanish	4,988
Irish	13,762	Ghanaian	4,581
Polish	10,836	Egyptian	3,592
Portuguese	7,886	Greek	3,338
Italian	6,733	Nepalese	2,950

A holistic approach – what can we do



Remember some of your patients

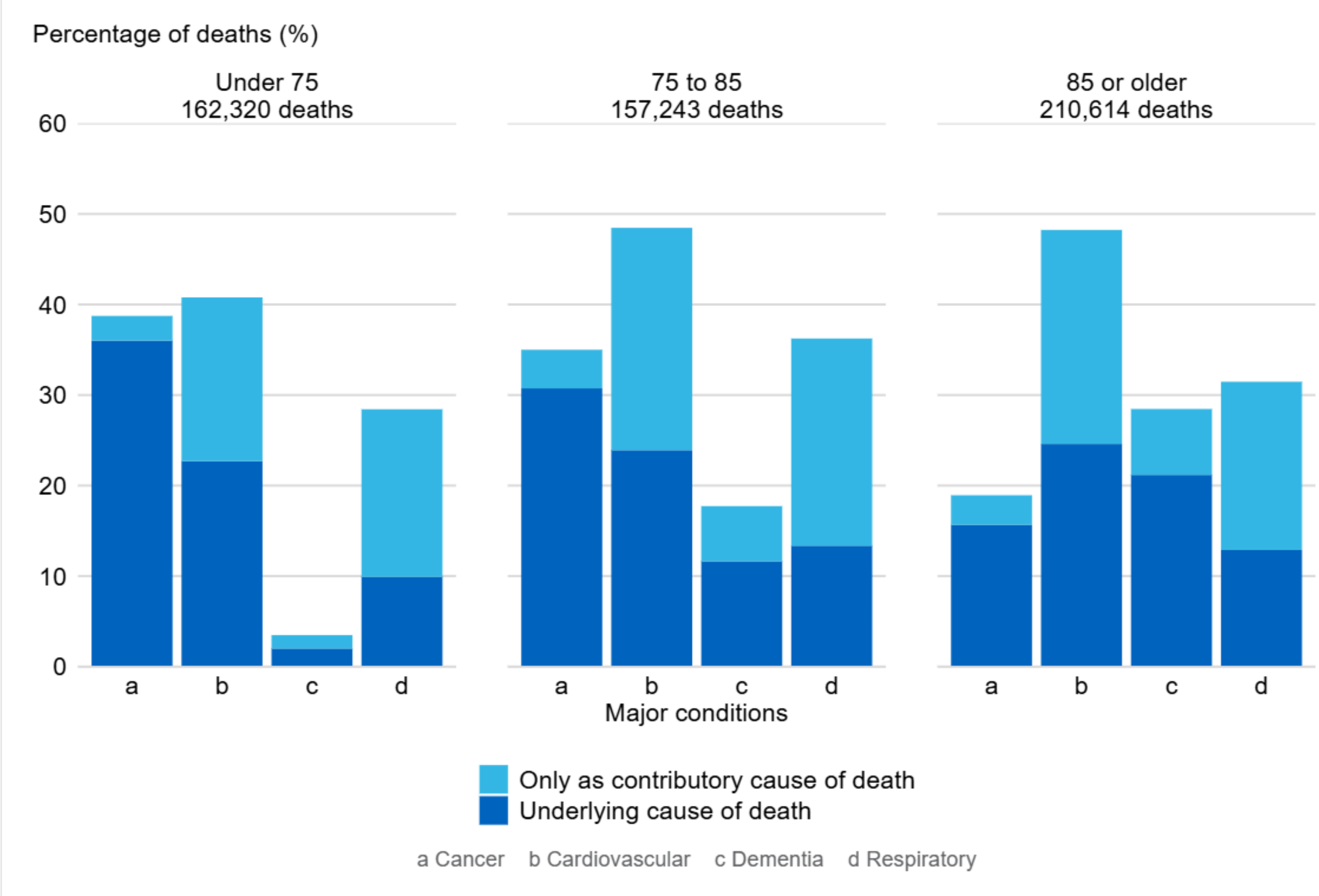


https://fingertips.phe.org.uk/profile/end-of-life

The deaths in each major condition group vary by demographic characteristics. For example;

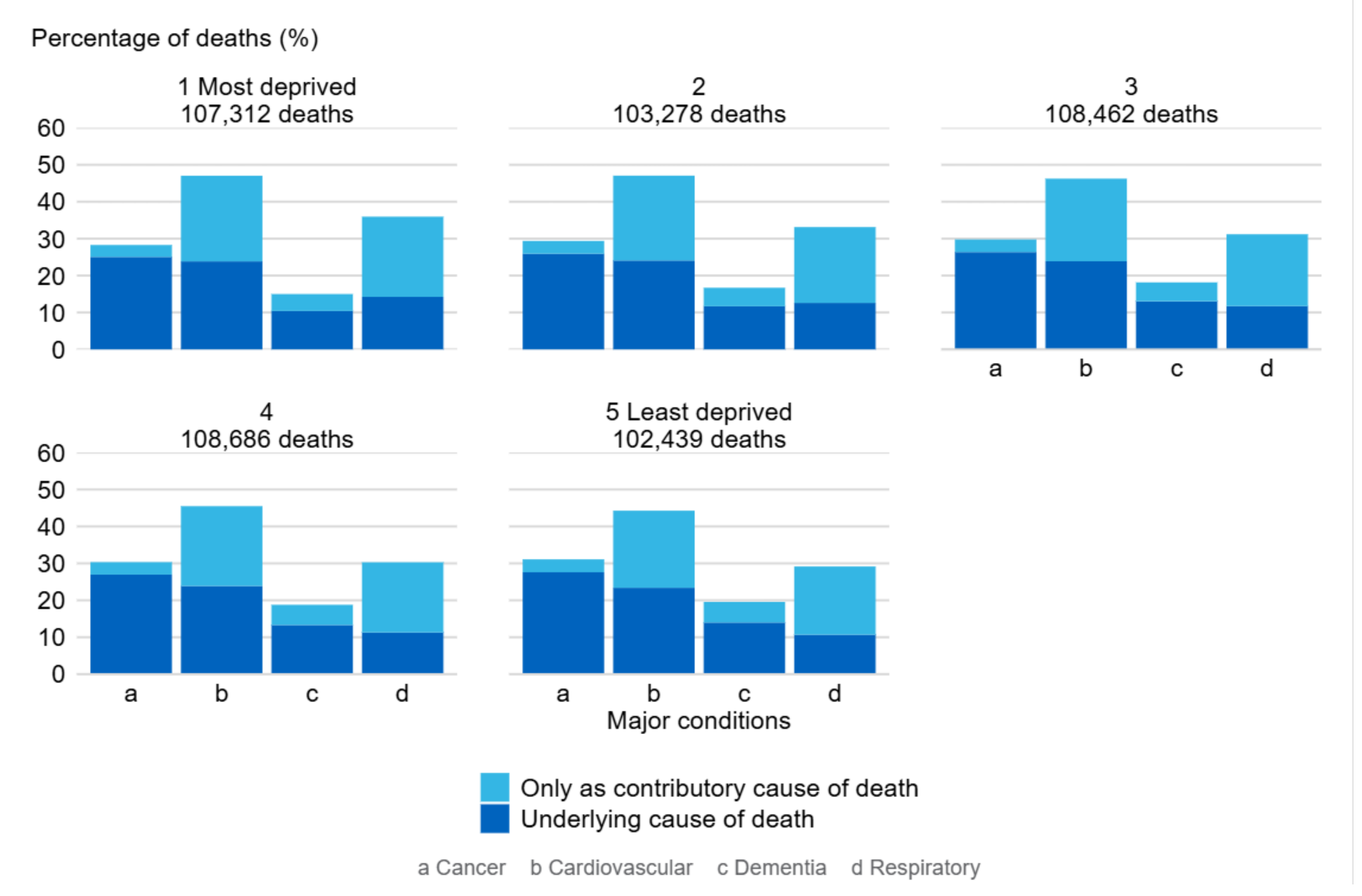
•people who died of cancer are on average the youngest, 42% of people who died of cancer were under 75 years compared to 31% of all deaths

•among people who died of dementia, 63% were female and 37% male compared to 49% female and 51% male for all deaths. They are also the most elderly with 67% aged 85 years or older compared 40% of all deaths



https://fingertips.phe.org.uk/documents/peolc_patterns_of_care_factsheet_2024.html

Percentage of people who died of or with 4 major conditions by deprivation, England 2024

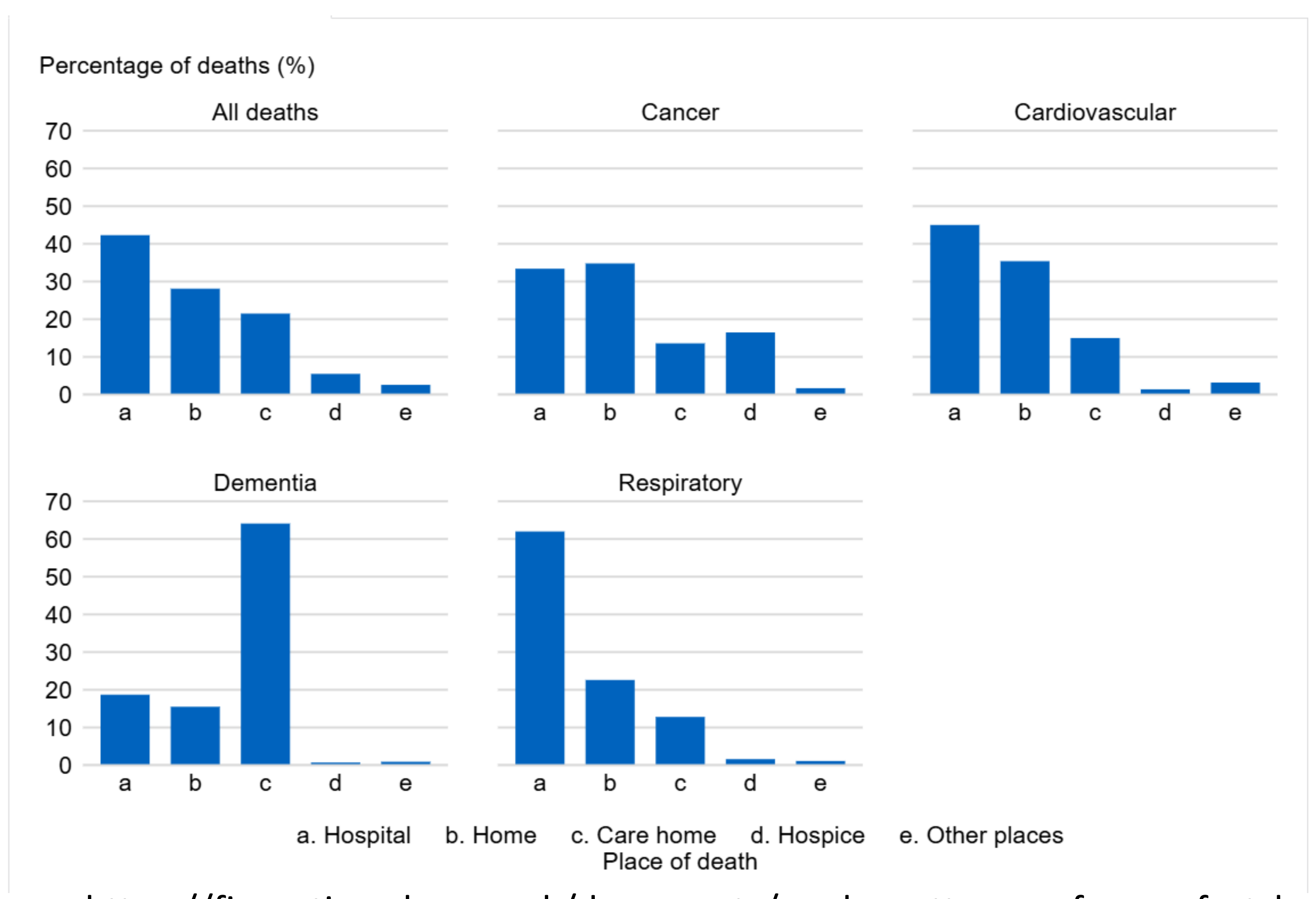


https://fingertips.phe.org.uk/documents/peolc_patterns_of_care_factsheet_2024.html

Access to Palliative Care is disease related

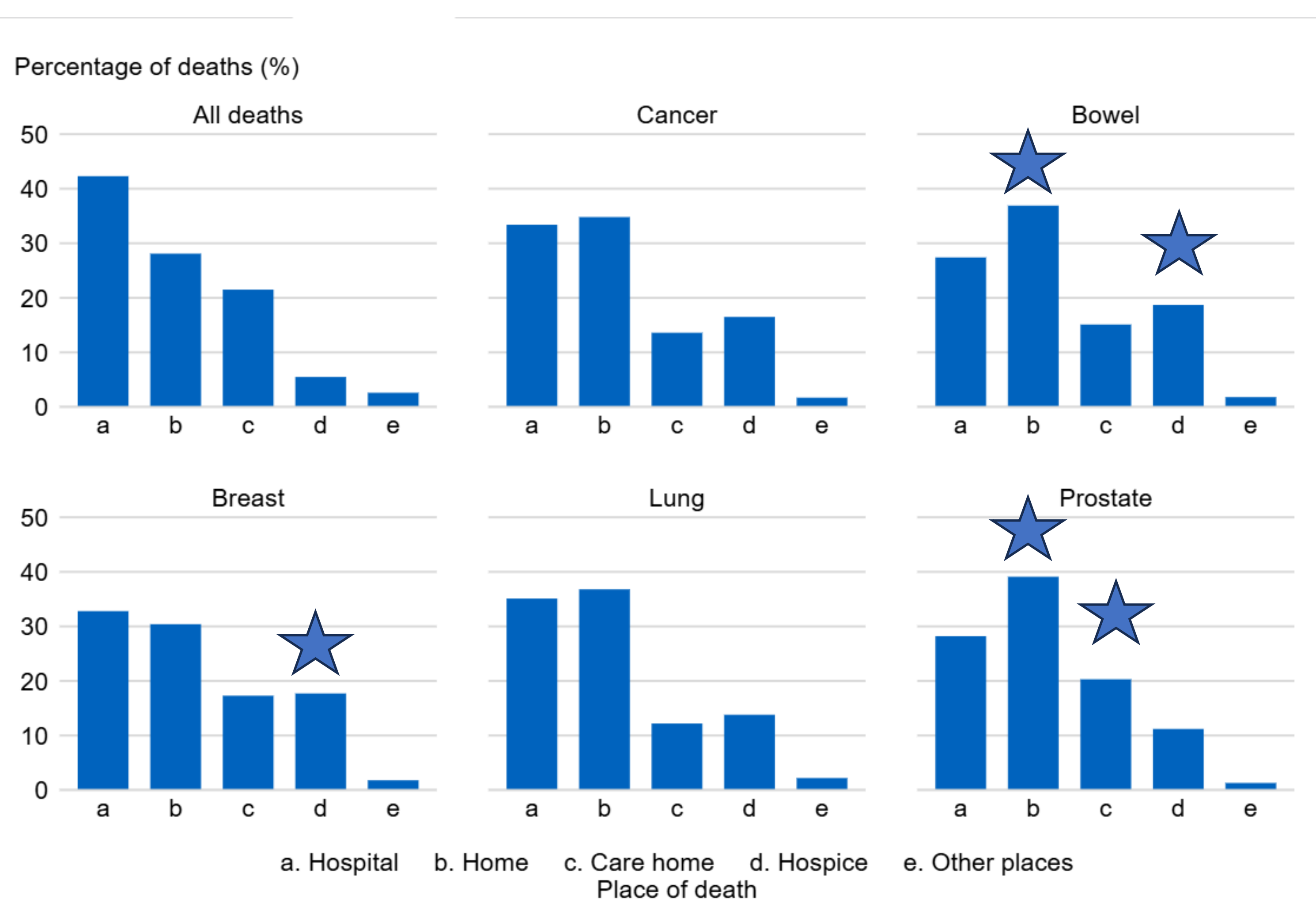
- the condition(s) people are living with in their final weeks can affect where they are cared for, access to Palliative Care and where they ultimately die; comparing the 4 major conditions with each other
  - people who died of cancer were the most likely to die at home (34.8% compared to 28.1% of all deaths) or in a hospice (16.5% compared to 5.5% of all deaths)
  - people who died of dementia were the most likely to die in a care home (64.1% compared to 21.5% of all deaths)
  - people who died of respiratory disease were most likely to die in hospital (62.0% compared to 42.3% or all deaths)
- https://fingertips.phe.org.uk/documents/peolc_patterns_of_care_factsheet_2024.html

Place of death for people who died of 4 major conditions, England 2024



https://fingertips.phe.org.uk/documents/peolc_patterns_of_care_factsheet_2024.html

Place of death for people who died of major cancer, England 2024



Inequalities by age, deprivation and ethnicity

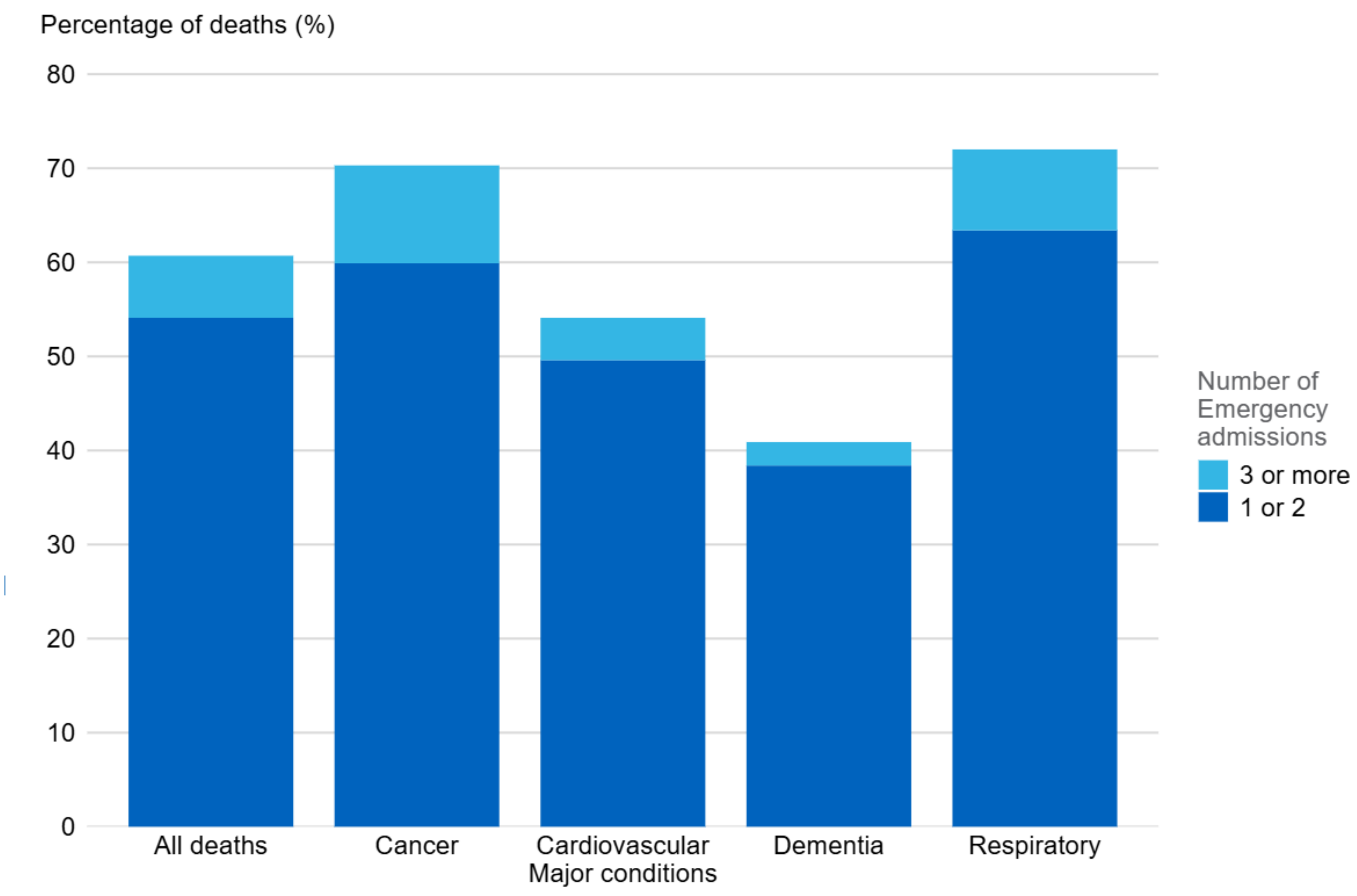
https://fingertips.phe.org.uk/documents/peolc_patterns_of_care_factsheet_2024.html

Time in hospital following emergency admissions in *last year of life*

12 months October 2021 to September 2022
All people and those near end of life

	Under 75 years	75 to 84 years	85 years or older	All ages
Total days in hospital (millions)	15.7	8.3	7.7	31.7
Days in hospital involving people in the last year of life (millions)	3.0	3.2	3.8	10.1
Percentage of all days in hospital that involve people in the last year of life	19%	39%	50%	32%

Percentage of people who have emergency hospital admissions during the final 3 months of life for people who died of 4 major conditions, England 2024



https://fingertips.phe.org.uk/documents/peolc_patterns_of_care_factsheet_2024.html

Urban vs Rural (17% 2024)
Challenging for all but especially older adults

Urban vs Rural

- Local Provision of community palliative care
- Distances
- Transport
- Costs of transport
- Proximity of family

Ethnicity

©2025 The Centre for the Art of Living and Dying Well

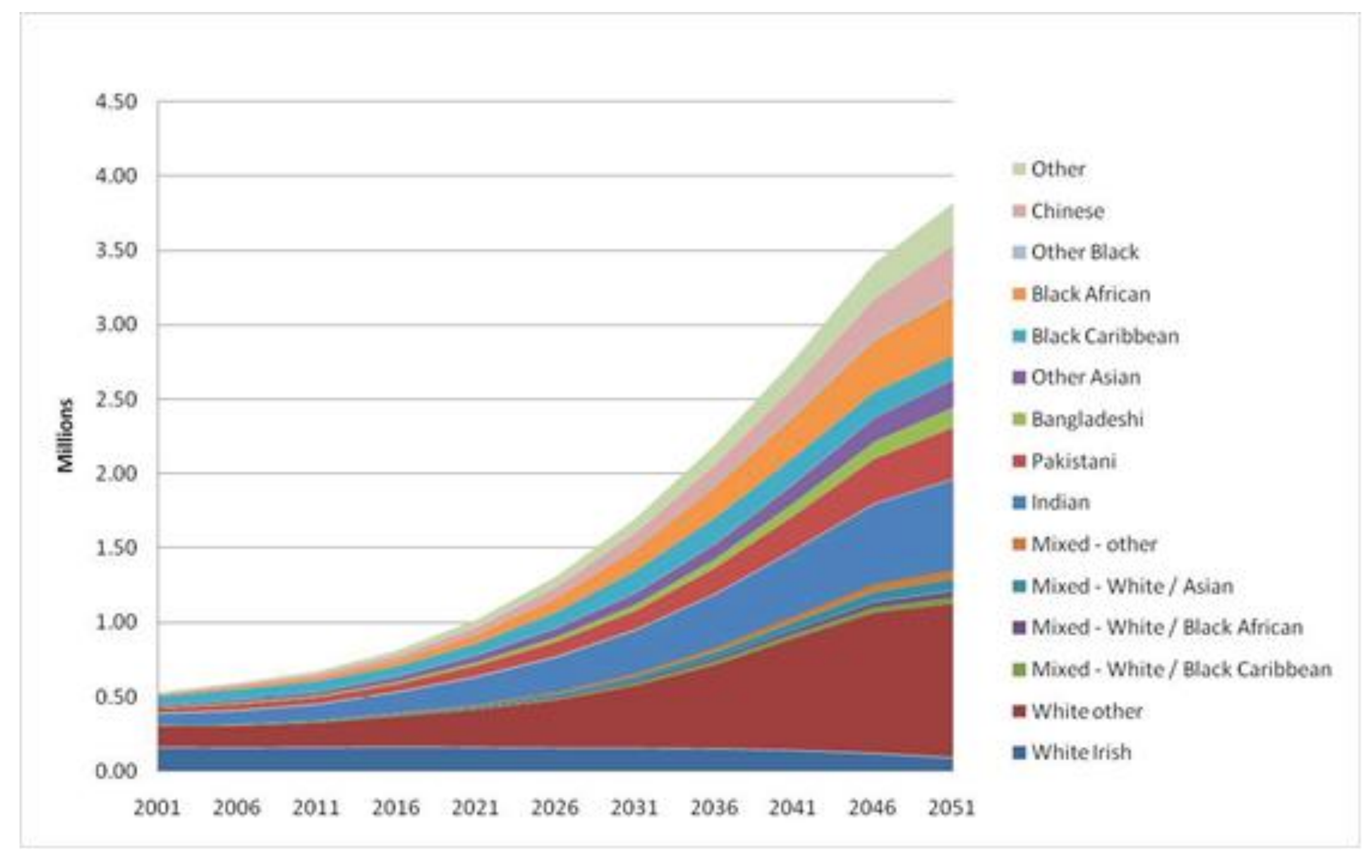
Distribution of all deaths by Ethnicity, England 2024

	Asian or Asian British	Black or Black British	Mixed	White	Other ethnic group	Not known
Distribution of all deaths by ethnic group						
Number of deaths (any cause)	17,418	9,021	2,423	474,455	1,752	25,108
Percentage of all deaths	3.3%	1.7%	0.5%	89.5%	0.3%	4.7%

2021 Census England and Wales data shows 74.4% identified as White British, 9.3% Asian, 4.0% Black, 2.9% Mixed, and 2.1% other groups. Non-white groups are younger

https://fingertips.phe.org.uk/documents/peolc_patterns_of_care_factsheet_2024.html

Not just aging but changing ethnic make-up of aging population



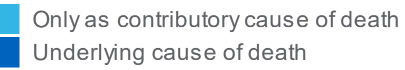
Source : Lievesley –The future ageing of the ethnic minority population of England and Wales, 2010

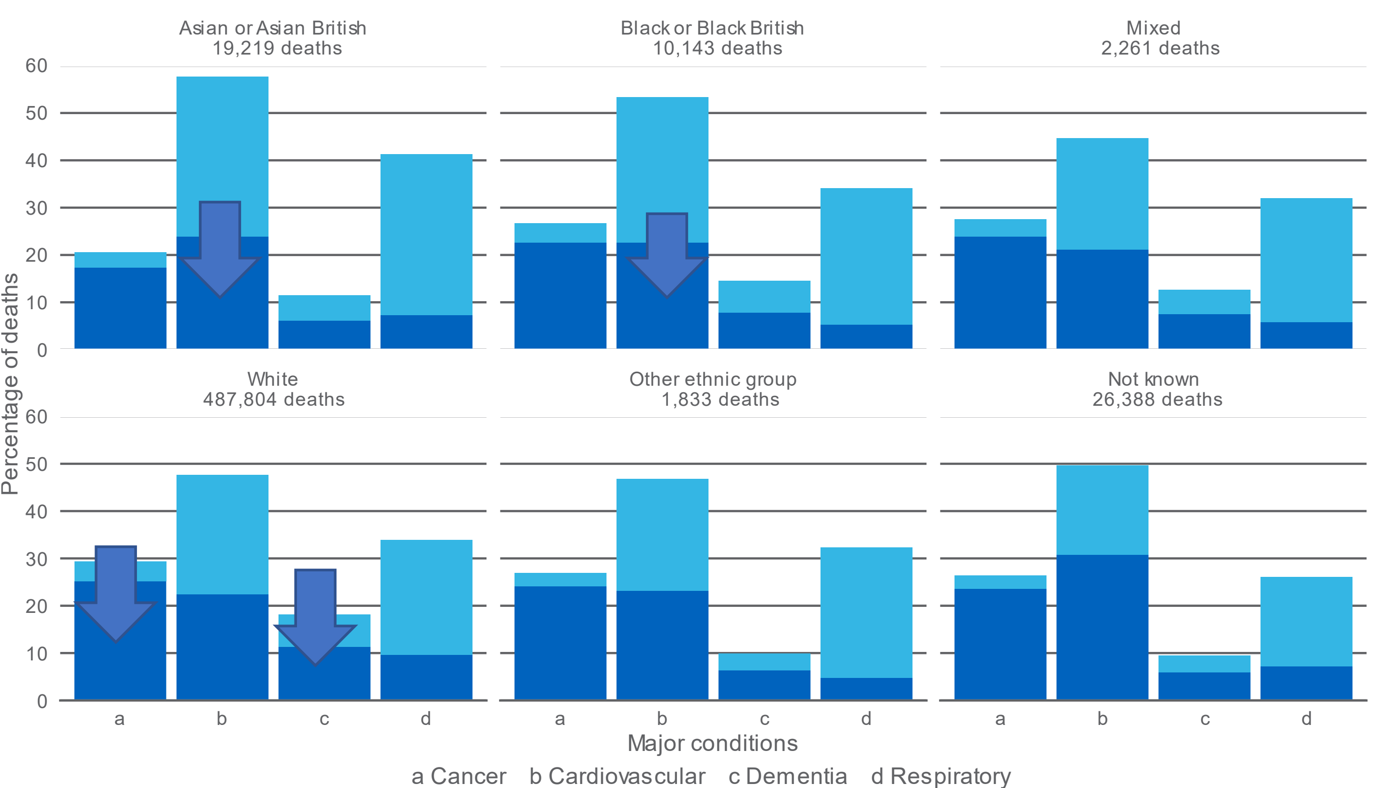
Demographics & Ethnicity

- Age at death
- Cause of death
- Health Literacy
- Financial resources
- Family resources
- Accomodation and suitability to die at home

- Intersectionality
  - Ethnicity and deprivation (but not for all groups)
  - Higher prevalence of social/medical challenges
  - Homelessness, alcohol and drug use, severe mental illness (in some groups)

Percentage of people who died of or with 4 major conditions by Ethnicity, England 2021

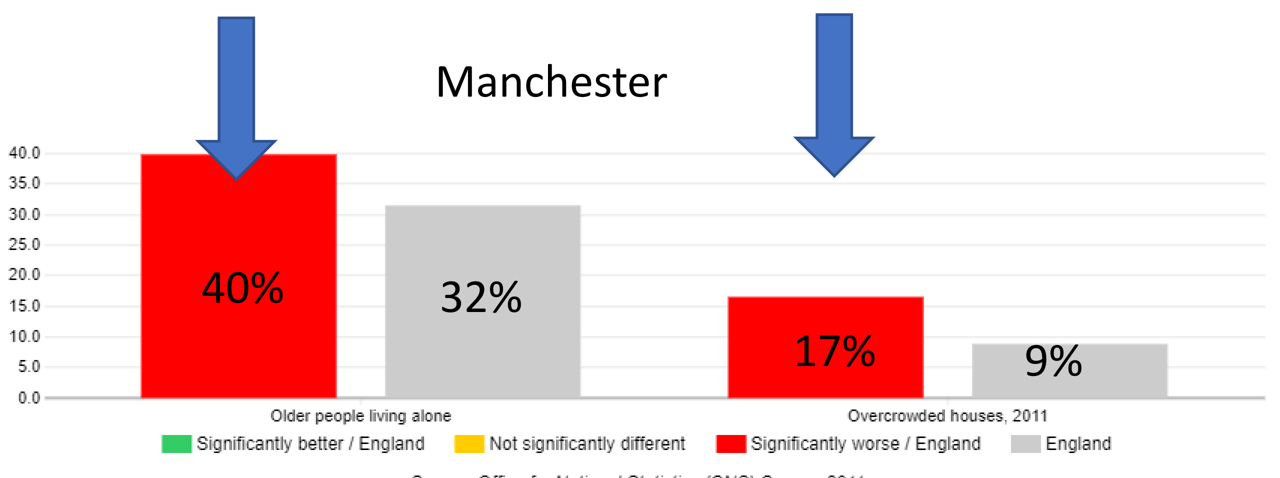




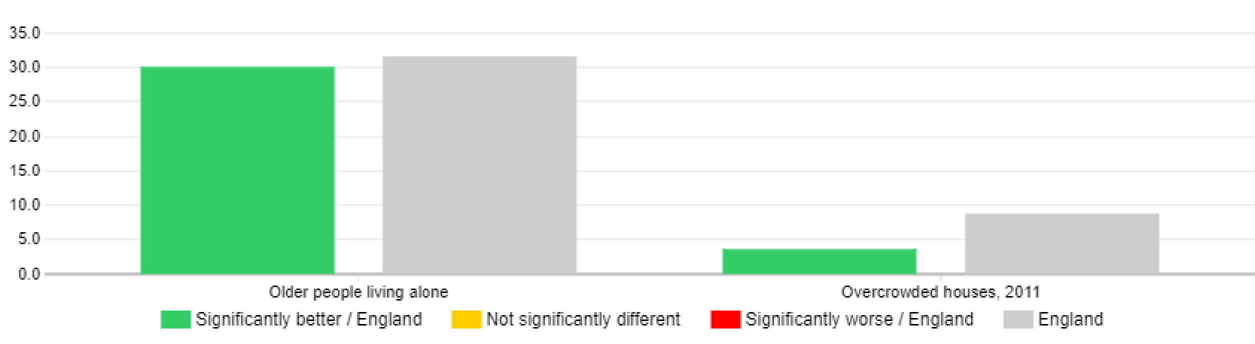
Note: still relatively small numbers of deaths in non-white groups and influence of age at death on cause

Housing and living environment – resources to die at home: lonely or overcrowded

Manchester



Cheshire East

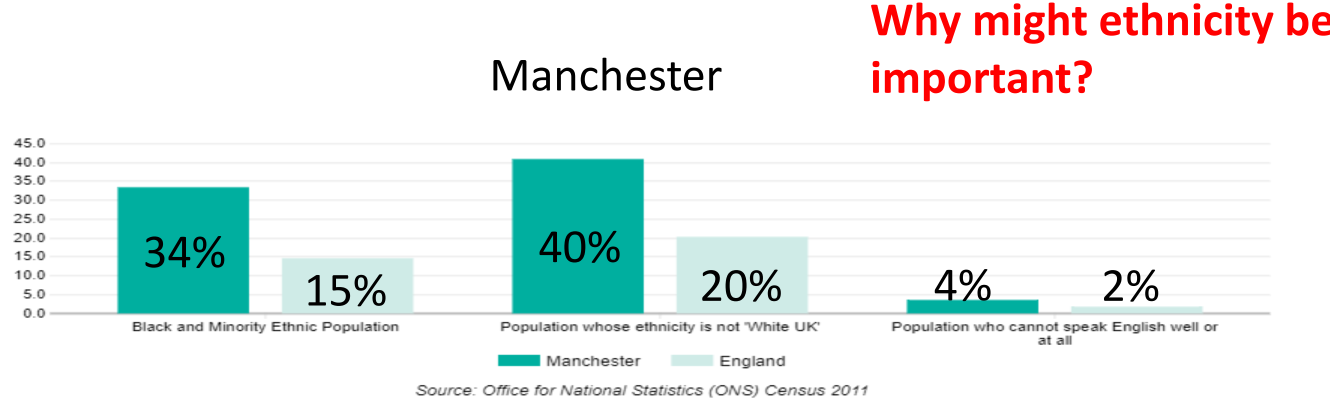


https://fingertips.phe.org.uk/profile/end-of-life

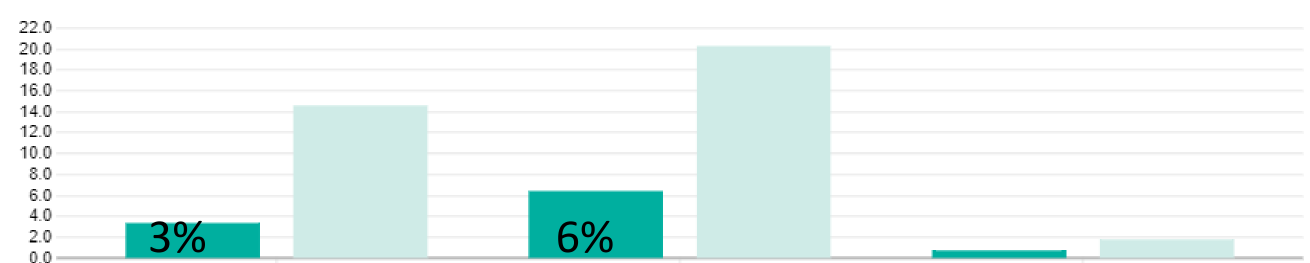
Ethnicity and language in different parts of England Ensuring culturally appropriate access to services – Person Focussed

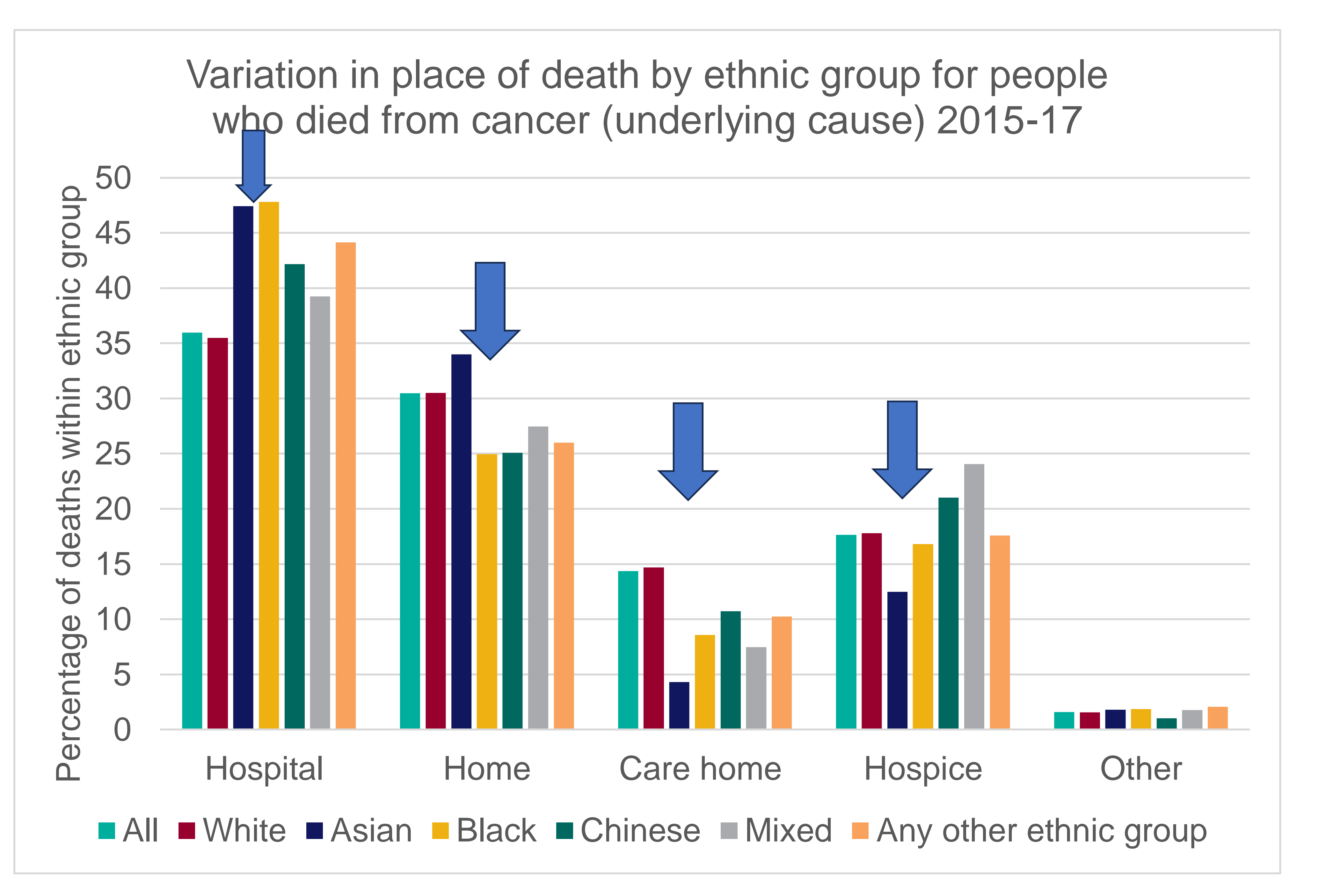
Why might ethnicity be important?

Manchester



Cheshire East

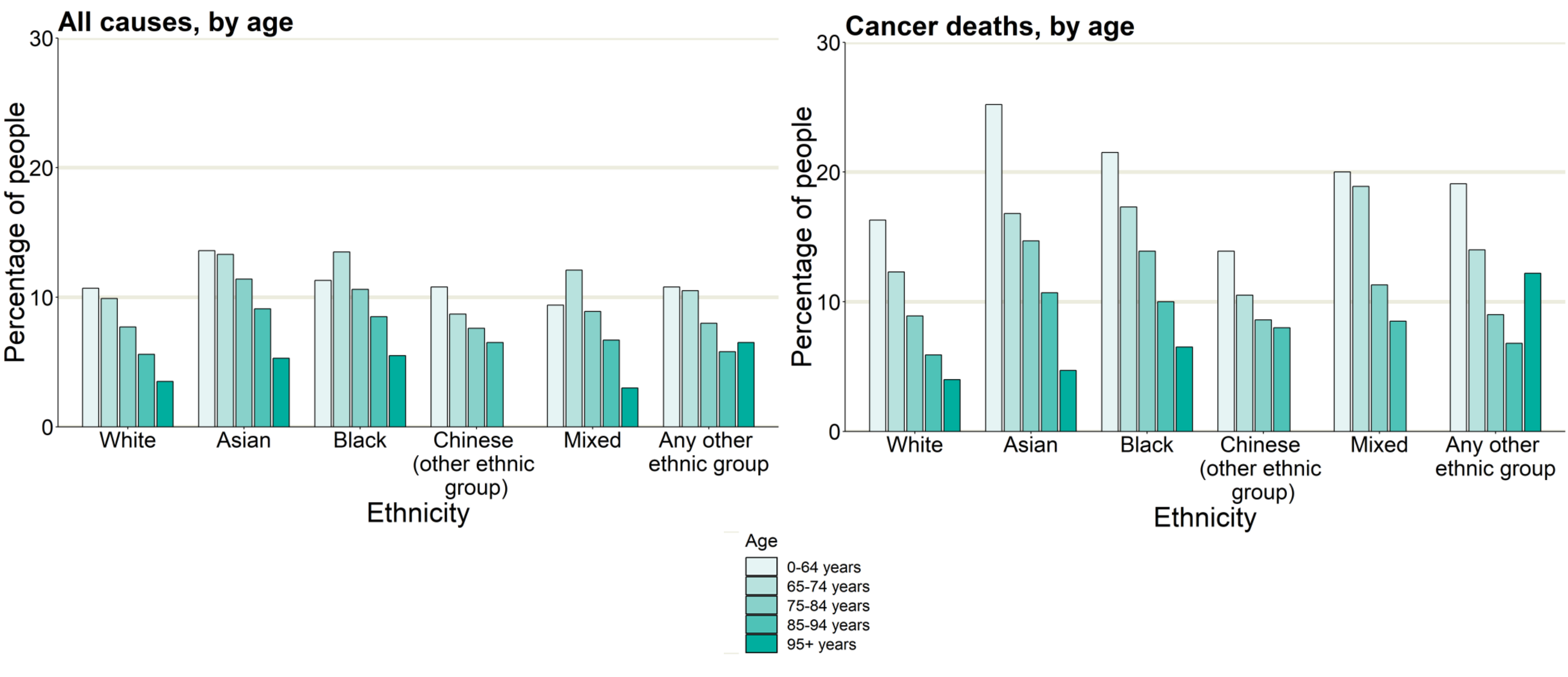



Variation in place of death by ethnic group for people who died from cancer (underlying cause) 2015-17
Percentage of deaths within ethnic group
50
45
40
35
30
25
20
15
10
5
0
Hospital
Home
Care home
Hospice
Other
All
White
Asian
Black
Chinese
Mixed
Any other ethnic group

Palliative Care and death at home as a Quality Indicator!

- Long-standing desire in Western World
- Not cross-cultural
- For people of Chinese origin a death at home may be perceived as ‘bad luck’ on the household
- For people of Japanese origin a death at home may be perceived by the community as the family lacking financial resources to take their loved one for ‘better’ care in hospital or not afford for selfish reasons
- For Nigerians they feel they must take their loved ones to hospital otherwise looks like neglect
- Asians Indians feel duty to care for loved one at home and not care home
- COMPLEX MIXED FAMILIES
- MIGRATION young people migrate for work

Proportion of people who died who had 3 or more emergency admissions in last 90 days of life (2015 – 2017)



Source : PHE analysis of ONS Mortality linked to Hospital admissions data © NHS Digital 2019

Ethnically Diverse Faith Perspectives on End-of-Life Care & Death Literacy

Community-Based Participatory Research, Birmingham · Research England · Rozario, Droney, Gadoud, Spear, Sanders, Phillips, McManus, Verne, Whitney, Doherty

St Mary's University · Royal Marsden · Lancaster University · Public Health Wales · Archdiocese of Birmingham

INTRODUCTION

Considerable inequity exists in end-of-life care across the UK, with cultural influences impacting death literacy. Birmingham has one of Europe's largest migrant populations (340,000+ Muslims, plus Buddhist, Hindu, Jewish and Sikh communities), yet these groups remain underserved in end-of-life care. This study responds to Lord Darzi's findings and Health & Social Care Committee recommendations.

AIMS

1. Co-produce culturally appropriate approaches to discussing death and dying
2. Identify cultural and faith-specific barriers and facilitators
3. Develop culturally sensitive recommendations

METHODS

Community-based participatory research (Feb - July 2025).

Community Advisory Group: 4 members (Hinduism, Buddhism, Islam, Sikhism), identified through the lead on Interfaith for Birmingham Archdiocese - community members and leaders.

Focus Groups: 2 groups of 9 participants from Islam, Hinduism, Sikhism, Judaism and Buddhism - faith leaders, community workers and members.

KEY TAKEAWAYS

- Cultural and religious practices matter at end-of-life
- Death is taboo amongst many ethnically diverse faith communities
- Two-way knowledge exchange bridges the equity gap
- Community-based participatory research works

KEY RECOMMENDATIONS

For Healthcare Services

- Build trust and communication with faith communities
- Provide private spaces for prayer and family gathering
- Train healthcare staff about different religious practices
- Invite faith representatives to produce clear staff guidance
- Make quick processing after death a priority where religiously required
- Provide a 24-hour contact for advice on religious rituals

For Faith and Community Organisations

- Offer workshops on death rituals and bereavement
- Work with healthcare staff to explain faith requirements
- Provide information bilingually and in visual formats
- Encourage open discussions about taboo subjects
- Promote understanding of different world views (Karma, Moksha, Mukti)
- Advocate for employers to recognise mourning practices

IMPACT and DISSEMINATION

Highlighted at a community knowledge exchange event marking the anniversary of Nostra Aetate (1965 Vatican Council Declaration on Interfaith Relations) at St Chad's Cathedral, Birmingham.

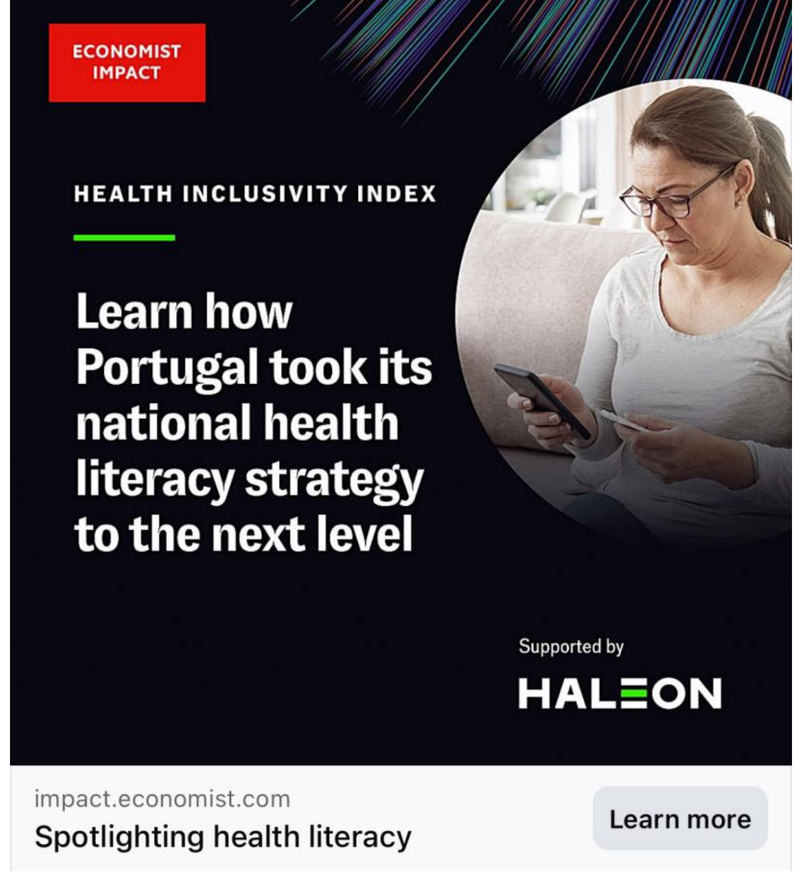
Findings are influencing local public health policy and now extending to London, in partnership with The Royal Marsden Hospital.

> "A very rare and very valuable set of insights into how each of the faiths approach dying, death, and the mourning period afterwards."
>
> Bishop Patrick McKinney
> Lead Catholic Bishop for Interreligious Dialogue

View full poster

Marie Curie Research into Practice Conference 2026 - Joint Runner-Up in the Joanna Mugridge Poster Prize.
maggie.doherty@stmarys.ac.uk
https://www.stmarys.ac.uk/research/centres/the-art-of-dying-well/index.aspx

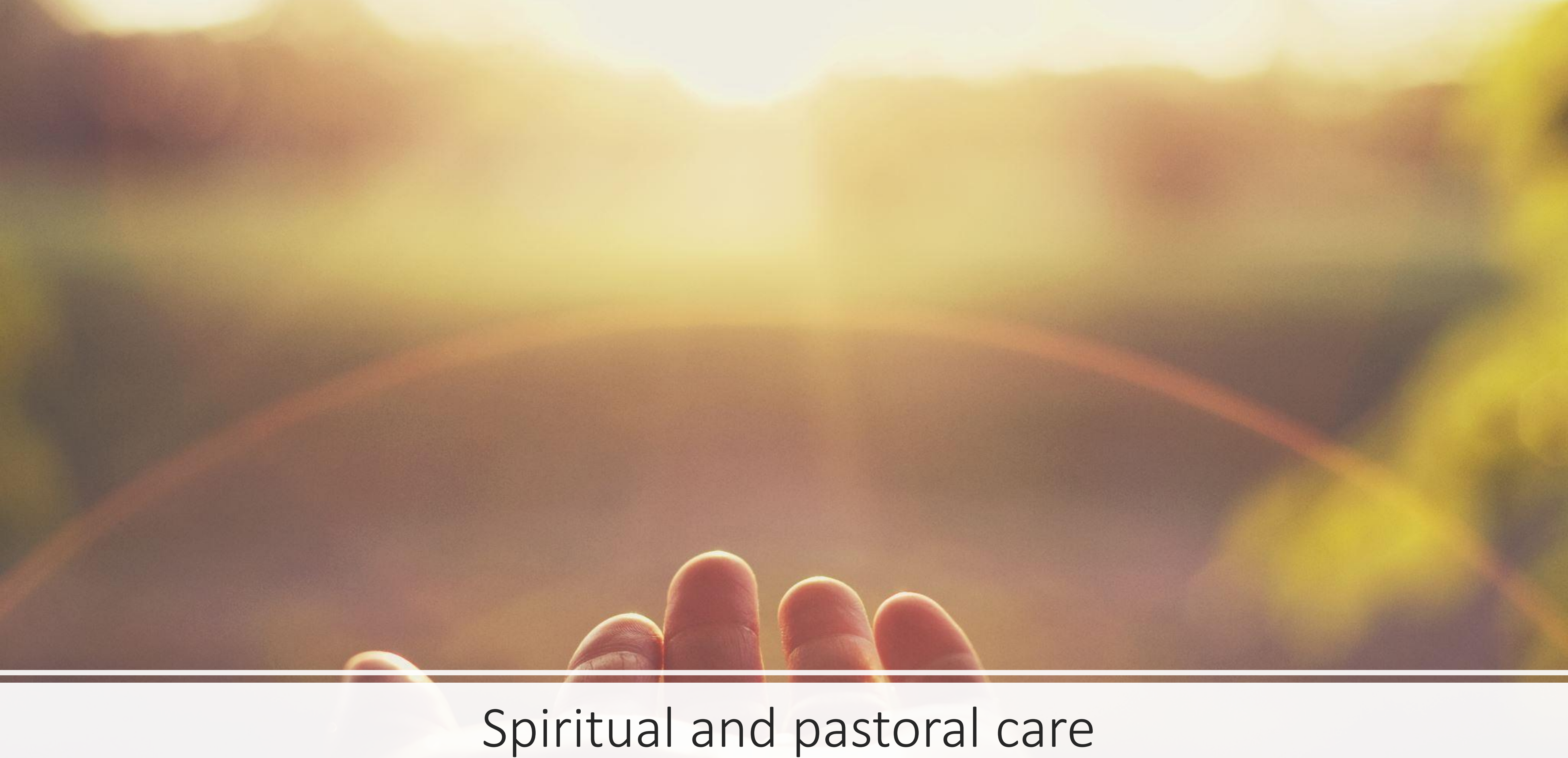
What happens when behavioural science meets public health? Read how Portugal's national strategy is delivering measurable impact in our case study.



Health Inclusivity Index

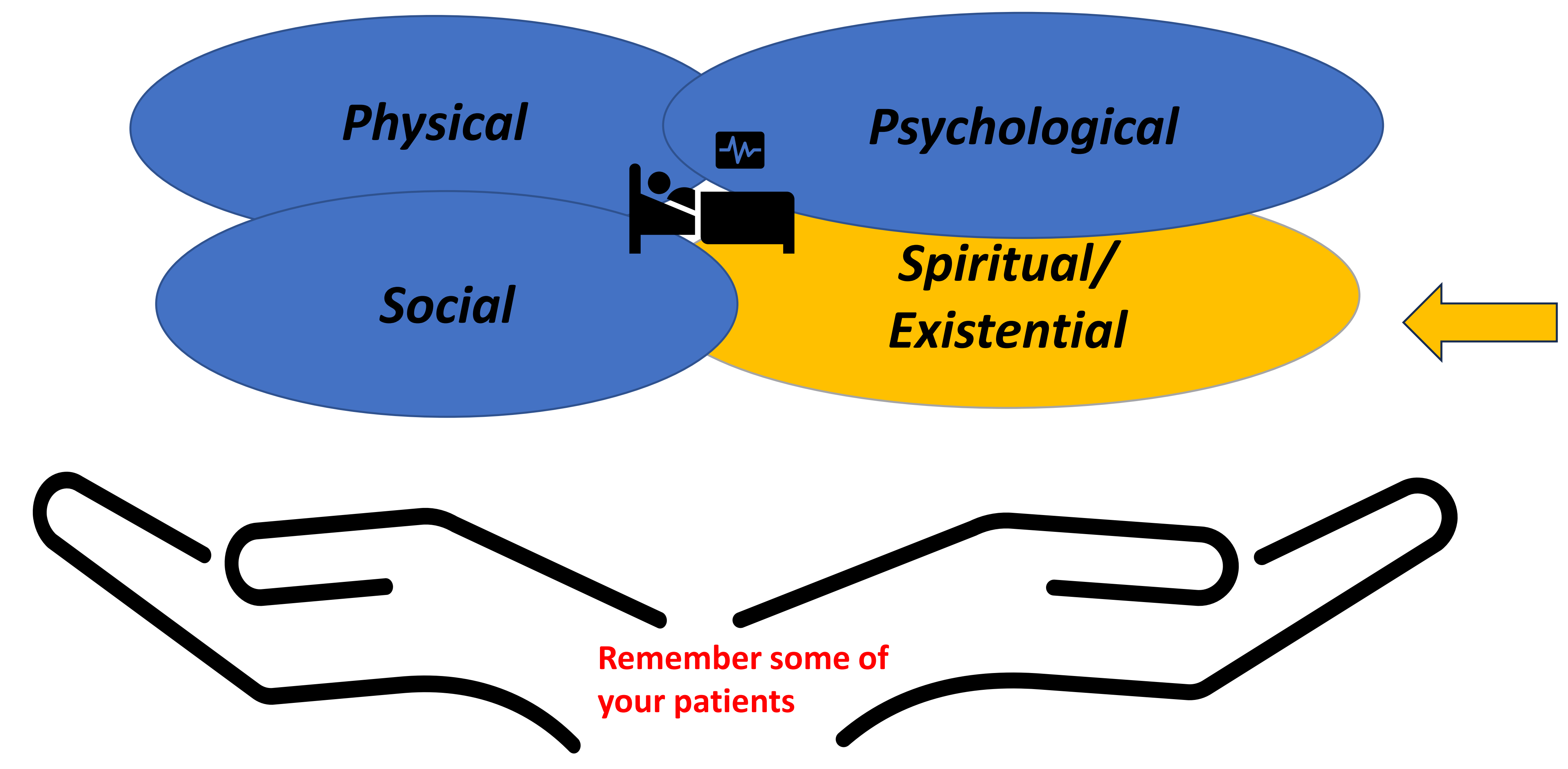
Explore the five key health literacy priorities

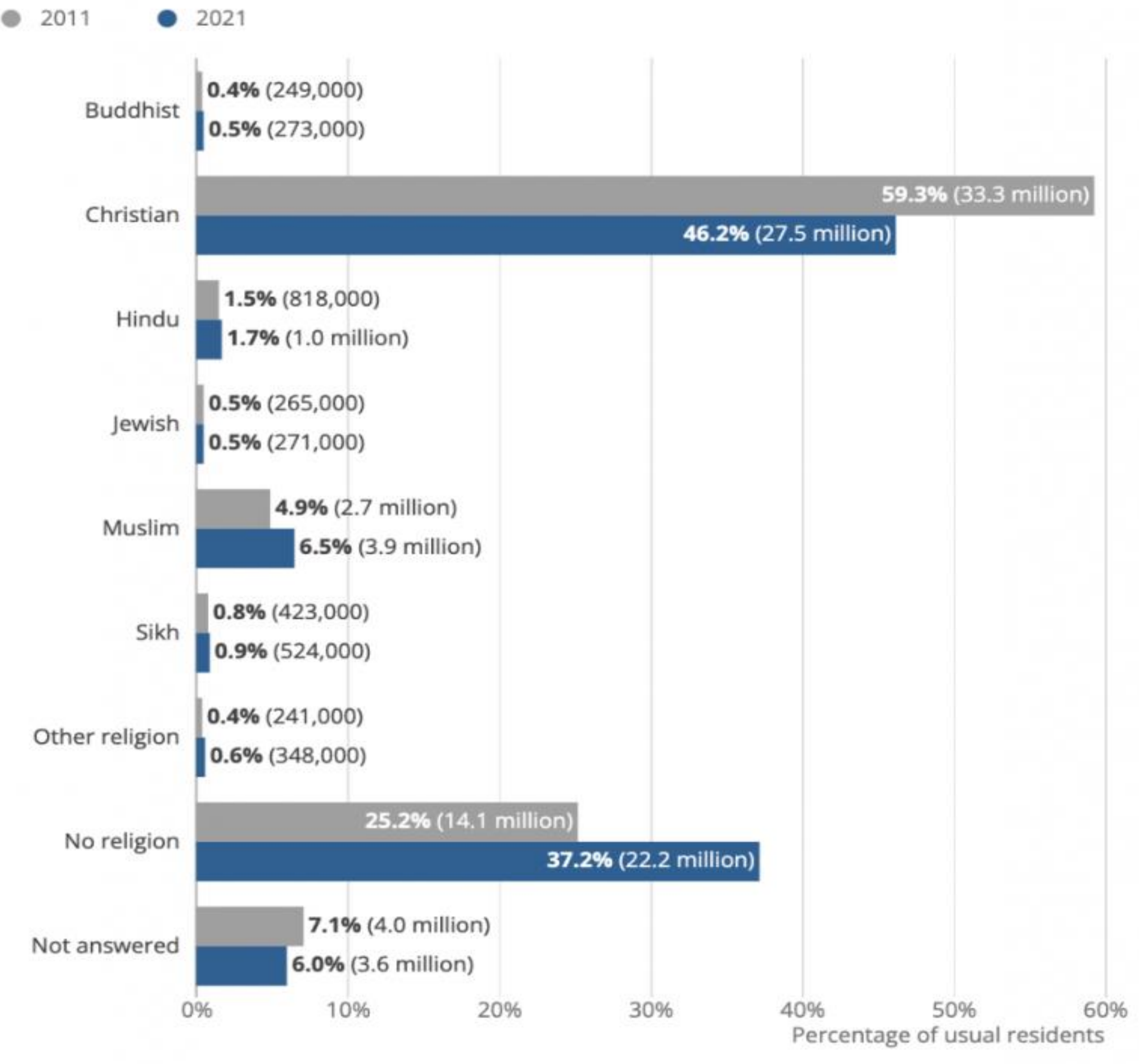
- Adopt a whole-of-government and whole-of-society approach
- Make health literacy a core capability and focus in health and social care organisations
- Develop and co-create high-quality, inclusive information resources
- Combat misinformation and strengthen critical appraisal skills
- Strengthen measurement, research and data use



Spiritual and pastoral care

A holistic approach

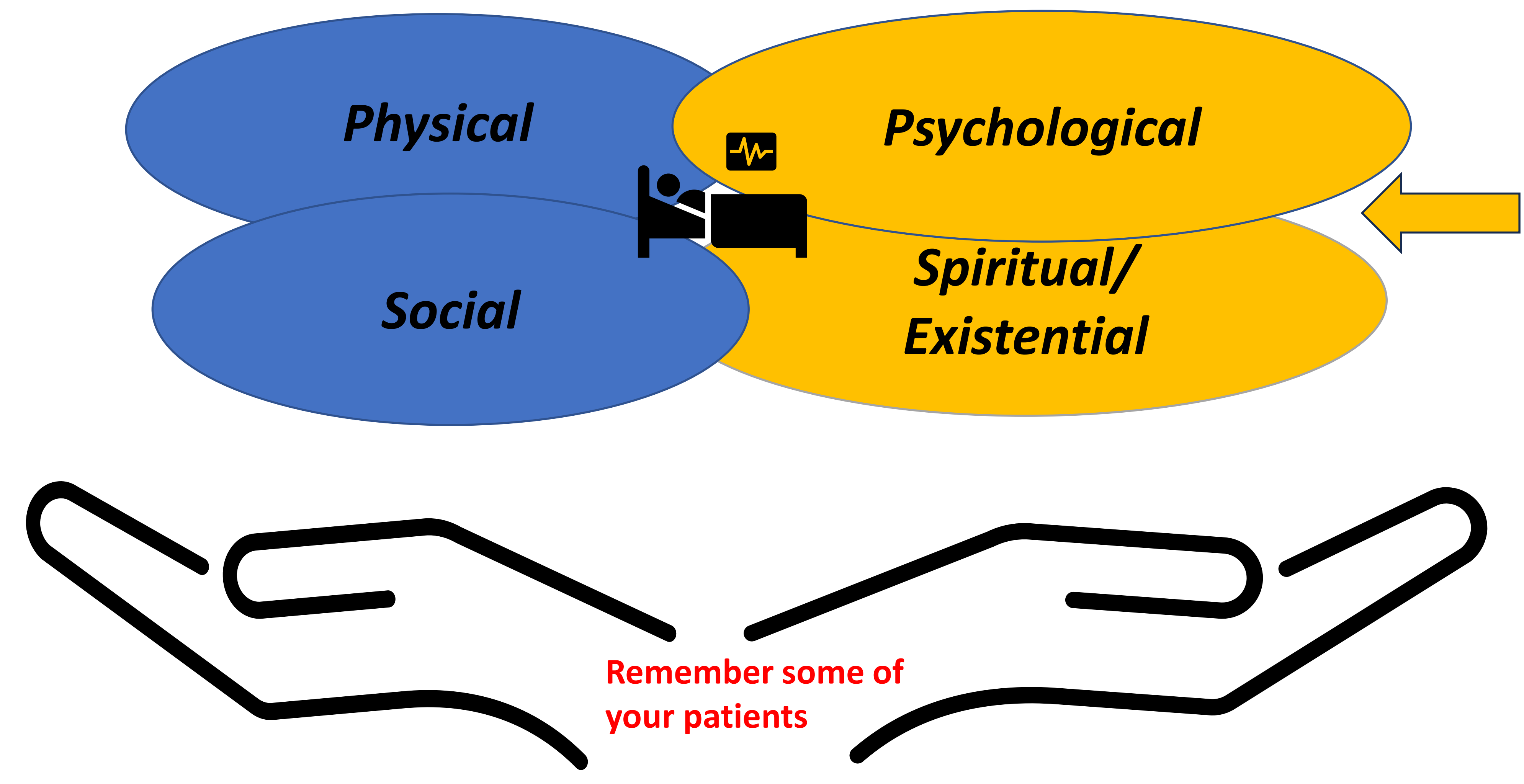



Religious composition, 2011 and 2021, England and Wales
2011
2021
Buddhist
0.4% (249,000)
0.5% (273,000)
Christian
59.3% (33.3 million)
46.2% (27.5 million)
Hindu
1.5% (818,000)
1.7% (1.0 million)
Jewish
0.5% (265,000)
0.5% (271,000)
Muslim
4.9% (2.7 million)
6.5% (3.9 million)
Sikh
0.8% (423,000)
0.9% (524,000)
Other religion
0.4% (241,000)
0.6% (348,000)
No religion
25.2% (14.1 million)
37.2% (22.2 million)
Not answered
7.1% (4.0 million)
6.0% (3.6 million)
0%
10%
20%
30%
40%
50%
60%
Percentage of usual residents

Why is Spiritual Care important?

Addressing spiritual needs isn't just about comfort; it's a vital part of holistic care that improves quality of life, helps patients and their loved ones cope, and can lead to better health outcomes by integrating spiritual strength into their treatment journey. Its not just about religion!

A holistic approach



Spiritual/Pastoral Care:

- Seeks to support the patient in their search for emotional wellbeing
- In terms of affirming trust and confidence in the service
- Realised through:
  - Empathy
  - Sympathy
  - Compassion
  - Honesty and sincerity

  - Religious Support which is using the resources of a particular religion

Spiritual and religious wellbeing can contribute to a person's overall wellbeing

Studies show that spiritual or religious beliefs and practices can create a positive mental attitude

This may help a patient feel better and actually cope better with the challenges of cancer diagnosis and treatment

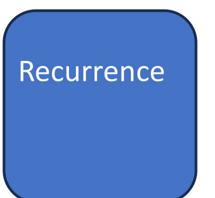
It can support and improve the well-being of family carers

Times in the pathway for a patient with cancer when they may benefit from Pastoral support

Symptoms Screening

Prognosis

Treat ment



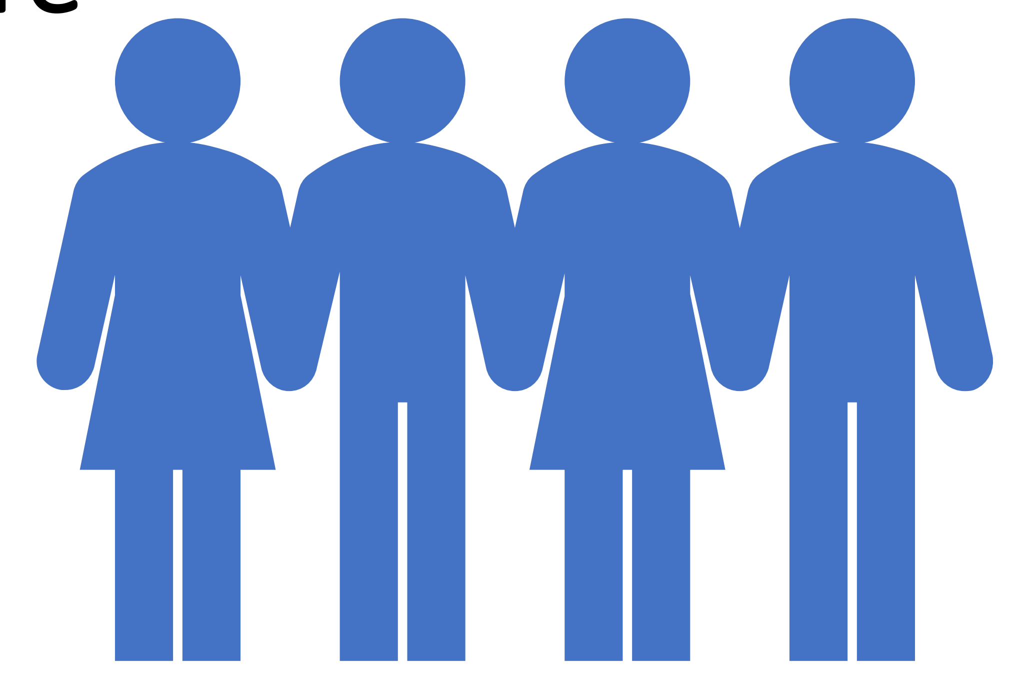
End of life

Fear
Anger
Why me?
What about my family
How will I cope?
Feelings of hopelessness/helplessness
Worries about 'lost future'

Religious or spiritual strength/support
Meaning for life in the face of suffering
Hope and optimism about the future
Freedom from regret
Satisfaction with life
A sense of inner peace

Complex Families challenges for pastoral care

- Ethnicities
- Religions
- Denominations
- Customs
- Generational ‘conflict’



Stand up and breath

We too will die!

A short, guided reflection on our own mortality

Death smiles at us all; all we can do is smile back

Marcus Aurelius
Meditations

What do you think?

Hippocrates cured the ills of many, but himself took ill…. Alexander, Pompey, and Julius Caesar laid waste while cities time and again…. But the hour came when they too passed away. Marcus Aurelius

Anomie (normlessness) in death and bereavement

- “The attitude to dying and the image of death in our societies cannot be completely understood without reference to the relative security and predictability of individual and the correspondingly increased life expectancy. Life grows longer, death further postponed. The sight of dying and dead people is no longer commonplace. It is easier in the normal course of life to forget death”

  Norbert Elias The Loneliness of the Dying (1985)

- “Modern Societies deny and defer death by turning the inevitable ending of life into a multitude of smaller ‘*non-ultimate*’ and potentially resolvable ‘*health hazards*’ and illnesses” Zygmunt Bauman (1998)

- In his model mortality is ‘deconstructed’ which leads to ‘endless defensive battles against aging and death’ Zygmunt Bauman Imitations of Postmodernity (1992)

- **Plus: lack of social norms as religiosity and cultural traditions are lost**

Does facing/reflecting on death have any benefits?

There is evidence that reflecting on death is beneficial

- Improves personal relationships (even in the short term)
- Reduces stress
- Allows us to live our lives/reprioritise
- Enables us to care better for people

What prompts us to think about our own mortality?

What prompts us to think about our own mortality? Feedback

- Our work
- The people we care for
- Custom or religion Family/friends/colleagues
- Media: disasters, war

What do we fear?

About getting closer to the end of life?

About other issues

What do we fear?

- Physical suffering
- Loneliness
- Our conduct when faced with suffering
- Suffering of our loved ones
- Extinction/nothingness
- Afterlife
- Missed/lost future
- Not to have made a difference/left a legacy

In what circumstances would you want to die?

What are the pros and cons for you..... or your loved ones

An unexpected death (acute medical, in sleep, traumatic)

A longer terminal illness

A short terminal illness

Physician Assisted Suicide/Euthanasia – not UK

Is facing/reflecting on death a personal responsibility?

Why?

Personal Responsibility to face death

- FOR US:
- Relieve ourselves of an underlying but possibly supressed anxiety
- Live a better life – reprioritise

- FOR OTHERS
- Better understand the people we care for and their families
- Plan for what we would like (not guaranteed)
- Leave things in order for our family and friends
- Help them not to fear our death

How prepared are you? Show of hands

- Who has an Advance Care Directive or similar
- Who has a Will?
- Who has Power of Attorney (legal representative if loose Mental Capacity
- Funeral Plan
- Home/finance in order
- Digital Legacy
- (Arrangements for Physician Assisted Suicide/Euthanasia –non-UK)

How prepared is the UK population?
What about in your country?

- **3-5% have Advance Care Plan, 70% never heard of them**
- **Will/Testament (37-53% of adults in UK have a Will, so 50-60% without a Will)**
- **Legal Power of Attorney for Health and Welfare and/or Finance**
  - **(~ 60% rich/educated people have LPAs and 20-40% overall)**
- **Next of Kin – most people as noted in hospital – no real power**
- **Funeral Plans (no formal statistics, estimate 10-30% have formal funeral plans)**
- **Digital Legacy (of people with a Will 12% include digital assets, ~70% ignore digital legacy, overall probably <10% have properly organised digital legacy.**

Problems stacking up ++

- Probably 0.5%-2% of people in the UK have all four plans in place
- So roughly 1 in 1,000 (or fewer) die fully prepared across all areas

- PROBLEMS FOR FAMILIES
- No authority to make care decisions when loved one lacks Mental Capacity
- No Will
- Unclear funeral wishes
- Locked or inaccessible digital accounts

Unfinished Business – what are our duties to others?

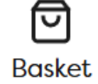
Not to leave a mess for them to clear

Leaving a Legacy

Impact on those left behind

Unresolved conflict (GUILT)

Search by title, author or ISBN



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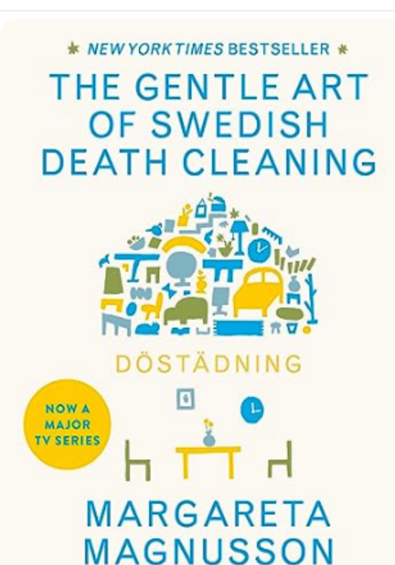

Dostadning
by Margareta Magnusson

£8.79 New RRP £9.99

Condition - **New**

40+ In Stock

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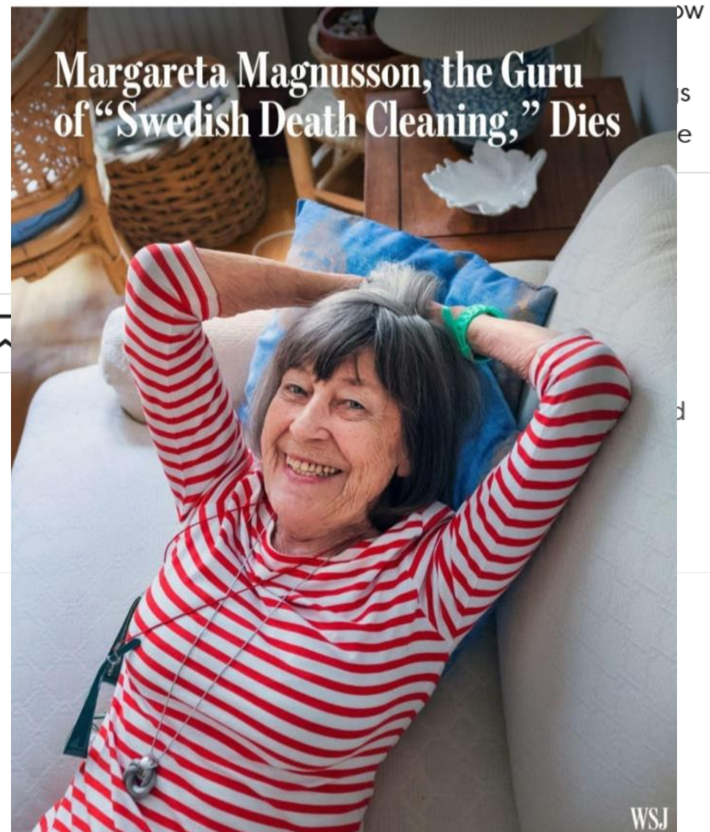
Get delivery by **Friday, 24th January** in the UK

7 reviews

Magnusson practiced what she preached. There was little left to tidy up after she died at the age of 91 on March 12 in Gothenburg, Sweden, where she was living in a retirement home. "The only thing I have to do now is talk to journalists," said her youngest daughter, Jane Magnusson, a documentary filmmaker, who several years ago made a short film about her mother.

Read more: 🔗 https://on.wsj.com/4bpcHhq



Digital Legacy

Dying Well · Bial Foundation Symposium

Digital Assets

- Passwords, email accounts and banking credentials
- Photographs, documents and cloud-stored files
- Subscriptions, domain names & intellectual property
- Legal access requires advance planning and documentation

Social Media After Death

- Accounts persist indefinitely unless actively managed
- Platform memorialisation policies vary significantly
- Loved ones may lack legal authority to access or close accounts
- Algorithmic reminders can cause unexpected grief

Memorialisation Platforms

- Dedicated services (e.g. Facebook Memorial, GoodTrust)
- Online obituaries and tribute sites
- AI-generated 'digital afterlife' tools raise ethical questions
- Raises questions of consent, identity and grief processing

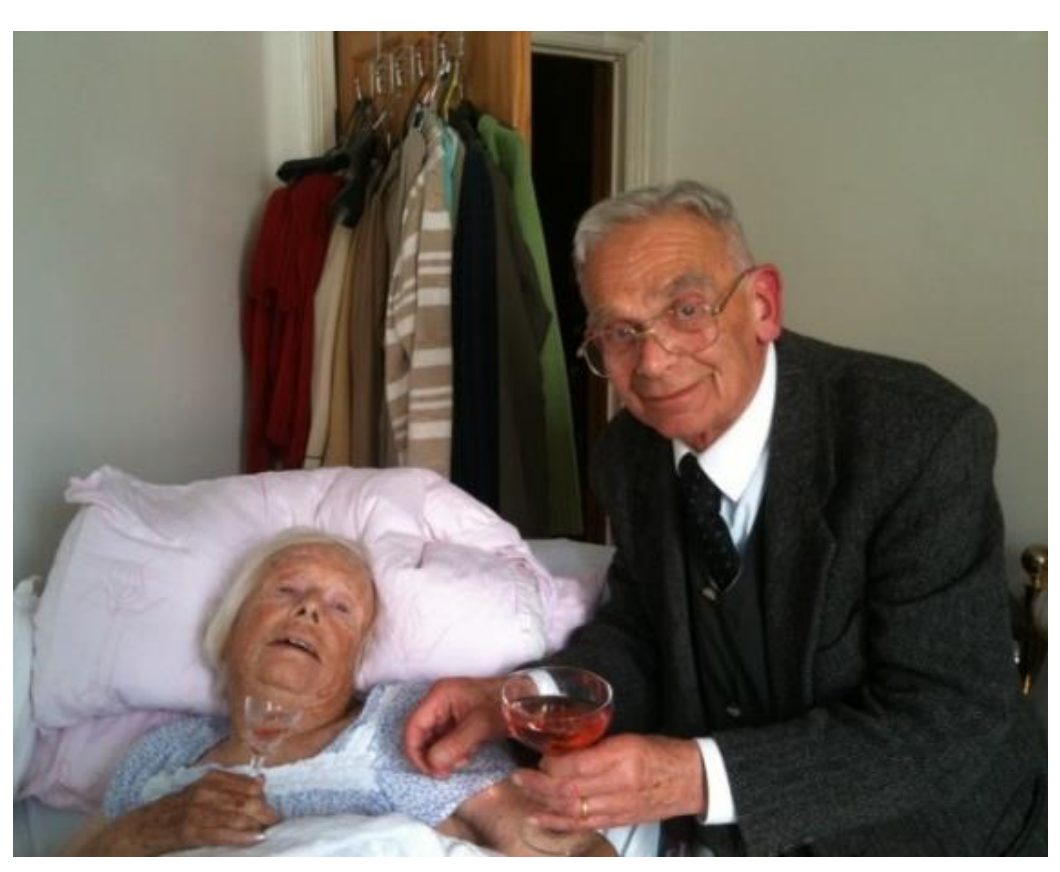
Planning Your Digital Legacy

- Appoint a 'digital executor' in your will or lasting power of attorney
- Maintain a secure, up-to-date record of accounts and wishes
- Specify social media preferences (memorialise, close or archive)
- Consider what digital content you wish to preserve or delete

Digital legacy planning is an emerging but critical dimension of end-of-life care

Do you think how we face dying is important for others? Do we have duties in dying?

Ars Moriendi



Observe, in short, how transient and trivial is all mortal life; yesterday a drop of semen, tomorrow a handful of spice or ashes. Spend, therefore, these fleeting moments on earth as Nature would have you spend them, and then go to your rest with good grace, as an olive falls in its season, with a blessing for the earth that bore it and a thanksgiving to the tree that gave it life.

Will you do anything different now? For you? For others?

For you?

- More reflection
- Change
- Living life to the full
- 'Bucket List'

For others?

- Finances Will
- Funeral Plan
- Legal Power of Attorney
- Saying 'I am sorry'
- Saying 'I love you'
- Sorting out your clutter/house
- Passing on wisdom
- Digital legacy

Have you encountered specific challenges caring for people from marginalised groups?

Discussion of one example.

Stigma or blinkers or fear regarding some groups

- People with Psychiatric Illness
- People who are dependent on alcohol or drugs
- The homeless
- People with Liver Disease

- “It is time to end all forms of stigma and discrimination against people with mental health conditions, for whom there is double jeopardy: the impact of the primary condition and the severe consequences of stigma”. Thornicroft G, Sunkel C, Alikhon Aliev A, et al.

Severe Mental Illness (SMI)

- Mental health disorders that are chronic, impair function, and require ongoing treatment
- Schizophrenia, bipolar disorder and psychosis
- **~ 35,000 deaths per year c.f. 35,000 lung cancer deaths (UK), 57%male**
- 2/3 of people with SMI die from physical conditions
- People with Severe Mental Illness die on average 20 years younger than people without SMI. ~40% <60 years
- 5x more likely to die <75 years than someone without SMI
- Gross inequalities 3x more likely to die in the most deprived fifth of the population than the least 4x variation by Local Government Areas

Improving access to Palliative Care is an imperative

- People die young
- Things are getting worse (temporal trends in risk factors)
- Patients are vulnerable to other threats e.g. COVID-19 (virus and lockdown)/Flu
- Overlap with other major conditions/lifestyle issues
- Patients may have social and psychological and spiritual problems in addition to their psychiatric diagnosis

- Very marked inequalities
  - In deaths
  - In risk factors
  - In access to care
  - Additional impact of ethnicity on access to healthcare/health literacy

The impact of the first year 2020 of the COVID-19 Pandemic on people with SMI aged 18-74

- 22.2% increase on previous annual number of deaths ~43,000 (c.f. 35,000)

- 7,785 people with SMI aged 18-74 died from COVID-19.

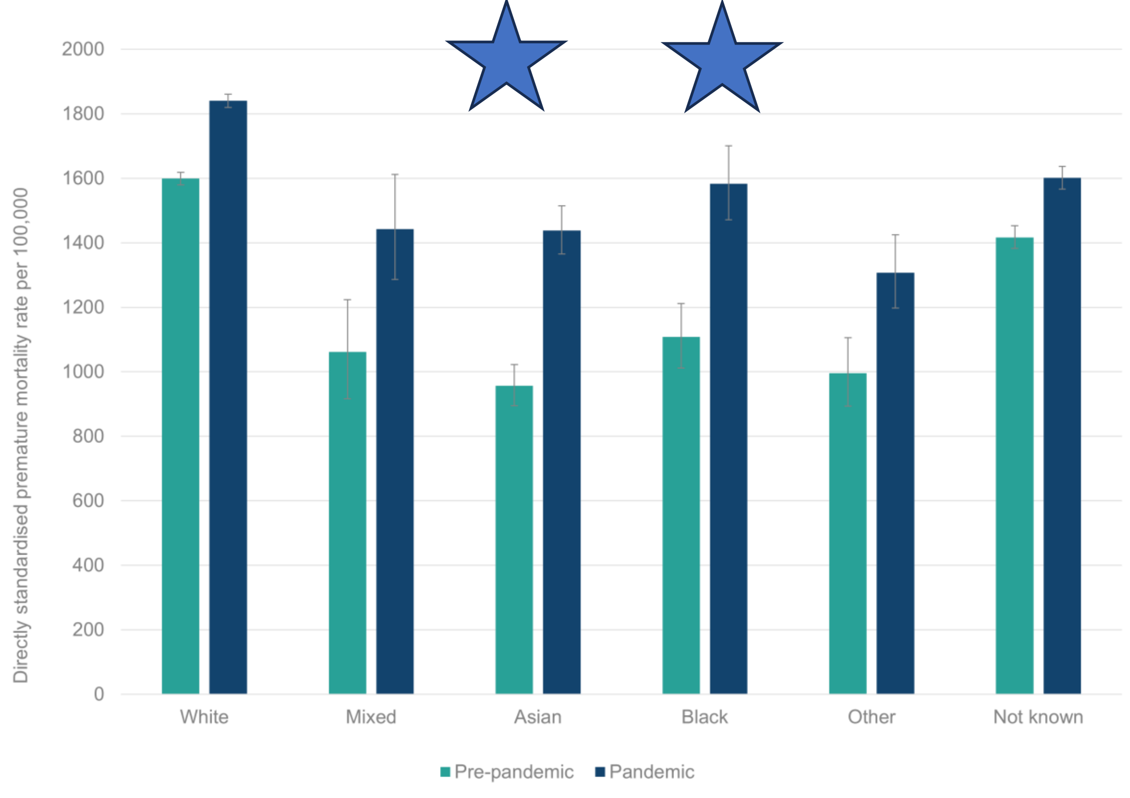
- 7,460 people with SMI aged 18-74 died from cancer an increase of 7%.
- 6,925 people with SMI aged 18-74 died from cardiovascular disease an increase of 12%
- 3,450 people with SMI aged 18-74 died from respiratory a *reduction* of 15%

- 2,795 people died from Liver Disease an increase of 28%,
- Alcohol related liver disease increased 40%
- Alcohol related liver disease accounted for 78.2% of premature deaths from liver disease in people with SMI
- compared with 67.5% in people without SMI
- The proportion of premature liver disease deaths due to ArLD in people with SMI prior to the pandemic was 71.6%

- 1,510 people with SMI died from accidental drug poisoning an increase of 22% Death by SUICIDE Increased

Premature mortality rate before and during the COVID-19 pandemic in people with SMI, by ethnicity

https://www.gov.uk/government/publications/premature-mortality-during-covid-19-in-adults-with-severe-mental-illness



Additional Psychological / psychiatric problems

- Dependency – alcohol, drugs
- Depression
- Anxiety
- Loss of status

- 6-7 fold higher premature mortality (< 75 years) from liver disease in people with severe mental illness
- Alcohol-related brain damage (~ 1in 8 young onset <65 years dementia is due to ARBD

Spiritual/religious need may be missed or misunderstood

- Visions, religious ideation may be part of condition
- Religion can be benign or harmful
- Spirituality can be very important at the end of life to affirm worth both personally and life
- Creativity can help to support spirituality

Place of death – inequalities for people with SMI

Ratio of percentage of deaths – SMI cohort to all deaths

Age	Sex	Hospital	Home	Care home	Hospice	Other places	% died in other place ?death by suicide
18-44	Male	0.78	1.17	1.48	0.61	1.08	25.4
45-54	Male	0.91	1.06	2.31	0.45	1.18	12.8
55-64	Male	1.02	0.89	2.59	0.52	1.22	
65-75	Male	1.11	0.51	3.25	0.49	0.76	
18-44	Female	0.77	1.32	0.75	0.39	1.43	15.9
45-54	Female	0.93	1.14	1.78	0.52	1.59	
55-64	Female	1.02	0.84	2.77	0.51	1.83	
65-75	Female	0.97	0.65	2.86	0.50	0.99	

Highlight indicates significant differences

McNamara, B., Same, A., Rosenwax, L. *et al.* Palliative care for people with schizophrenia: a qualitative study of an under-serviced group in need. *BMC Palliat Care* 17, 53 (2018). https://doi.org/10.1186/s12904-018-0309-1

- Individual/patient factors:
- Late presentation
- Interaction between SMI and physical disease especially drugs e.g. Clozapine
- Not recognising distress in people with SMI
- Fear, enhanced loss of self
- Problems processing complex information are increased – so much info
- Mental Capacity

- Social/ environmental factors:
- Social isolation and not used to social network
- Stigma
- Family estrangement leading to loss of advocates
- Homeless, hostel, living alone
- Hospital default place of care
- Healthcare staff not used to care for people with SMI
- Mental health staff not used to care for people with physical disease

McNamara, B., Same, A., Rosenwax, L. *et al.* Palliative care for people with schizophrenia: a qualitative study of an under-serviced group in need

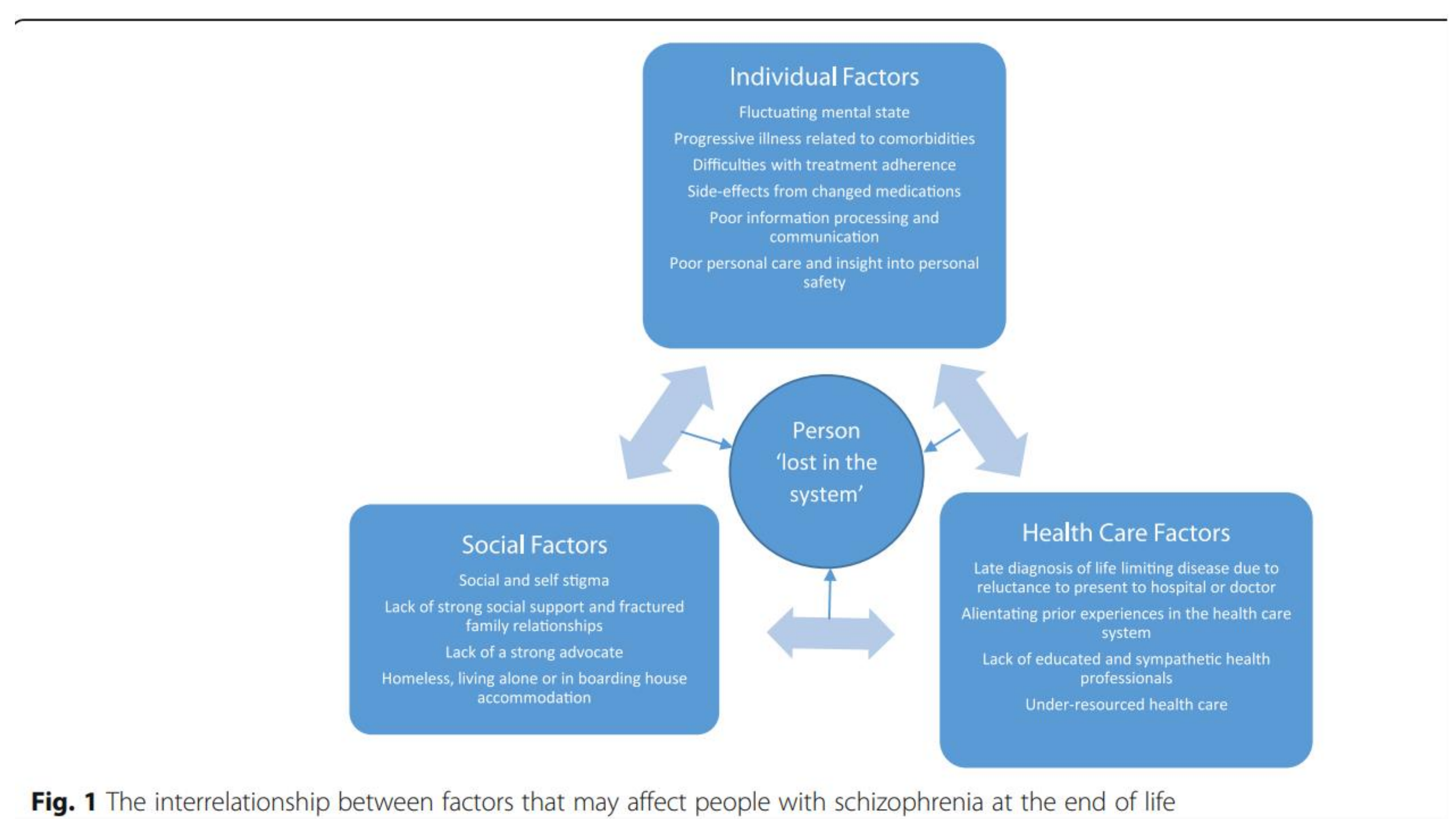


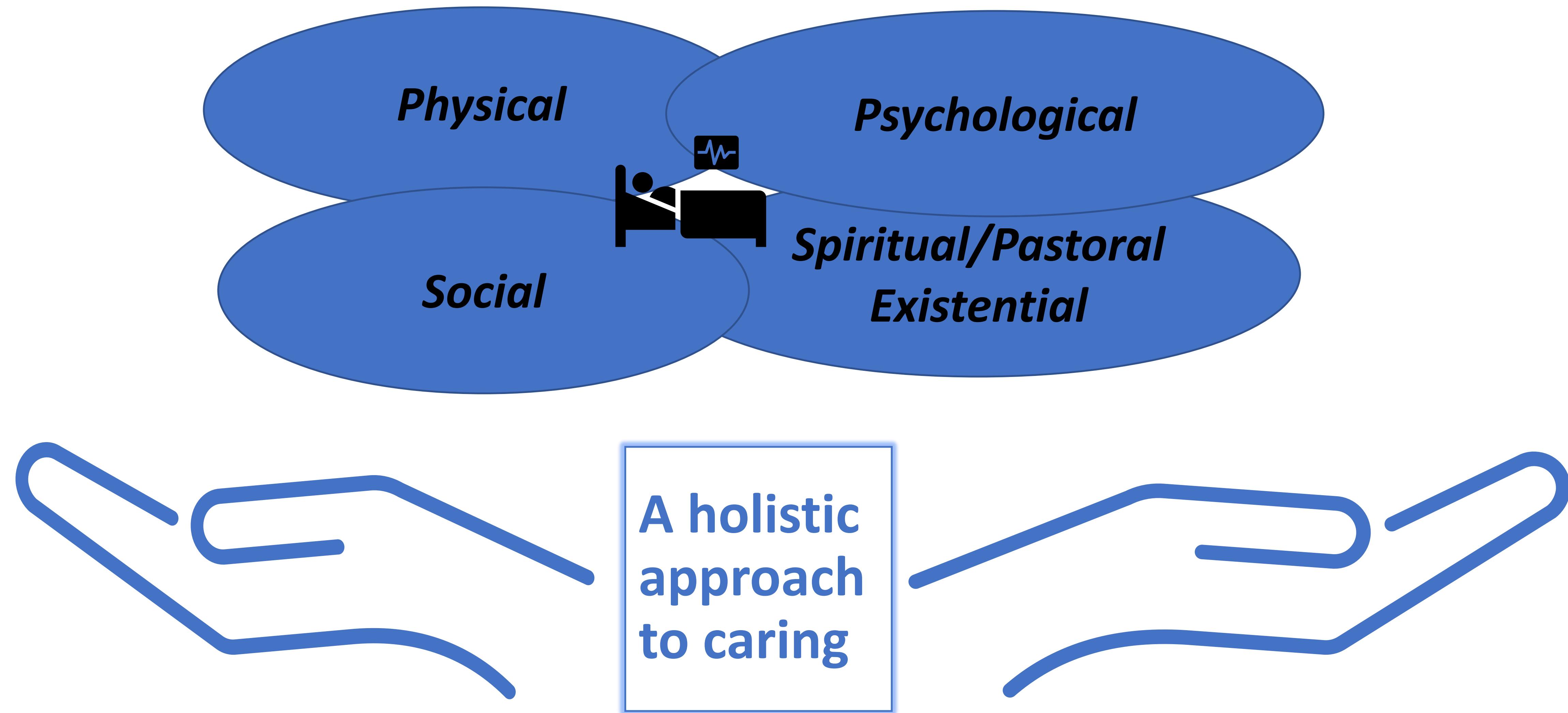
Fig. 1 The interrelationship between factors that may affect people with schizophrenia at the end of life

Social problems +++

- Loss of work and social status
- Poor accommodation
- Homelessness
- Loss of family support, Social Service involvement with children
- Interface with criminal justice system (victims and perpetrators)
- English not the first language – poor health/social services literacy
- Asylum seekers
- No recourse to public funds

Discussion of experience improving end of life support for vulnerable and marginalised groups

We propose that caring for the dying and those who love them is not simply about good medical care –
it is a wider governmental and societal/personal responsibility



Priorities?

- Address 'Anomie'
- Educate the population and encourage them to take control – family, friends, 'Compassionate Communities'
- Death literacy
- Educate Health and Social Care Professionals – not just the role of Palliative Care Specialists
- Ensure adequate social care staff
- Special support for the most vulnerable

What would you prioritise?

Evidence of a 'new spring' for End-of-Life Care

- Palliative care must become a civic responsibility and not just solely a professional one.

- The future is ripe for new partnerships and cooperation between local communities and the professional services that live and work among them.

- https://fingertips.phe.org.uk/profile/end-of-life

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