Equity in Access to Palliative Care

World Hospice and Palliative Care Day Special Lecture 2021

Project ECHO
Palliative Care - Canada
BY Pallium Canada

WORLD HOSPICE & PALLIATIVE CARE DAY

Presented by: Professor Irene J. Higginson, OBE
King's College London and Cicely Saunders Institute
Date: October 14th, 2021

Territorial Honouring

Agenda

Welcome
Christopher A. Klinger, PhD
Chair, End-of-Life Issues Theme Team, National Initiative for the Care of the Elderly (NICE)
Research Scientist, Pallium Canada

The Palliative Care ECHO Project
Jeffrey B. Moat, CM
CEO, Pallium Canada

Special Lecture
Professor Irene J. Higginson, OBE
King's College London and Cicely Saunders Institute

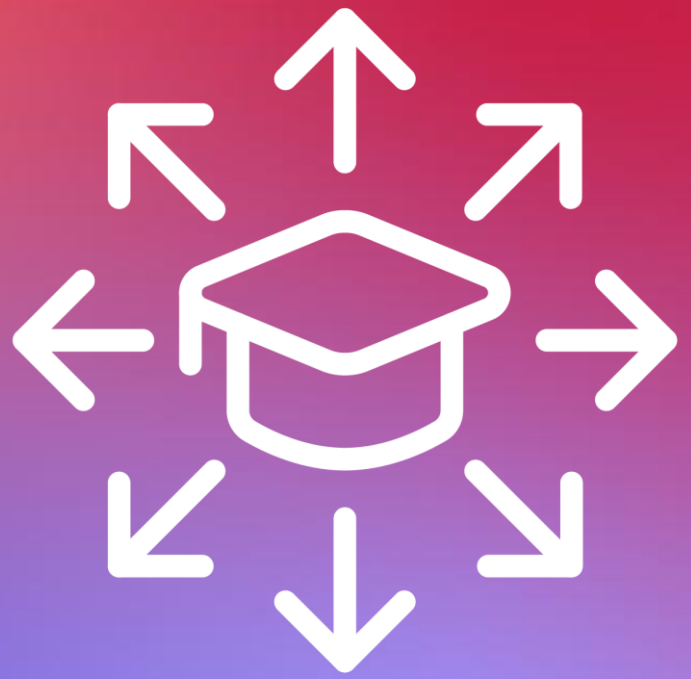
Question and Answer Session
Please click the Q&A icon and type your question(s) to the speakers there, we will try to get to as many of them as possible

Award Ceremony
Esme Fuller-Thomson
Director, Institute for Life Course and Aging, University of Toronto

Welcome and Reminders

- Please introduce yourself in the chat
- Your microphones are muted. There will be time during this session for questions and discussion. Please add your questions in the Q&A function
- Please use the chat function if you have any comments or are having technical difficulties.
- This session is being recorded and will be made available via *ehospice Canada*

The Palliative Care ECHO Project



About Project ECHO

- Project ECHO (Extension for Community Healthcare Outcomes) was developed in 2003 at the University of New Mexico
- Designed to create virtual communities of learners who are then able to provide better care to patients in their communities
- Uses videoconferencing technology and a “hub and spoke” education model to connect health care providers in communities (“spokes”) with teams of specialists and expert at regional and national centres (“hubs”)

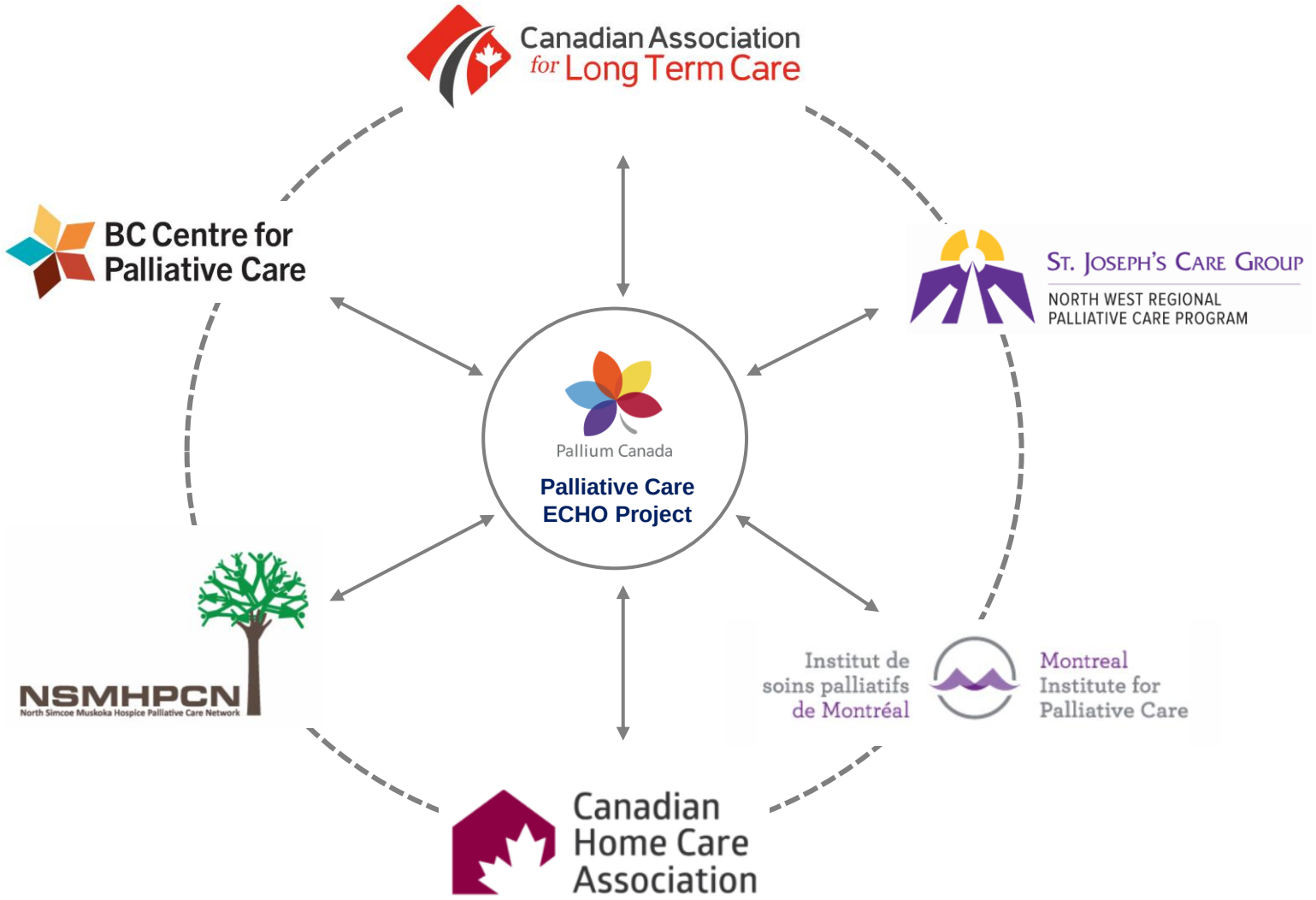
The Palliative Care ECHO Project

- 5-year national initiative, led by Pallium Canada and its Hub Partners from across Canada
- This project aims to cultivate communities of practice and establish continuous professional development among health care providers across Canada who care for patients with life-limiting illness

- The Palliative Care ECHO Project is supported by a financial contribution from Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.

Health Canada Santé Canada

Hub and Spoke Model



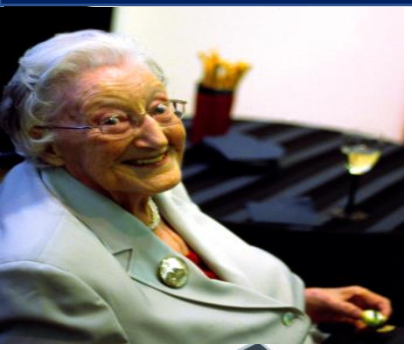
ECHO Programs

- Delivered through Pallium Canada & its hub partners
- Tailored to the needs of learners in the “spokes”
- Often include interactive, case-based discussions
- Cover a variety of topics:

Hub	Programs
Pallium Canada	Personal Support Workers COP, Palliative Heart COP, QI Collaborative, Long-Term Care COP etc.
BC Centre for Palliative Care	Pediatric Series, Psycho Social Series
North Simcoe Muskoka Hospice Palliative Care Network	Toolkit Series (e.g., the Surprise Question, ESAS etc.)
Canadian Home Care Association	Pain and Symptom Management at Home
Montreal Institute for Palliative Care	Interactive Family Caregiver Series
North West Regional Palliative Care Program	Palliative Care for Rural and Underserviced Communities

Equity in Access to Palliative Care

World Hospice and Palliative Care Day
Special Lecture



Cicely Saunders International
Better care at the end of life

Collaborating Centre for Palliative Care, Policy and Rehabilitation

KING'S College LONDON

Leave No-One Behind – Equitable access to Palliative Care for the 21st century

2021 World Hospice and Palliative Care Day Special Lecture

Irene J Higginson

Professor of Palliative Care & Policy

King's College London, Cicely Saunders Institute

@ij_higginson

www.kcl.ac.uk/cicelysaunders

Equitable access to palliative care for the 21st century

- Population, health & social care changes in the 21st century
- Key facts: palliative care in the early 21st century? What can palliative care offer?
- Reflections on equity in palliative care?
- Breathlessness – a neglected symptom – and some solutions..
- 7 point action plan for better palliative care

> ***You matter because you are you, and you matter to the end of your life.*** *We will do all we can not only to help you die peacefully, but also* ***to live until you die.****"*
>
> *Dame Cicely Saunders, founder of the modern hospice movement*

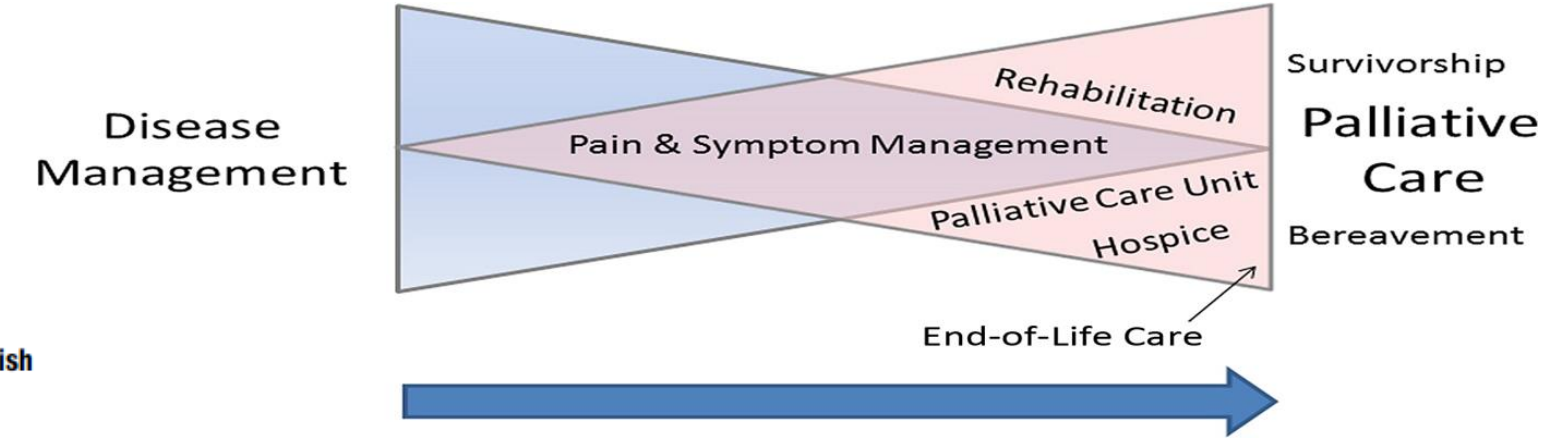
Modern Palliative care: 'Needs driven individualised care' – for those with life threatening, life limiting illness

Puts the person and those important to them before their disease.
The relief of suffering, with holistic and compassionate care is an essential component of care for those affected by life threatening illness.

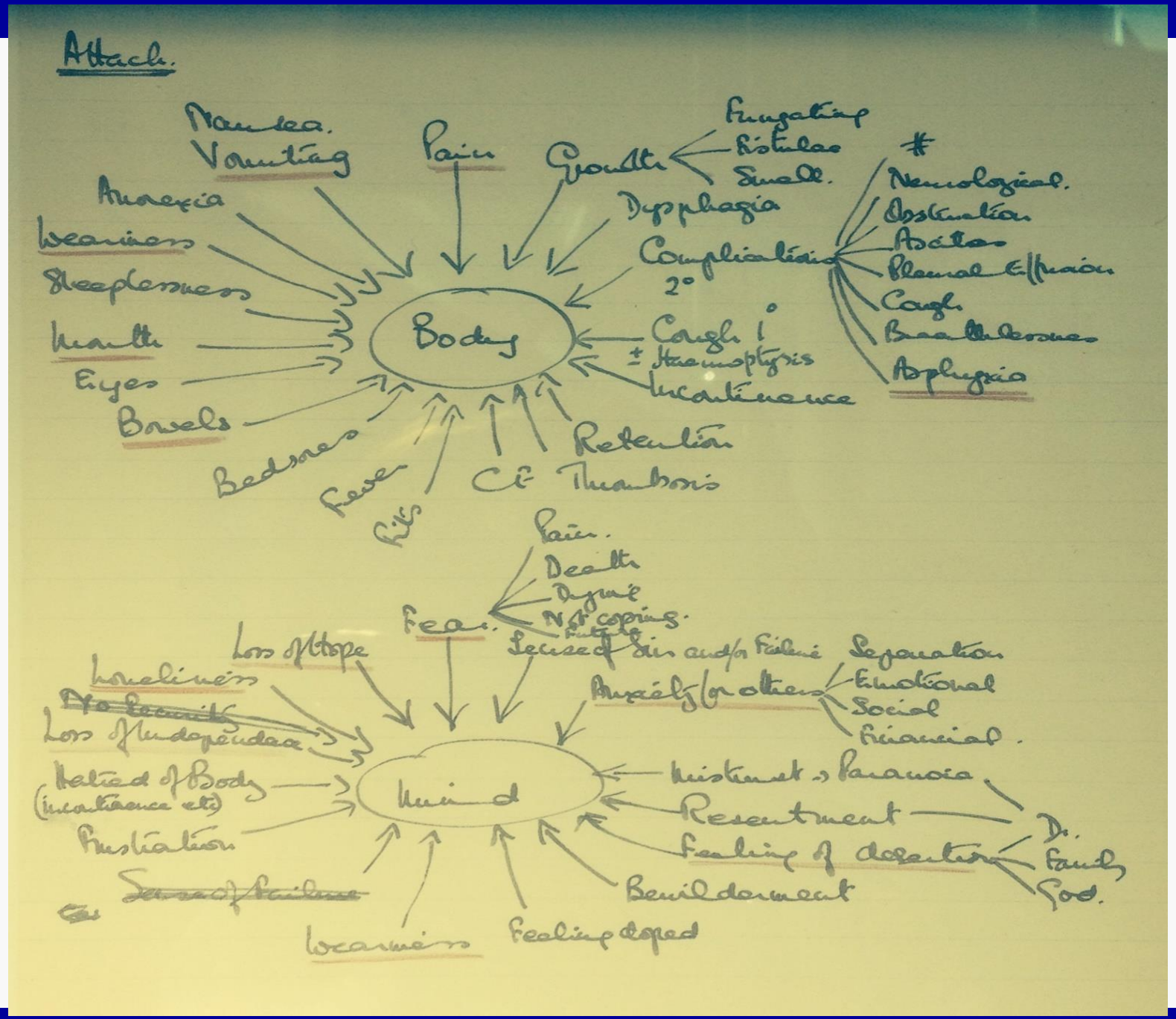
'We must somehow give everything we can to these people that says "you matter because you are you," everything to enable the patient to live up until he dies, and the family to go on living afterwards.'

Cicely Saunders 'A death in the family: a professional view' British Medical Journal, 6 January, 1973, p30–31.

Palliative care aims to add quality to remaining life. There is no evidence that it shortens life expectancy, if anything it's the opposite.



Hawley, P J Pain Symptom Manage. 2014 Jan;47(1):e2-5.

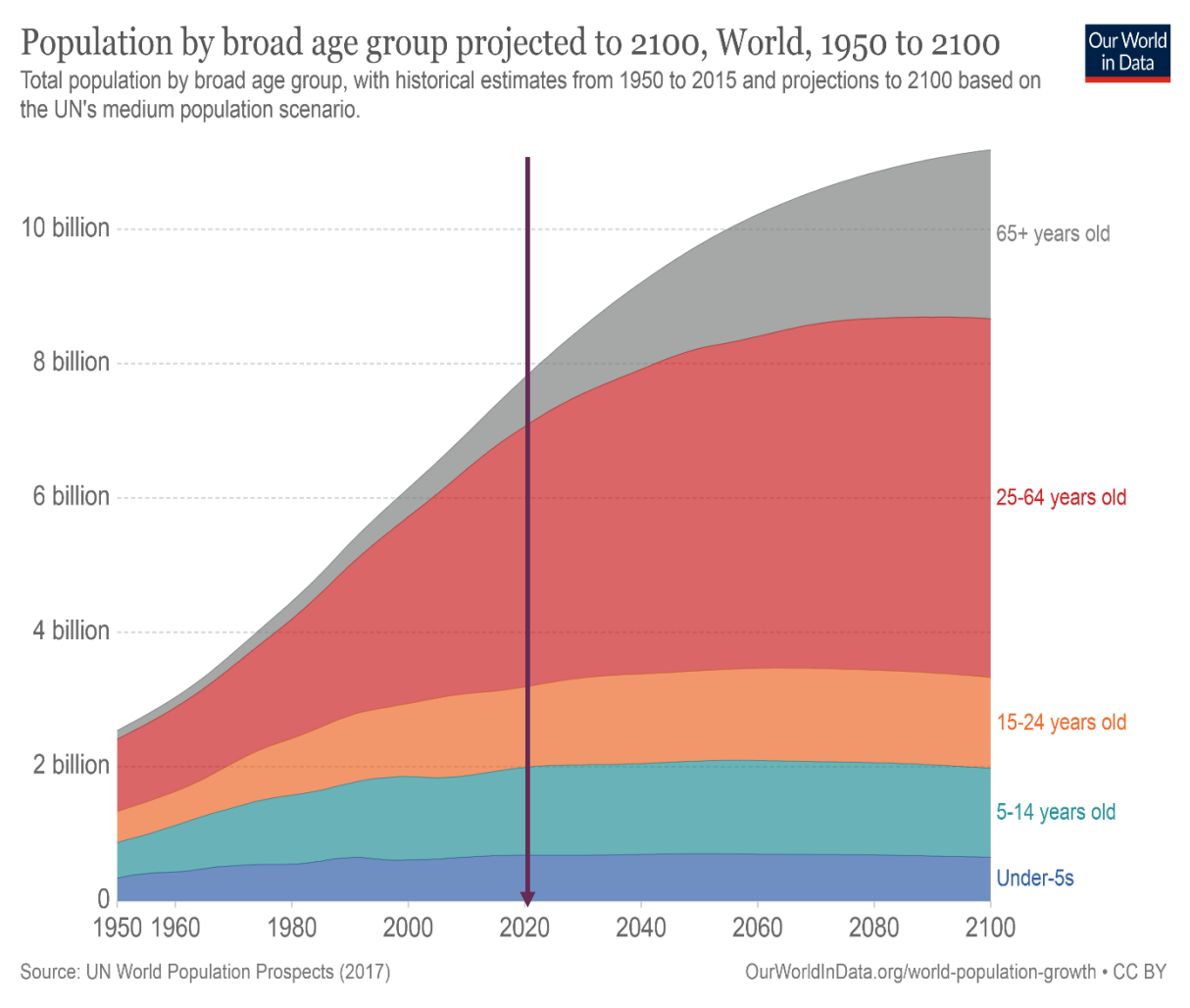


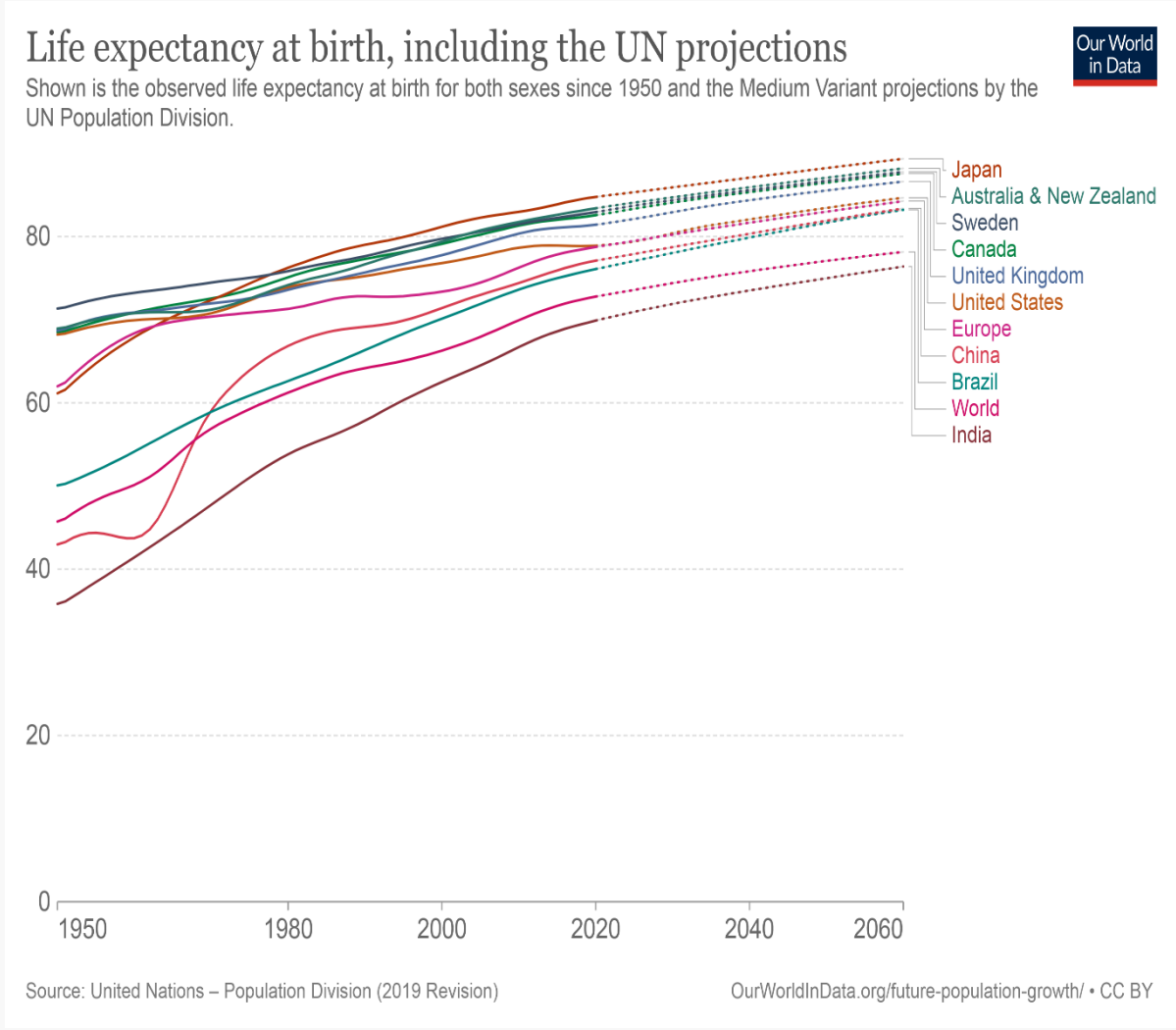
Cicely Saunders model of palliative care

science, plus caring…

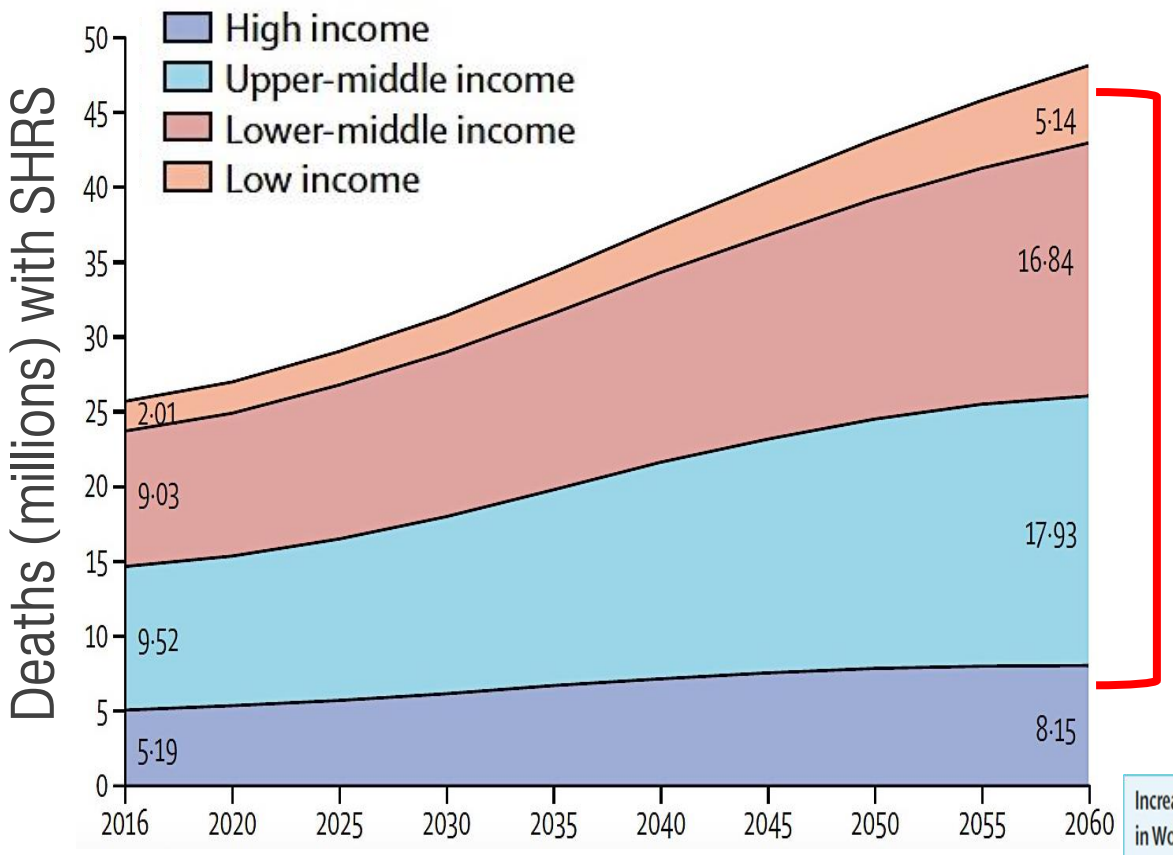
In science (research, education) & in care

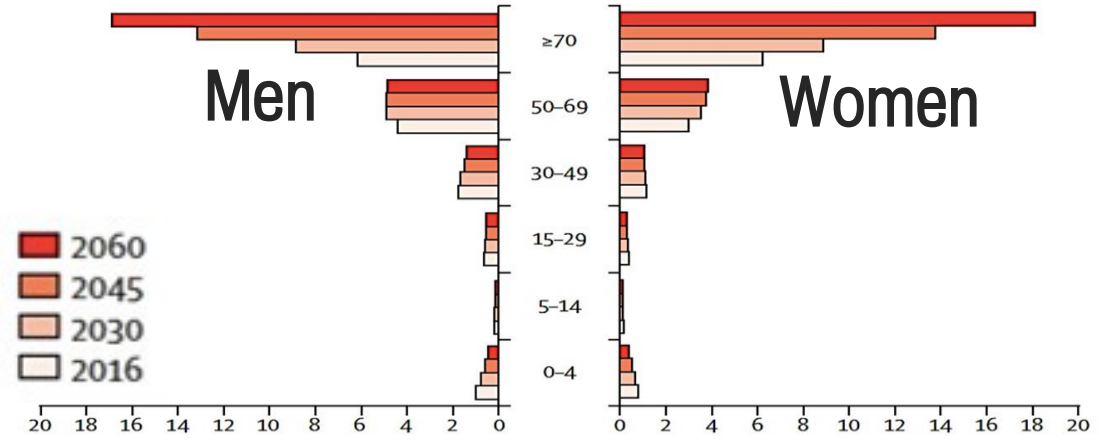
Palliative care context: central to 21st century, with growing populations, increased life expectancy

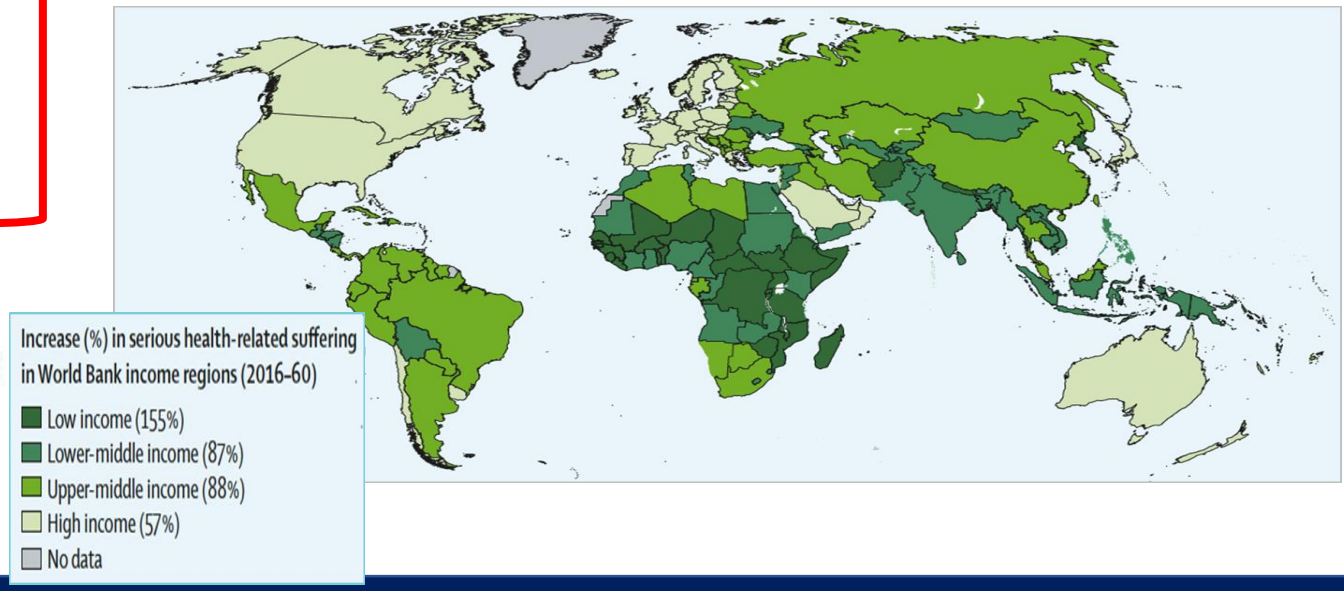




Back to Palliative Care: Needs (*as measured by Serious health-related suffering*) are projected to escalate, especially aged >70 years & in low-income countries







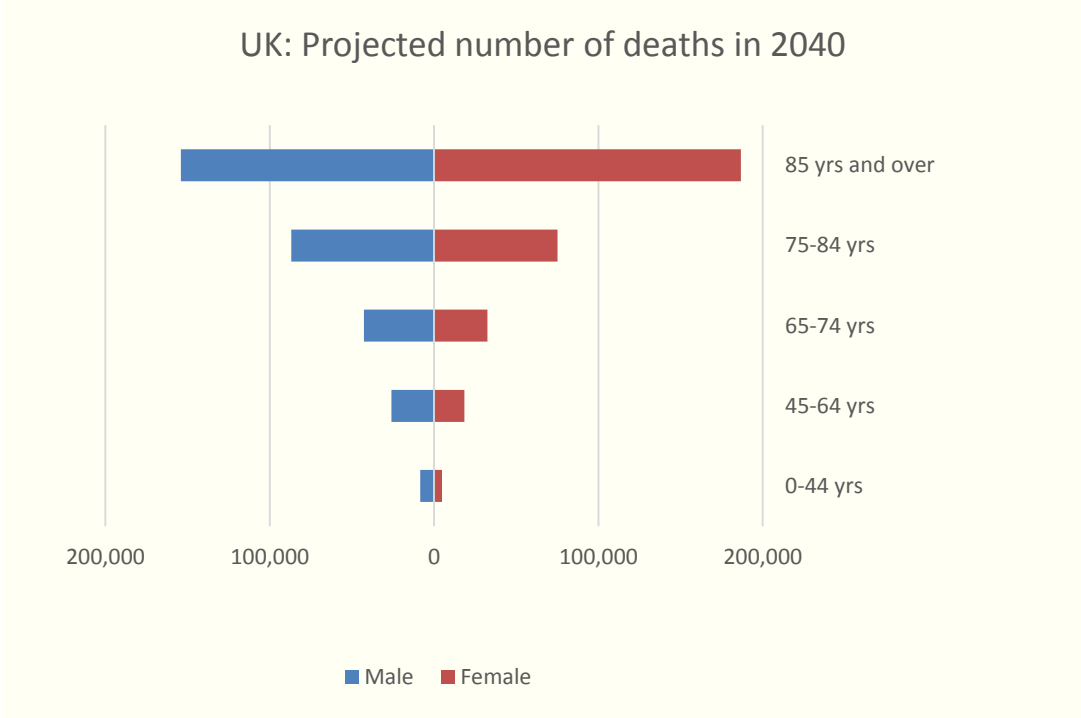
Sleeman et al, The Lancet Global Health 2019

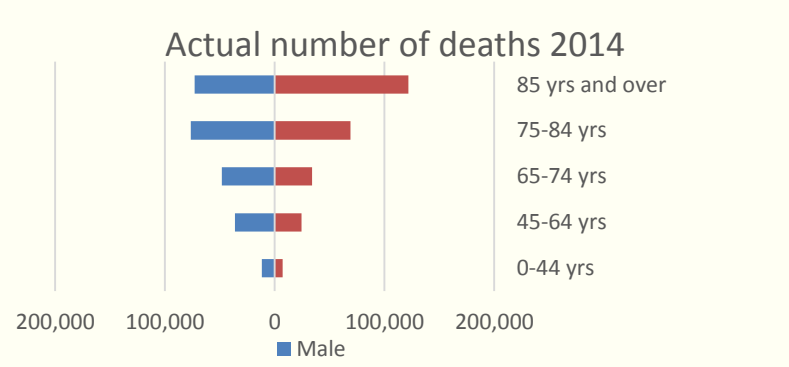
UK perspective - growing need for palliative care

- **20% of healthcare resources** spent in last year of life
- **80%+ deaths from chronic & progressive conditions** with complex comorbid needs
- **PEoLC is central** element of the NHS's responsibility
- **By 2040, 25% increase in annual deaths, most over 85 years &**
- **>42% increase with people needing palliative care**

Yet:

- Care quality at end of life often not optimal
- NHS budgets increasingly constrained
- Palliative care improves quality **without** increasing costs to NHS or society, and possibly saving money



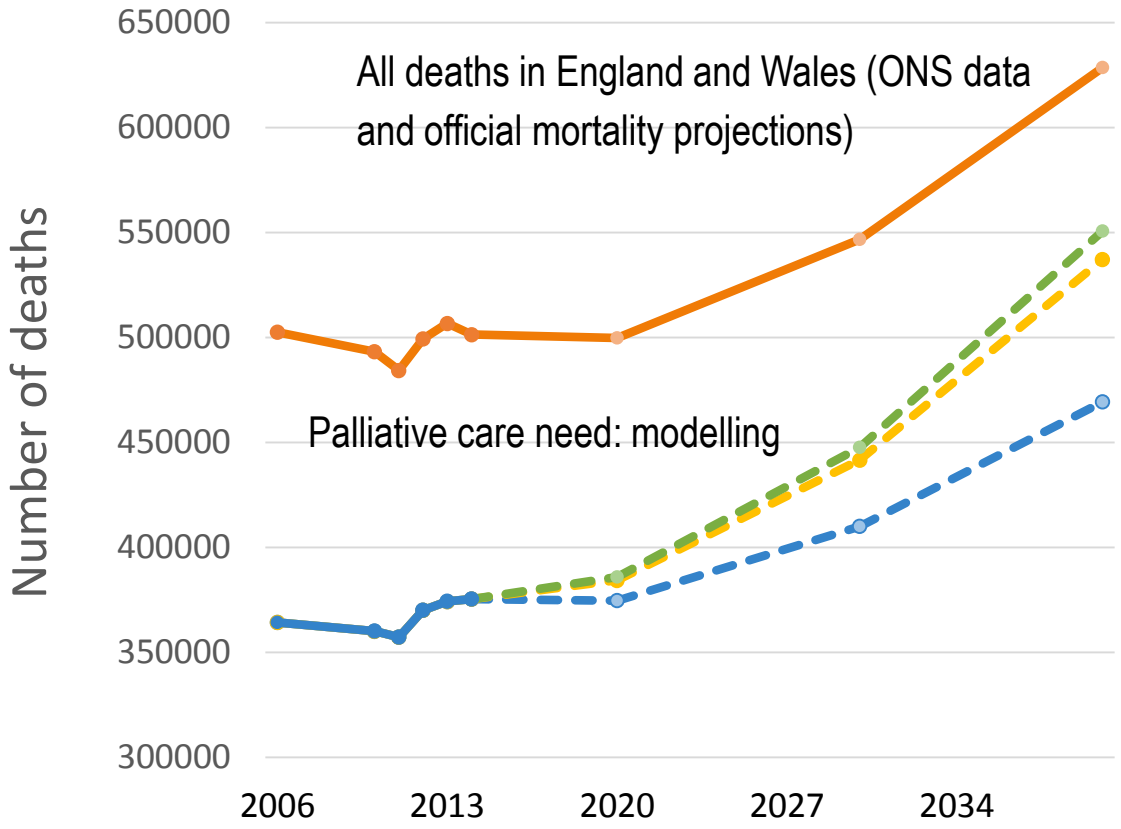


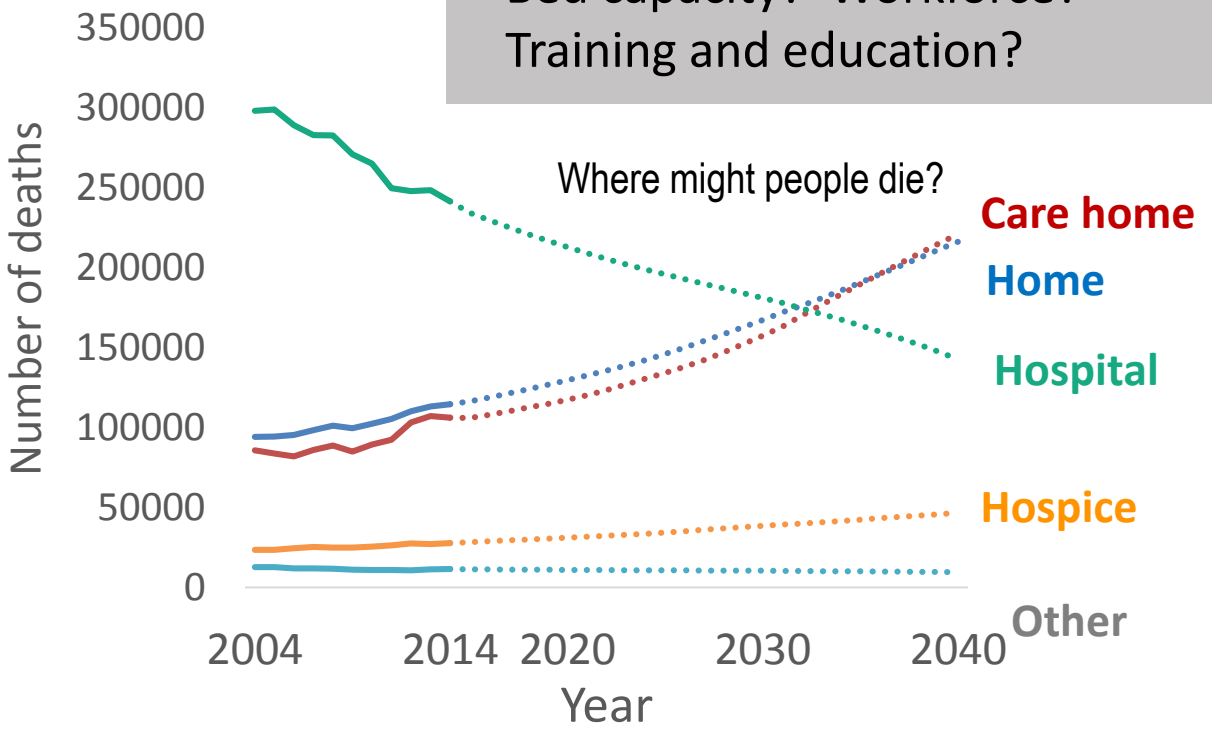
Source: Bone et al Palliat Med. 2018;32(2):329-336.

UK perspective – Projections: numbers & where will people be cared for ?

If trends continue (which they may not) 235,000 more deaths in community?

Bed capacity? Workforce?
Training and education?





Sources: Etkind et al. BMC Medicine (2017) 15:102

Bone et al Palliat Med. 2017 Oct 1:269216317734435.

The future of health and social care?

- Paradox: increased specialisation for increased multimorbidity..
- Rising challenges to healthcare safety due to complexity, communication
- What workforce for direct care
- Role of robotics, AI, computerised therapies?
- Role of different professionals, what will we need?
- Growth in empowerment, awareness for some communities

Palliative care – important in all care settings, many clinicians practice palliative care for some, plus specialist teams

- Multiprofessional teams of dedicated staff trained in palliative care, doctors, nurses, and often social workers and therapists
- Provide expertise in pain and symptom management, holistic and psychosocial care, decision making, advance care planning, end of life care and often bereavement support
- Include support in the multiple settings – support patient where they need to be cared for (one service may provide support several settings):
    1. Inpatient palliative care unit – ward within hospital, or free standing hospice
    2. Hospital palliative care team
    3. Home palliative care team
    4. Home nursing

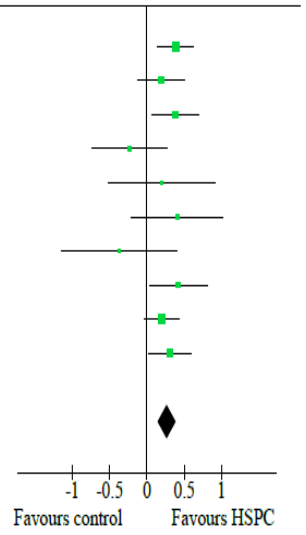
Consistence evidence in favour of palliative care on improving quality of life, symptoms, people being cared for where they wish

Hospital based palliative care teams

Analysis 1.1. Comparison 1: Patient health-related quality of life, Outcome 1: HSPC versus usual care on patient HRQoL: adjusted endpoint values

Study or Subgroup	HSPC Mean	HSPC SD	HSPC Total	Control Mean	Control SD	Control Total	Weight	Std. Mean Difference IV, Random, 95% CI
Bakitas 2009	141.27	26.25	145	131.14	26.62	134	20.3%	0.38 [0.15 , 0.62]
Bakitas 2015	129.9	14.04	72	127.2	14.2	83	11.7%	0.19 [-0.13 , 0.51]
El-Jawahri 2016	94.33	20.31	80	86.6	20.27	77	11.8%	0.38 [0.06 , 0.69]
McCorkle 2015	78.33	12.47	25	81.34	12.81	39	4.7%	-0.23 [-0.74 , 0.27]
O'Riordan 2019	-40	26.24	16	-45.4	26.83	14	2.3%	0.20 [-0.52 , 0.92]
Rodin 2019	114.37	32.69	22	100.61	33.54	20	3.2%	0.41 [-0.20 , 1.02]
Tattersall 2014	4.8	0.83	13	5.1	0.72	13	2.0%	-0.37 [-1.15 , 0.40]
Temel 2010	98	15.1	60	91.5	15.8	47	8.0%	0.42 [0.03 , 0.80]
Temel 2017	80.1	12.12	145	77.7	12.08	153	21.9%	0.20 [-0.03 , 0.43]
Vanbutsele 2018	61.98	23.95	92	54.39	25.19	94	14.0%	0.31 [0.02 , 0.60]
Total (95% CI)			670			674	100.0%	**0.26 [0.15 , 0.37]**

Heterogeneity: Tau² = 0.00; Chi² = 9.30, df = 9 (P = 0.41); I² = 3%
Test for overall effect: Z = 4.67 (P < 0.00001)
Test for subgroup differences: Not applicable

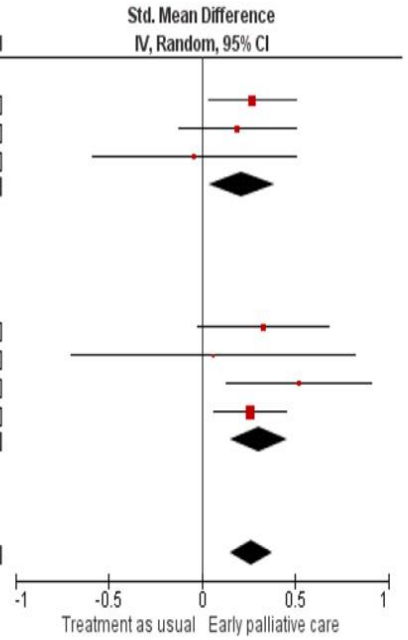


Bajwah S, et al Cochrane Database Syst Rev. 2020 Sep 30;9.

Early palliative care in cancer

Figure 4. Forest plot of comparison: 1 Health-related quality of life, outcome: 1.1 Health-related quality of life.

Study or Subgroup	Std. Mean Difference	SE	EPC Total	TAU Total	Weight	Std. Mean Difference IV, Random, 95% CI
1.1.1 Co-ordinated care model						
Bakitas 2009	0.27	0.12	145	134	24.5%	0.27 [0.03, 0.51]
Bakitas 2015	0.19	0.16	72	83	13.8%	0.19 [-0.12, 0.50]
McCorkle 2015	-0.04	0.28	23	28	4.5%	-0.04 [-0.59, 0.51]
Subtotal (95% CI)			240	245	42.7%	**0.21 [0.03, 0.39]**
Heterogeneity: Tau² = 0.00; Chi² = 1.06, df = 2 (P = 0.59); I² = 0%						
Test for overall effect: Z = 2.33 (P = 0.02)						
1.1.2 Integrated care model						
Maltoni 2016	0.33	0.18	64	65	10.9%	0.33 [-0.02, 0.68]
Tattersall 2014	0.06	0.39	13	13	2.3%	0.06 [-0.70, 0.82]
Temel 2010	0.52	0.2	60	47	8.8%	0.52 [0.13, 0.91]
Zimmermann 2014	0.26	0.1	140	141	35.2%	0.26 [0.06, 0.46]
Subtotal (95% CI)			277	266	57.3%	**0.31 [0.15, 0.46]**
Heterogeneity: Tau² = 0.00; Chi² = 1.77, df = 3 (P = 0.62); I² = 0%						
Test for overall effect: Z = 3.89 (P = 0.0001)						
Total (95% CI)			517	511	100.0%	**0.27 [0.15, 0.38]**
Heterogeneity: Tau² = 0.00; Chi² = 3.44, df = 6 (P = 0.75); I² = 0%						
Test for overall effect: Z = 4.47 (P < 0.00001)						
Test for subgroup differences: Chi² = 0.61, df = 1 (P = 0.44), I² = 0%						



Haun MW, et al Cochrane Database Syst Rev. 2017 Jun 12;6:

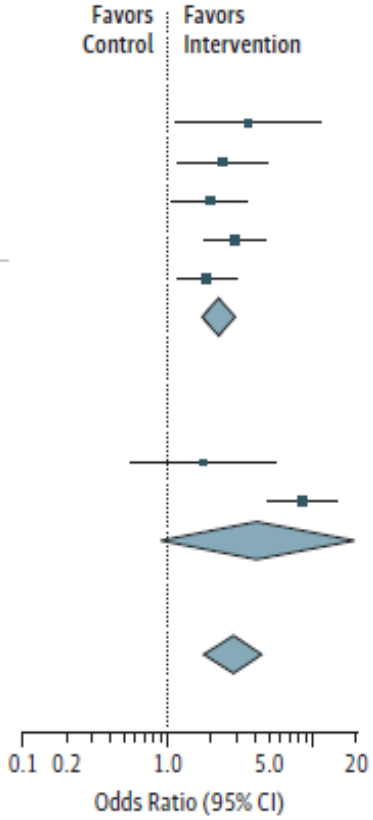
Does palliative care affect whether death is at home, across diseases? – YES more likely

- OR 2.21 (95%IC 1.31 to 3.71) home death compared with conventional care

- Meta-analysis 7 trials,
- 1222 patients, majority cancer

Figure. Odds of Dying at Home With Home Palliative Care Compared With Usual Care

Study or Subgroup	Home Palliative Care: No. of Events	Home Palliative Care: Total No. of Patients	Usual Care (Control): No. of Events	Usual Care (Control): Total No. of Patients	Odds Ratio (95% CI)
Randomized Clinical Trials					
Zimmer, 1985	20	28	7	15	2.86 (0.78-10.53)
Jordhøy, 2000	22	90	11	73	1.82 (0.82-4.06)
Grande, 1999	124	186	25	43	1.44 (0.73-2.84)
Brumley, 2007	81	117	54	108	2.25 (1.31-3.88)
Bakitas, 2009	69	111	63	115	1.36 (0.80-2.31)
Subtotal (95% CI)	316	532	160	354	1.73 (1.28-2.33)
Heterogeneity: I^2 = 0.0%					
Test for overall effect: P = .0003					
Controlled Clinical Trials					
Axelsson, 1998	13	41	4	15	1.28 (0.34-4.78)
Ahlner-Elmqvist, 2008	53	117	16	163	7.61 (4.05-14.31)
Subtotal (95% CI)	66	158	20	178	3.44 (0.60-19.57)
Heterogeneity: I^2 = 83%					
Test for overall effect: P = .16					
Total (95% CI)	382	690	180	532	2.21 (1.31-3.71)
Heterogeneity: I^2 = 71%					
Test for overall effect: P = .003					



Gomes et al. Cochrane data base of reviews, 2013 Jun 6;6:CD007760.

Effect of palliative care on health and social care costs…

- In hospital cost savings greater with earlier referral after admission to hospital (prospective cohort study with propensity matching, US data)
- *May P et al J Clin Oncol. 2015 Sep 1;33(25):2745-52.*

Table 3. Estimated Treatment Effect on Total Cost, by Time to Consult

Treatment: Time of Consultation After Hospital Admission (percentile)	No. of Patients			Estimated Treatment Effect ($) (95% CI)	*P*	Implied Saving (%)*
	UC	PC	All			
Any time (100th)	713	256	969	153 (−1,266 to 1,572)	.83	−2
Within 20 days (97.5th)	713	249	962	−706 (−2,007 to 596)	.29	7
Within 10 days (95th)	713	244	957	−927 (−2,283 to 429)	.18	10
Within 6 days (90th)	713	231	944	−1,312 (−2,568 to −56)	.04	14
Within 2 days (75th)	713	197	910	−2,280 (−3,438 to −1,122)	< .01	24

Abbreviations: PC, palliative care; UC, usual care.
*Implied saving in total cost of hospital stay from receiving treatment compared with receiving UC only.

Multimorbidity: is increasing over time (irrespective of age), by age, and is higher in those who are deprived

Co-morbidities in deprived (dark blue circles) are more common than in affluent populations

Source: Barnett et al, Lancet 2012; 380: 37-43

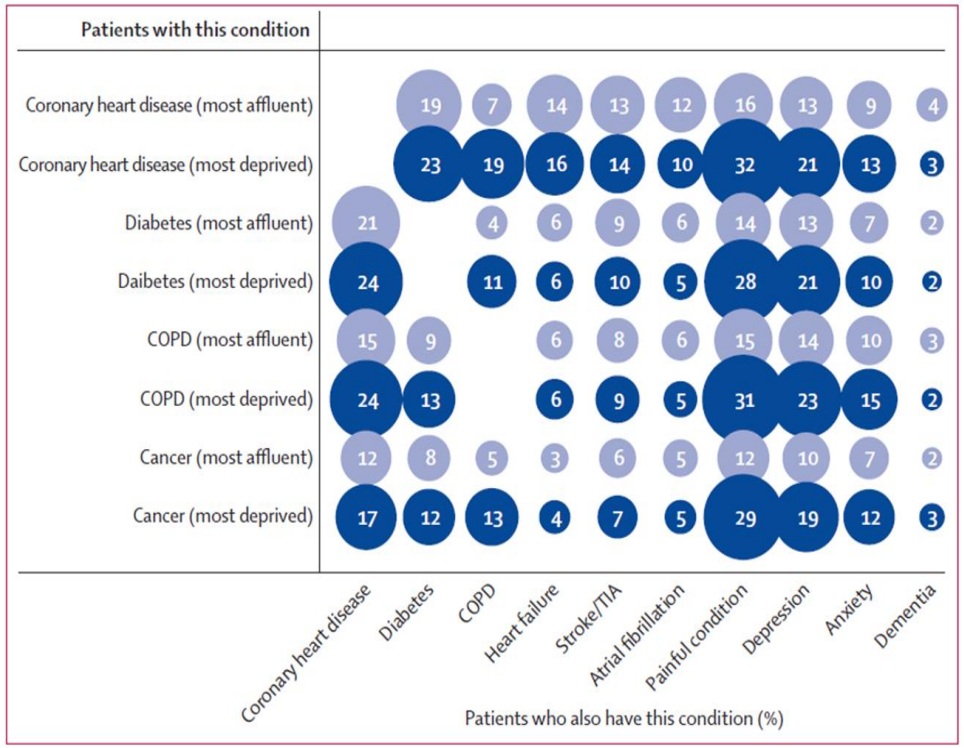


Figure 4: Selected comorbidities in people with four common, important disorders in the most affluent and most deprived deciles
COPD=chronic obstructive pulmonary disease. TIA=transient ischaemic attack.

Multimorbidity: a priority for global health research

April 2018

The Academy of Medical Sciences

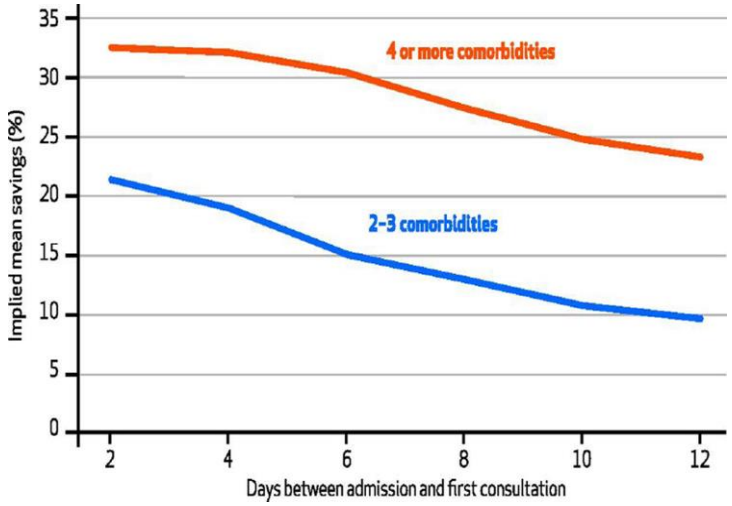
Research priority 6: How can healthcare systems be better organised to maximise the benefits and limit the risks for patients with multimorbidity?

It was noted throughout our evidence gathering that, when exploring models of care for multimorbidity, there may be opportunities to take guidance from fields such as geriatric and palliative medicine where multimorbidity is largely the norm.

Cost savings greater when patients have multimorbidity..

Receipt of a palliative care within two days of admission associated with:
22 percent lower costs, comorbidity score of 2–3; 32 percent lower costs for those with a score of 4 or higher

May P et al, Health Aff (Millwood). 2016 Jan;35(1):44-53.



Economics of Palliative Care for Hospitalized Adults With Serious Illness
A Meta-analysis

JAMA Intern Med. doi:10.1001/jamainternmed.2018.0750
Published online April 30, 2018.

Peter May, PhD; Charles Normand, DPhil; J. Brian Cassel, PhD; Egidio Del Fabbro, MD; Robert L. Fine, MD; Reagan Menz; Corey A. Morrison; Joan D. Penrod, PhD; Chessie Robinson, MA; R. Sean Morrison, MD

Table 3. Subsample Analyses: Pooled ATETs by Total Elixhauser Index at Admission[a]

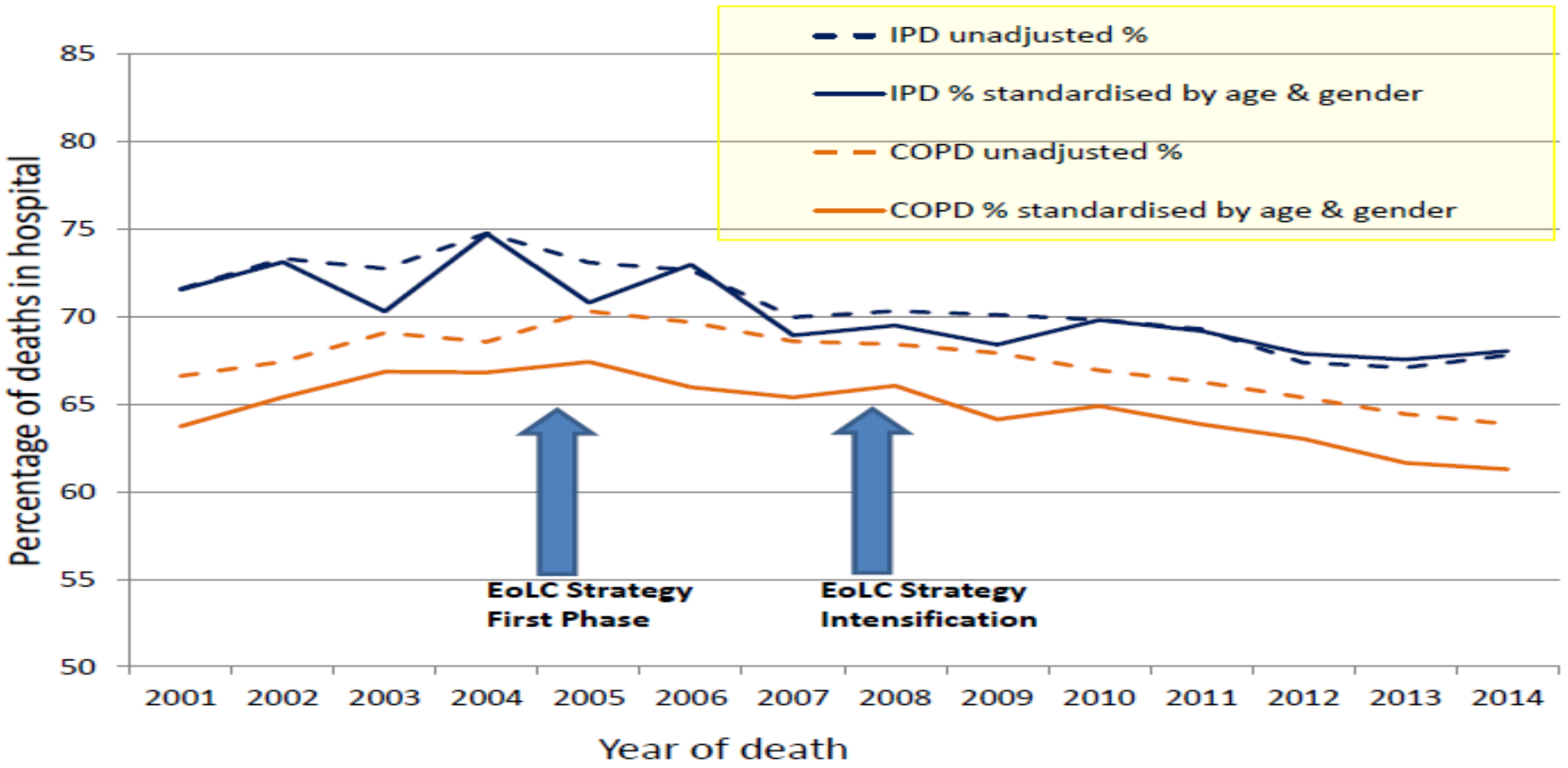
Diagnosis Group, Elixhauser Index	Pooled Sample Size: UC Group (n = 121 943)	PC Group (n = 4580)[b]	All (N = 126 523)	Pooled Estimated ATET, $ (95% CI)
All				
≤1	34 755	1028	35 783	−2041 (−2425 to −1658)
2	28 697	968	29 665	−2524 (−3186 to −1862)
3	24 983	950	25 933	−3745 (−4401 to −3089)
≥4	33 508	1634	35 142	−4865 (−5553 to −4177)

So what next:

- Ensure palliative care **expertise** is fully available in all settings
  - Tackle inequity
  - Care available 24/7, competent, evidence based,
  - Better integration and co-ordination
  - Treatments, therapies & care improved through research

Does multimorbity matter? Trends of where people die as the UK End of Life Strategy was introduced

England 2001-14, respiratory disease, n=380,232 (COPD (334,520), IPD (45,712))

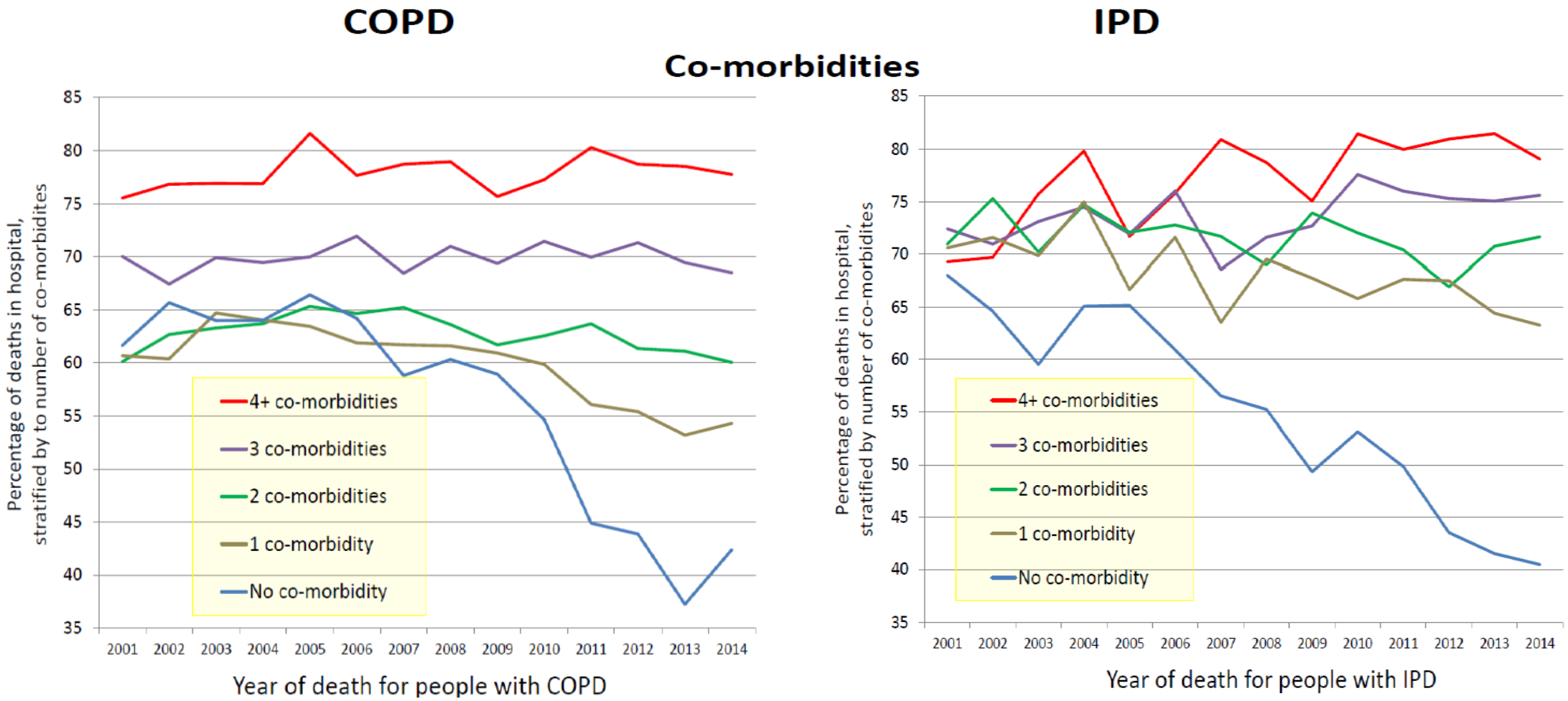


Source: Higginson et al BMC Med. 2017 Feb 1;15(1):19.

Multimorbidity affects how and where people die –

UK EoLC Strategy affected those people without co-morbidities, no change for those with ≥ 2

England 2001-14, respiratory disease, n=380,232 (COPD (334,520), IPD (45,712))



Source: Higginson et al BMC Med. 2017 Feb 1;15(1):19.

Inequity: Where you live and who you are affects whether and how you gain access to hospices

Original Article

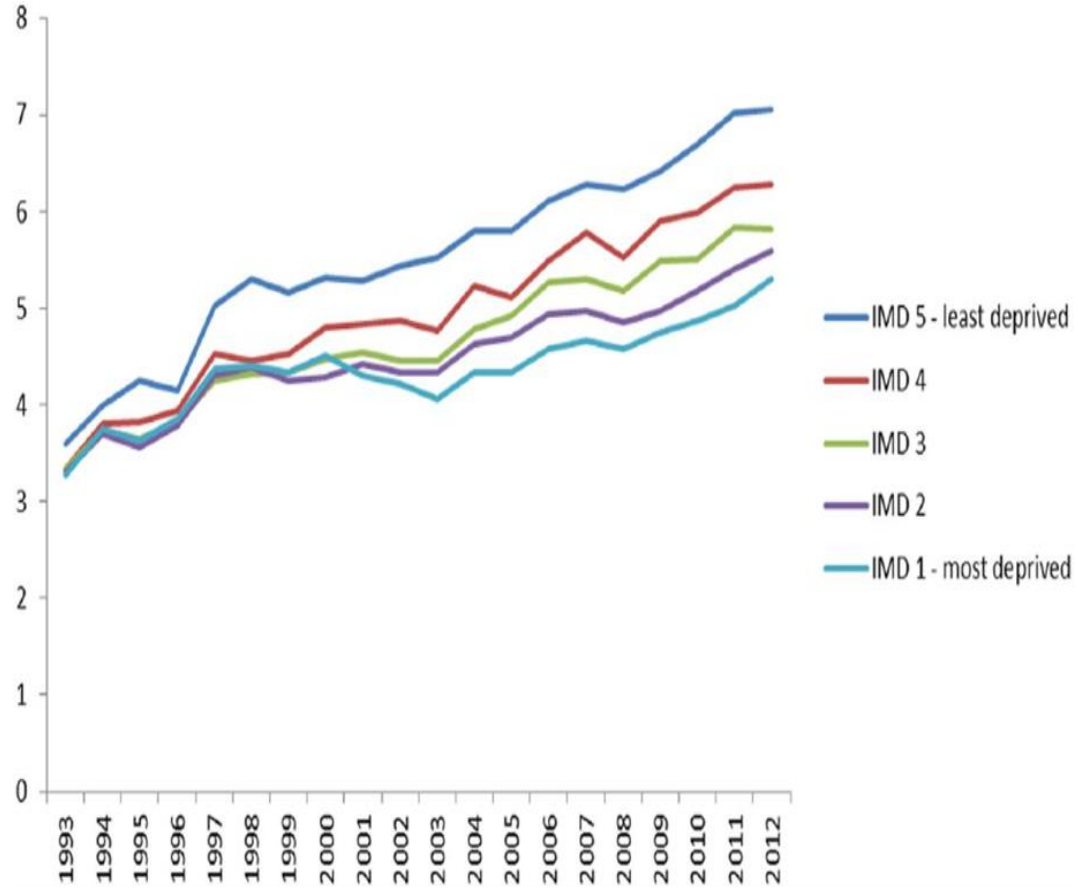
PALLIATIVE MEDICINE

The changing demographics of inpatient hospice death: Population-based cross-sectional study in England, 1993–2012

Palliative Medicine
1–9

DOI: 10.1177/0269216315585064
pmj.sagepub.com
SAGE

Katherine E Sleeman[1], Joanna M Davies[1], Julia Verne[2], Wei Gao[1] and Irene J Higginson[1]



Katherine E Sleeman et al. Palliat Med 2015;0269216315585064

OPEN ACCESS Freely available online

PLOS ONE

Does Ethnicity Affect Where People with Cancer Die? A Population-Based 10 Year Study

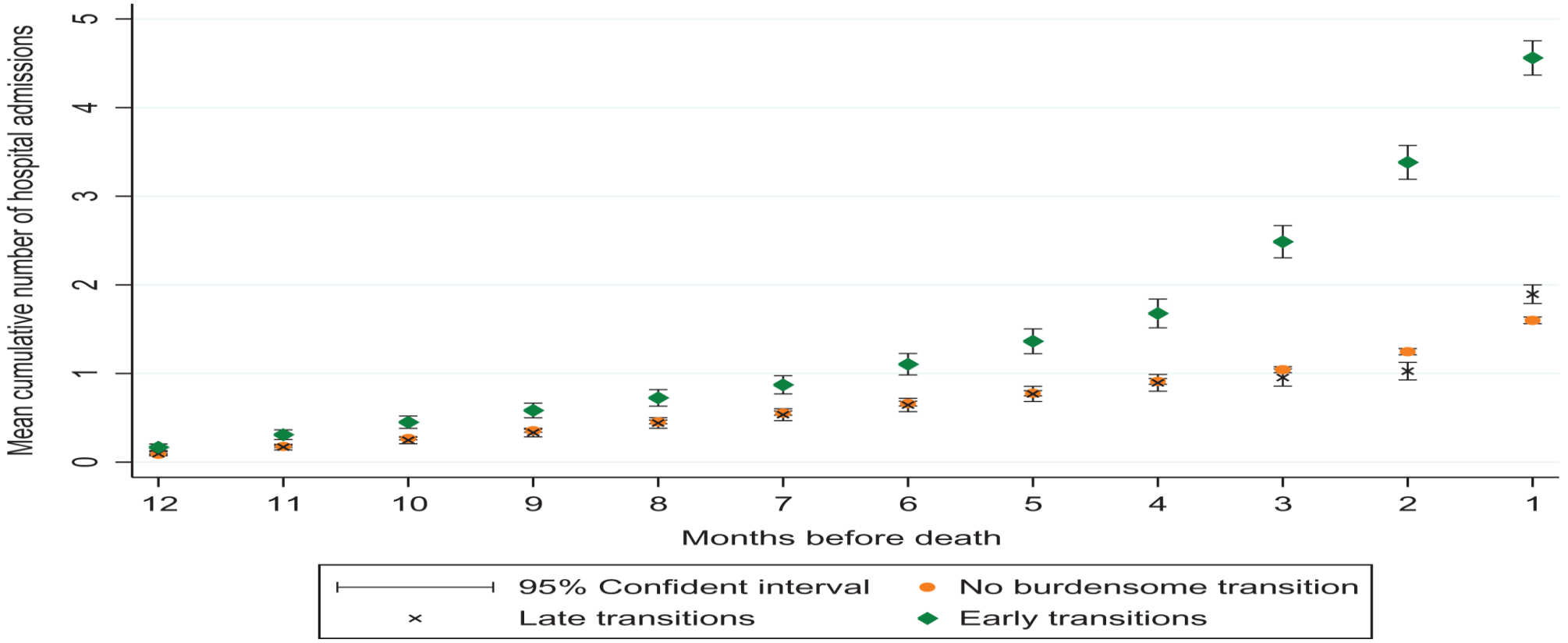
Jonathan Koffman*, Yuen King Ho, Joanna Davies, Wei Gao, Irene J. Higginson

King's College London, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation, London, United Kingdom

Neglected populations, emergency use ..

People with dementia, Emergency Department use increases towards the end of life

Fig. Mean of the cumulative number of hospital admissions in the last year of life



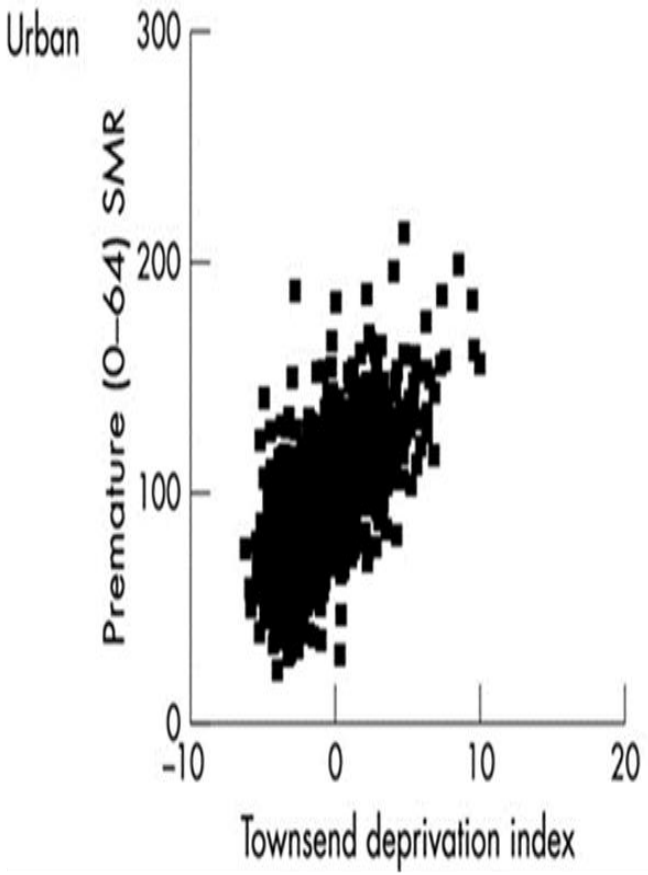
Source: Leniz, Higginson, Stewart and Sleeman, *Age and Ageing* 2019

Inequalities and injustice in palliative care: a hypothesis of catalytic interactions

1. Two strands of inequalities in palliative care
   - Those that **pervade across health and social care** and society, existing also in palliative and end of life care
   - Those **specific** to palliative and end of life care, due to its nature
2. These seemingly *small things* when together are **reciprocal catalysts**
3. *Whole greater than the sum of the parts*..
4. 'Accelerates' systemic injustices..

1. Pervade… Socio-economic status – and many other characteristics

Interested in inequalities, I wondered .. *was variation by socioeconomic status also present in palliative care?* ..e.g. where people died



H Jordan et al. J Epidemiol Community Health 2004;58:250-257

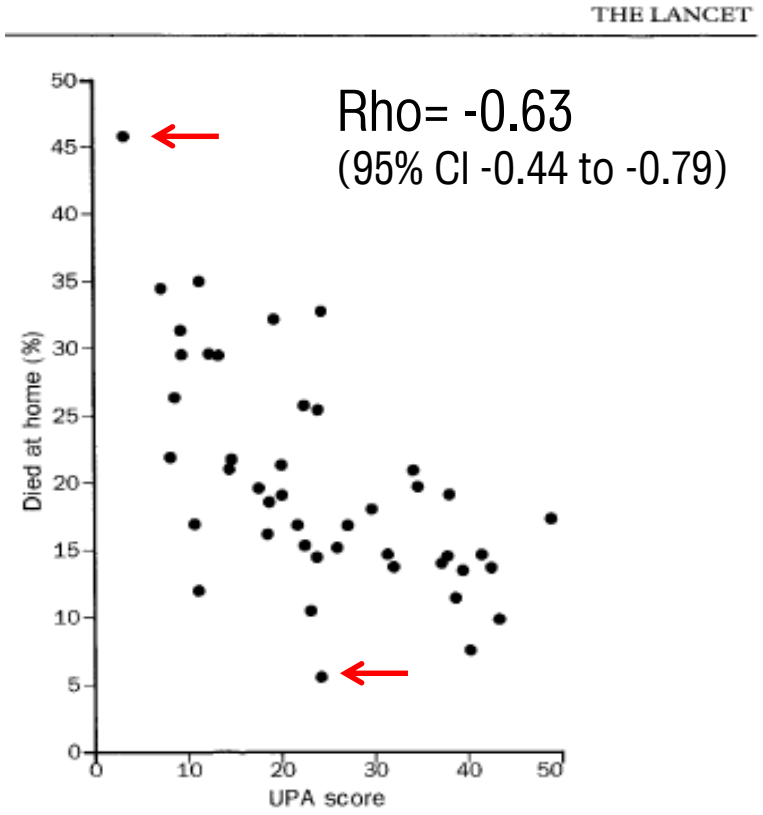


Figure: **Percentage of people who died at home from cancer versus underprivileged area score (UPA) in 44 electoral wards in central and north-west London**
Spearman's *r* –0·63 (95% CI –0·44 to –0·79).

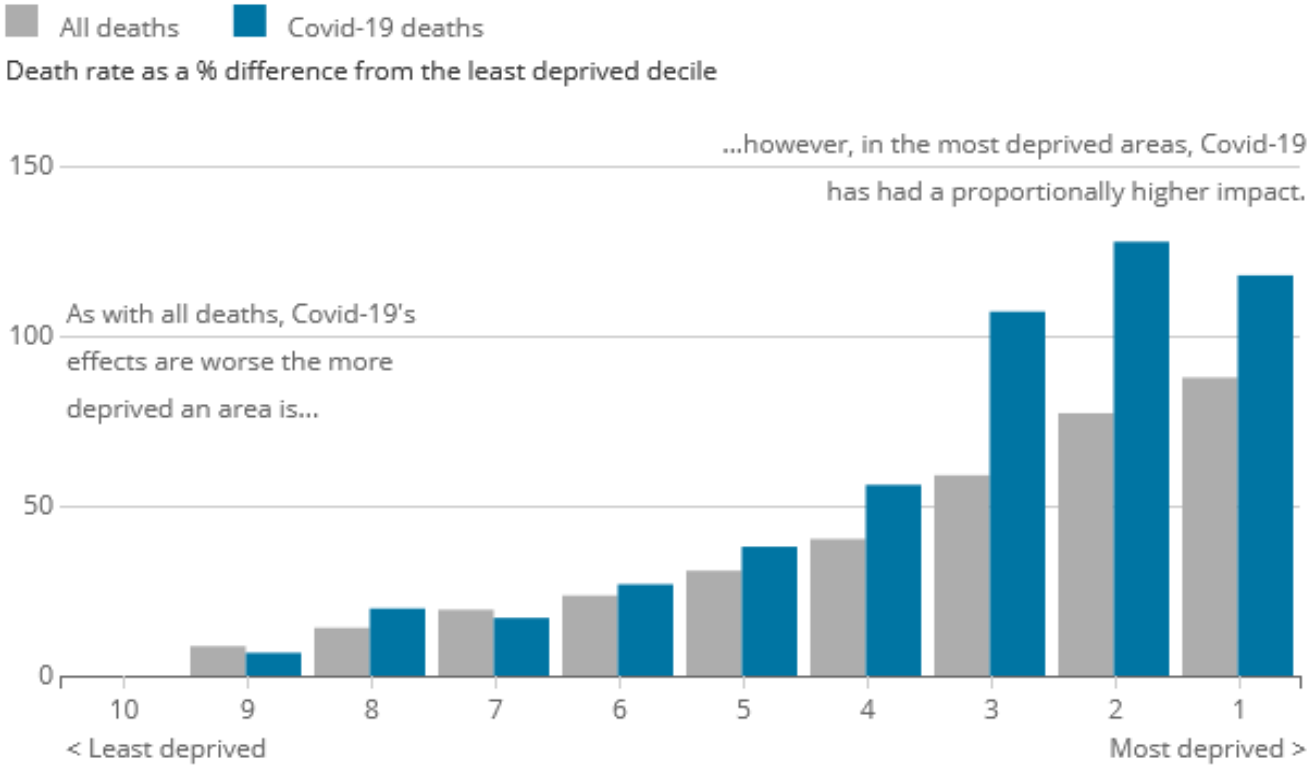
Higginson et al, Lancet 1994 Aug 6;344(8919):409.

- 44 'electoral' wards
- Proportion of home deaths (over 5 years)
- In one ward 5% died at home
- In another 46% died at home
- Deprivation (as assessed by underprivileged area score – a index of 8 aspects of affluence or not) was inversely correlated with home death proportions

Pervade: *Socioeconomic status*.. Similar findings in Genoa, Italy, but using unemployment levels.. … The disparity continues..

Costantini M, Fusco F, Bruzzi P (1996) *Informatore Medico Oncologico* **5**: 21-24

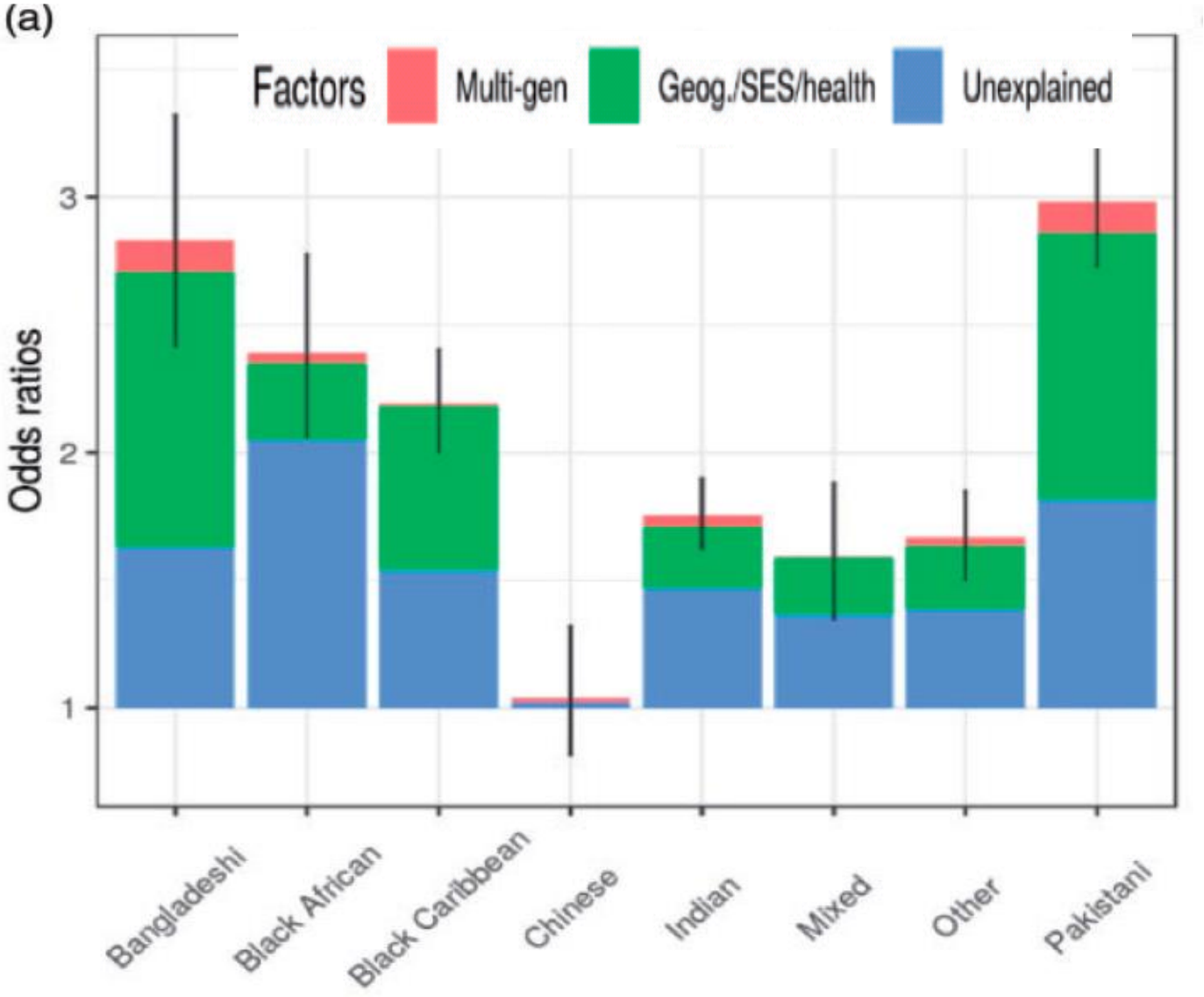
Move to 2020… All cause death rate is higher in deprived areas: Plus covid had a proportionately greater impact



https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsinvolvingcovid19bylocalareasanddeprivation/

Increased odds of dying from covid for people from ethnic minority groups

- impact of household, socio-economic status/health & 'unexplained'



Age-adjusted odds ratios of COVID-19 death for men >65 years in ethnic minority groups compared to those of white ethnic group with

(i) part explained by living in a multi-generational household

(ii) part explained by other individual and household characteristics, e.g. geographical, socioeconomic factors and pre-pandemic health

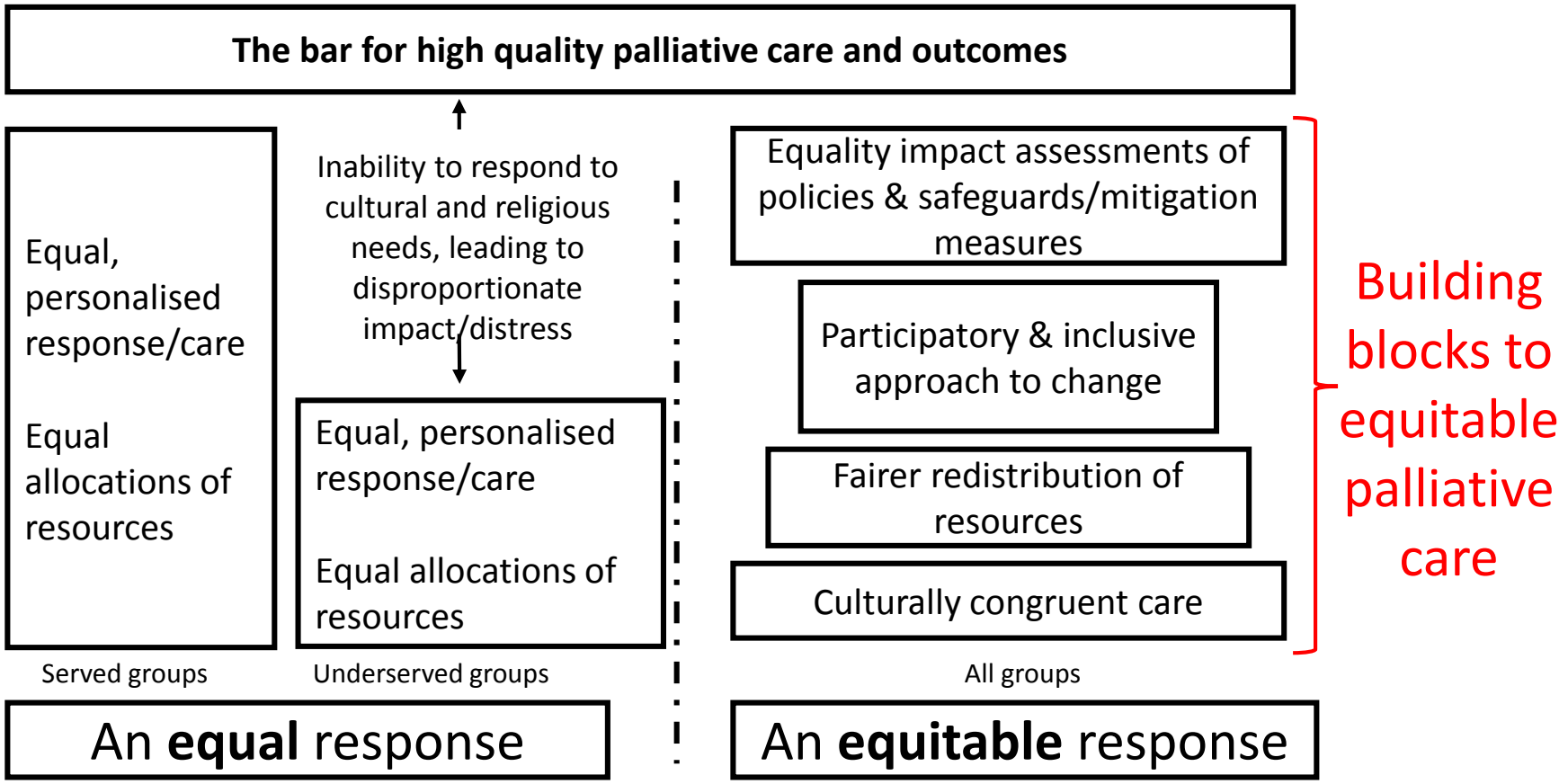
(iii) residual component that is not explained by model

Nafilyan et al.. J R Soc Med. 2021 Apr; 114(4): 182–211.

The response of services to people from ethnic minority groups, also shows inequality.. data from *CovPall* multinational study..

277 UK services; 34% had cared for people with Covid-19 from ethnic minority groups

Restricted visiting and communication challenges impacted disproportionately on ethnic minority groups



Recommendations

- Flexible policies - account for patients' communication and religious needs.
- Assess impact of policies on patients and families from ethnic minority groups.
- Include specifically targeting issues around language and distress caused by 'one size fits all' policies.
- Formal safeguards and mitigation against the negative impact of policies on these groups

Bajwah S, et al. 2021. Equal but inequitable: BMJ SuPaC

2. Palliative care specific:

I. The absent voice..

The dissatisfied dead cannot noise abroad the negligence they have experienced." (Hinton 1967 Dying)…

Patient & Public Involvement in Palliative and end of life care, slowly growing, and essential..

Industry funding of patient and health consumer organisations: systematic review with meta-analysis

BMJ 2020;368:16925

Alice Fabbri,[1] Lisa Parker,[1] Cinzia Colombo,[2] Paola Mosconi,[2] Giussy Barbara,[3] Maria Pina Frattaruolo,[3] Edith Lau,[1] Cynthia M Kroeger,[1] Carole Lunny,[4] Douglas M Salzwedel,[4] Barbara Mintzes[1]

II. The stigma.. As a barrier to referral and to building the field..

Evidence of Palliative Care Stigma: The Role of Negative Stereotypes in Preventing Willingness to Utilize Palliative Care

Megan Johnson Shen, PhD[1], Joseph D. Wellman, PhD[2]

Specifically, Study 1 results indicate that patients who choose palliative care are viewed with more negative stereotypes (e.g., lazy, quitter) and less positive stereotypes (e.g., brave, hero) than those who choose chemotherapy, highlighting the existence of stigma. This builds upon prior research which has demonstrated that "battle" language, such as referring to "fighting the battle against cancer" or "losing the battle," is prevalent in some forms of serious illness

Palliat Support Care. 2019 August ; 17(4): 374–380.

3. Specific: Insufficient 'palliative care' – *'access abyss', 'data abyss', knowledge abyss', 'capacity abyss'*

- More specialist palliative care services and hospices than ever before
- Yet still insufficient to provide specialist care or support/training for generalist services
- Growth not keeping up with escalating need
- Generalist palliative care – training, skills & ability to remain up to date – patchy
- Essential medicines lacking in many parts of the world
- Lack of basic data on how many people receive palliative care, problems they have, effects
- Lack of new knowledge / research for treatment & care

CovPall - Improving palliative care for people with COVID-19 by sharing learning

- Survey of palliative care services & hospices; followed by study of symptoms & outcomes
- Survey: 458 responses: 277 UK, 85 Rest of Europe, 95 Rest of World
- Palliative care and hospice services active in caring and were affected.
  - 81% had cared for patients with suspected / confirmed COVID-19;
  - 77% had staff with suspected / confirmed COVID-19
- **First three publications out : https://www.medrxiv.org**
  - **Overall impacts: response, shortages, lack of 'integration' and recognition of palliative care services**
  - **Challenges of advance care planning**
  - **Frugal innovations made**

Patients dying from and with severe symptoms due to COVID-19 - three main categories:

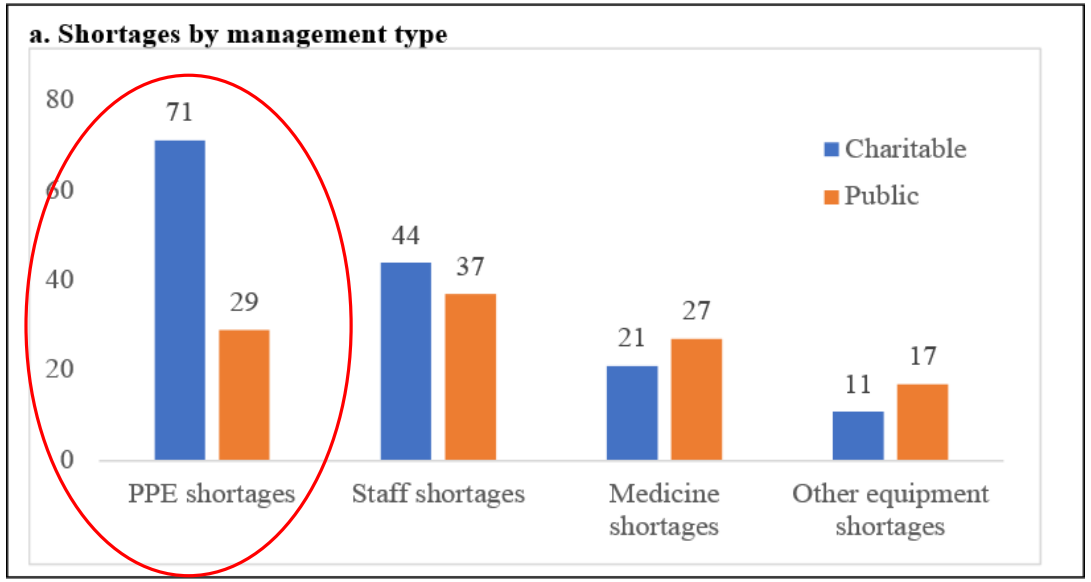
- **underlying conditions and/or multimorbid** not previously known to palliative care (70% of services)
- already **known to palliative care** services (47% of services)
- **previously healthy**, now dying from COVID-19 (37% of services).

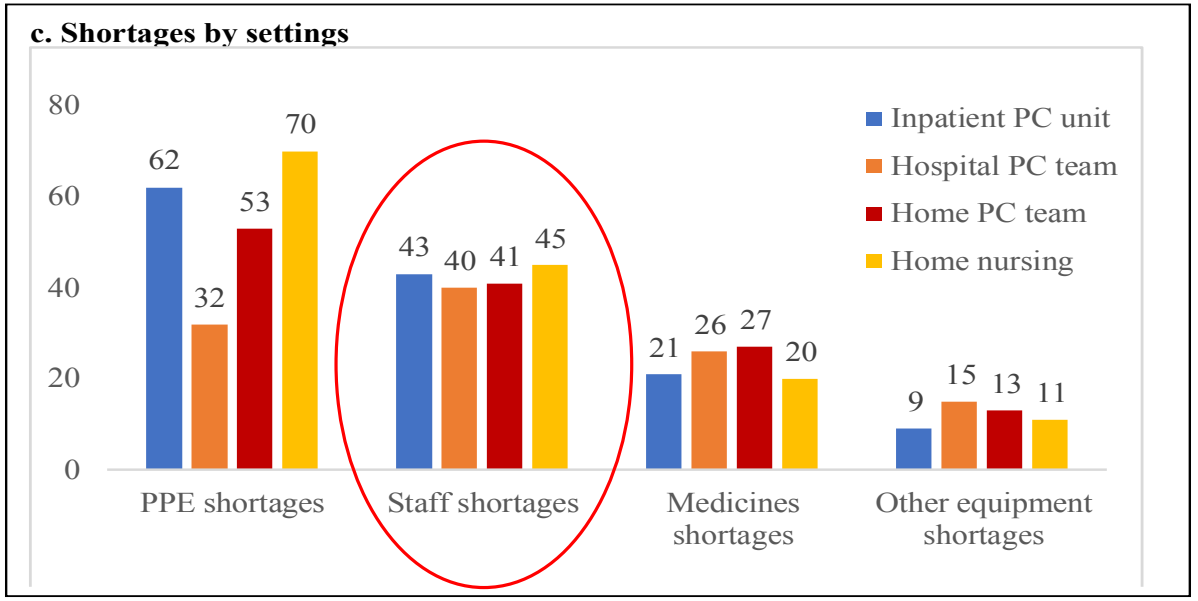
CovPall
Palliative care in COVID-19

CovPall - Improving palliative care for people with COVID-19 by sharing learning

See Oluyase et al. *https://www.medrxiv.org/content/10.1101/2020.10.30.20221465v1.full.pdf*

- Reduced inpatient palliative care unit activity in free standing units
- Increase in activity for home care & hospital teams
- Financial concerns, some staff taking pay cuts, concerned for service viability, especially charity
- Shortages were common: especially of staff and personal protective equipment
- Palliative care services were **overwhelmed**, yet **overlooked** in national response.
- Need integration, recognition, support…





4. Access to palliative care haphazard –based on 'referral'

- Evidence is: receiving palliative care is better in terms of person centred outcomes and societies economics than not; and early access is better than late
- Systems of entry into palliative care rely on 'the referring clinician' identifying that the person needs palliative care
- Patients miss out on the best in care, .. Especially diseases other than cancer, multimorbidity, breathlessness etc
- A routine system of identification and referral would help this..
- Could be based on symptoms or problems e.g. using Integrated Palliative care Outcome Scale (IPOS) or another holistic assessment

Influences on emergency department attendance among frail older people with deteriorating health: a multicentre prospective cohort study

A.E. Bone [a,*], C.J. Evans [a,b], L.A. Henson [a], S.N. Etkind [a], I.J. Higginson [a]

Public Health 194 (2021) 4–10

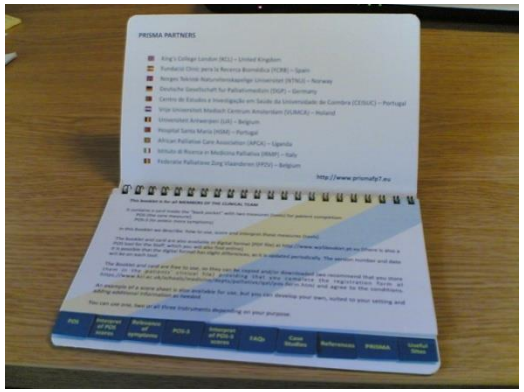
Contact with family doctor:
It's like trying to make an appointment with the Pope (82-year-old female).

Participants described how aspects of hospital care paradoxically hindered recovery. ..Themes were poor quality of food & sleep, acknowledged as being important for recovery.

May 2014 – World Health Assembly resolution on palliative care, to be integrated into health systems –
UICC said – essential health care service for people with chronic and life limiting illness

Can we get better at triggering a palliative care assessment - easy to use measures: E.g. Integrated Palliative care Outcome Scale (POS) and POS-Symptoms

- Developed and validated in **many countries, settings and disease**
- **10 questions, rated 0 – 4**
- **Open question for patient concerns**
- **Time to complete 5 minutes**
- **http://pos-pal.org/**



Can these triggers be digitally provided

Can be called the Integrated Patient care Outcome Scale (POS) –
Is this needed ? - Sometimes ….
But palliative care be explained

Triggering referrals for palliative care in fluctuating diseases,

Source: Maddocks et al Lancet. 2017 Sep 2;390(10098):988-1002.

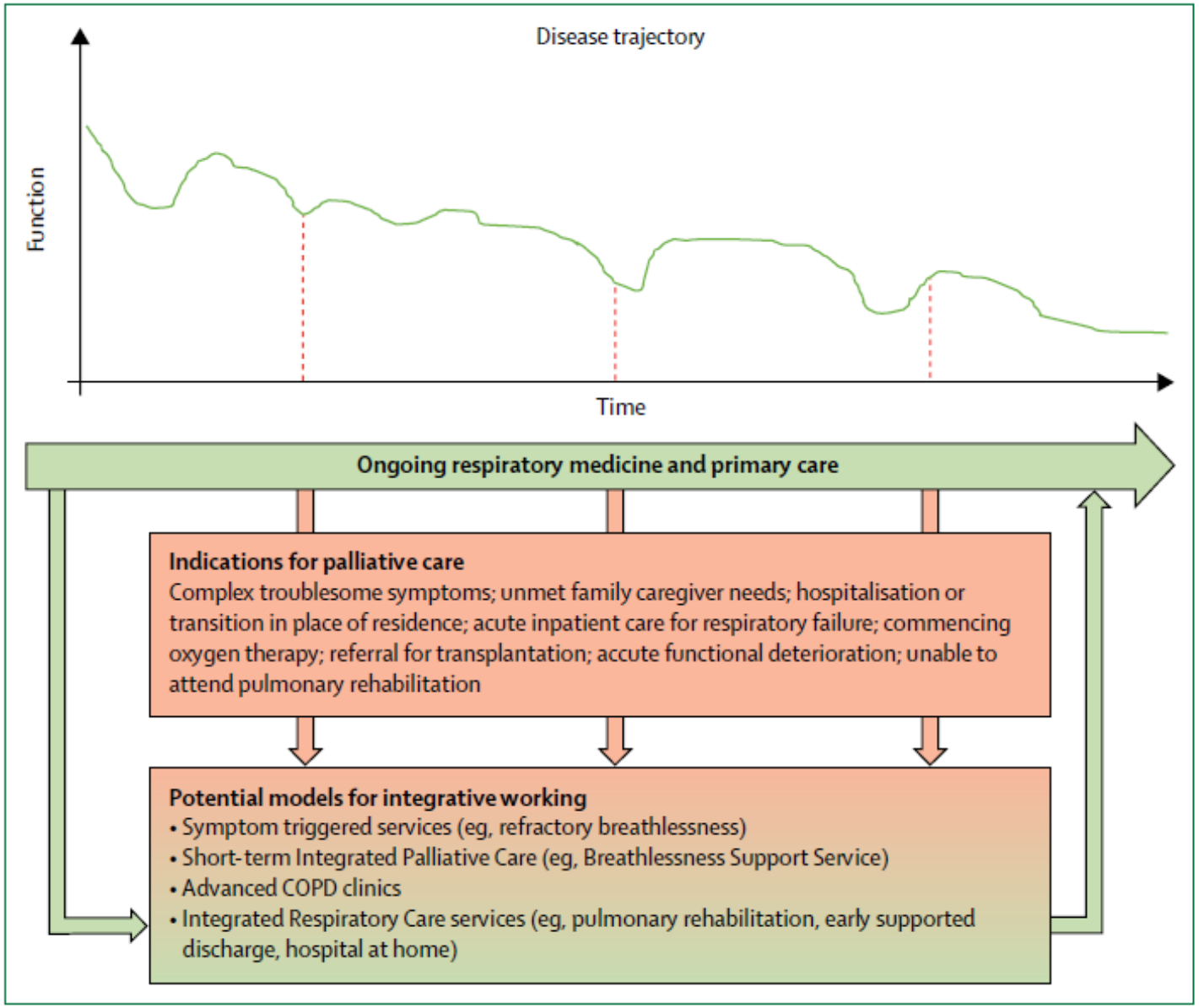


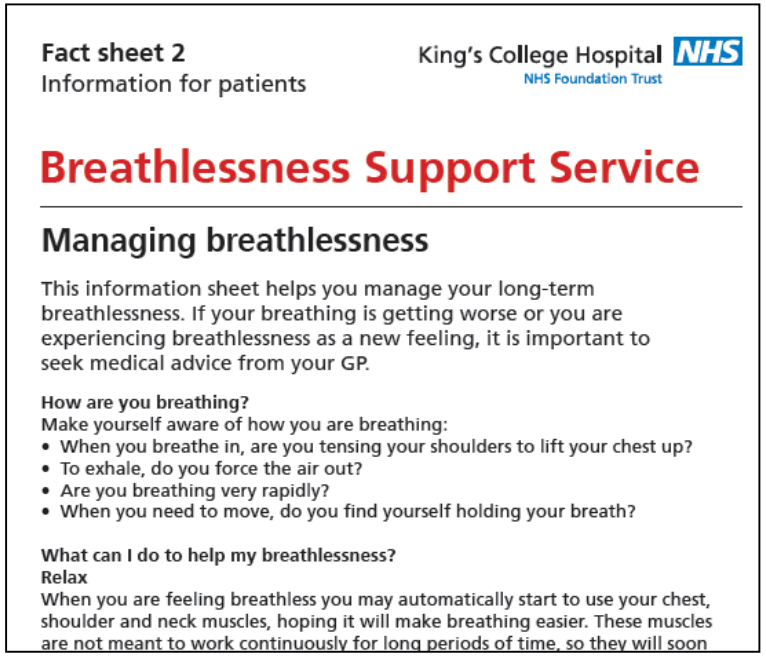
Figure 3: **Models of integrative working with palliative care for people with COPD**
COPD=chronic obstructive pulmonary disorder.

Results of the Multi-Speciality Holistic Service, triggered by Breathlessness

Higginson et al. Lancet Respir Med 2014;2(12):978-87

- Early palliative care integrated with respiratory services
- 16 % improvement in QoL
- No difference in costs to health care

	Breathlessness support service group (n=42)	Control group (n=40)	Difference between breathlessness support service and control (95% CI)	p value
Primary outcome (CRQ mastery)*†	4·15 (1·7)	3·57 (1·4)	0·58 (0·01 to 1·15)	0·048
Secondary outcomes				
NRS breathlessness average 24 h‡	5·38 (2·2)	5·71 (2·1)	−0·33 (−1·28 to 0·62)	0·49



Fact sheet 2
Information for patients

King's College Hospital NHS
NHS Foundation Trust

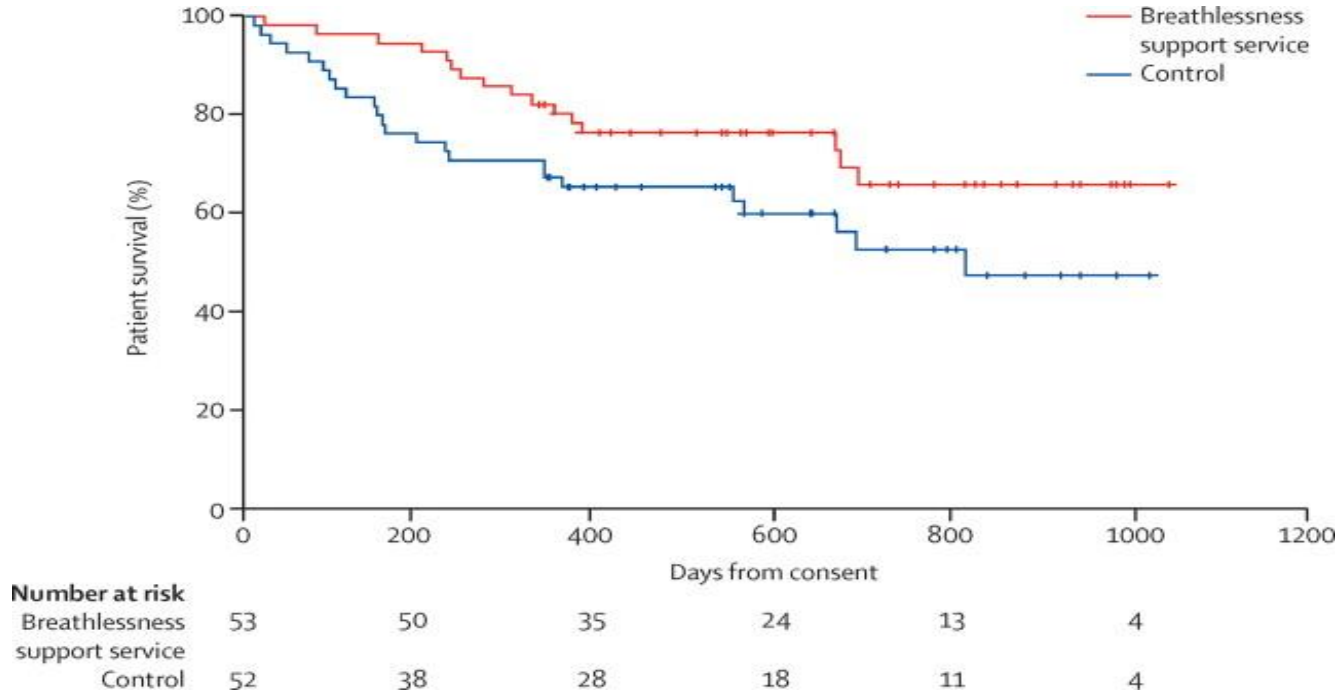
Breathlessness Support Service

Managing breathlessness

This information sheet helps you manage your long-term breathlessness. If your breathing is getting worse or you are experiencing breathlessness as a new feeling, it is important to seek medical advice from your GP.

How are you breathing?
Make yourself aware of how you are breathing:
- When you breathe in, are you tensing your shoulders to lift your chest up?
- To exhale, do you force the air out?
- Are you breathing very rapidly?
- When you need to move, do you find yourself holding your breath?

What can I do to help my breathlessness?
Relax
When you are feeling breathless you may automatically start to use your chest, shoulder and neck muscles, hoping it will make breathing easier. These muscles are not meant to work continuously for long periods of time, so they will soon



Respiratory research

OPEN ACCESS

ORIGINAL ARTICLE

Holistic services for people with advanced disease and chronic breathlessness: a systematic review and meta-analysis

Lisa Jane Brighton,[1] Sophie Miller,[1] Morag Farquhar,[2] Sara Booth,[3] Deokhee Yi,[1] Wei Gao,[1] Sabrina Bajwah,[1] William D-C Man,[4,5] Irene J Higginson,[1] Matthew Maddocks[1]

- Meta-analysis of 37 articles; 18 different breathlessness support services or similar
- Improvements favouring intervention in
  - numeric rating scale distress due to breathlessness (n=324; mean difference (MD) −2.30, 95% ci −4.43 to −0.16, p=0.03) and
  - Hospital anxiety and Depression Scale (HaDS) depression scores (n=408, MD −1.67, 95% ci −2.52 to −0.81, p<0.001)

Maddocks M, et al, NIHR Journals Library; 2019
Brighton LJ, et al Thorax. 2019; 74(3):270-281.

Key messages

What is the key question?

- What are the outcomes, recipients' experiences and therapeutic components of holistic services for chronic breathlessness in people with advanced disease?

What is the bottom line?

- Overall these services reduce patient distress due to breathlessness and may improve psychological outcomes of anxiety and depression.
- Despite wide variability in content and delivery, recipients value tailored interventions and expert staff providing person-centred, dignified care.

Why read on?

- This is the first review to synthesise available quantitative and qualitative evidence around holistic services triggered by breathlessness, which may serve as an appropriate referral indicator for early integration of palliative care.

Breathlessness triggered service – *How did it work?*

- **Patient and family holistic by palliative care / respiratory**
- **Home tool kit**
  - **Hand held fan / water spray**
  - **Information sheets**
    - Breathlessness commonly asked questions
    - Managing breathlessness
    - Pacing
    - Hand held fan
    - Distraction techniques
    - Positions to ease breathlessness
  - **Relaxation CD**
  - **Crisis plan**
  - **Breathlessness poem (Jenny Taylor)**
- **Home visit by physiotherapy/ occupational therapy;** walking aids, home adaptations, exercise / muscle strengthening DVD or equivalent, reinforces clinic advice

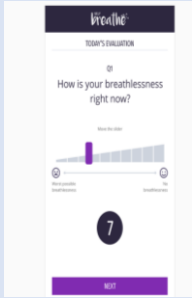
https://www.kcl.ac.uk/cicelysaunders/research/symptom/breathlessness

Next steps – moving to digital, self-help & support

SELF breathe

Self–guided, internet–based intervention:
Feasibility randomised controlled trial

NIHR funded (Reilly)



The importance of competence, skills and presence, especially in home care

model shows from research the 'key ingredients of being able to support people at home'

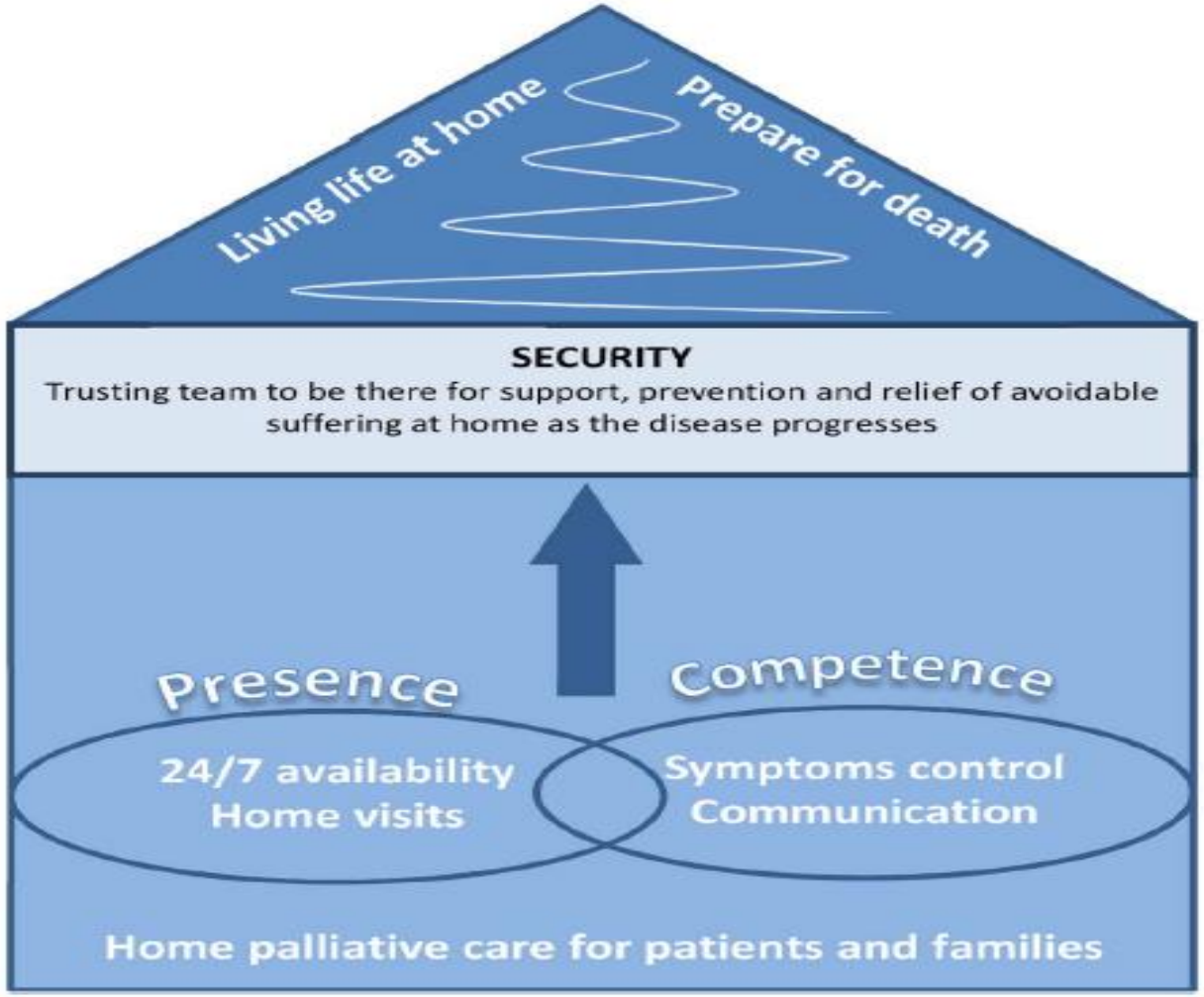


Figure 1 Lines-of-argument synthesis: simplified model of the experiences of patients' and caregivers' with home palliative care.

Results of a meta-ethnography

Source: Sarmento et al BMJ Support Palliat Care. 2017 Feb 23.

Free of charge online platform dedicated to improving breathlessness management.

Evidence based and aimed at clinicians, allied health professionals and managers.

Course is available for all.. Go to

https://learninghub.kingshealthpartners.org/ - Or .. **www.tinyurl.com/e-breathe**

and choose ‘breathlessness’ course

A Seven point action plan: for Better Palliative Care

https://cicelysaundersinternational.org/action-plan-for-palliative-care/

1 **Provide palliative care expertise in places where people are cared for: hospitals, care homes, hospices and at home**

2 **Make joined up care a reality**

3 **Empower patients and carers to have greater choice and control over the things that are important to them**

Including when to be referred to palliative care

A Seven point action plan: for Better Palliative Care

4 **Invest in community care services**

5 **Provide healthcare professionals and carers with high-quality palliative care training**

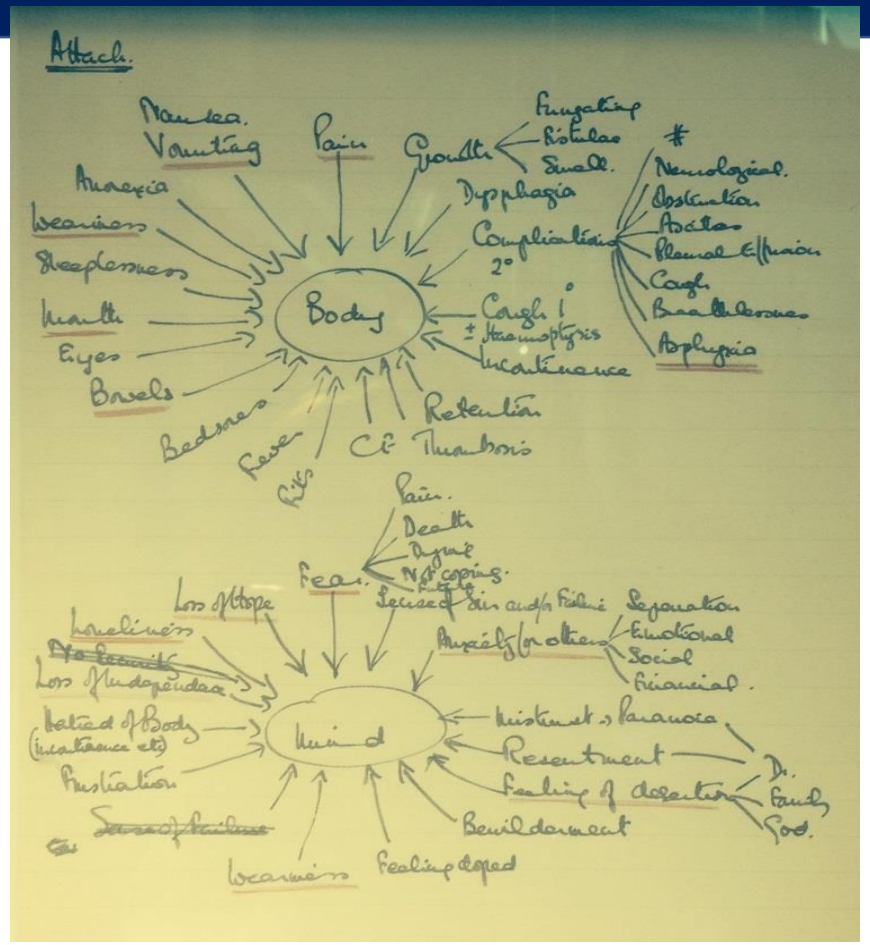
6 **Use outcome measures to embed a system of continuous learning and improvement**

7 **Fund world-leading research into palliative care**

Are palliative care methods & approaches a solution for much of health and social care.. Putting the person before the disease..

https://cicelysaundersinternational.org/action-plan-for-palliative-care/

Take Home Messages



- Palliative care is central to the future of health care
- It is growing in need
- Understands the multimorbid population – should be central to future needs
- Suffers from inequities just as other health care, and has added inequities specific to palliative care
- Ensure palliative care expertise is fully available
- Improve the triggers, perhaps with symptom led triggers, e.g to holistic breathlessness support services
- 7 point action plan – would it be useful to you
- Opportunity to build research, capacity, knowledge

Our science is the science that puts the person before their disease

Question and Answer Session

Question and Answer Session

Please click the Q&A icon and type your question(s) to the speakers. We will try to get to as many of them as possible.

Esme Fuller-Thomson, PhD

Professor Irene J. Higginson, OBE

Award Ceremony

Certificate of Recognition

This award is given to

Professor Irene J. Higginson, OBE

For the World Hospice and Palliative Care Day Special Lecture 2021:

'Equity in Access to Palliative Care'

Project ECHO Palliative Care - Canada BY Pallium Canada

WORLD HOSPICE & PALLIATIVE CARE DAY

NICE National Initiative for the Care of the Elderly / Initiative nationale pour le soin des personnes âgées

FACTOR-INWENTASH FACULTY OF SOCIAL WORK UNIVERSITY OF TORONTO Institute for Life Course & Aging

Thank You

Project ECHO
Palliative Care - Canada
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WORLD HOSPICE & PALLIATIVE CARE DAY

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