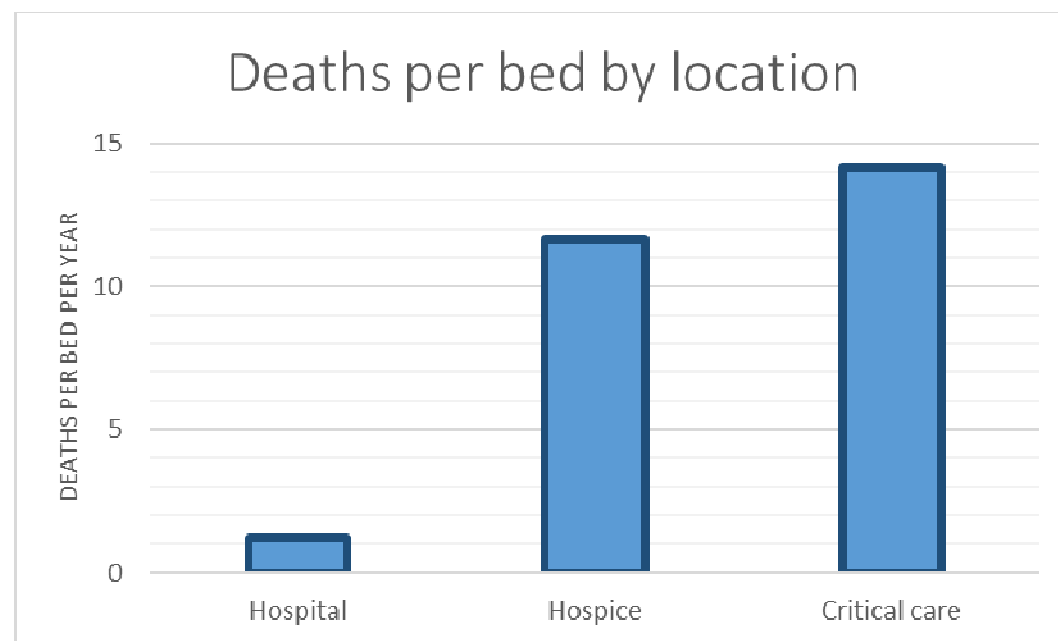
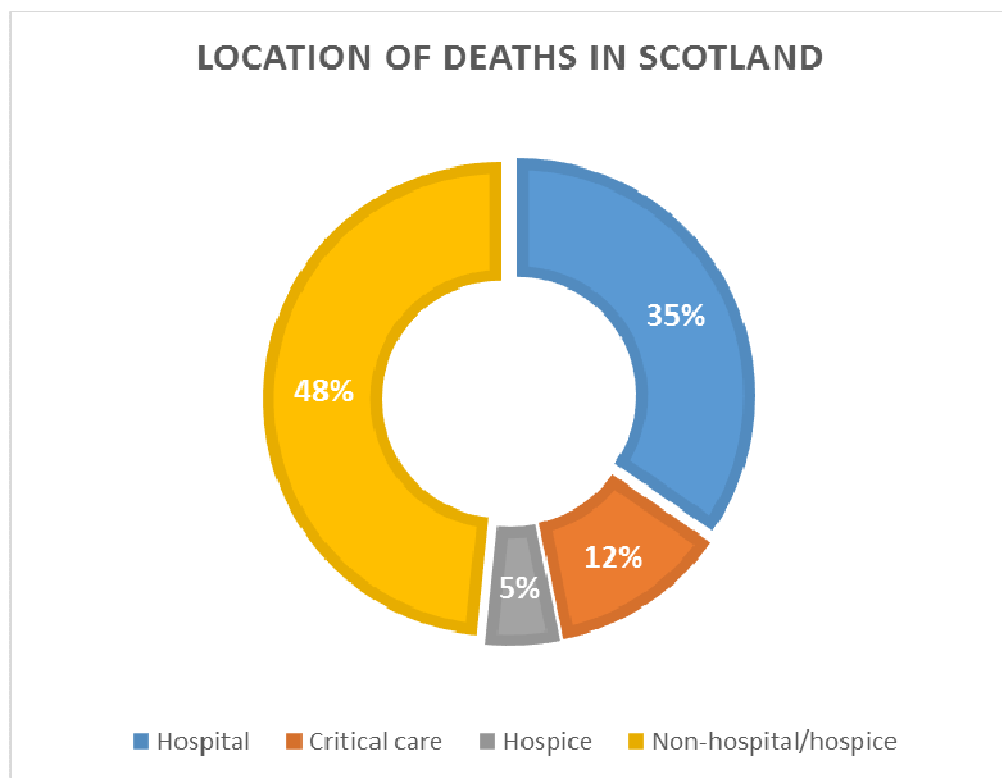


Death and dying at the frontiers of medical possibility

Nazir Lone

Senior Clinical Lecturer in Critical Care
University of Edinburgh; NHS Lothian

Deaths in critical care – in context



The role of hospice care in Scotland: <https://www.hospiceuk.org/what-we-offer/publications?page=2>

<http://www.sicsag.scot.nhs.uk/docs/2017/2017-08-08-SICSAG-Report.pdf?35>

Critical care deaths are deaths occurring during a terminal hospitalisation which includes an admission to ICU, HDU or a combined unit. Hospital deaths are deaths within 30 days of hospital admission

Life support or delaying death?

- Providing life support treatment can be the 'easy' option
- Patient-focussed decision-making takes time

Case history: Kenneth

- 84 year old retired lawyer
 - Chronic disease of diabetes, hypertension
 - Slowing up over past year
- Severe abdominal pain
- Emergency ambulance transfer to ED
- Immediate resuscitation and CT scan

Case history: Kenneth

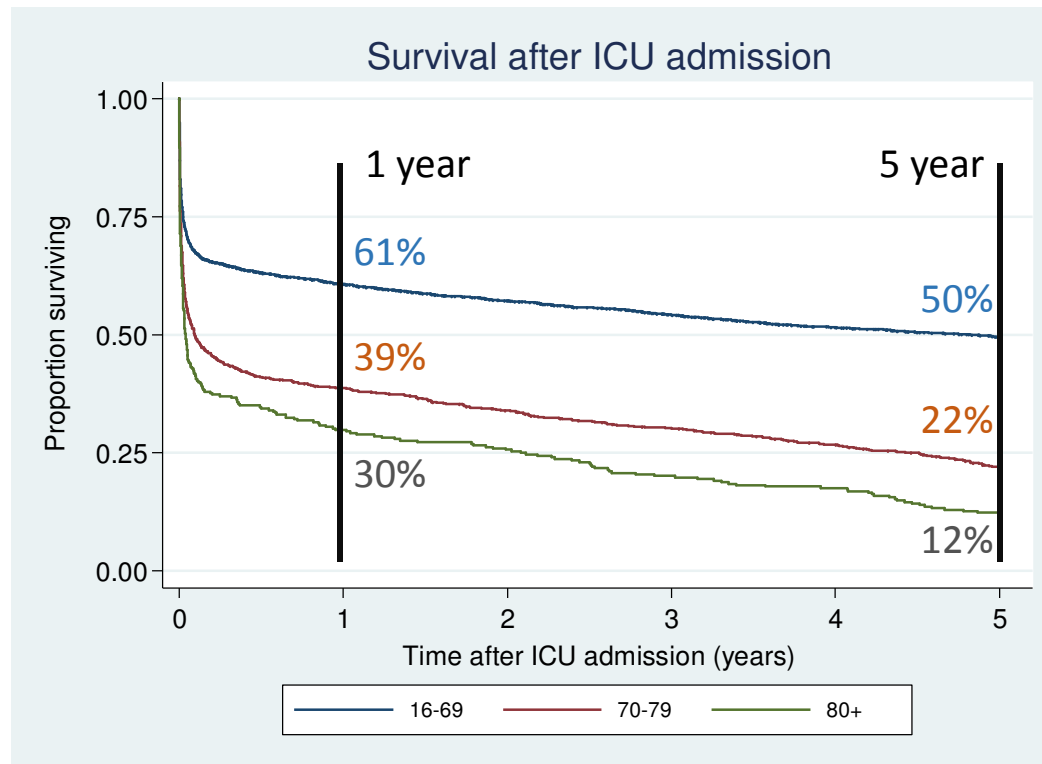
- Diagnosis: probable perforated bowel
- But rapidly developing multiorgan failure due to septic shock
- Requires immediate laparotomy and stabilisation with life support therapy
- Conversation with patient

Making the right decision

- Evidence and data
 - Treatment success
 - Treatment burden
 - Dealing with uncertainty
- Communication
 - Understanding the patient's viewpoint
 - Communicating the evidence
 - Arriving at a decision
- Doing all of this in a time pressured setting...

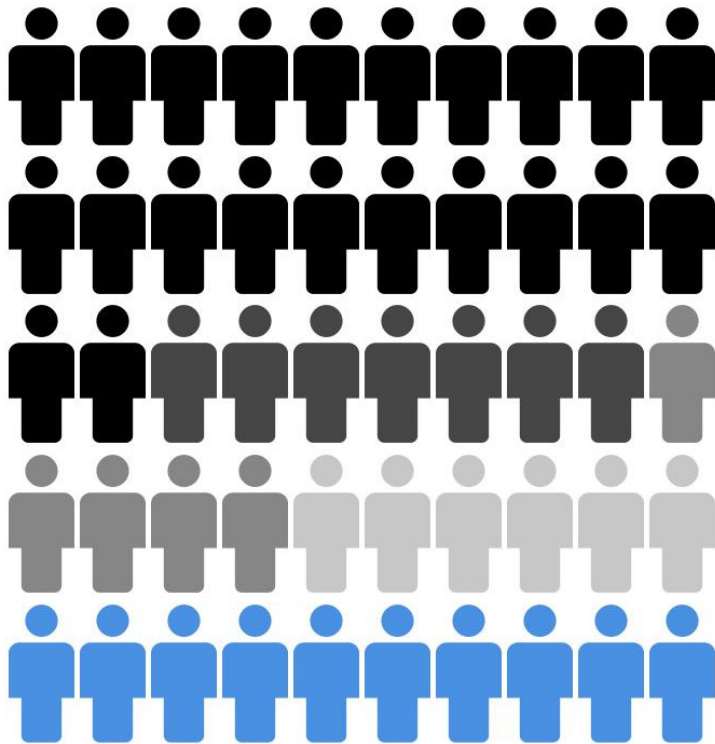
The evidence: treatment benefits

Survival stratified by age



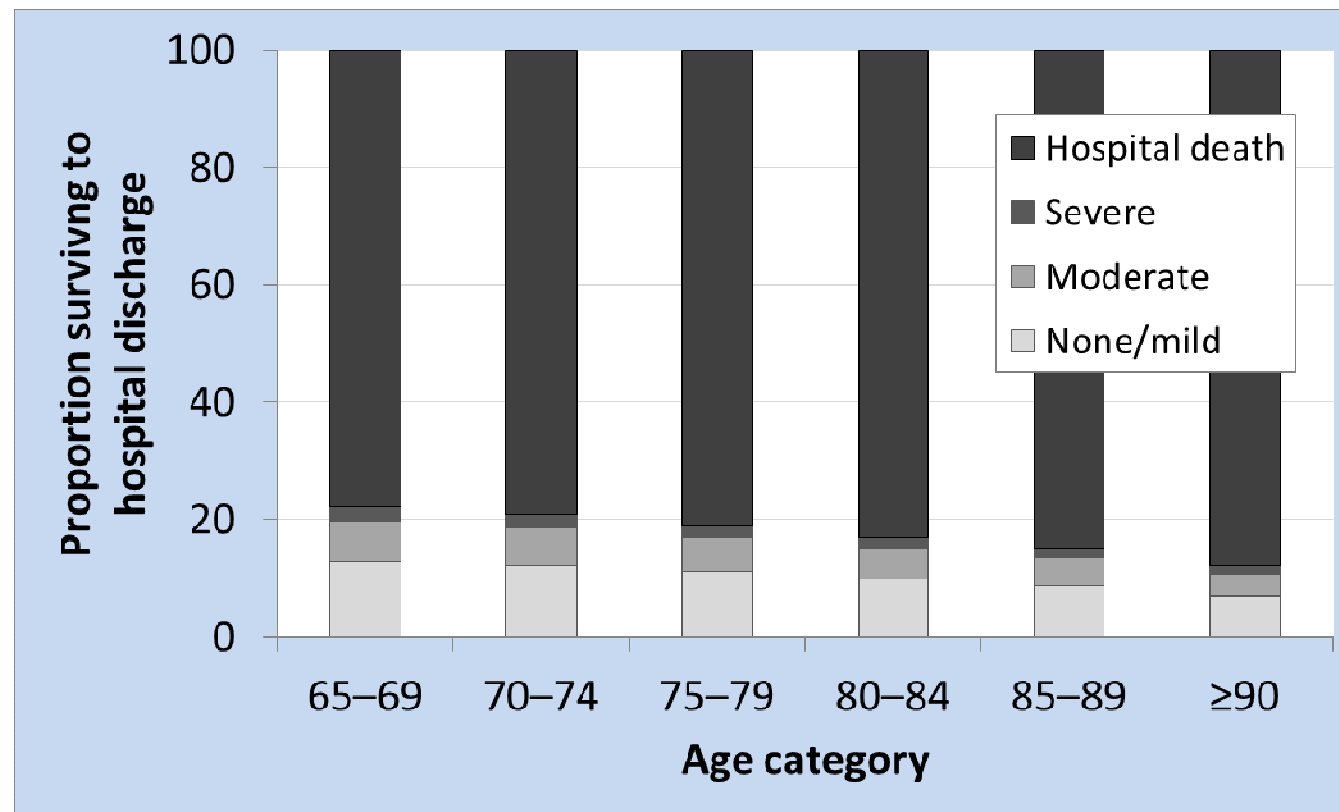
Lone et al. (2015) *Unpublished*.

Outcomes after ICU admission with alcoholic liver disease



- For every 50 people who are admitted to ICU with ALD
 - 22 die in the ICU
 - 7 die after ICU but during the same hospital stay
 - 5 survive to leave hospital but die within 1 year of ICU admission
 - 6 survive the first year but die within 5 years of ICU admission
 - 10 are still alive 5 years after ICU admission

Outcomes after in-hospital cardiac arrest



Chan et al. (2013) *N Engl J Med* 368:1019-26.

Ehlenbach et al. (2009) *N Engl J Med* 361:22-31.

The evidence: treatment burdens

Supporting carers after ICU survivorship

THE NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

One-Year Outcomes in Caregivers of Critically Ill Patients

Jill I. Cameron, Ph.D., Leslie M. Chu, B.Sc., Andrea Matte, B.Sc.,
George Tomlinson, Ph.D., Linda Chan, B.A.Sc., Claire Thomas, R.N.,
Jan O. Friedrich, M.D., D.Phil., Sangeeta Mehta, M.D.,

van Beusekom et al. *Critical Care* (2016) 20:16
DOI 10.1186/s13054-016-1185-9

Critical Care

RESEARCH

Open Access

Reported burden on informal caregivers of ICU survivors: a literature review

Ilse van Beusekom^{1,2*}, Ferishta Bakhshi-Raiez^{1,2}, Nicolette F. de Keizer^{1,2}, Dave A. Dongelmans^{2,3}
and Marike van der Schaaf^{4,5}



Psychosocial Outcomes in Informal Caregivers of the Critically Ill: A Systematic Review*

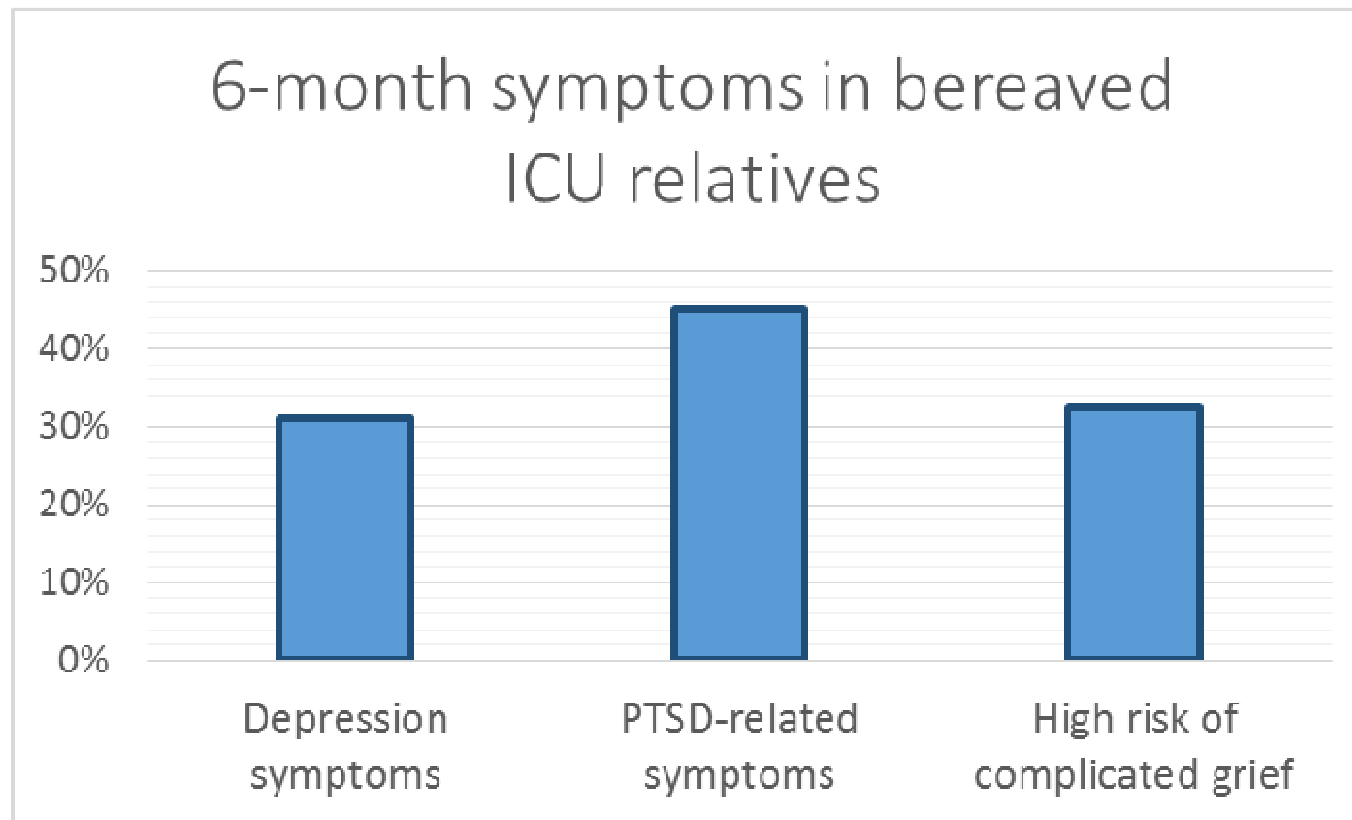
Kimberley J. Haines, B Health Science (Physiotherapy)¹;
Linda Denehy, PhD, B Applied Science (Physiotherapy)²;
Elizabeth H. Skinner, PhD, B Physiotherapy (Hons)³;
Stephen Warrillow, MBBS, FCICM, FRACP⁴;
Sue Berney, B Physiotherapy, M Physiotherapy, PhD¹

Cameron et al *N Engl J Med* 2016;374:1831-41.

Haines et al *Crit Care Med* 2015; 43:1112–1120

van Beusekom et al. *Critical Care* (2016) 20:16

Bereavement after critical care



Kentish-Barnes et al. Intensive Care Med (2017) 43:473–484.

Case history: Kenneth

- Survived difficult operation
- Very slow improvement
- Complicated by further infection
- Required life support for 10 days
- Challenging family discussions regarding re-escalation of life support
- On day 12 patient could join discussion about future care

Communication

Original Investigation | CARING FOR THE CRITICALLY ILL PATIENT

Prevalence of and Factors Related to Discordance About Prognosis Between Physicians and Surrogate Decision Makers of Critically Ill Patients

Douglas B. White, MD, MAS; Natalie Ernecoff, MPH; Praewpannarai Buddadhumaruk, RN, MS; Seoyeon Hong, PhD; Lisa Weissfeld, PhD; J. Randall Curtis, MD, MPH; John M. Luce, MD; Bernard Lo, MD

Communication With Family Caregivers in the Intensive Care Unit Answers and Questions

Elie Azoulay, MD, PhD; Nancy Kentish-Barnes, PhD; Judith E. Nelson, MD, JD

Shared decision making is increasingly accepted as an optimal model for defining overall goals of care and making major health care decisions affected by the values and preferences

In this issue of *Critical Care Medicine*, the results of a multicenter study of the prevalence of and

Research

Effect of communication skills training on outcomes in critically ill patients with life-limiting illness referred for intensive care management: a before-and-after study

Neil R Orford,^{1,2,3} Sharyn Milnes,^{1,2} Nicholas Simpson,^{1,2} Gerry Keely,¹ Tania Elderkin,¹ Allison Bone,¹ Peter Martin,^{2,4} Rinaldo Bellomo,^{3,5} Michael Bailey,³ Charlie Corke^{1,2}

Improving communication







Making Communication Even Better

Improving access to health and social care services for people who have hidden or explicit communication support needs



A DVD and learner's workbook

Policy developments

**REALISING
REALISTIC
MEDICINE**

Chief Medical Officer's
Annual Report 2015-16

RESPECT Recommended Summary Plan for
Emergency Care and Treatment for:

Preferred name

1. Personal details

Full name

NHS/CHI/Health and care number

Date of birth

Address

Date completed

2. Summary of relevant information for this plan (see also section 6)

Including diagnosis, communication needs (e.g. interpreter, communication aids) and reasons for the preferences and recommendations recorded.

Details of other relevant planning documents and where to find them (e.g. Advance Decision to Refuse Treatment, Advance Care Plan). Also include known wishes about organ donation.

3. Personal preferences to guide this plan (when the person has capacity)

How would you balance the priorities for your care (you may mark along the scale, if you wish):

Prioritise sustaining life, even at the expense of some comfort

Prioritise comfort, even at the expense of sustaining life

Considering the above priorities, what is most important to you is (optional):

4. Clinical recommendations for emergency care and treatment

Focus on life-sustaining treatment as per guidance below

Focus on symptom control as per guidance below

Now provide clinical guidance on specific interventions that may or may not be wanted or clinically appropriate, including being taken or admitted to hospital +/- receiving life support:

CPR attempts recommended
Adult or child

For modified CPR
Child only, as detailed above

CPR attempts **NOT** recommended
Adult or child

5. Capacity and representation at time of completion

Does the person have sufficient capacity to participate in making the recommendations on this plan?

Yes / No

Do they have a legal proxy (e.g. welfare attorney, person with parental responsibility) who can participate on their behalf in making the recommendations? If so, document details in emergency contact section below

Yes / No / Unknown

6. Involvement in making this plan

The clinician(s) signing this plan is/are confirming that these recommendations have (circle at least one):

A been recorded after discussion involving this person, who has sufficient mental capacity to participate in making relevant decisions

B where appropriate, been discussed with a person holding parental responsibility

C in the case of a person who does not have sufficient mental capacity to participate in relevant decision-making, been made in accordance with capacity law

D been made without involving the patient (or best interests/overall benefit meeting if the patient lacks capacity)

If D has been circled, state valid reasons here. Document full explanation in the clinical record.

Date, names and roles of those involved in discussion, and where records of discussions can be found:

7. Clinicians' signatures

Designation (grade/speciality)	Clinician name	GMC/NMC/HCPC Number	Signature	Date & time
Senior responsible clinician				

8. Emergency contacts

Role	Name	Telephone	Other details
Legal proxy/parent			
Family/friend			
GP			
Lead Consultant			
Other			

9. Confirmation of validity (e.g. for change of condition)

Review date	Designation (grade/speciality)	Clinician name	GMC/NMC/HCPC number	Signature



home about us get involved where can i get support? resources news awareness week

YOU ARE HERE: HOME + NAZIR

nazir



"It's not as simple as 'you can save this life therefore you must.'"

Usually we can do something but everything has a risk, a downside, a real price to pay for the person – pain, distress, or brain damage which leaves you living in a state you never wanted to be in.

It may be that a treatment is probably not going to work, but there is a small chance it might work.

If it seems likely the person will die even with life support treatment, what we may be doing is just deferring death by 5 days, 1 week, 2 weeks.

So we speak to relatives to try and figure out 'what would this person want us to do?'"

Nazir, Critical Care Doctor



Dying Matters

What can you do?

You can do something to help someone cope with dying, death and bereavement

Dying Matters

Dying Matters Awareness Week

8th-14th May 2017

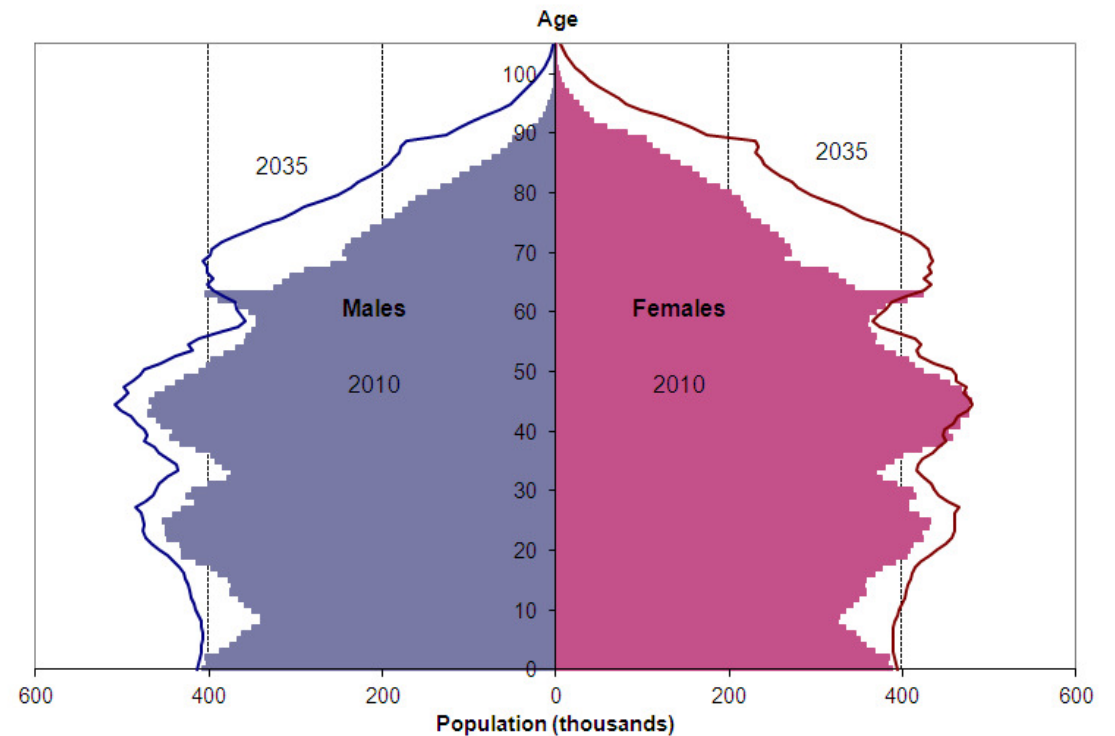
www.dyingmatters.org

www.facebook.com/DyingMatters

twitter.com/DyingMatters

The future

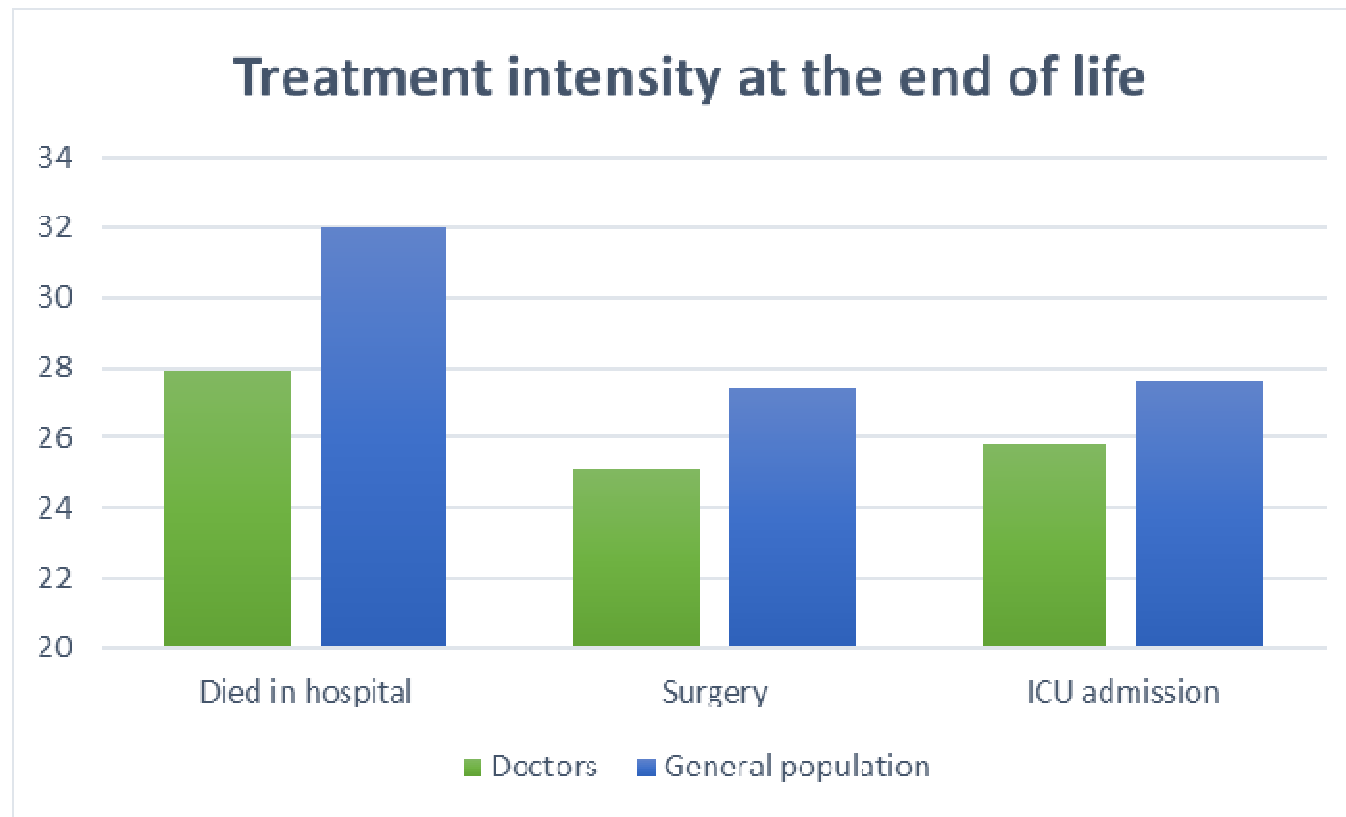
Estimated and projected age structure of the United Kingdom population, mid-2010 and mid-2035



<https://www.theguardian.com/lifeandstyle/ng-interactive/2017/sep/18/how-death-has-changed-over-100-years-in-britain>

<http://www.ons.gov.uk/ons/rel/npp/national-population-projections/2010-based-projections/sum-2010-based-national-population-projections.html>

What do doctors choose at the end of life?



Weissmann et al (2016) *JAMA* 315(3):303.

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