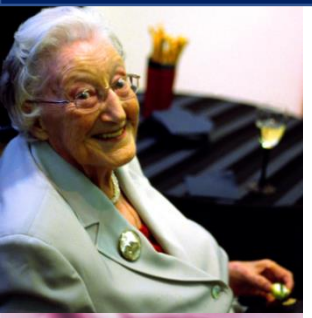

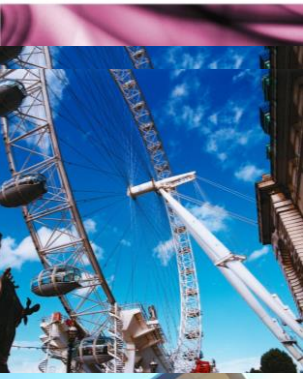

Cicely Saunders International
Better care at the end of life

WHO Collaborating Centre for
Palliative Care and Rehabilitation

KING'S College LONDON

Achieving Evidence-based Change in Palliative Care

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Outline

- What do we mean by evidence-based change
  - Definitions and models of evidence-based practice and of change at individual and organisational level (examples across field)
  - Models of change, and implementation science
- Taking a step back – Do we want evidence-based change?
- Evidence based-change in palliative care: what do we need to make it happen..
- Future challenges…
- What might we learn from some leaders of the past..

What do we mean by evidence-based change

Intention behind all evidence-based practice: 'conscientiously, explicitly and judiciously use the best available evidence to increase the likelihood of a favourable outcome'.(i)

(i) Barends, E., Rousseau, D.M. and Briner, R.B. (2014), Evidence-Based Management: The Basic Principles, Center for Evidence-Based Management, Amsterdam

Achievement of evidence-informed decision making (EIDM) requires integration of evidence into all practice decisions by identifying and synthesizing evidence, then developing and executing plans to implement and evaluate changes to practice.(ii)

(ii) Clark EC, et al. BMC Health Serv Res. 2024 Apr 1;24(1):405.

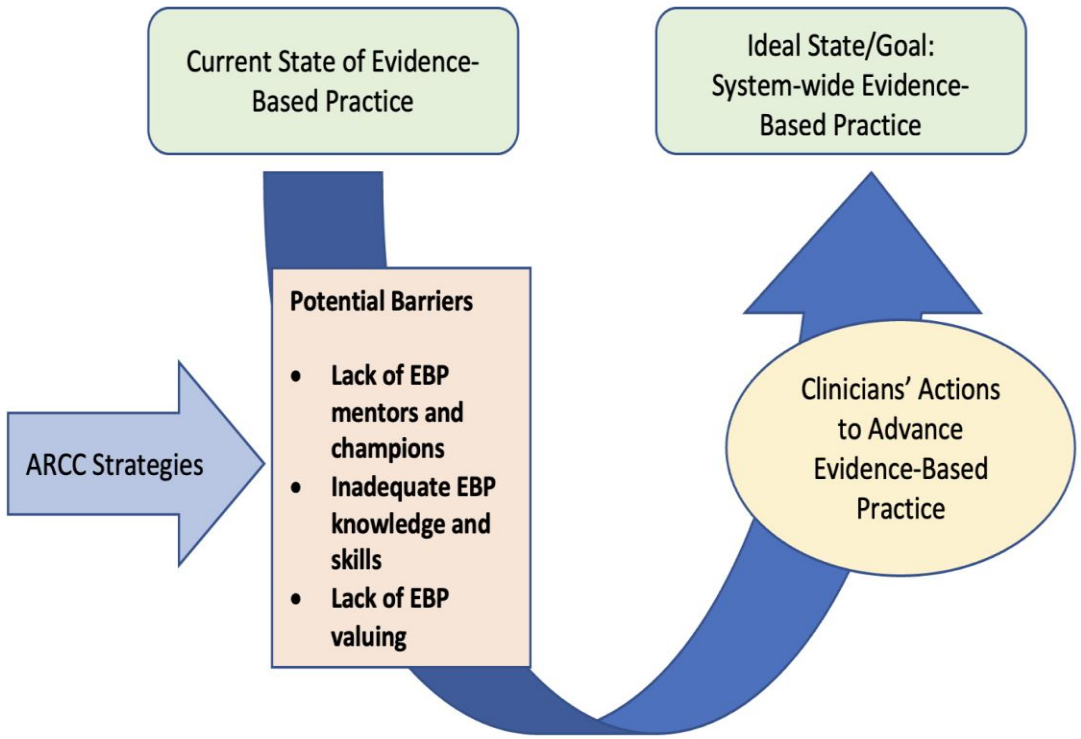
Change = 'making something different or to replace something with something else'..(iii)

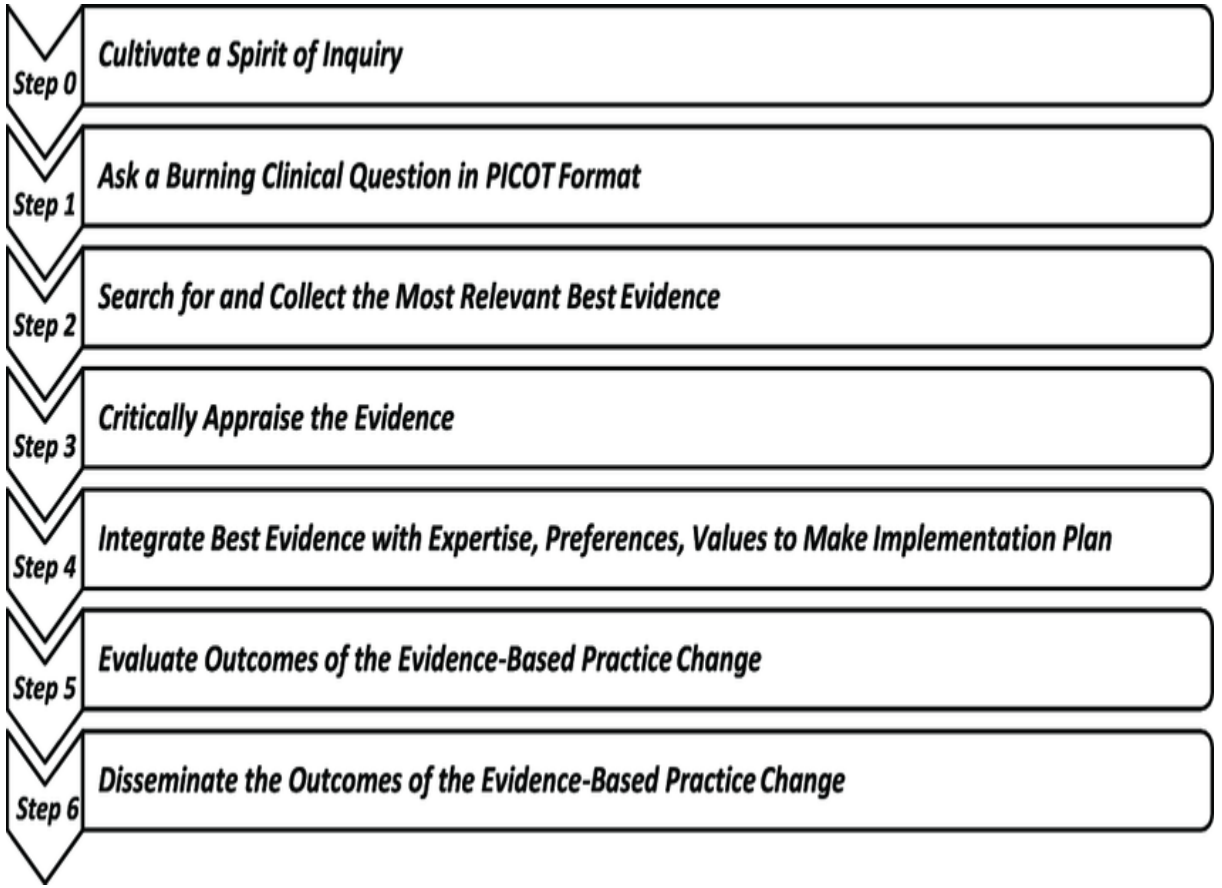
(iii) Oxford University Press, Oxford Languages dictionary

Evidence-based change: at what level?

- individual clinician
- individual service or organisation
- region
- field or speciality (e.g. palliative care)
- health care funders (NHS, ICBs, 3rd party payers)
- government policy
- international organisation
- .. others..

Multiple models of evidence-based change, e.g.





The ARCC (Advancing A Research and R Clinical practice through C close Collaboration) model, Fineout-Overholt, Levin, Melnyk; & Melnyk and Fineout-Overholt's (2018) seven-step evidence-based practice process

Evidence-based organisational change

- The intention behind all evidence-based practice is to conscientiously, explicitly and judiciously use the best available evidence to increase the likelihood of a favourable outcome
- Achievement of evidence-informed decision making (EIDM) requires the integration of evidence into all practice decisions by identifying and synthesizing evidence, then developing and executing plans to implement and evaluate changes to practice.

What strategies do people use?

Clark *et al. BMC Health Services Research* (2024) 24:405

RESEARCH Open Access

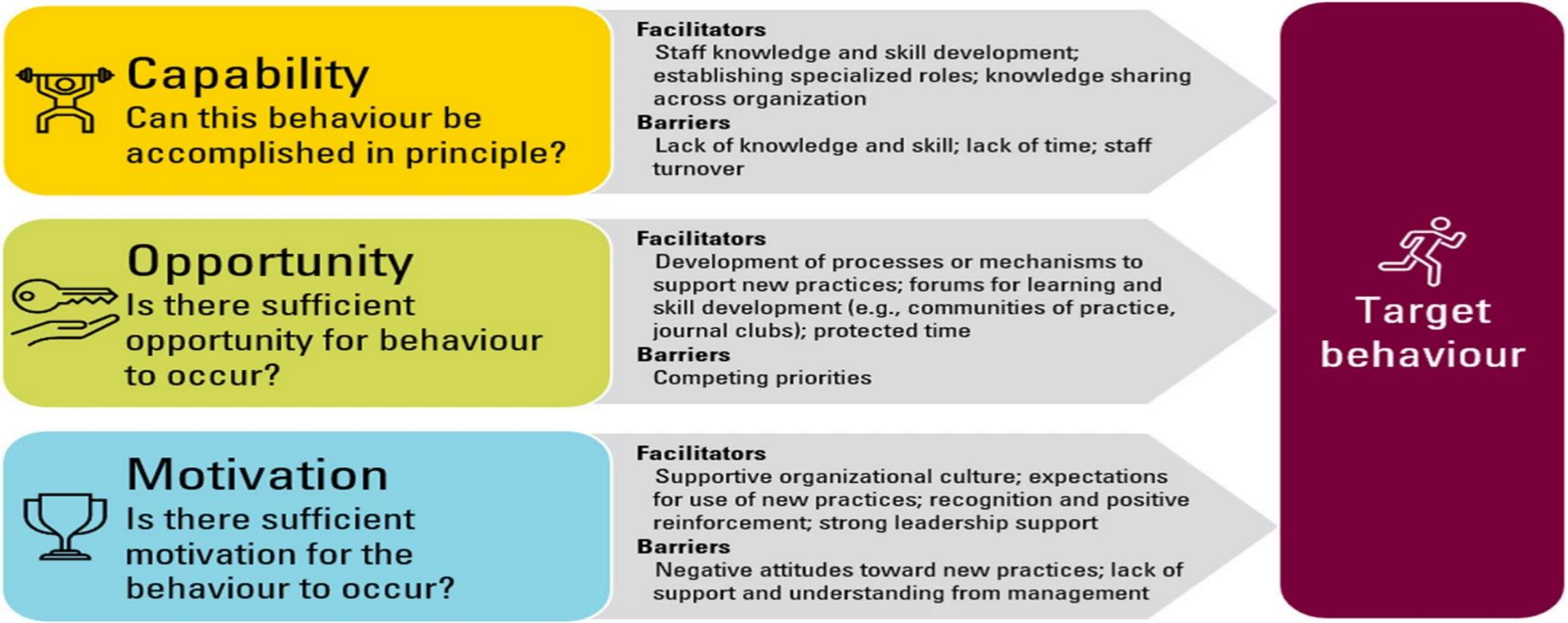
Strategies to implement evidence-informed decision making at the organizational level: a rapid systematic review

Emily C. Clark[1], Trish Burnett[1], Rebecca Blair[1], Robyn L. Traynor[1], Leah Hagerman[1] and Maureen Dobbins[1,2*]

Strategy	Studies
Establishing specialized roles, e.g., Knowledge Brokers	22 Studies
Building staff capacities for evidence-informed decision making through education and training	11 Studies
Research or academic partnerships	3 Studies

- 37 included studies
- Most conducted in primary care settings (n = 16) and public health settings (n = 16), some in social services (n = 3), child and youth mental health (n = 1), occupational health (n = 1).
- Most studies conducted in USA (n = 17), followed by Canada (n = 12), Australia (n = 5), Europe (n = 3).
- Study designs: case reports (n = 18), single group pre-/post-test studies (n = 10), qualitative studies (n = 7), and **randomized controlled trials (RCTs) (n = 2)**. Both RCTs evaluated the implementation of organizational EIDM.
- **Lack of any comparison group hampered quality of studies and conclusions**.
- Mostly focussed on barriers and facilitators

COM-B model for behaviour change & facilitators and barriers for implementing evidence in organisations

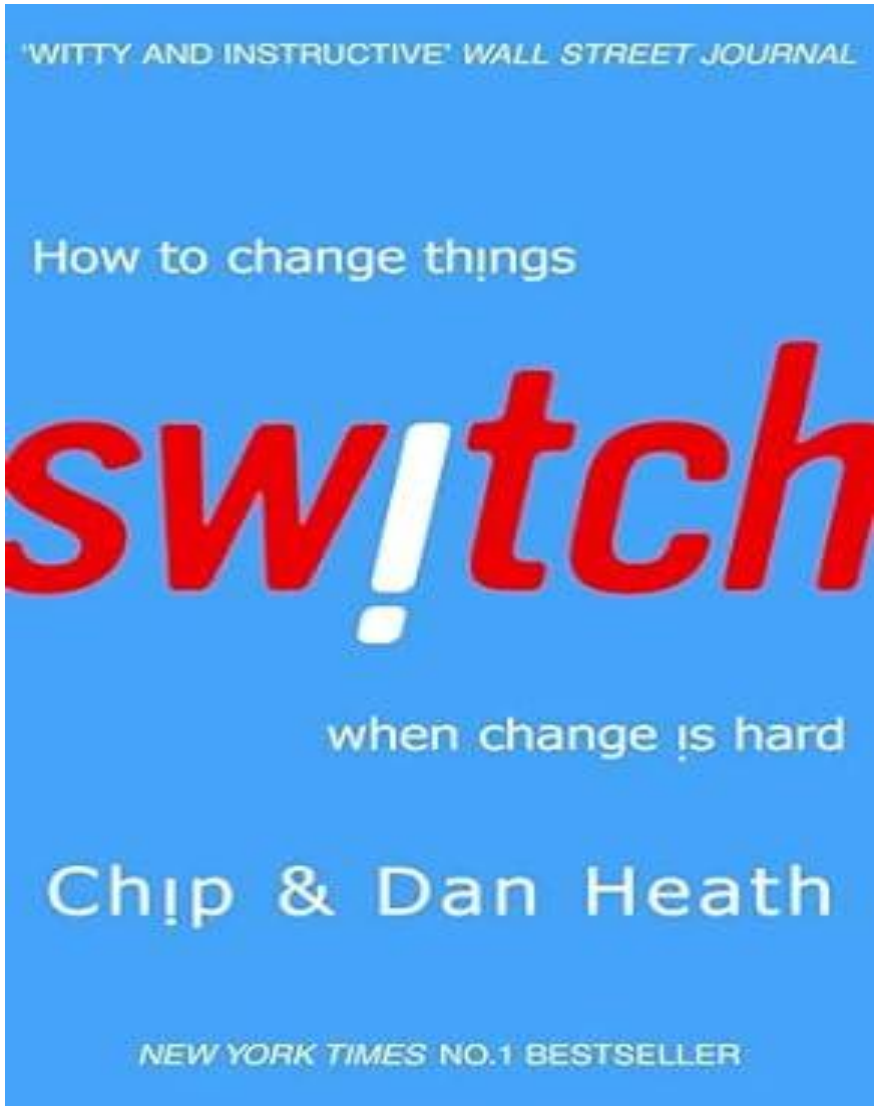


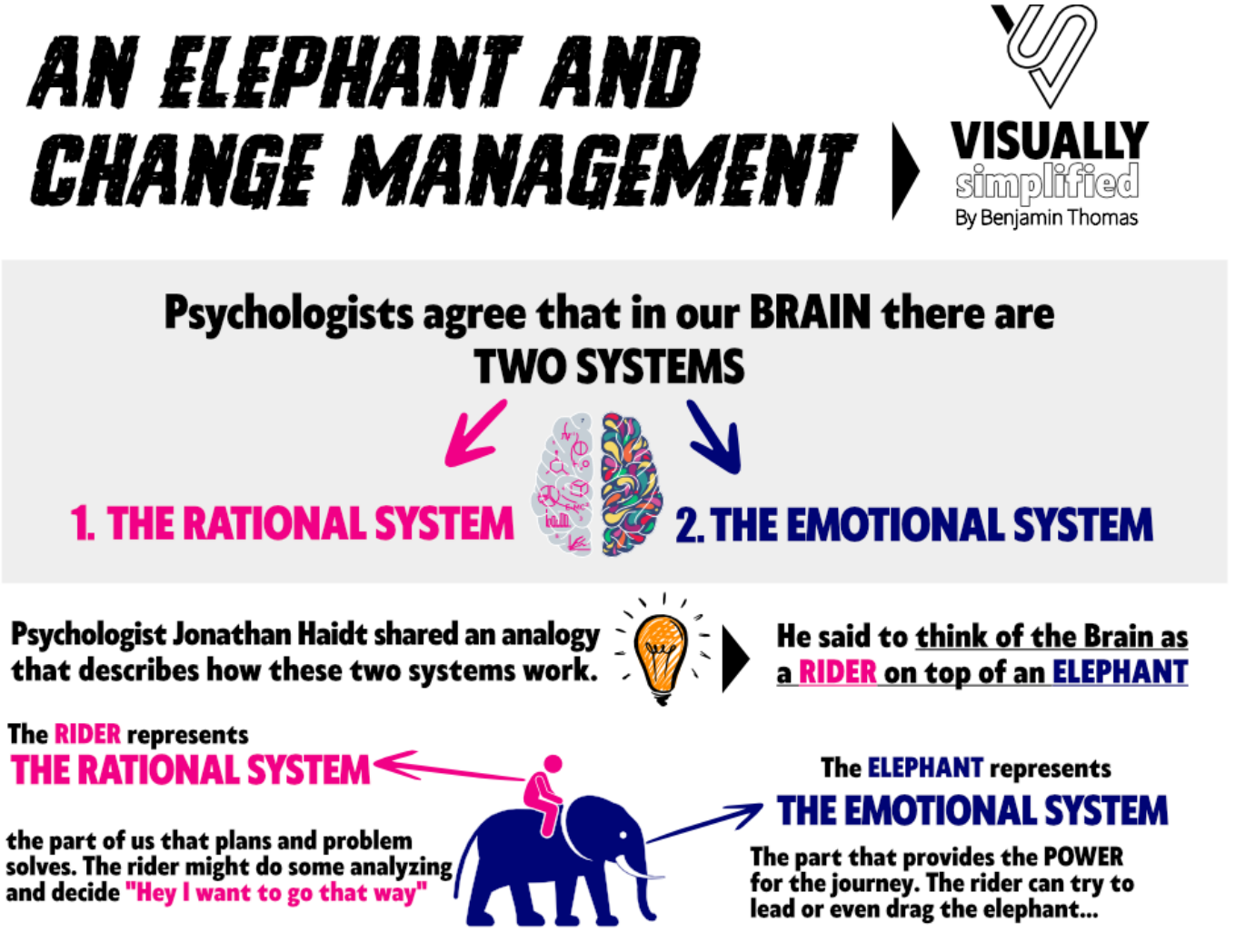
Source: Clark, E.C., et al Strategies to implement evidence-informed decision making at the organizational level: a rapid systematic review. BMC Health Serv Res 24, 405 (2024)

Implementation Science

- examines methods & strategies that enable successful implementation of practice .. @Mark Pearson lecture..
  - established in early 2000s in response to gap between best evidence & behaviour change
  - commonly cited takes 17–20 years for clinical innovations to become practice.. Aims to speed this up
- many frameworks, models, and tools, e.g.
  - Knowledge to Action (process model to guide the process of translating research into practice)
  - Determinant Frameworks (Describes determinants that are hypothesized to influence implementation outcomes (e.g., fidelity, skillset, reinforcement) – e.g.
    - PARIHS (Promoting Action on Research Implementation in Health Services)
    - Theoretical Domains Framework (TDF) integrates several theories into 14 core domains.
    - CFIR: (Consolidated Framework for Implementation Research) is a practical guide for assessing barriers and enablers during implementation
    - Creating Learning Environments for Compassionate Care (CLECC) – adapted for palliative care
  - Classic Theories e.g.
    - Rogers' Diffusion of Innovation - implementation, or diffusion of behaviour change, is a social process
    - COM B (Capability, Opportunity, Motivation, Behaviour) uses behaviour change wheel to support intervention designs
    - NPT (Normalization Process Theory) aims at assessing how behaviour change is embedded into regular routines. Includes a 16-item assessment scale centred on four core constructs

Learning from wider change management..
Chip and Dan Heath – 'Switch'





Chip and Dan Heath – 'Switch'

...But if these two ever disagree

THE ELEPHANT HAS A SIX TON WEIGHT ADVANTAGE

It is this POWER IMBALANCE that makes change or adopting NEW BEHAVIORS VERY HARD.

To get them both to to head to a new direction we also need to consider the PATH which represents THE EXTERNAL ENVIRONMENT.

The RIDER and the ELEPHANT are more likely to complete a journey together if we can shorten the distance and remove any obstacles in their way.

SO TO LEAD SUSTAINING CHANGE - WE NEED TO DO THREE THINGS

1. DIRECT THE RIDER

Make the destination clear: *if the rider isn't sure of where he/she is headed then they will lead the elephant in circles. Often what looks like resistance is actually a lack of clarity.*

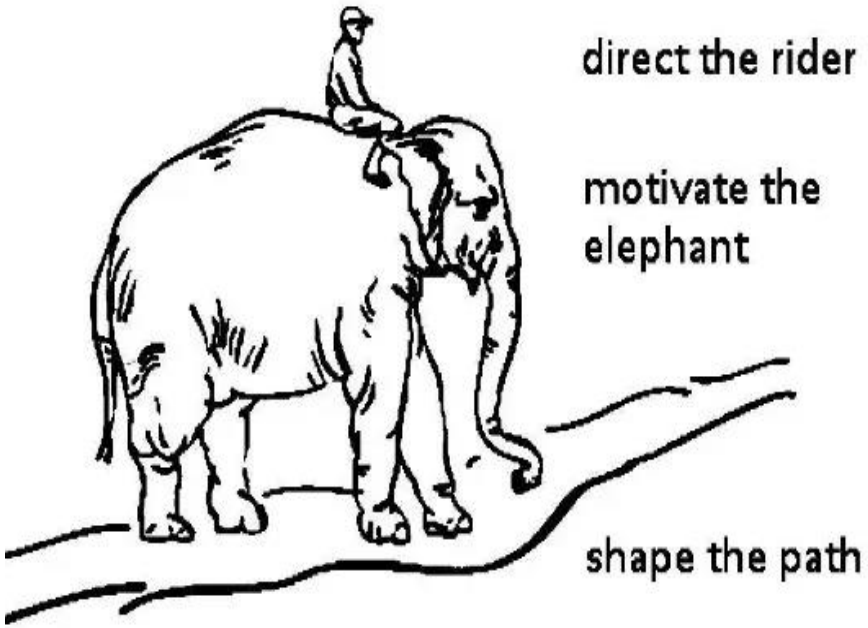
2. MOTIVATE THE ELEPHANT

Inspire people to feel the need to change: *The rider may get their way temporarily through close monitoring and force but not for very long. Ultimately the elephant will always overpower the rider and the rider will be exhausted. Often what looks like laziness is actually exhaustion.*

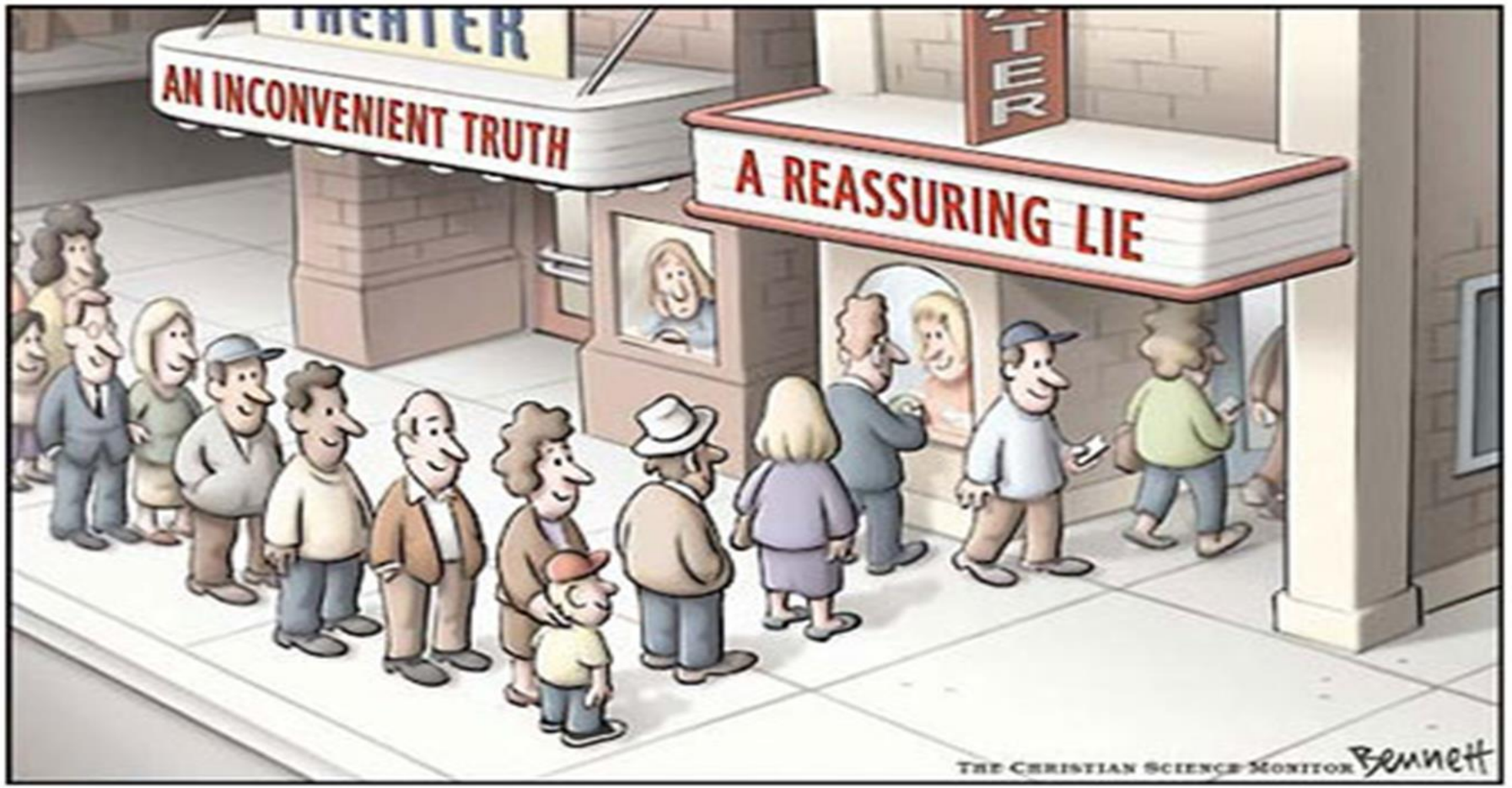
3. SHAPE THE PATH

Make Change specific: *Focus on the surrounding environment, be specific about obstacles that lie ahead, set milestones that are close and easy to achieve and narrow the focus to the destination, so that the Elephant and the rider are more likely to stay together toward the goal. Often what looks like a people problem is actually a situation problem.*

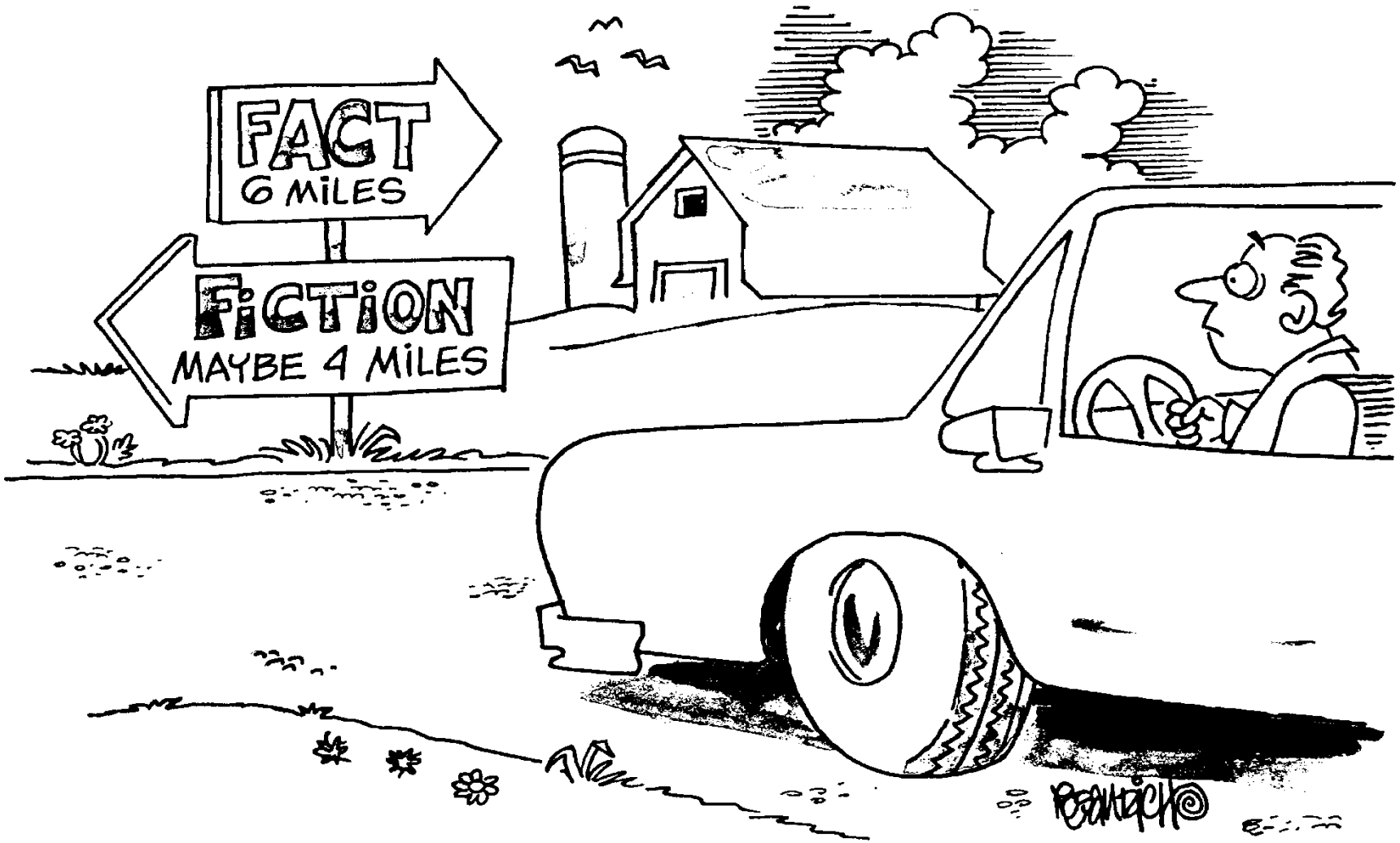
Adapted from the book ***Switch: How to change things when Change is hard*** by Chip and Dan Heath. *Visually Simplified by Benjamin Thomas*



Let's take a step back..
Do we want evidence-based change?



Why do we want evidence-based change?



Seven alternatives to evidence-based practice

KING'S College LONDON

Basis of clinical practice

Basis for clinical decisions	Marker	Measuring device	Unit of measurement
Evidence	Randomised controlled trial	Meta-analysis	Odds ratio
Eminence	Radiance of white hair	Luminometer	Optical density
Vehemence	Level of stridency	Audiometer	Decibels
Eloquence (or elegance)	Smoothness of tongue or nap of suit	Teflometer	Adhesin score
Providence	Level of religious fervour	Sextant to measure angle of genuflection	International units of piety
Diffidence	Level of gloom	Nihilometer	Sighs
Nervousness	Litigation phobia level	Every conceivable test	Bank balance
Confidence*	Bravado	Sweat test	No sweat

*Applies only to surgeons.

Source: Isaacs D, Fitzgerald D. Seven alternatives to evidence based medicine BMJ 1999; 319 :1618

Why and how do we want evidence-based change?

What if we don't change at all
and something magical happens?

Evidence-based change in palliative care: what do we need to make it happen..

Agree is gap in knowledge and that change is needed..

E.g. what is going wrong now.. Or what will go wrong

Examples:

- Shift in palliative care from only cancer to including other diseases (evidence that people with diseases other than cancer had similar symptoms or problems.. Followed by research to manage those symptoms and problems)
- Lack of research in breathlessness, and no treatments, to emerging studies, and evidence now for non-pharmacological treatments
- Covid – palliative care missing from response, demonstrated need and later what was effective..

Palliative care evidence-based change: what do we need to make it happen..

Evidence is generated…

Research results shared and read

Research results delivered and published

Methods for research …

Outcome measures, right samples, minimise bias, right questions

Funding for research …

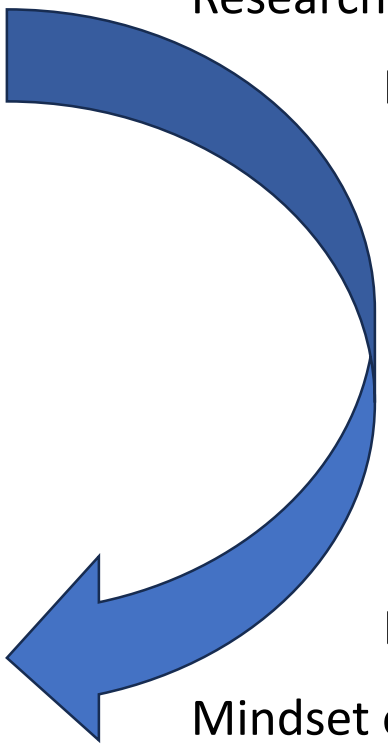
Enough skilled people and premises to do research

Research conducted at the right time to be useful

Appropriate journal and peer review of the work

Equipoise and good balance in reporting results

Mindset of innovators / those advocating change to use evidence



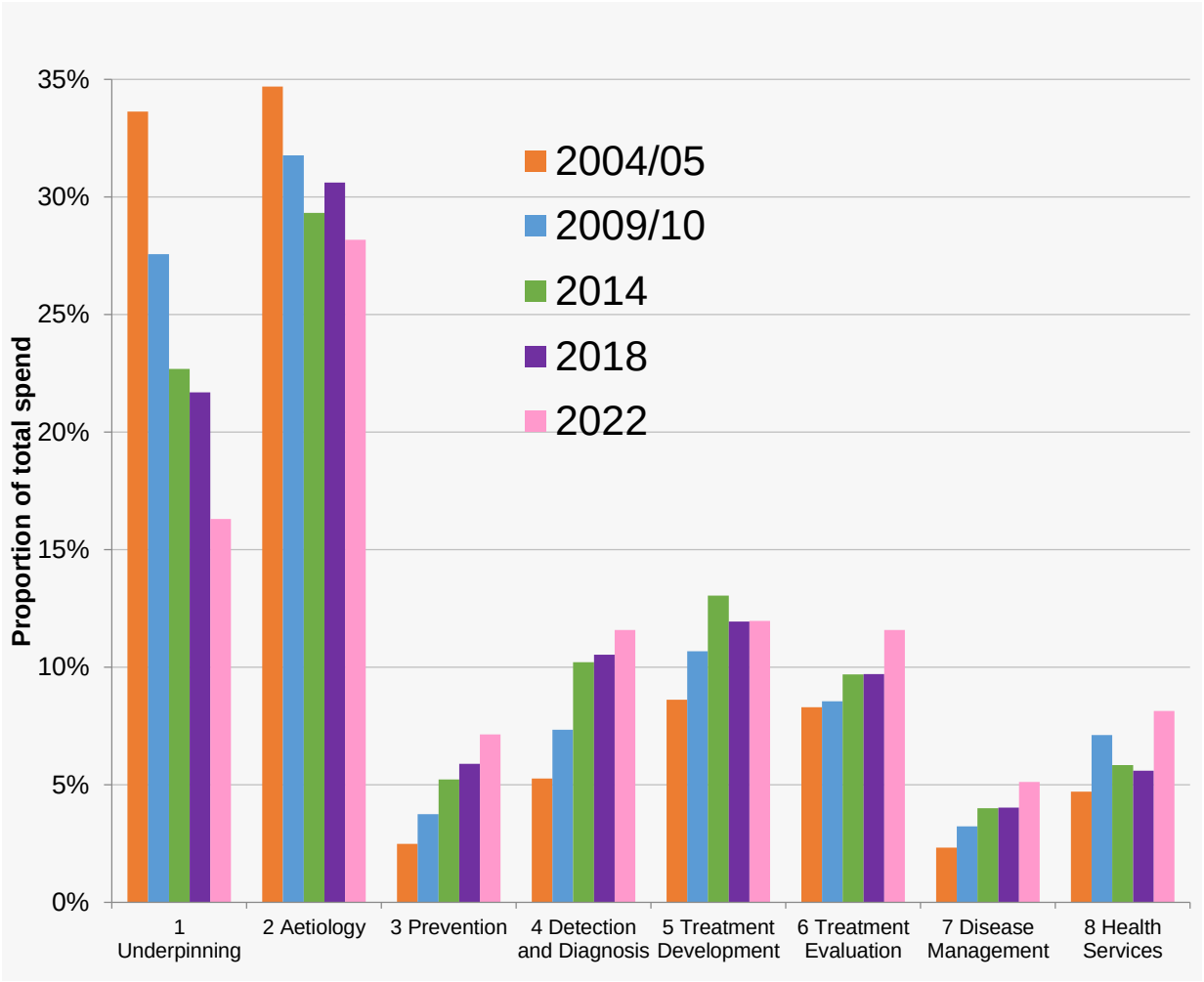
Palliative care evidence-based change: what do we need to make it happen..

Research funding and capacity

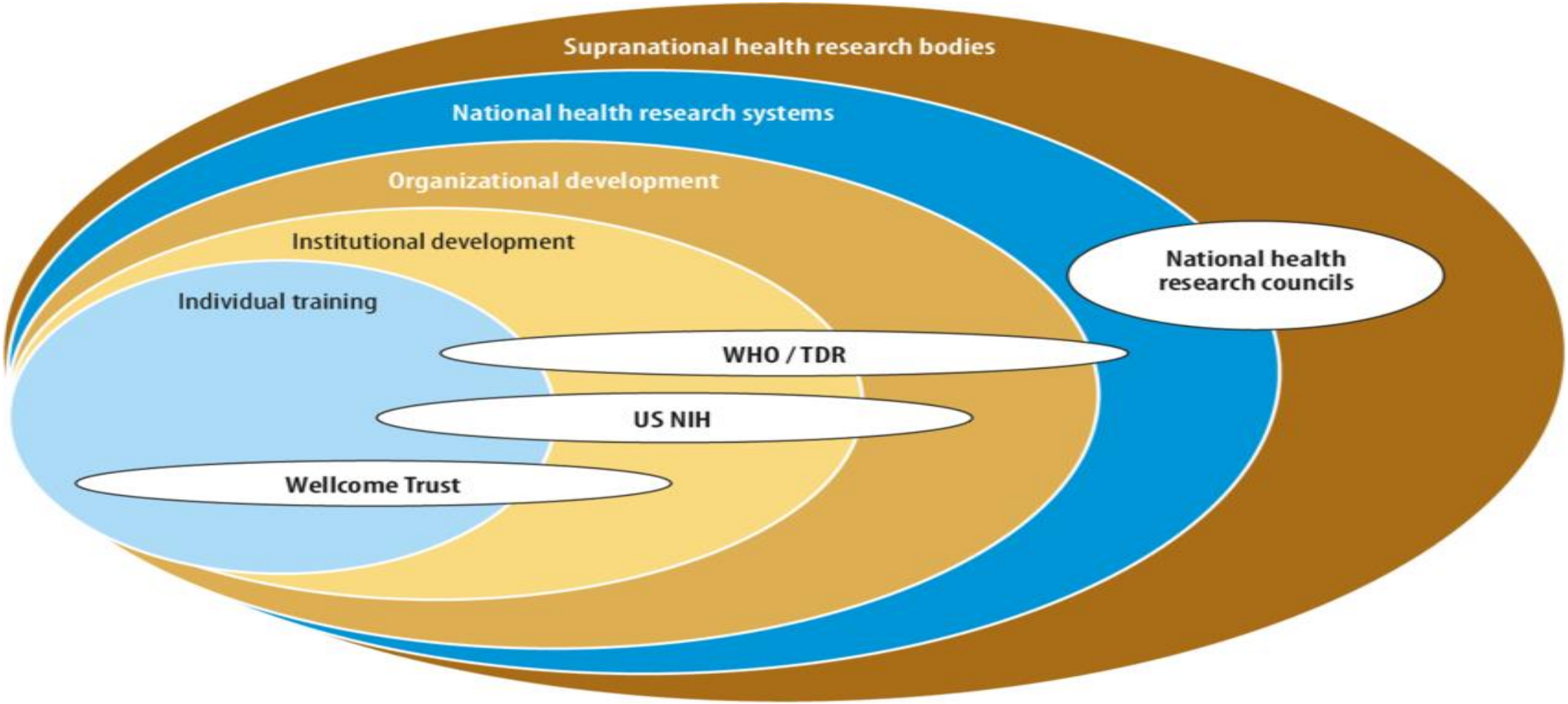
- Funding for health relevant research in the UK (Govt, charity etc) has increased 2004-2022
- Over £4bn of spend within the UK (2022); £2.8bn spent directly on research projects; £1.4bn on infrastructure
- But.. much of this growth occurred 2004-2009; near flat 2009/10-2022 & real-terms decrease in health research funding 2018-2022
- Palliative & End of Life Care is within 'Disease Management' and was (of total spend): 0.08% (2004), 0.10% (2009), 0.16% (2014), 0.21% (2018), 0.23% (2022) (23p in every £100)

Source: UK Health Research Analysis 2022 (UK Clinical Research Collaboration , 2023), formally published 1 Feb 2024. https://hrcsonline.net/reports/analysis-reports/uk-health-research-analysis-2022/

Trends in % of health care research spending by area, UK



Need research capacity: individuals and systems



Need valid, reliable, appropriate, sensitive to change, outcomes

https://pos-pal.org/

Valuable for

- Needs assessment
- Communication
- Audit
- Research
- Monitoring

Need to be:

- Responsive to change
- Valid
- Reliable
- Acceptable (incl culturally & time)

Need valid, workable, efficient methods.. MORECare

Higginson et al. BMC Medicine 2013, 11:111
http://www.biomedcentral.com/1741-7015/11/111

RESEARCH ARTICLE Open Access

Evaluating complex interventions in End of Life Care: the MORECare Statement on good practice generated by a synthesis of transparent expert consultations and systematic reviews

Irene J Higginson[1*], Catherine J Evans[1*], Gunn Grande[2], Nancy Preston[2,3], Myfanwy Morgan[4], Paul McCrone[5], Penney Lewis[6], Peter Fayers[7,8], Richard Harding[1], Matthew Hotopf[9], Scott A Murray[10], Hamid Benalia[1], Marjolein Gysels[1,11], Morag Farquhar[12], Chris Todd[2] and on behalf of MORECare

36 items, including in equator.. https://www.equator-network.org/reporting-guidelines/morecare-statement/

	Recommendations
Introduction/ background	1. Present theoretical framework for the intervention and levels of need established 2. Present objectives appropriate to the level of intervention development
Design	3. Indicate and justify stage in MRC guidance for development and evaluation of complex interventions, e.g. feasibility, preliminary evaluation, efficacy/cost effectiveness and wider effectiveness 4. Feasibility stages should test both feasibility of the intervention and of methods of evaluation, including outcome measurement 5. Justify methods, considering appropriate use of existing data sets and secondary analysis as these may produce rapid information 6. Justify methods of empirical studies considering mixed methods, observational studies and randomised trials
Study team	7. Ensure involvement from: (i) consumers, patients and caregivers; (ii) relevant clinicians; (iii) relevant methodologists to develop study questions, questionnaires and procedures and (iv) researchers familiar with the challenges in EoLC studies 8. Ideally involvement should be well established and continuing, beyond a specific study, with joint meetings or rotations between clinical and research staff

We know that patients and families want to take part in research and it can be done ethically, even when people lack capacity..

Gysels et al. BMC Medical Research Methodology 2012, 12:123
http://www.biomedcentral.com/1471-2288/12/123

BMC Medical Research Methodology

RESEARCH ARTICLE Open Access

Patient, caregiver, health professional and researcher views and experiences of participating in research at the end of life: a critical interpretive synthesis of the literature

Marjolein H Gysels*, Catherine Evans and Irene J Higginson

Results: Of a total of 239 identified studies, 20 studies met the inclusion criteria, from: the US (11), the UK (6) and Australia (3). Most focused on patients with cancer (12) and were conducted in hospices (9) or hospitals (7). Studies enquired about issues related to: EoL care research in general (5), specific research methods (13), and trial research (2). The studies evaluating willingness to participate in EoL care research showed positive outcomes across the different parties involved in research. Factors influencing willingness were mainly physical and cognitive impairment. Participating in research was a positive experience for most patients and carers but a minority experienced distress. This was related to: characteristics of the participants; the type of research; or the way it was conducted. Participatory study designs were found particularly suitable for enabling the inclusion of a wide range of participants.

Conclusion: The evidence explored within this study demonstrates that the ethical concerns regarding patient participation in EoL care research are often unjustified. However, research studies in EoL care require careful design and execution that incorporates sensitivity to participants' needs and concerns to enable their participation. An innovative conceptual model for research participation relevant for potentially vulnerable people was developed.

Evans et al. BMC Medicine (2020) 18:221
https://doi.org/10.1186/s12916-020-01654-2

BMC Medicine

RESEARCH ARTICLE Open Access

Processes of consent in research for adults with impaired mental capacity nearing the end of life: systematic review and transparent expert consultation (MORECare_Capacity statement)

C. J. Evans[1,2*], E. Yorganci[1], P. Lewis[3], J. Koffman[1], K. Stone[1], I. Tunnard[1], B. Wee[4], W. Bernal[5], M. Hotopf[6], I. J. Higginson[1] and on behalf of MORECare_Capacity

Results: Of the 5539 articles identified, 91 met eligibility. The studies encompassed people with dementia (27%) and in palliative care (18%). Seventy-five percent used observational designs. Studies on research methods (37 studies) focused on processes of proxy decision-making, advance consent, and deferred consent. Studies implementing research methods (30 studies) demonstrated the role of family members as both proxy decision-makers and supporting decision-making for the person with impaired capacity. The TEC involved 43 participants who generated 29 recommendations, with consensus that indicated. Key areas were the timeliness of the consent process and maximising an individual's decisional capacity. The think-tank ($n = 19$) refined equivocal recommendations including supporting proxy decision-makers, training practitioners, and incorporating legislative frameworks.

Conclusions: The MORECare_C statement details 20 solutions to recruit ALC nearing the EoL in research. The statement provides much needed guidance to enrol individuals with serious illness in research. Key is involving family members early and designing study procedures to accommodate variable and changeable levels of capacity. The statement demonstrates the ethical imperative and processes of recruiting adults across the capacity spectrum in varying populations and settings.

Further MORECare guides on:

- ‘Best practice’ to develop and evaluate palliative and EoLC services
- Recommendations for managing missing data, attrition and response shift
- Outcome measurement selection and use
- Ethical issues
- Mixed methods, interdisciplinary
- Health economics

- For more see: https://www.kcl.ac.uk/research/morecare

Plus books, e.g. 2nd edition written & due later this year

The Future..?

The Future of Medical Care?

Demographic, Population & Advancement Challenges: pressures on the system and shrinking workforce

Breathlessness

> 5 health conditions

Frailty / dementia

- Two-thirds of adults >65 years expected to be living with multimorbidity by 2035
- Health care spending as % GDP ⬆ 50% in last 20 years
- Global fiscal challenges
- Health care creates 4.4% of emissions
- Solutions largely overlooked for most complex patients, (highest cost, poorest outcomes)
- Many people with multimorbidity leave hospital more ill than when they entered
- **Inequity is widening**, emergency attendance in deprived areas double
- **Workforce shortages**
- Population challenges increasing most rapidly in lower & middle income countries

Unless we act wisely, things will get worse .. everywhere

Multimorbidity increases by age, by deprivation, and is increasing over time

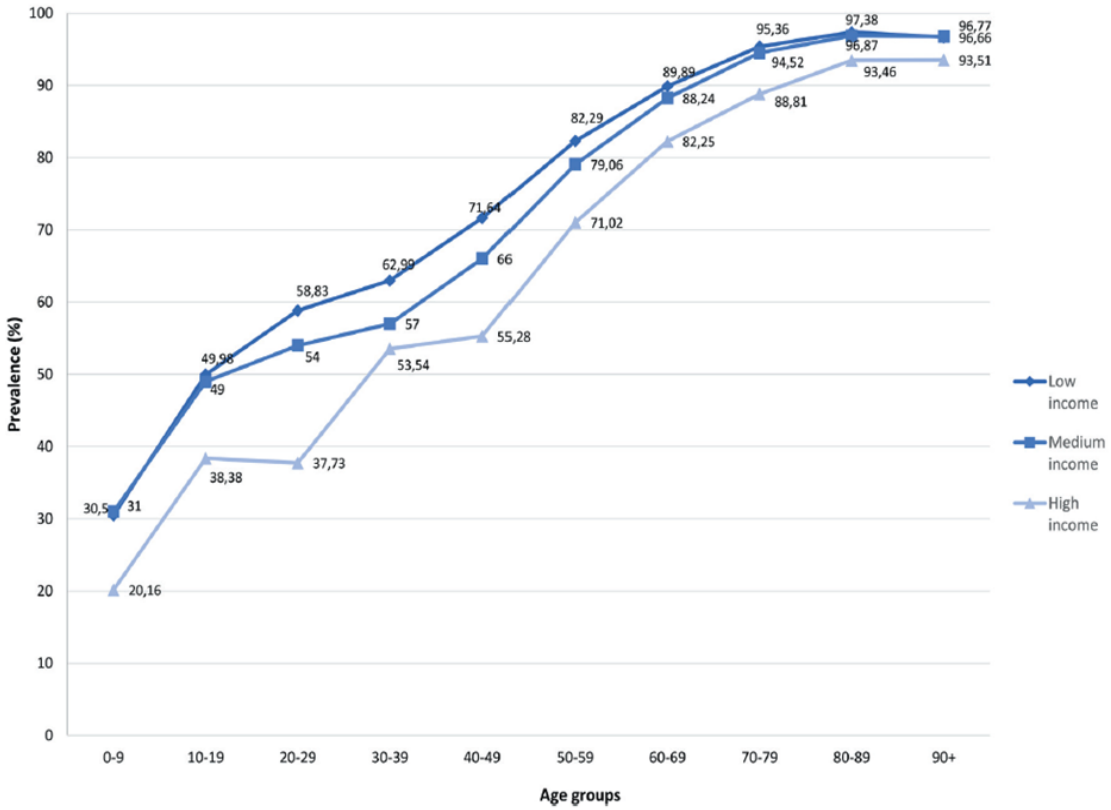


Figure 2. Prevalence of multimorbidity by age group and annual gross income. Annual gross income based on the prescription co-payment rate (low income <€18000, medium income €18000-€100000, and high income >€100000).

Source: Moreno-Juste A et al, J Glob Health 2023; 13:04014.

People living in deprived areas are:

- less likely to be cared for at home towards the end of life
- less likely to die at home
- less likely to access palliative care

Source: Davies JM, et al PLoS Med.

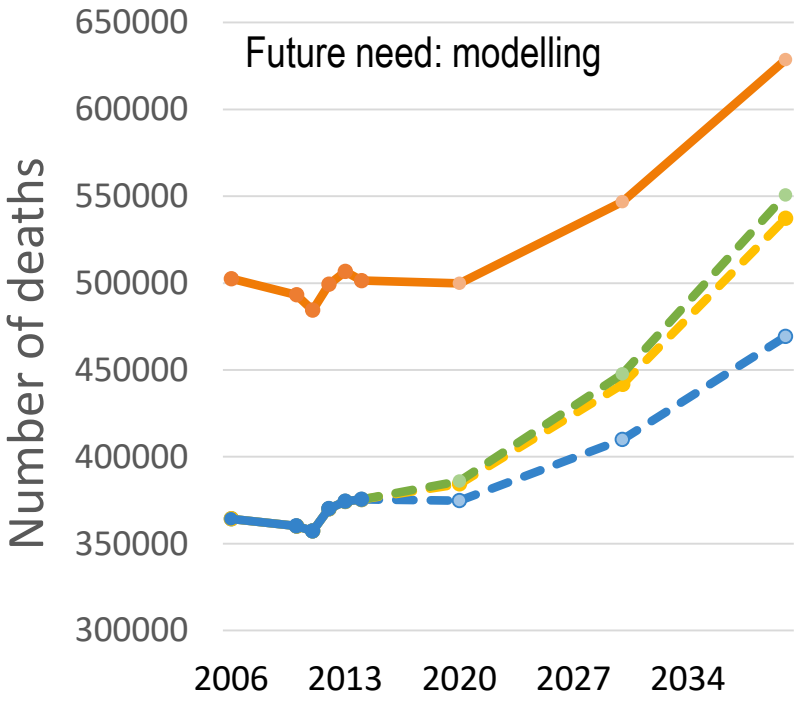
New health policy changes often miss benefiting those people in deprived areas, those with multimorbidity, those from different ethnic groups.

Sources: Bajwah S, et al, BMJ Support Palliat Care. Higginson IJ, et al, BMC Med

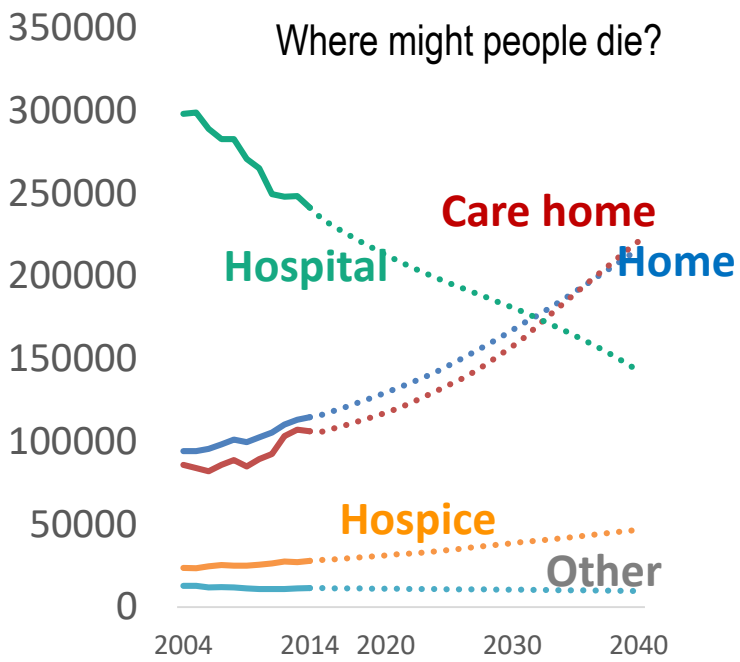
Is a risk with new initiatives such as virtual wards ..

Escalating need of complex illness. Currently, last year of life - 20% health care costs and 1:3 people in hospital

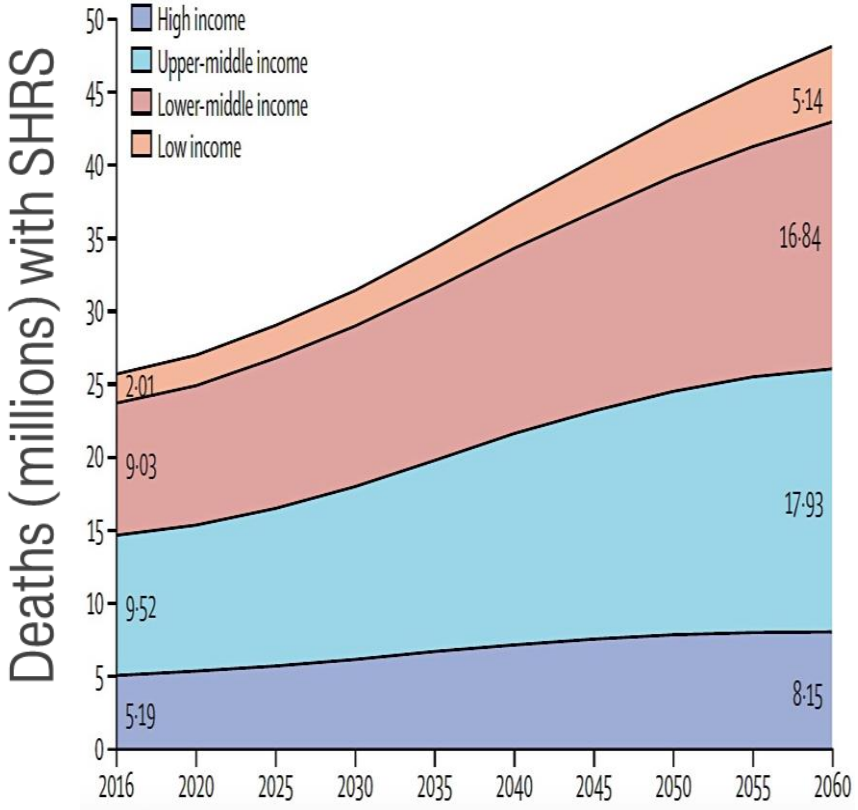
All deaths in England and Wales (ONS data and official mortality projections)



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



Deaths with serious health related suffering (SHRS) are projected to climb



Sources: Etkind et al. BMC Medicine (2017) 15:102
Bone et al Palliat Med. 2017 Oct 1:269216317734435.

Sleeman et al, The Lancet Global Health 2019

WHO report: Acute worldwide shortage in nursing
State of the World's Nursing Report - 2020

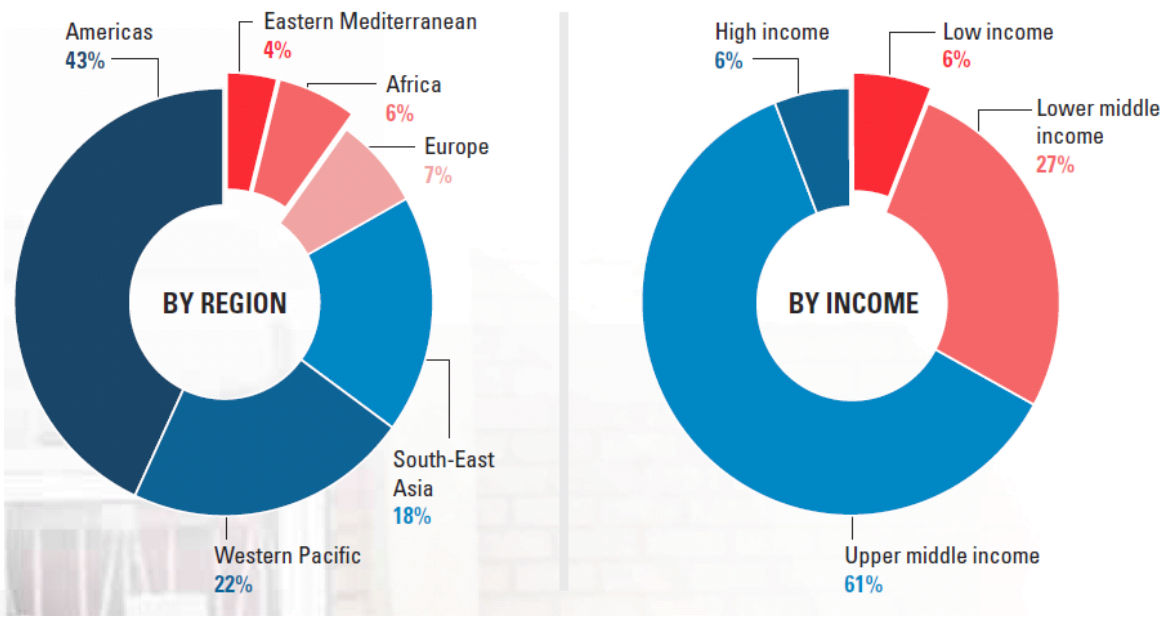
KING'S College LONDON

The global nursing workforce is 27.9 million, of which 19.3 million are professional nurses. This indicates an increase of 4.7 million in the total stock over the period 2013–2018, and confirms that nursing is the largest occupational group in the health sector, accounting for approximately 59% of the health professions. The 27.9 million nursing personnel include 19.3 million (69%) professional nurses, 6.0 million (22%) associate professional nurses and 2.6 million (9%) who are not classified either way.

The world does not have a global nursing workforce commensurate with the universal health coverage and SDG targets. Over 80% of the world's nurses are found in countries that account for half of the world's population. The global shortage of nurses, estimated to be 6.6 million in 2016, had decreased slightly to 5.9 million nurses in 2018. An estimated 5.3 million (89%) of that shortage is concentrated in low- and lower middle-income countries, where the growth in the number of nurses is barely keeping pace with population growth, improving only marginally the nurse-to-population density levels. Figure 1 illustrates the wide variation in density of nursing personnel to population, with the greatest gaps in countries in the African, South-East Asia and Eastern Mediterranean regions and some countries in Latin America.

To address the shortage by 2030 in all countries, the total number of nurse graduates would need to increase by 8% per year on average, alongside an improved capacity to employ and retain these graduates. Without this increase, current trends indicate 36 million nurses by 2030, leaving a projected needs-based shortage of 5.7 million, primarily in the African, South-East Asia and Eastern Mediterranean regions. In parallel, a number of countries in the American, European and Western Pacific regions would still be challenged with nationally defined shortages. Figure 3 shows projected increases in numbers of nurses by WHO region and by country income group.

Figure 3 **Projected increase (to 2030) of nursing stock, by WHO region and by country income group**



What is the role of evidence-based change in palliative care in the future..?

- Much to offer the 'crisis' in health care, because we understand complexity and can develop evidence in such situations
- Can we embrace and make more of:
  - **Self-care / self-management and carer support interventions** (e.g. Self-Breathe developed from breathlessness support service – https://www.kcl.ac.uk/managing-breathlessness-in-advanced-illness

    https://openres.ersjournals.com/content/9/2/00508-2022

    Can we widen the definition of workforce (volunteers?) and blur boundaries, should we talk of a 'careforce'..
  - **Frugal innovations** (e.g. battery-operated syringe driver.. Digital technology, home monitoring, AI)
  - **Community and co-design,** help to support care where people want to be, work with communities on development, patient and public engagement and involvement taken even further, changing societal attitudes
  - **Research capacity building** (methods, including implementation, co-design, efficient studies, inclusive research)
  - **Collaboration** (many valid questions, need to build on earlier work, and do more impactful studies well)

What might we learn from some ‘great’ leaders who changed practice and policy

John Snow

- 1813 – 1858, Physician and Anesthetist
- Traced source of London cholera outbreaks, including the famous public water pump.
- Inspired fundamental changes in water and waste systems, at a time when bacterium were not discovered, and cholera was thought to be airborne.
- Discovered the new science of epidemiology.

Florence Nightingale

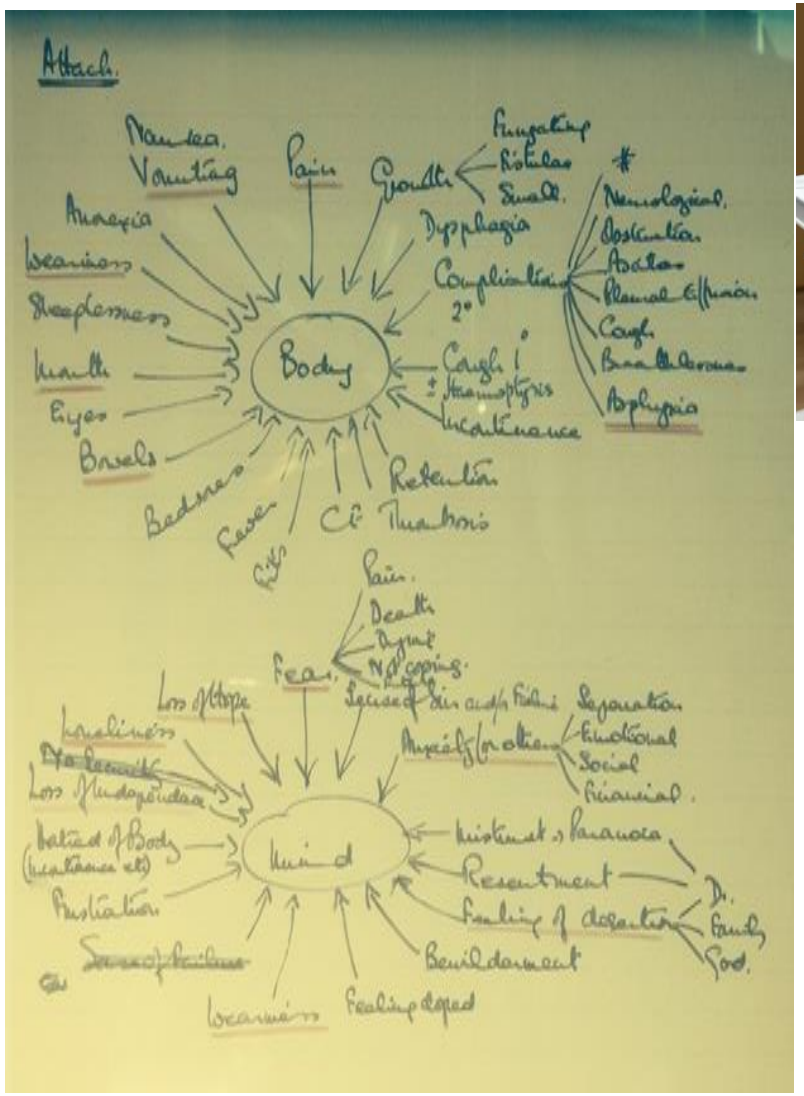
- 1820 –1910, Mathematician and Nurse
- Managed and trained nurses, reorganising care for wounded soldiers
- Professionalised nursing roles for women and founded first Nursing School
- Early founder of statistics

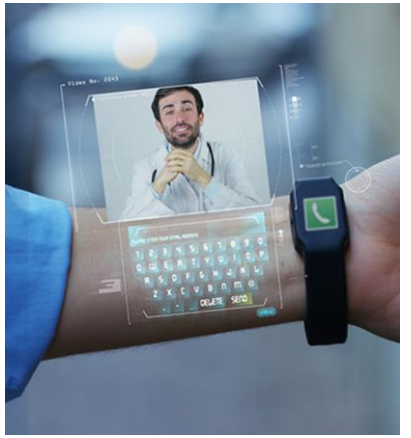
Cicely Saunders

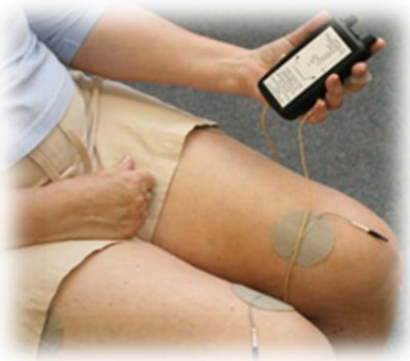
- 1918 –2005, Nurse, Social Worker, Physician
- Founder of modern palliative care
- Introduced research and evidence

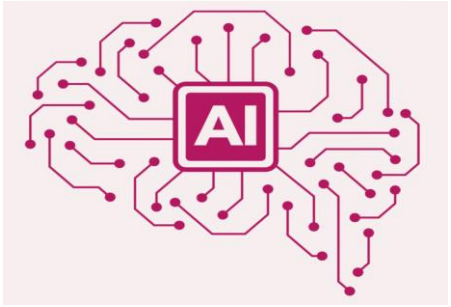
- **Meticulous evidence (collecting data on the ground, repeated testing, visiting places and seeing) to illuminate problem**
- **Changed own mind based on evidence**
- **Graphics (maps, ‘rose chart’, images (patient’s painting of their pain), clear explanation and stories**
- **Did something about it**
- **Perseverance (it took a long time, often in the face of political pressure against them)**

Future for evidence-based change in palliative care: while continuing to embrace mind and body



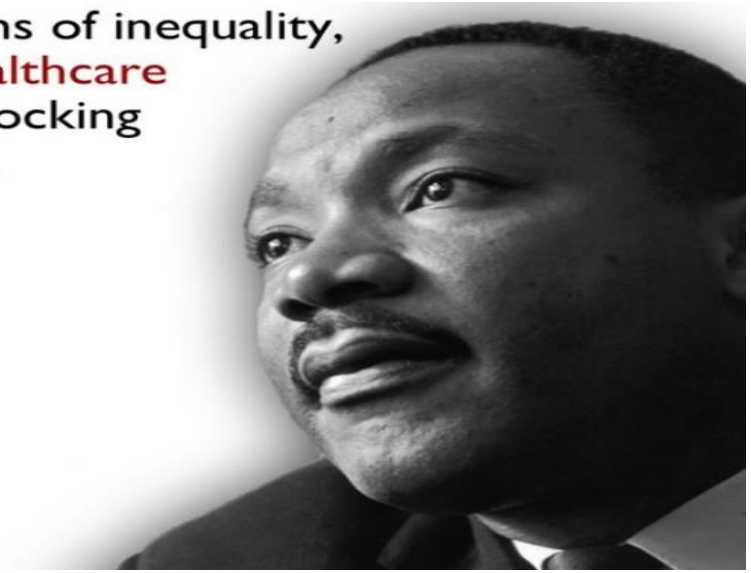






Of all the forms of inequality, injustice in healthcare is the most shocking and inhumane.

Dr. Martin Luther King, Jr.
March 25, 1966



Take home messages

- Evidence-based change
  - Consider models of evidence-based practice, what level individual or organisational
  - Models of change, implementation science, and Chip and Dan Heath, elephant, rider and path
- Why and how do we want evidence-based change in palliative care?
- When do we want evidence-based change? Only after peer review..
- Evidence based-change in palliative care: key requirements: need for change (the concern), evidence in generated, research funding, capacity, research methods, study design, outcome measures, appropriate journals, dissemination
- Future challenges… growth in multimorbidity and suffering and role of palliative care in embracing self-care, carer support, frugal innovation, communities..

THANK YOU!

Discussion and questions

- What do you think of these hypotheses?
- How does this relate to your situation?
- What would you prioritise?