

End of life care in care homes. Developing PhD research plans

Susannah Browne, St Luke's Hospice PhD Fellow

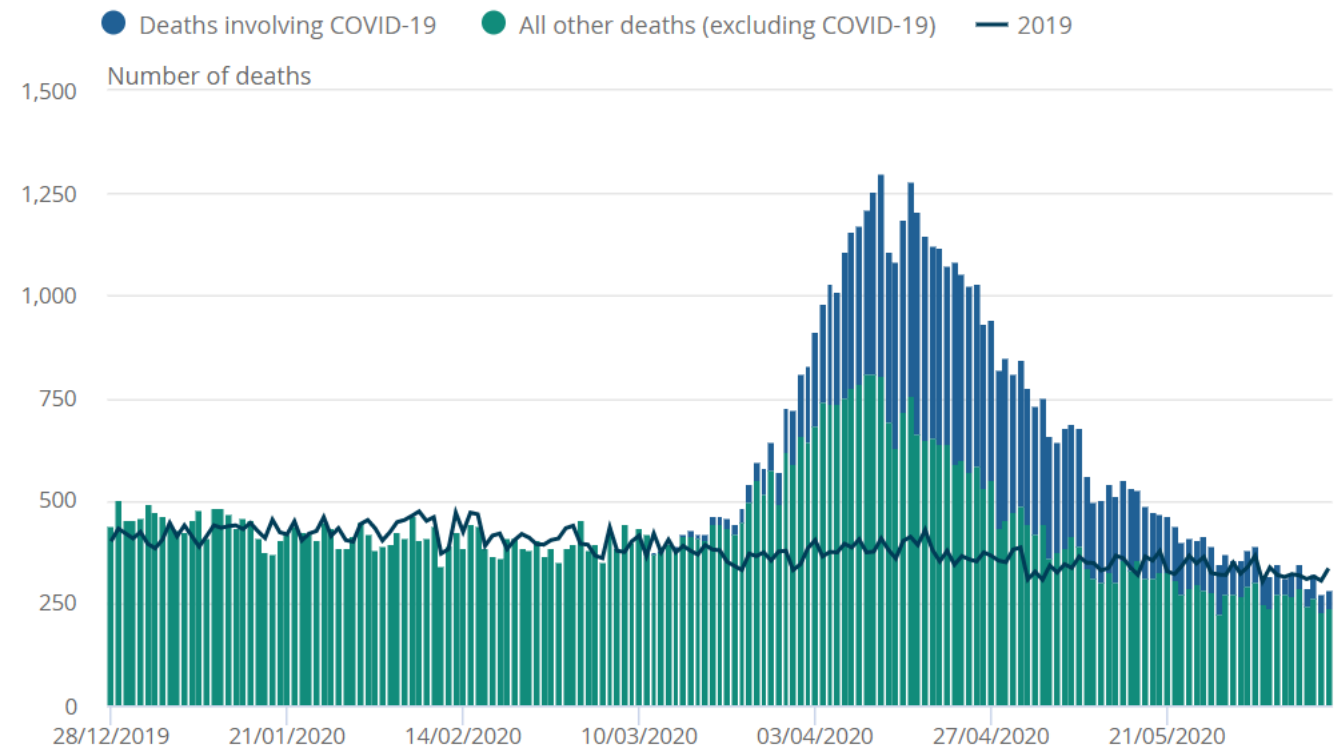
Supervision Team: Professor Stephen Barclay, Professor Mike Kelly, Dr Robbie Duschinsky (Cambridge), Dr Charles Daniels (St Luke's)

Background:

- The pandemic saw care home deaths rise from a rolling average of 7 *per* 1000 a week to 21 *per* 1000 in April 2020
- Resultant pressure on GP care provision to Care Homes has reduced from mandatory fortnightly visits to 'as required'
- End of Life Care in Care Home is Systemic, relying on interdependencies within the system
- Outcome measurement is mainly at the Individual patient level; evaluations don't consider effects on other parts of the system
- Overall long term impact is assumed but not overtly stated making measurement difficult

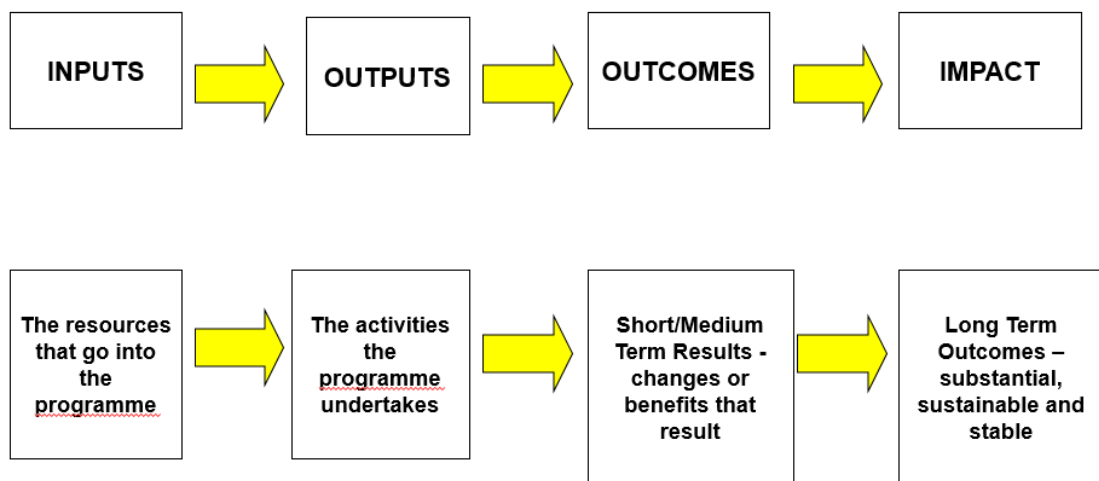
Deaths involving COVID-19 in the care sector, England and Wales: deaths occurring up to 12 June 2020 and registered up to 20 June 2020 (provisional) ONS (2020)

Number of deaths of care home residents from 28 December 2019 to 12 June 2020, registered up to 20 June 2020, England and Wales



Logic Mapping: Disaggregating a Programme of Activity into its Components

Simplest Form

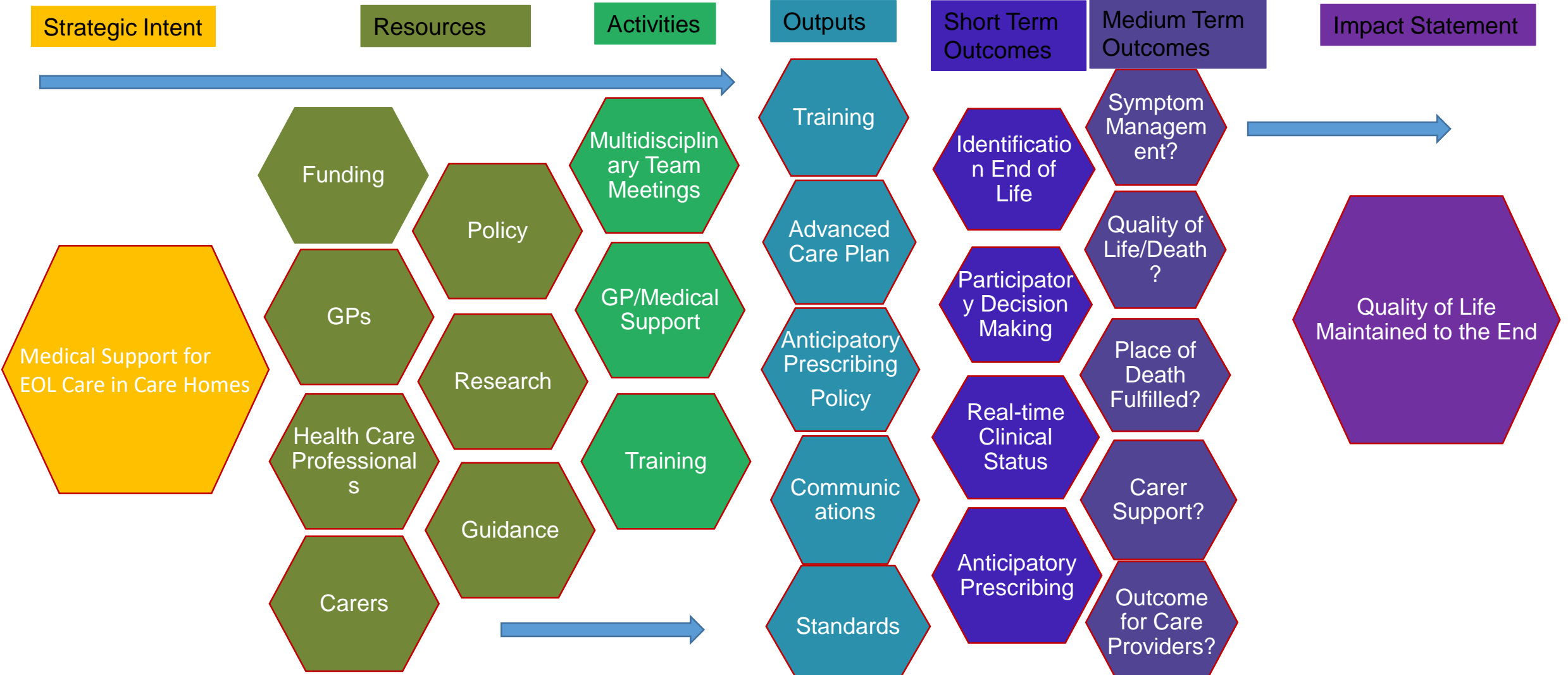


In its simplest form a logic map provides a visual representation of a programme of activity, from its intent to its intended impact. It depicts all the resources and activity currently available to make a programme work e.g. funding, skillsets and the things that are done. It enables interdependencies and assumptions to be surfaced as well as what is working and where gaps in knowledge lie.

OUTCOMES <i>What results for individuals, families, communities</i>		
SHORT <i>Learning</i>	MEDIUM <i>Action</i>	LONG-TERM <i>Conditions</i>
Changes in <ul style="list-style-type: none"> • Awareness • Knowledge • Attitudes • Skills • Opinion • Aspirations • Motivation • Behavioral intent 	Changes in <ul style="list-style-type: none"> • Behavior • Decision-making • Policies • Social action 	Changes in Conditions Social (well-being) Health Economic Civic Environmental

Ultimately a logic map allows us to focus on providing short, medium and long term outcomes – long term meaning sustainable impact. It surfaces what works and what isn't thereby facilitating positive service transformation.

Provisional Logic Map Depicting Medical Provision of End of Life Care in Care Homes

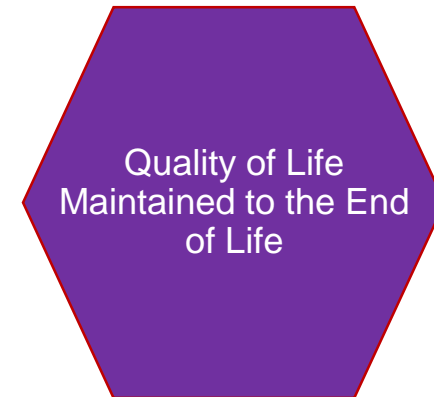


Defining Impact: Medical Provision in Support of End Of Life Care in Care Homes

Facilitator: Ben Bowers

Quality of Life to the End of Life

- How does this strike you as an overarching impact statement?
- What should the impact statement capture?
- What's missing – should the needs of other actors be considered e.g. carers, medical professionals, care home staff, care home owners?



Thinking Prompt:

OUTCOMES <i>What results for individuals, families, communities.....</i>		
SHORT <i>Learning</i>	MEDIUM <i>Action</i>	LONG-TERM <i>Conditions</i>
Changes in <ul style="list-style-type: none">• Awareness• Knowledge• Attitudes• Skills• Opinion• Aspirations• Motivation• Behavioral intent	Changes in <ul style="list-style-type: none">• Behavior• Decision-making• Policies• Social action	Changes in <ul style="list-style-type: none">ConditionsSocial (well-being)HealthEconomicCivicEnvironmental

Defining Short and Medium Term Outcomes

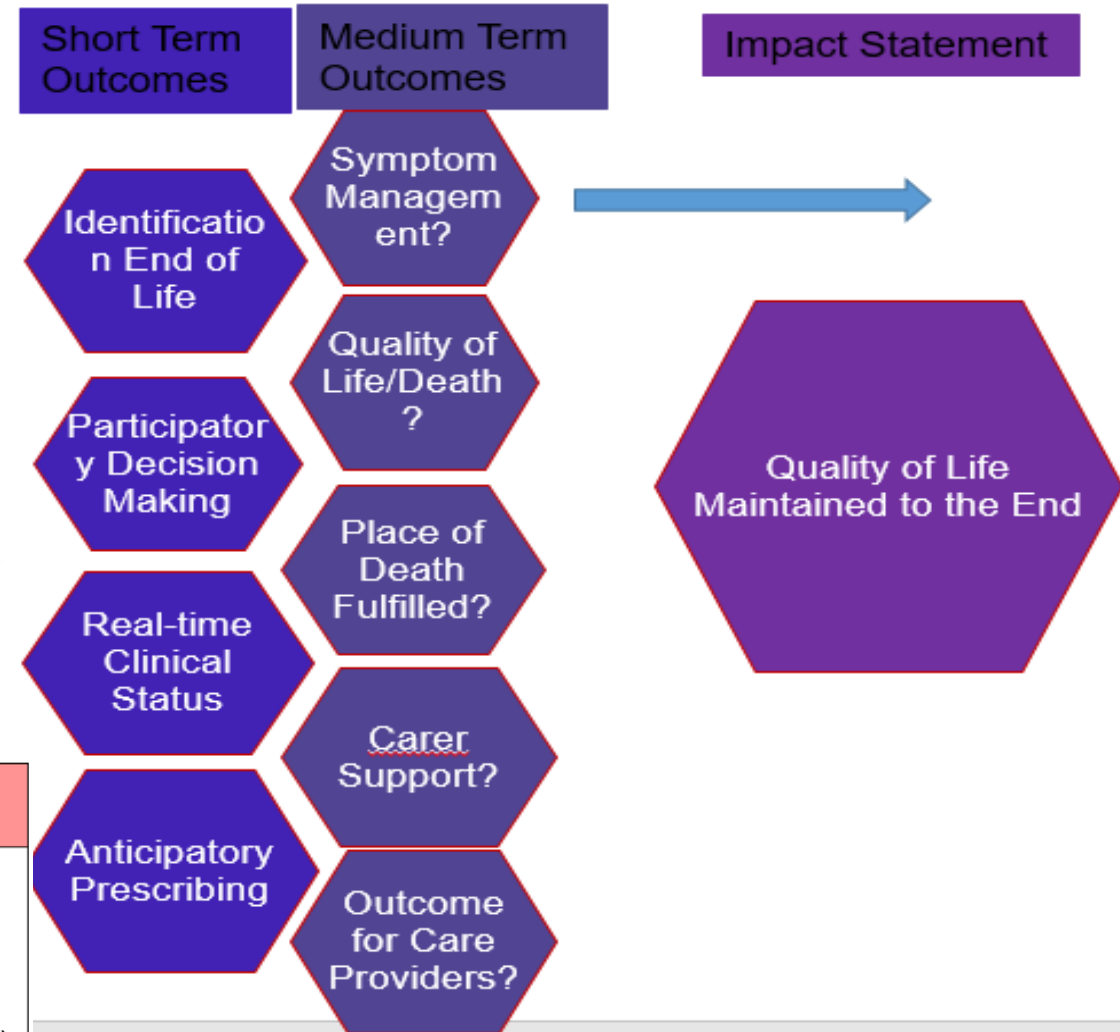
Facilitator: Dr Simon Etkind

- delivering short and medium term outcomes are key to achieving impact
- given that the impact statement is fixed.....and thinking about medical support of end of life care in the context of care homes
- Are these outcomes correct?
- What outcomes are missing?
- Where are our gaps in knowledge about delivering these outcomes?

Thinking Prompt



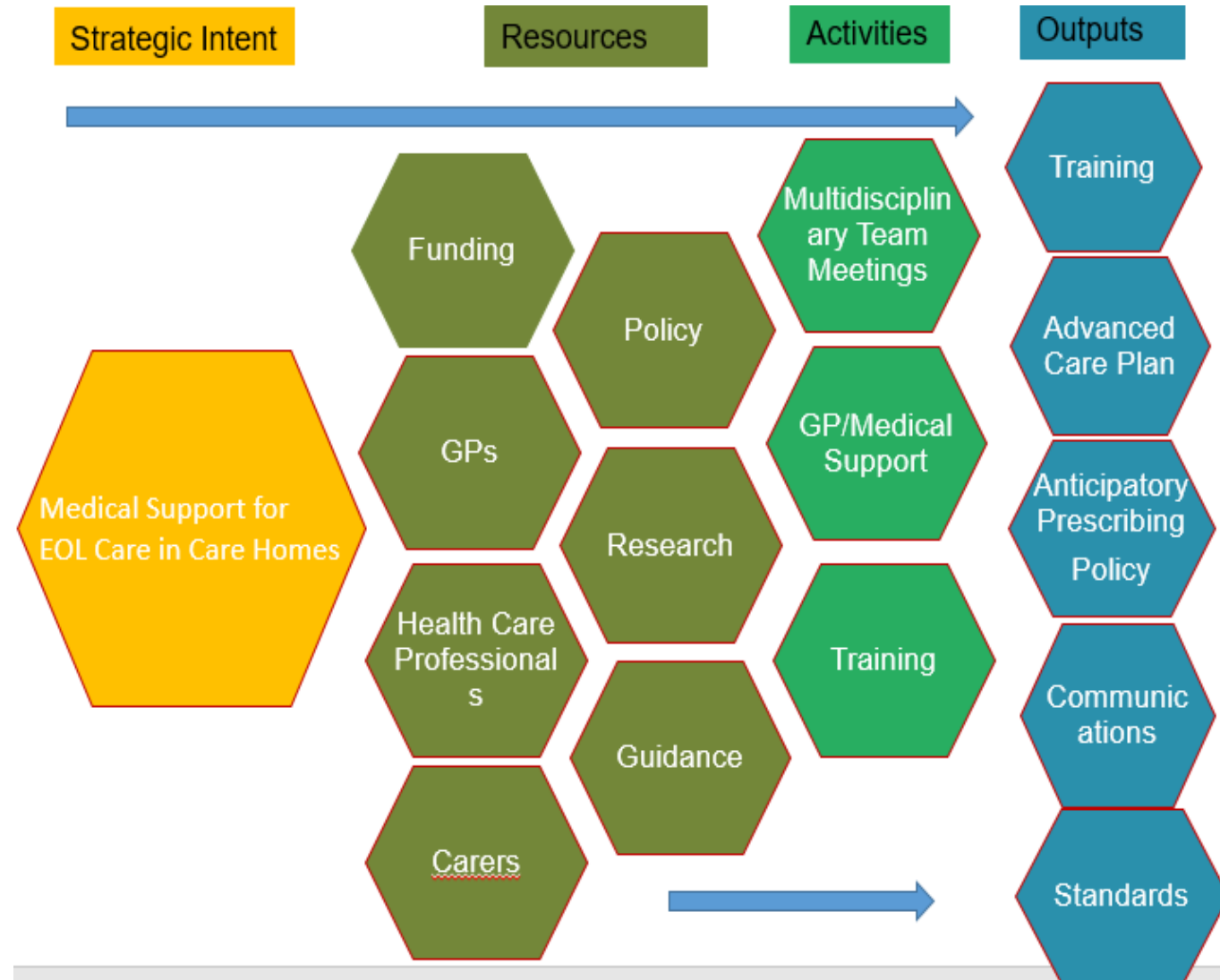
OUTCOMES <i>What results for individuals, families, communities.....</i>		
SHORT <i>Learning</i>	MEDIUM <i>Action</i>	LONG-TERM <i>Conditions</i>
Changes in • Awareness • Knowledge • Attitudes • Skills • Opinion • Aspirations • Motivation • Behavioral intent	Changes in • Behavior • Decision-making • Policies • Social action	Changes in Conditions Social (well-being) Health Economic Civic Environmental



Understanding Inputs, Resources and Outputs

Facilitator: Susannah Browne

- delivering short and medium term outcomes are key to achieving impact
- given that the impact statement is fixed.....and thinking about medical support of end of life care in the context of care homes
- What resources are available?
- What activities take place?
- Are there other outputs being generated?
- Where are our gaps in knowledge about how resource, activities and outputs facilitate the delivery of outcomes?
- Multi-disciplinary working – does it work?



Summing Up

- Demand for the care home sector will continue to rise as our population ages
- Both the health sector and big business are aware that efficiencies can be driven through improved connectivity between social care and health services
- This work is timely – Covid has aired the gaps in our care system; post covid will see HM Treasury clawing back resources and private contractors seeking to increase their bottom line in the context of the fiscal squeeze
- Now is the time to surface the key principles for optimising end of life medical provision at end of life in care homes

Thank you for your time and please do stay in touch
sb2435@medschl.cam.ac.uk twitter @SusannahBrowne

Tweet about this talk #pelicam

Bibliography

- Edwards N and Curry N (2020) "Deaths in care homes: what do the numbers tell us?", Nuffield Trust comment; Bunting, M (2020) Labours of Love: The Crisis of Care, Granta
- ONS (2020) [Rolling annual death registrations by place of occurrence, England, period ending Quarter 4 \(Jan to Mar\) of financial year 2019 to 2020](#)
- Laing Buisson (2021) Care Homes For Older People UK Market Report 31ed
- Deaths involving COVID-19 in the care sector, England and Wales: deaths occurring up to 12 June 2020 and registered up to 20 June 2020
- (provisional) **Provisional figures on deaths involving the coronavirus (COVID-19) within the care sector, in England and Wales;** [Deaths involving COVID-19 in the care sector, England and Wales - Office for National Statistics \(ons.gov.uk\)](#)
- <https://www.longtermplan.nhs.uk/>; <https://www.nice.org.uk/guidance/ng142>; <https://www.england.nhs.uk/publication/enhanced-health-in-care-homes-framework/>; <https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life>; <http://endoflifecareambitions.org.uk/>; <https://www.skillsforcare.org.uk/Home.aspx>; <https://www.england.nhs.uk/gp/investment/gp-contract/>; <https://www.england.nhs.uk/publication/investment-and-evolution-update-to-the-gp-contract-agreement-20-21-23-24/>
- https://www.england.nhs.uk/wp-content/uploads/2015/11/new_care_models.pdf
- <https://www.england.nhs.uk/wp-content/uploads/2020/03/update-to-the-gp-contract-agreement-v2-updated.pdf>
- Chapman, J. (2004) System Failure: Why Governments must learn to think differently. Demos
- <https://onlinelibrary.wiley.com/doi/full/10.1111/j.1468-0009.2005.00397.x>
- <https://uk.sagepub.com/en-gb/eur/the-dynamics-of-social-practice/book235021>
- [EAPC White Paper on outcome measurement in palliative care: Improving practice, attaining outcomes and delivering quality services - Recommendations from the European Association for Palliative Care \(EAPC\) Task Force on Outcome Measurement - PubMed \(nih.gov\)](#)
- [Welcome to Gold Standards Framework](#)
- <https://www.rcgp.org.uk/daffodilstandards>
- <https://www.ichom.org/>
- [Overview | End of life care for adults | Quality standards | NICE](#)
- [International Collaborative for Best Care for the Dying Person. Delphi Study: Consensus on the content of the International Collaborative 10/40 Model \(2020\)](#)