

Making the case for investment in palliative and end of life care: A guide for Integrated Care Boards





Acknowledgements

We are grateful to the following organisations for their financial investment, guidance and assistance on the development of this guide



Commissioning Better Outcomes

Commissioning Better Outcomes is supported by £40 million from The National Lottery Community Fund.

- End of Life Care is one of the projects funded by the Commissioning Better Outcomes programme
- The National Lottery Community Fund is the largest community funder in the UK and distributes over £30million a week for good causes across the UK, thanks to National Lottery players.
- REACT project that feature on page X was supported by The National Lottery Community Fund's Commissioning Better Outcomes programme.

SOCIAL Social Finance

The Care and Wellbeing Fund was set up in 2015 to test whether social investment could be deployed to support improved health outcomes and be a tool for sustainable innovation and transformation in the health and social care sector.

The Fund is managed by Social Finance who are a not-for-profit helping partners design, fund and scale solutions to complex and enduring social issues.

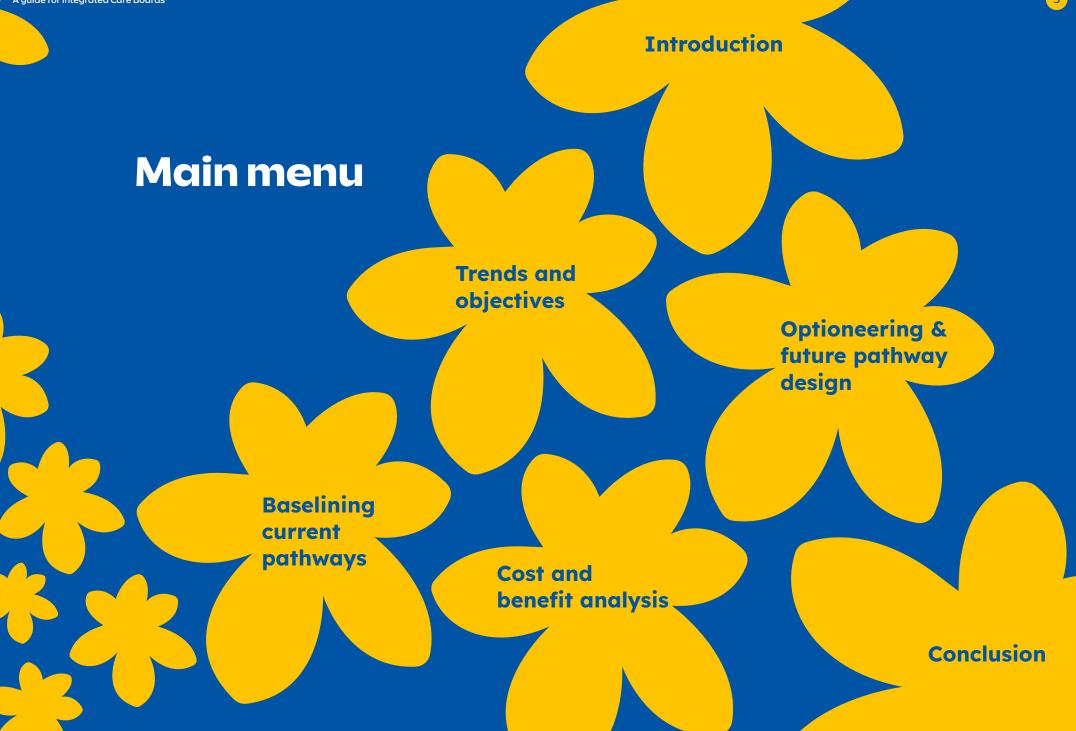
Social outcomes contracts are a funding approach where money is invested at risk and only repaid if and when certain outcomes are achieved – such as enabling more people to die in their preferred place.











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Introduction



How to use this toolkit

Each section is designed to be easily navigable and interactive, allowing you to:

- Jump to specific sections using the hyperlinked table of contents or 'Main menu' button at the top of each page.
- Follow the step-by-step commissioning process with clear instructions and visual guides.
- Use case studies and personas to understand practical applications of the commissioning strategies.
- By following this toolkit, your team will be able to develop a comprehensive business case for commissioning high-quality PEoLC services that meet the needs of your local population.

Who should use this toolkit?

This toolkit is tailored for:

- Commissioners and planners within Integrated Care Boards.
- Health and social care providers.
- Finance teams involved in evaluating the value of PEoLC investments.
- Any stakeholders involved in the delivery or funding of PEoLC services.

Additional pro bono support is available from KPMG and Marie Curie for ICBs wishing to use this toolkit to explore system and service changes in palliative and end of life care for your local population. To find out more about this support offer, please contact: **local@mariecurie.org.uk**



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Introduction

The purpose of this guide is to support Integrated Care Boards to understand the value case for investment in palliative and end of life care services.

The guide can be used to support economic appraisals in business cases, and to help you deliver on your legal responsibility to commission palliative care services in the Health & Care Act. The guide can help you to produce a formal business case for investment in growing an existing service or for developing a brand new one, or it can be used to explore and determine whether the proposed service changes are worthwhile.

Palliative and end of life care (PEoLC) is an approach that improves the quality of life of patients and their families and carers facing the problems associated with life-threatening or life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, including physical, psychosocial and spiritual. The purpose of PEoLC services is to improve the quality of life of patients and their families and unpaid carers, and to help ensure that everyone has the best possible experience of dying, death and bereavement. In addition to bringing benefits for patients and those caring for them, PEoLC can also help to relieve pressures on your wider health and care system. When such care is provided to a high standard and in an integrated way in community settings, it can help patients to live well for longer with multiple health conditions and prevent them entering into a crisis at the end of their lives. Such crises often result in distressing and expensive ambulance call outs, A&E visits, and emergency hospital admissions.

We hope this guide helps your team to invest in the services needed to transform palliative and end of life care for your local population, while also navigating the significant system and budget pressures you are facing at the present time.

This work has been supported by KPMG as part of their national charity partnership with Marie Curie.

Notes

The Health & Care Act 2022 introduced a new legal responsibility to commission palliative care services in every part of England. The Act requires your Integrated Care Board to commission palliative care services that are appropriate for meeting the needs of your local population.



The value case for investment in palliative and end of life care

Defining economic value & beyond

The purpose of PEoLC services is to improve the quality of life of patients and their families and unpaid carers, and to help ensure that everyone has the best possible experience of dying, death and bereavement. These services have an intrinsic value which cannot be captured through economic measures alone. However, at this time of significant pressures on health and social care budgets, and rising demand for PEoLC due to our ageing population, both commissioners and providers of these services are increasingly being asked to capture the value of PEoLC services in economic terms.

This guide is intended to help meet the need for a practical guide on how to capture the value of PEoLC in economic terms. It uses cost-benefit analysis, a widely-used method including by HM Treasury in its Green Book . We encourage use of this guide alongside and not as a substitute for other approaches which capture the intrinsic value of these services to your local populations, including direct involvement of people with lived experience and under-served communities.

Evidence from recent research on economic value of PEoLC

In a review of academic studies and grey literature on this topic between 2014 and early 2024, including an economic evaluation of PEoLC services based in the UK, studies found:

- Improved end-of-life care quality with potential cost savings per resident in the last month of life due to reduced hospitalisation, with policies being cost effective; and
- Increasing community and home management calls and decreasing ambulance and primary care calls, compared to previous patterns, leading to potentially lower system costs

Increasingly, economic evaluations of PEoLC are grappling with challenges that are common to any economic evaluation:

- Achieving sample size, managing drop out and finding appropriate control groups; and challenges that are unique to PEoLC: capturing whole system costs and system changes; measuring quality when years of life are less relevant than quality of remaining life; adhering to rigid timeframes for RCTs where there are fluid trajectories of illness to death;
- Meaningful measurement of costs and benefits to carers and volunteers.

Most studies published in the UK between 2014 and 2024 had these important limitations. There is a clear need for more investment in research in this area, both in developing appropriate methodologies and in funding large scale economic evaluations of PEoLC.



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The value case for investment in palliative and end of life care (...continued)

Evidence from recent research on economic value of PEoLC

Academic evidence

The most robust evidence from randomised controlled trials (RCT) includes a study¹ evaluating integration of general palliative care into long term care settings in a cluster RCT of 6 European countries including the UK. It found integration of PEoLC into these settings increased quality of end of life and decreased costs, predominantly due to lower costs of hospitalisation:

- **Improved quality of end of life**, and retained general quality of life, in intervention compared to usual care facilities
- €983 less was spent per resident in last month of life due to decreased length of hospital admissions on lower cost wards
- Net monetary benefit identified, and intervention found to be cost effective (less costly and more effective) when measuring quality of end of life, and cost minimising (less costly and equally effective) when measuring general quality of life
- Other smaller RCTs reported a mix of findings from **studies** of **breathlessness interventions** and community PEoLC

Observational and service evaluation studies²) introducing PEoLC for specific patient groups in acute settings or in cancer care centres reported cost savings due to reductions in unplanned admissions and bed days compared to previous patterns or national benchmarks.

Grey literature evidence

- Grey literature analysis of Marie Curie services compared to 'normal care' estimated 2.5 fewer bed days in the last 90 days of life and potential cost savings, noting uncertainties in estimates of some health and care services.
- Service evaluation of a 6-month pilot specialist palliative care advice line addition to a 111 service found outcomes resulting in increasing community and home management calls and decreasing ambulance and primary care calls, compared to previous patterns³).

Sources

² For example, Stewart, E., et al, 2022. Cancer centre supportive oncology service: health economic evaluation. BMJ supportive & palliative care, 13:228-233.

https://doi:10.1136/bmjspcare-2022-003716

¹ Wichmann, A.B., Adang, E.M.M., Vissers, K.C.P. et al. Decreased costs and retained QoL due to the 'PACE Steps to Success' intervention in LTCFs: cost-effectiveness analysis of a randomized controlled trial. BMC Med 18, 258 (2020). https://doi.org/10.1186/s12916-020-01720-9

³ Nuffield Trust, 2014, Exploring the cost of care at the end of life, NHS SE Clinical Delivery and Networks; NHSE and NHS Improvement, 2019, 111 Palliative Care Pilot Interim Report. https://www.southeastclinicalnetworks.nhs.uk/wp-content/uploads/2021/02/SECDN-111-Interim-Report-February-2019.pdf



Introduction

Key steps towards understanding the case for investment



Map trends and state your objectives

- Step 1 Frame your problem
- Step 2 Define the outcomes you are seeking

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Understand and quantify the current patient journey(s)

- Step 3
 Baseline your current patient journeys
- Step 4 Baseline your current PEoLC services

- Prioritise options through longlisting, shortlisting, and future patient journey(s)
- Step 5 Define your critical success factors
- **Step 6** Identify a long list of potential options
- Step 7 Shortlist your preferred options
- Step 8 Specify future patient journeys

- Determine cost and benefits
- Step 9 Determine costs and benefits
- Step 10 Model costs and benefits over time
- Step 11 Evaluate unquantifiable costs and benefits

- Conclude and present findings
- **Step 12** Summarise and present value case

Links to Step slides





5 6 7 8 9 10 11



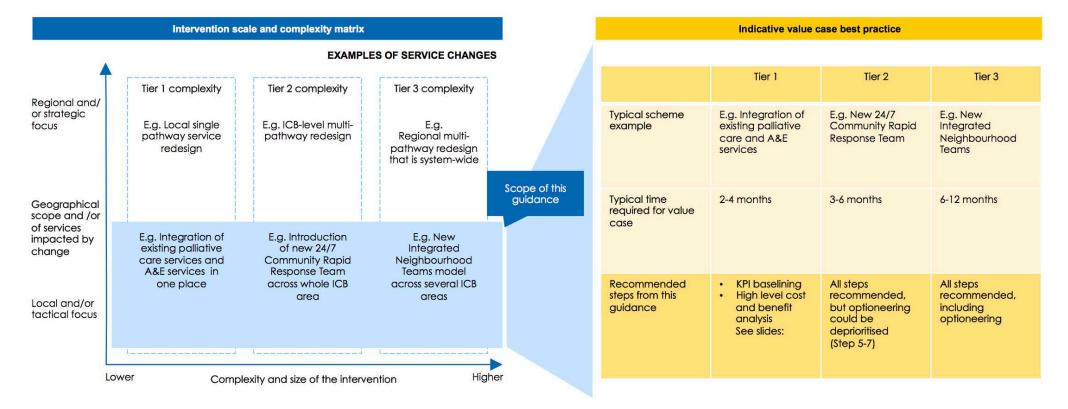


Introduction

Defining the right level of analysis

When developing the value case for an investment the amount of analysis done should be proportionate to the scale and complexity of the change that is being considered. This is to avoid unnecessary work when considering small changes to existing services, and also to ensure that new, complex, or large-scale interventions are treated with the rigour they require. The below diagram gives some examples of palliative and end of life care service changes and interventions and shows where each could sit within the scale /complexity matrix.*

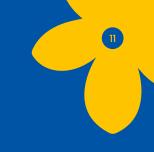
Start by determining the right level of analysis for the changes you are considering. Just use some sections of this guide if not all of them are required for the changes you are considering.



Notes

*Regardless of the Tier that is selected, time will be required for commissioning and/or procurement and the mobilisation of the new approach.





Key steps to make the case for investment in PEoLC



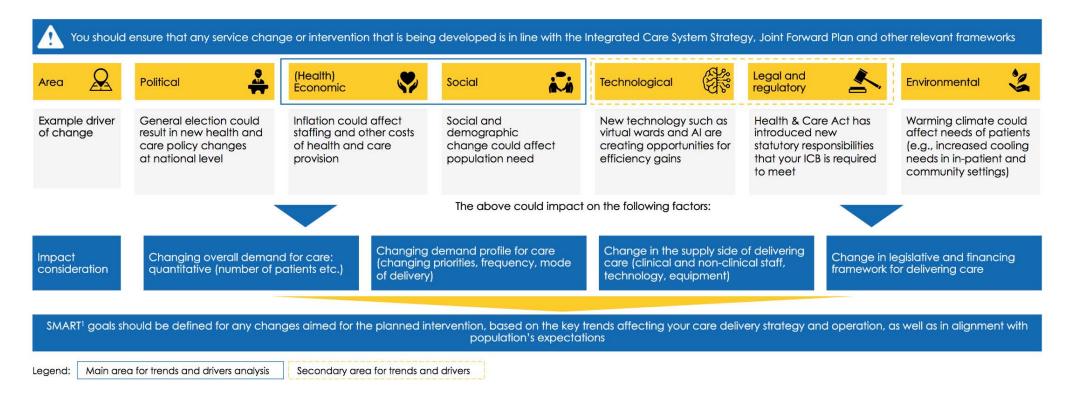
Trends and objectives Steps 1 - 2







You will need to identify key drivers of change i.e. wider trends and shaping forces that affect local population demand for palliative and end of life care and your ability to meet that demand. PESTLE (Political, Economic, Sociological, Technological, Legal and Environmental) analysis can help you to identify and understand these better.

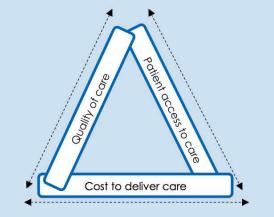






You will need to define your key strategic goals which need to be aligned with your investment objectives for the service change or intervention you are considering.

Healthcare trilemma – think about your overarching strategy and goals: three well-known competing health care priorities exist: access, quality, and cost containment. While the trilemma is not fixed (e.g., costs are changing constantly), the framework provides a useful way of thinking about your overall objectives and where you would like to position your ICB through any intervention.



Define your investment / intervention objectives: formulate 3–5 SMART outcomes against which success of the project/programme can be measured. Investment objectives for a programme or project should describe clearly what your ICB is seeking to achieve in terms of targeted outcomes and provide the basis for post evaluation. So the key question to answer is "Why are you undertaking this project?"

The HM Treasury guidance recommends setting between 3 and 5 meaningful SMART objectives. These will typically address one or more of the following five generic drivers for intervention and spend:

Effectiveness – to improve the quality of public services in terms of the delivery of agreed outcomes, e.g. by meeting new policy changes and operational targets.

Efficiency – to improve the delivery of public services in terms of output, e.g. by improving the output of services whilst minimising unit costs.

Economy – to reduce the cost of public services in terms of the required inputs, e.g. through 'invest to save' schemes and spend on innovative technologies.

Compliance – to meet statutory, regulatory or organisational requirements and accepted best practice, e.g. new health and safety legislation or building standards.

Replacement – to re-procure services in order to avert service failure, e.g. at the end of a service contract or when an enabling asset is no longer fit for purpose.

Each objective needs to have a measure and a date against which the progress can be tracked. As well as articulating the desired outcomes, strategic objectives are the main success measures of a programme or project. They should form part of the assessment of options and part of the plan for realising benefits.

NHS England ask for priority investment objectives to be identified, which the 'do minimum' (later explained) option must address.





Key steps to make the case for investment in PEoLC



Baselining current pathways Steps 3 - 4





Step 3 - Baseline your current patient journeys

You should seek to understand some typical patient journeys through your health and care system including within and across different settings and services, including primary care, emergency care, acute care and specialist palliative care services. You will also need to consider which individuals and groups in your local population are experiencing inequalities in access to or experience of generalist and specialist palliative care services. Please avoid considering only physical health needs because palliative and end of life care is a multi-disciplinary approach which seeks to also meet other patient needs such as for psychological and social support. You will also need to consider the needs of unpaid carers as they play an important role in meeting patient needs and their own health may be at risk if they are not properly supported in their caring role.

This step is recommended for Tier 2 or 3 interventions as described on <u>Slide 6</u>

Agree and develop example personas – developing personas provides a way of understanding patient experience and behaviours

- Review patient data and feedback to understand which groups of patients are large users of palliative and end of life care services e.g. those aged 65+. Consider also which groups in your local population experience unequal access to these services e.g. those aged 85+, with non-malignant conditions, living in areas of deprivation, and other groups that experience health inequalities.
- Based on the above and considering your ICB strategic priorities, develop personas which capture the needs, challenges, behaviours, and motivations of the example patient. See Appendiix Two for example personas with different health conditions and social characteristics.
- Test these personas with clinicians and others providing palliative and end of life and also with people with lived experience of these services.

Understand and develop current state patient journey - map current state patient journey to understand patient experience

- Using the persona, map the patient journey including individual "touchpoints" the patient has with palliative and end of life care services in different settings, with both generalist and specialist clinicians and non-clinical staff.
- Consider the positive and challenging aspects of the patient's journey and how it could be improved e.g. via better co-ordination, communication, geographical reach or 24/7 access to services.
- This exercise could be done in the form of a workshop or 1:1 discussions with patients or / and clinical staff or reviewing any existing patient journeys.

Validate current state patient journey - test and refine the current state patient journey

• Test current state patient journey with patients, carers, relatives or clinical and non-clinical staff to incorporate any feedback. Take particular care to understand the perspectives of unpaid carers.

Notes

*Persona and journey mapping can be difficult and complex.

We recommend for first time users keeping this simple and high level. If there are parts of your organisation skilled in service design, customer experience please reach out to them



Step 3 - Baseline your current patient journeys (...continued)

Typical pathway outputs

	POPULATION HEALTH MANAGEMENT	N	IDENTIFICATION AS END OF LIFE			
ė	(NA)		NA			
ins.				21	22	23
	Lives independently at home	Attends regular GP appointments	Having an acute episode	Unable to access GP	Contacts 111	Attends A&E
re.	Lives independently at home	Attends regular GP appointments	Having an acute episode	Unable to access GP	Contacts 111	Attends A&E
sppening at each t	Phil lives at home and regularly feels lonely as he doesn't have any support from friends, family or neighbours.	With no other support options, Phil regularly attends GP appointments to manage his weight issues, diabetes, angina and heart failure.	Phil experiences severe breathlessness and dizziness after walking up the stairs.	Phil is unable to access his GP as it is after closing hours, so he calls 111 for advice.	111 advise that Phil attends A&E. He waits 5 hours for an ambulance.	After initial consultation in A&E. Phil is triaged and admitted for further investigations.
:/Providers and providers involved in	(c) New item	Primary care		Primary care ① 111	€ A&E	
5 from the experience		Regular engagement with primary care to monitor condition Phil values some face-to-face contact				 Staff supported Phi with investigations Phi feels releved that he is in a place of safety and finds comfort in being connected with people
Lourney journey of Phil	+10 Cool	Carel for				
	Bad Isolated					Hopeful
	-10		Scared	Distressed	Confused	
es	(c) No community support	Phil's worsening mobility makes it difficult for him to attend the GP surgery	(c) Unable to do basic tasks	(C) Unable to access GP	() Long ambulance wait times	🙁 Further tests
es and points of failure		As Phil lives in a rural area, it takes a long time to get to the GP surgery				Phil does not have any of his personal items with him so has to use hospital gowns and toiletries where available
ibes ve improve Phil's e ²			Identification as end of life			
	Lives independently at home	Attends regular GP appointments	Having an acute episode	Unable to access GP	Contacts 111	Attends A&E
	Social prescribing may help but this is difficult in rural areas - he could be part of social groups, friendship	Digital device used to track Phil virtually	Access to a heart failure nurse	111 Having his full health history	Digital device to monitor his health	Digital device used to Phil track virtually or being of a virtual ward



Step 4 - Baseline your current PEoLC services

Identify the specific Key Performance Indicators that will be impacted by your service change or intervention and collect baseline data – in alignment with Step 2 where you defined the outcomes you were seeking to achieve.

Look into each step of the current journey to understand demand, capacity, and any bottlenecks.

Quantify current patient journey & PEoLC services

Understanding the baseline will help to develop a longlist of interventions and determine the incremental costs and benefits of the shortlisted interventions compared to the baseline.

The below provides an illustrative example of the type of data to consider (this is not an exhaustive list).

		1		
	(Potential) demand for services	Supply to deliver services	Productivity and efficiency	
Operationa I KPIs	 Number of (3+ emergency) admissions, inpatient bed days in last 3 months of life % of people over 65 living alone % of deaths in hospital/hospice/care home/private home % of deaths due to malignant versus non-malignant causes % of deaths in specific population groups (see on Slide <u>56</u> in Appendix 2) 	 Number and capacity of existing specialist palliative care units/ community-based PEoLC services (FTE) and capacity of out of hours pharmacy/GP/district nurse Any local information on availability of bereavement services Existing telecare or telehealth service supply (# of services, # patients using service) or potential for it 	 Number of delayed discharges from hospital in a given year Lapse of time until care plan in place Average length of time to be triaged at ED 	Select the type of operational or outcome KPls that should be improved
Outcome KPIs	 Cost of services & value of capacity Potential for avoided non-elective admissions, inpatient admissions bed day cost, A&E visit cost or hospice bed days costs (incl. average length of stay and marginal bed day costs) Cost of palliative care provision inc. specialist palliative care beds (either in-patient or hospice at home) System value created by freeing capacity and meeting previously unmet patient demand 	Quality of care for patients # patients with / offered an Advance Care Plan Patients being cared for in preferred place and dying in preferred place # of patients added to supportive palliative care register Patient reported quality and satisfaction outcomes # of settings using patient reported quality of life measures e.g. IPOS ¹	Quality of care for carers & family Carer reported quality and satisfaction outcomes and burden 	by the intervention (what is the "case for change"?)

Caveat

Often information is limited or not readily available both at Trust or System level and a certain intervention aim to introduce a new service with new features (IPOS roll-out), hence the above list is a possible list of KPIs that could be used for baselining, not a 'minimum list'.

Notes

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We recommend for first time users keeping this simple and high level. If there are parts of your organisation skilled in service design, customer experience please reach out to them.





Key steps to make the case for investment in PEoLC



Optioneering and future pathway design Steps 5 - 8





Step 5 - Define your critical success factors

Critical success factors (CSFs) are the attributes essential for successful delivery of the project, against which the initial assessment of the options for the delivery of the project will be appraised. They define the minimum acceptable solution rather than the ideal solution. The CSFs for a project must be crucial, not merely desirable, and not set at a level that could exclude important options at an early stage of identification and appraisal.

The Green Book provides a starting point for identifying and agreeing CSFs:

CSF categories	You would like to create specific pass/fail measure(s) (on the right) that assess the options in terms of how well they		
Strategic fit and meeting business needs	 Meet the agreed spending objectives, related patient and organisation needs and service requirements Provide holistic fit and synergy with other strategies, programmes and projects 		
Potential Value for Money (VfM)• Optimise social value (social, economic and environmental), in terms of the p benefits and risks			
Supplier capacity and capability	 Match the ability of potential suppliers to deliver the required services Appeal to the supply side 		
Potential affordability	Can be financed from available fundsAlign with resourcing constraints		
Potential achievability	 Are likely to be delivered given an organisation's ability to respond to the changes required Match the level of available skills required for successful delivery 		

Illustrative:

Example illustrative specific pass / fail CSFs
 1: Option provides clinicians with the data they need at the point of care – there is an opportunity to deliver improved clinical service experience 2: Option has the opportunity to deliver improved patient experience
3: Option drives required effectiveness and productivity improvements4: Option delivers the required infrastructure upgrades
5: Option can be delivered commercially and can be sourced from existing pre-approved suppliers on pre-approved frameworks
6: Programme and transition costs can be met from available funding 7: Ongoing revenue costs can be met from existing budget
8: Option can be delivered within time constraints9: Option is supported by key stakeholders

A guide for Integrated Care Boards





Step 6 - Identify a long-list of potential options

Padical change

Once you have identified the key challenges in the patient pathways that you would like to prioritise addressing, the next step is to develop a longlist of interventions or options for how to do this. These could vary from small or incremental service changes to large scale or brand new interventions depending on the problem they are aimed at resolving. At this stage you might already exclude some options that you can be certain will not meet your Critical Success Factors.

The'What':

Innovation and change need:

- Different challenges in the care delivery process will likely require different levels and depths of intervention and changes to the status quo. Getting this right is vitally important.
- Previous steps (trend, baselining) should be the key input for identifying the right intervention point(s). Once this is pinpointed, the identification of potential intervention should come next. This is likely to be an iterative process.
- Innovation can be classified across 2 dimensions into 4 types of change categories based on the level of change and whether it is directly or indirectly patient focused – see diagram opposite.
- Quite often, the idea for a "winning" intervention exists already within the organisation, but this should not lead you to ignore the identification of other potential ways for delivering the required change.

 Delivery model innovation New ways of delivering new services e.g. 24/7 single point of access for PEOLC services Significant infrastructure investment e.g. in new specialist palliative care ward at hospice or hospital Fervice innovation Providing new service e.g., bereavement support Providing single services in new ways e.g. addition of virtual ward to existing specialist services Investment in rtaining or in HR, Finance, IT or other systems 		Radic	al change	
 Service innovation Providing new service e.g., bereavement support Investment in electronic shared care records Investment in training or in HR, finance, IT or other systems 	facing	 New ways of delivering new services e.g. 24/7 single point of access for PEoLC 	 investment Significant infrastructure investment e.g. in new specialist palliative care ward at hospice or 	 adopted by other ICB e.g. via NHS Futures Platform Blue ocean ideation, creative brainstorming approach Test your ideas with your local PEoLC provider
		 Providing new service e.g., bereavement support Providing single services in new ways e.g. addition of virtual ward to existing 	 infrastructure innovation Investment in electronic shared care records Investment in training or in HR, Finance, IT or other 	and care system Co-design with people with lived experience and NHS and charitable hospice workforce, including both clinical and non-clinical staff. Some combination of the above methods is ideal and you may want to make use of external advice and

The'How':

Incremental change



Step 7 - Shortlist your preferred options

Options need to be vetted against the critical success factors (CSFs) identified earlier. One useful framework to drive the identification of the key points of the intervention options is to use the SWOT framework.

Longlist of potential options as interventions identified in Step 6:

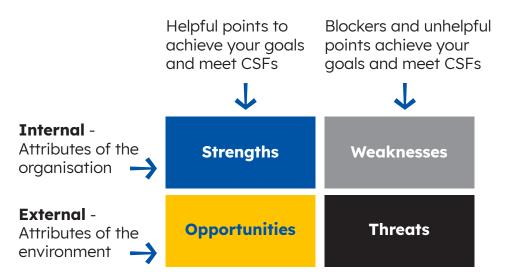
- **Option 1** Describe options, high level in order to be able to assess them against the CSFs
- Option 2 -

Option 3 -

Option

During this analysis, you will aim to assess whether each longlisted option has the potential to fulfil your CSFs and overall strategic goals. SWOT analysis provides a useful framework to allow you to fill your decision making matrix (next slide). Going through each options' strengths, weaknesses, opportunities and threats will help you to shortlist your preferred option(s).

SWOT framework:



You should evaluate all relevant options identified earlier based on the SWOT matrix. Try to make sure that it is not a tick box exercise, but a strategic insight gathering which helps you exclude options and arrive to your shortlisted options.





Step 7 - Shortlist your preferred options (...continued)

A value case should identify a minimum of three shortlisted options for further appraisal. These should be assessed against the critical success factors (CSFs) and include at a minimum:

the business as usual option, the 'Do minimum' option (option usually with narrower scope), and an option with larger scope to make the detailed appraisal more meaningful.

Shortlisting matrix:	Illustrative:			
Specific pass / fail critical success factors – as specified in Step 5	Option 1	Option 2	Option 3	Option 4
CSF #1	~	~	~	~
CSF #2	*	~	v	×
CSF #3	~	~	v	v
CSF #4	~	~	v	×
CSF #5	~	~	v	×
CSF	*	~	v	v
		option to	ptions + BAU be taken vard	



Step 8 - Specify future patient journeys

Map out the future patient journeys with key activities based on the interventions you have shortlisted. Your aim should be to build future pathways which provide improved access and experience for different types of typical patients and their unpaid carers. Using the current patient journeys and improvement opportunities identified in your baselining process, develop some ideal future patient journeys which address the key challenges identified in the existing journeys around access and experience to PEoLC.

This step is recommended for Tier 2 or 3 interventions as described on <u>Slide 6</u>

Develop future state patient journey – using information from the current state patient journey develop the future state patient journey

Through the development of the current state patient journey a set of improvement opportunities should have been identified related to the "touchpoints" to address the challenges at these stages. This may include for example improved access to electronic shared care records including advance care plans or better co-ordination or communication during transitions between different services. These improvement opportunities can be used to design practical steps to improve the future state patient journey.

Validate future state patient journey – test and iterate the future state patient journey

• Test and iterate future state patient journeys through 1:1 discussions or workshops with patients, unpaid carers, staff and if appropriate groups experiencing health inequalities to incorporate any feedback.

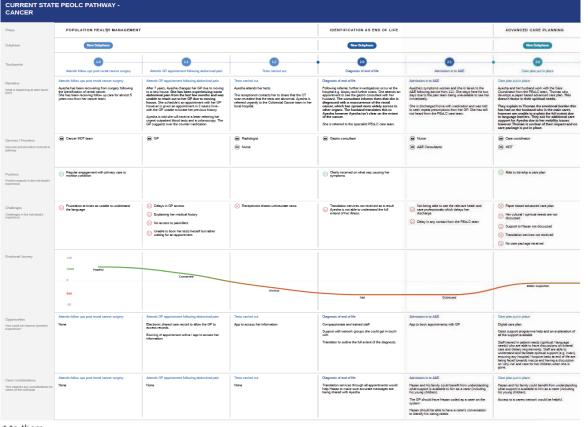
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Typical pathway outputs



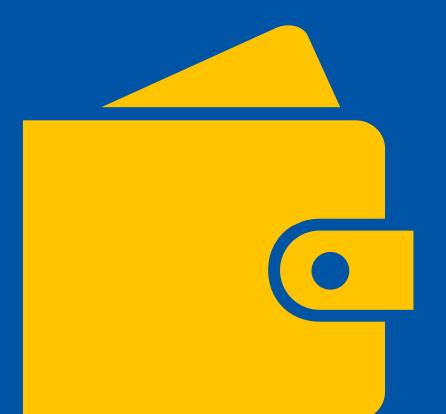




Key steps to make the case for investment in PEoLC



Cost and benefit analysis Steps 9 - 11







Identifying the costs of the intervention

The following provides an overview of the costs which should be included in a value case.

Capital expenditure (Capex)	Operating expenditure (Opex)
Land and property	Rent
Construction costs	Salaries and wages, training costs
Refurbishment costs	Utility bills
Certain professional fees	Inventory costs / supplies
Equipment (furniture, fittings, lighting and wiring)	Communications
Cost of technology	Payroll
Replacement or upgrading of assets	Insurance
Computers or servers	Licences and subscriptions

The two main costs to consider are capital expenditure and operating expenditure:

Capital expenditure involves the cost of acquiring or updating existing assets which is usually an upfront investment. The 'lifetime' of the asset should be included in the appraisal period.

Operating expenditure, also known as revenue costs, are the day-to-day running, management and overhead costs. These costs tend to be recurring and can range from printing costs to the wages of employees.



Step 9 - Determine costs and benefits (...continued)

Identifying the costs of the intervention

The purpose of valuing benefits is to ascertain whether an option's benefits are worth its costs, and to allow alternative options to be compared systematically in terms of their net benefits or costs.

Cash releasing benefits

These benefits reduce the costs of organisations in such a way that the resources can be re-allocated elsewhere. This typically means that an entire resource is no longer needed for the task for which it was previously used e.g. a reduction in operating costs could be achieved through a provider collaborative sharing 'back office' costs such as administrative, HR and finance staff instead of each having their own. The 'golden rule' is that all benefits must be quantified where possible. Benefits may be direct (to the organisation) or indirect, and typically fall into four main categories:

Non-cash releasing benefits

This usually involves reducing the time that a particular resource takes to do a particular task e.g. improved quality of life for patients and unpaid carers is often a benefit of early access to palliative care (QALY).

Quantitative benefits

These benefits can be quantified, but cannot be monetised. The extent to which quantifiable benefits are measured will depend on their significance. However, as a general rule, every effort should be made to quantify benefits financially wherever possible and proportionate to do e.g. improved health and wellbeing of staff is a material benefit in PEoLC provision because it can result in better retention of key staff.

Qualitative benefits

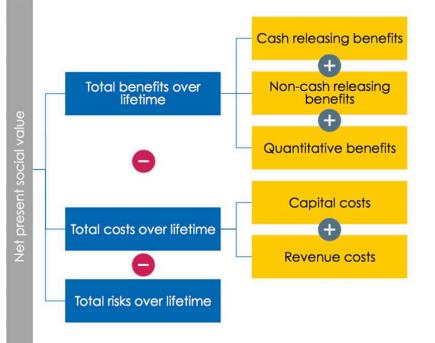
These are the qualitative benefits, which are of value to the public sector that cannot be easily quantified e.g. improved coordination and integration of the wider health and care system can be difficult to quantify but can improve the quality of experiences that patients, unpaid carers and professionals have when they operate within the system.



Step 10 - Model costs and benefits over time

General principles of economic modelling:

Principle	Definition
Time horizon	Costs and benefits should be calculated over the lifetime of an intervention. A time horizon of 10 years is a suitable working assumption for many interventions or up to 60 years for new buildings and infrastructure.
Net present social value	This shows the present value of future costs and benefits to UK society that have been discounted over the life of the intervention. This includes direct and indirect costs and benefits to the organisation, and wider social (indirect) costs and benefits to society.
Risks (costed)	Specify the main risks associated with the achievement of the intervention's outcomes and the proposed counter measures for mitigation and management. Risk is the possibility of an event occurring that adversely impacts on the intervention. Focus on the 20% of the risks which are likely to provide 80% of the intervention's risk values. This should include the cost of mitigation and the expected costs if risks materialise. The extent to which risk is identified allows the initial estimates of optimism bias to be reduced.
Discounting	A discount rate should be used to convert all costs and benefits to 'present values'. It is set at 3.5%, with the exception of patient outcomes (e.g., QALYs), which uses a lower rate of 1.5%.
Real terms	Costs and benefits in appraisal of public value should be estimated in 'real' prices (i.e., removing the effect of inflation).
Incremental impact	This measures the incremental impact of the discounted values for the shortlisted options against the Business as Usual option as the base value.
Optimism bias	Adjusting for optimism bias involves either increasing cost estimates and decreasing and delaying the receipt of estimated benefits by a certain percentage.
Benefit-Cost ratio [BCR]	BCR = Total Benefits / Total Costs





Best practice suggestion

You will need to engage your finance colleagues to ensure that the modelling is done appropriately and in line with all (internal and external) guidance and standards.



Step 10 - Model costs and benefits over time (...continued)

You will need to determine how the benefits and costs of each option differ from the Business as Usual option.

The business as usual (BAU) option (also known as Option 0)

should be quantified in absolute terms and then presented alongside the results of the appraisal which show the incremental effect of options.

	Option 0 – BAU	Option 1	Option 2
Costs			
Capital costs	≂.	[option 1 – option 0]	[option 2 – option 0]
Revenue costs	-	[option 1 – option 0]	[option 2 – option 0]
Costed risks	-	[option 1 – option 0]	[option 2 – option 0]
Total incremental costs	-	[capital + revenue]	[capital + revenue]
Benefits			
Cash releasing benefits (CRB)	447 976	[option 1 – option 0]	[option 2 – option 0]
Non-cash releasing benefits (NCRB)		[option 1 – option 0]	[option 2 – option 0]
Quantitative benefits (QB)	7	[option 1 – option 0]	[option 2 – option 0]
Total incremental benefits	-	[CRB + NCRB + QB]	[CRB + NCRB + QB]
Value for money			
Net Present Social Value (NPSV)	-	[total incremental benefits – total incremental costs]	[total incremental benefits – total incremental costs]
Benefit-Cost ratio (BCR)	-	[total incremental benefits / total incremental costs]	[total incremental benefits / total incremental costs]

Note

it is not necessarily always the case that the BAU option does not incur any costs. For example, the BAU option may incur additional costs as a result of not pursuing the intervention – an example being increasing avoidable admissions due to poorly co-ordinated services in community settings, or backlog maintenance due to outdated infrastructure. The BAU option is also likely to have a higher risk profile (costed risks) which explains the reason for intervention.



Step 11 - Evaluate unquantifiable costs and benefits

Key for qualitative benefit scoring and ranking

Where benefits are not easily quantifiable, or not practical to be quantified, but are clearly material to the decision process then these qualitative benefits should also be assessed and taken into consideration in identifying the 'preferred option'. However, every effort should be made to quantify the benefits.

Definition	Symbol
Benefit is not applicable to this option – there are no initiatives that will drive this benefit that is included in the option.	\bigcirc
This option would realise some of this benefit, but it would be the smallest value of all the options.	
This option delivers more benefit than options rated lower, but the quantity of realisable benefit is closer to the lower option than to the option rated as highest.	
This option delivers more benefit than options rated lowest, but the quantity of realisable benefit is closer the option rated as highest than option rated as lowest.	
This option delivers the maximum benefit out of the options.	





Key steps to make the case for investment in PEoLC



Conclusion Step 12





Step 12 - Summarise and present the value case

Summarising and presenting your findings – best practice suggestions

It is important to draw key conclusions when summarising the value case. For example, the following should be considered:

- Presenting key measures such as total costs, total benefits, and unmonetised costs and benefits
- The choice of time horizon for the appraisal and rationale for that choice
- Outlining key modelling assumptions, including references and sources
- Clearly presenting the uncertainty including optimism bias and sensitivity analysis
- The Business As Usual (BAU) option should be quantified in absolute terms and presented alongside the results of appraisal which show the incremental effect of options
- The value for money measures (NPSV and BCR) should be presented

 the threshold for health spending is 4. So, for every £1 spent,
 £4 is generated in quantified benefits

Summarising the value case & additional context setting

We recommend referencing in your summary the statutory guidance on the new legal duty in the Health & Care Act for ICBs to commission palliative care services that meet the needs of their local populations.

The statutory guidance on the new legal duty requires that ICBs should have "a clear vision of how the package of services they commission locally deliver against the Ambitions Framework and should actively seek out commissioning resources to achieve this."

Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026 sets out a vision for how to improve end of life care through partnership and collaborative action in order to achieve the following five ambitions:

- Each person is seen as an individual
- Each person gets fair access to care
- Maximise comfort and wellbeing
- Care is co-ordinated
- All staff are prepared to care





Case Studies

REACT Model in Bradford





Worked Case Study 1 - REACT: Making the case for investment in the REACT model in Bradford

REACT

The Marie Curie REACT service is delivered in partnership with Bradford Teaching Hospitals Foundation Trust and is funded via a 3 year social outcomes contract through the Care and Wellbeing Fund overseen by Social Finance. Macmillan Cancer Support and Better Society Capital are investors, and grant funding is provided by the National Lottery Community Fund's Commissioning Better Outcomes programme.

Background trends and strategic case for change

Bradford City area was a national outlier for the percentage of people who had three or more unplanned admissions in the last 90 days of life.

People in Bradford City had worse outcomes than people living in similar areas and were spending more time in hospital than they needed to.

Patients in their last year of life (LYOL) were spending an average of 38 days in hospital. There were concerns regarding A&E capacity, which could be increased by reducing hospital stays for LYOL patients.

Health and social care staff at Bradford Teaching Hospital were at risk of facing burnout due to the pressures they experienced. Staff survey found that 47% of staff felt unwell due to work-related stress, up 10% from 2020 (from the previous year).

Root cause analysis

Bradford District is ranked as the 13th most deprived local authority in England and the 2nd most deprived in Yorkshire and Humber

Recent cohort analysis of national datasets highlighted that those living in the most deprived areas are more likely to attend an A&E department, and be admitted to hospital more often than those living in the least deprived areas.

A significant number of patients (see below at KPIs) were not registered for Goldline services (nurse-led, 24/7 telephone and video consultation service, staffed by experienced NHS clinicians to provide a round-the-clock single point of contact for patients with serious illness who may be in their last year of life).

Patients who were not registered for Goldline could have greater difficulty knowing who to contact for advice in a crisis and are therefore more likely to call an ambulance or attend hospital.



Worked Case Study 1 - REACT: Making the case for investment in the REACT model in Bradford

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(...continued)

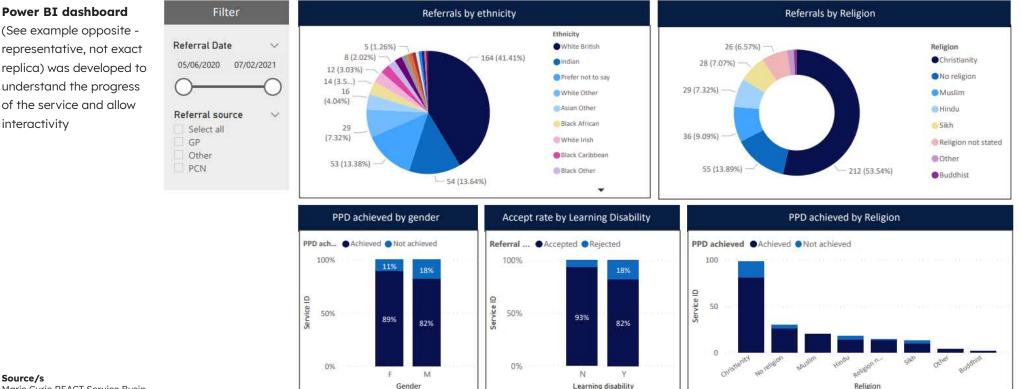
KPI and outcome monitoring

Unplanned admission:

12.6% of people in the Bradford City area and 9.4% of people in Bradford District had 3 or more unplanned admissions in the last 90 days of life, versus a Right Care Cluster range of 7.5 -10.2% and England Average of 7.5%.

Goldline registration:

Data from 2018 showed only 44% of predictable deaths in the City CCG were registered on Goldline (150 patients), compared to 60% in District (1,227 patients) and 75% in other comparable areas.



Source/s Marie Curie REACT Service Busin



Worked Case Study 1 - REACT: Problem statement and intervention design

Based on the trend and KPI analysis, outlined on the previous slide, the following problem statement was made

by the project team focusing on designing the appropriate intervention:

Core problem statement:

A number of people with PEoLC needs are not currently accessing PEoLC services.

Gaps in service contributing to the problem statement:

Chere was no dedicated community face to face rapid response service for those in the last year of life. This is felt by the system acutely out of hours. There was an agreement from all community providers that this was a significant gap. In this case study we did not explore the optioneering phase. This model arose from strong and collaborative working relationships between local partners and discussions they held about possible challenges they faced.

The following intervention was suggested:

Provide a 24/7 rapid response community nursing team with the support of a senior palliative care clinician.

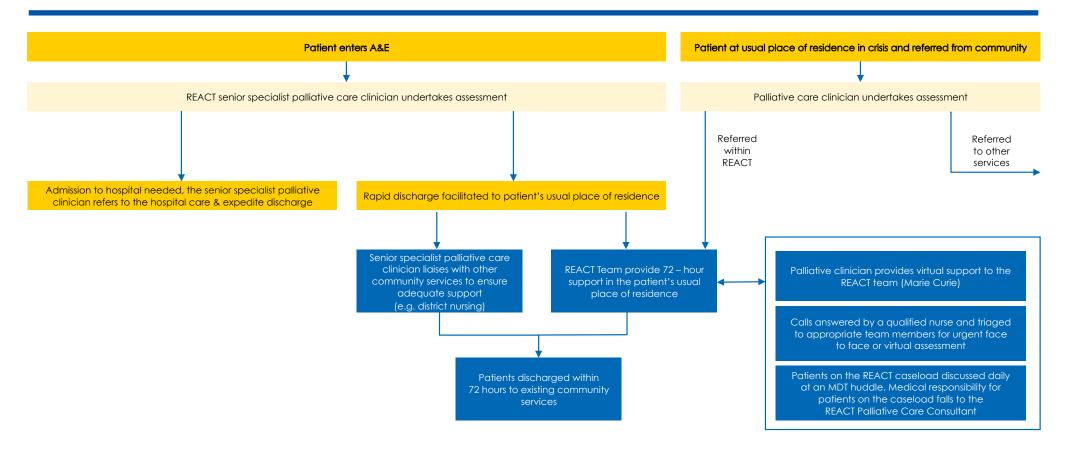
Actively identify those patients in A&E who are likely to be in their last year of life and supports rapid discharge.

Roll out a solution that aims at stepping up referrals from the community.



Worked Case Study 1 - REACT: Future service & pathway design

The below referral and service pathway was developed to address the problem statement and support patients:





Worked Case Study 1 - REACT: Cost and benefit identification









Refer to Slide 25



Not exhaustive list of benefits identified.

Capacity releasing benefit	Non-cash releasing benefits	Quantitative benefits	Qualitative benefits
Reduction in total length of stay (LoS) in LYL in the PEoLC	Reallocation of staff time Clinical staff can spend time	Improved patient outcomes through faster access to care	Positive patient and carer feedback
population.	treating other patients as	e.g., improved access to	Improved patient experience
	a result of reduced hospital	palliative care services and	leading to better bereavement
Subsequent potential cost saving - having applied bed	admissions for PEoLC care.	identification of palliative care need; subsequent benefits for	for carers.
day tariff value.	Capacity and resource	patient and family; improved	Workforce benefits
	reallocation	and earlier referrals to hospital	Increased value from upskilled
	Via faster elective recovery.	palliative care team and	workforce and increased
		lowered A&E waiting times.	workforce wellbeing.
	Upskilling of Emergency		
	Department clinicians.	Wider reach of PEoLC	System-wide benefits
		services in patient cohort	Integrated partnership
		e.g., higher proportion of	working, increased
		patients seen who were not	collaboration.
		previously known to any	
		palliative care services.	



Determine incremental costs and benefits

The costs and benefits should be incremental to the business as usual (BAU) option which provides a baseline, quantified in Step 4, against which the shortlisted options should be compared. Note: the below presents an example with illustrative ('dummy') data of a potential return on investment of an intervention for palliative and end of life care. While the below does not adjust for discounting, a discount rate¹) should be ideally applied to convert all costs and benefits to 'present values', especially when looking at costs and benefits over a longer term.

Category		Calculation	Assumptions (Illustrative figures)	BAU	Preferred option - REACT	
Annual Costs	Total annual costs: Service cost			-	£0.9m	
Annual Benefits	Total annual benefit: System Value Created via increasing capacity	Capacity created (measured in total bed days per year) = Number of patients in LYL who are expected to avoid admission due to intervention* x Average length of NEL stay for patients in LYL. System value = Capacity Created x Bed day value * Ideally based on evidence of unmet need, with the service sized appropriately i.e. what proportion of in-scope patients could be expected to avoid admission. Otherwise, use capacity of the designed service.	5.5k bed days saved p/a (at full scale of the service) £450 / bed day tariff value	-	£2.5m (in year 2, after ramping up services)	
Totals (not	Net Social Value	Total benefits – Total costs	N/A	-	£1.6m	
discounted)	Benefit Cost Ratio	Total benefits / Total costs	N/A	-	2.7	

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Notes

¹ As per the current Green Book guidance: Rate of 3.5% should be applied to discount non-QALY related benefits, while 1.5% of rate should be applied to QALY related benefits

(essentially non-cash releasing benefits that impact quality-adjusted life year of patients). Given the above example, as the benefit is identified to be cash-releasing non-QALY, 3.5% rate should be used.



Worked Case Study 1 - REACT: Cost and benefit quantification (...continued)

Modelling of costs and benefits over time

Year	1	2	3
Total costs	£0.9m	£0.9m	£0.9m
Total benefits	£1.5m	£2.5m	£2.5m
Net benefit	£0.6m	£1.6m	£1.6m
Discounted net benefits (@3.5% discount rate)	£0.6m	£1.5m	£1.4m



Net present social value (undiscounted)





Qualitative benefit scoring and ranking

Using the REACT intervention, the following table sets out the qualitative benefits identified and an assessment of

achievability of these benefits across the shortlisted options (incremental to the BAU option).

Qualitative benefit	BAU	REACT
Positive patient and carer feedback.	\bigcirc	
Workforce benefits.	\bigcirc	
System-wide benefits.	\bigcirc	

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Case Studies

IMPaCT Model





Worked Case Study 2 - IMPaCT: Real life example of the value case for a Single Point of Access

Providers had spotted significant challenges with poorly co-ordinated services and worked with commissioners to develop a single point of access to improve patient outcomes and reduce system pressures.

Background trends and strategic case for change

An English metropolitan area which serves an urban population of c.700,000 faced increasing pressure for delivering high quality end of life and palliative care services.

The ICB realised that some of their current processes and the design for care delivery was not up to the ever-increasing level of need and challenges. This was resulting in:

- More hospital admissions in the last days of life
- Fewer people dying at home
- A smaller proportion of people on the GP palliative and end of life care register than the national average
- Highly distressing experiences for patients and their carer(s)

KPI and outcome quantification

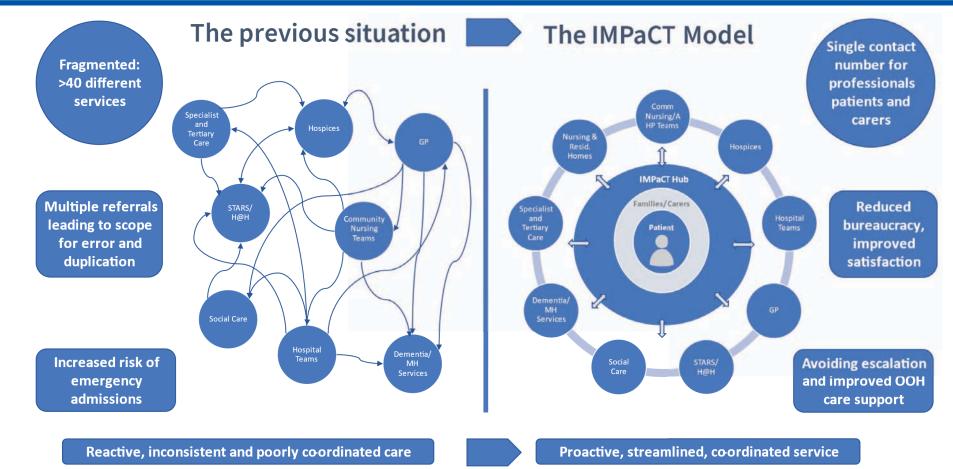
Key Indicators	Average England (2019-2020) ¹⁾	Specific area
Proportion of people who have +3 emergency hospital admissions in the last 90 days of life	9.1%	9.4%
Proportion of people who were admitted to hospital in the last 90 days of life	67.9%	69.9%
Proportion of people who died in their usual place of residence	44.5%	37.5%
Proportion of people dying in hospital	46.0%	52.1%
Proportion of hospital admissions ending in death that were +8 days	49.5%	52.8%
Proportion of patients who died whose GP identified they needed palliative care	45.3%	44.8%



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(....continued

Understanding the current processes / pathways



Notes

The IMPaCT service is delivered by Marie Curie in partnership with Liverpool University Hospitals NHS Foundation Trust / Woodlands Hospice.



Worked Case Study 2 - IMPaCT: Problem statement and intervention design

Based on the trend and KPI analysis, outlined on the previous slide, the following problem statement was made by the project team focusing on designing the appropriate intervention:

Local palliative and end of life care services were fragmented and difficult for patients and carers to navigate with the following specific issues:

- Multiple referrals leading to scope for error and duplication
- Increased risk of emergency admissions
- · Reactive, inconsistent and poorly co-ordinated care
- Fragmented > 40 different services

Given the problem was a relatively well understood issue where it was assumed that no major system-wide intervention was required, optioneering phase of the value case development phase was left out of the service design improvement process this time.

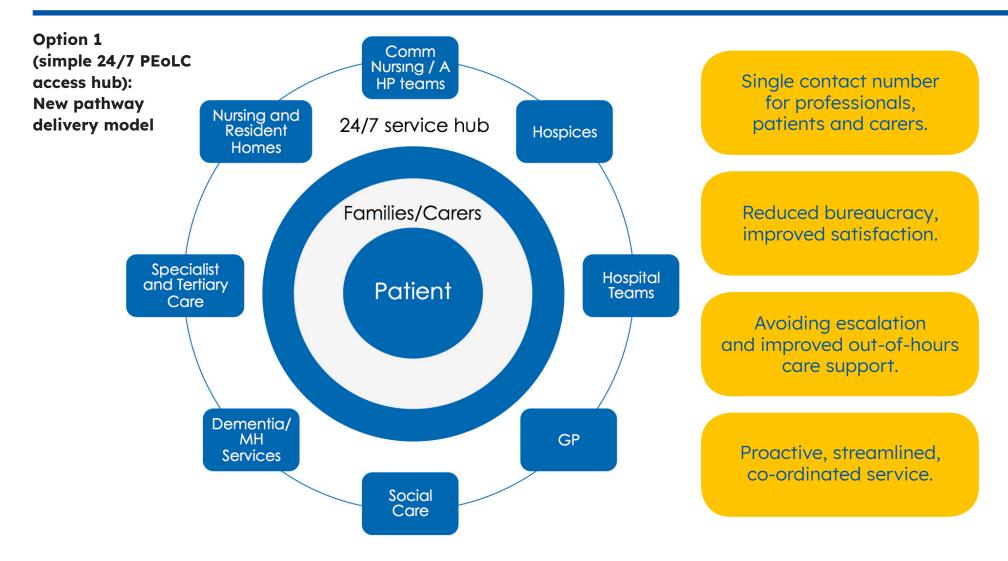
The following intervention was suggested:

24/7 telephone advice lines providing a single point of access to palliative and end of life care (PEoLC) services based on NICE Guidelines NG142 and NG6.

As a potential scale up of the model, consideration was given to introducing a Rapid Response service in the community.

Worked Case Study 2 – IMPaCT: Future service & pathway design

The project team designed a new operating model by creating two specialised palliative and end of life care hubs, by having a single point of access and referral to services through a designated palliative and end of life care phone line.



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Worked Case Study 2 - IMPaCT: Cost and benefit identification







Refer to Slide 25

Not exhaustive list of benefits identified.

Datient experienceImproved coordination of careable to die in theirGreater coordination of care across service boundaries through the 24/7 PEoLC single access hub.
ice with appropriate Greater coordination of care across service boundaries their preference. through the 24/7 PEoLC single access hub.
port, including at t is their preference. across service boundaries through the 24/7 PEoLC single access hub.
is their preference. through the 24/7 PEoLC single access hub.
access hub.
wellbeing and
y Improved operational data
alliative care services An increase in the proportion of
y distressing for people on the palliative and
asily accessible end-of-life supportive care
improve morale and register.
uctivity losses.
Improved reputation of ICS
due to improvements in PEoLC
patient outcomes.



Determine incremental costs and benefits

The costs and benefits should be incremental to the business as usual (BAU) option which provides a baseline, quantified in Step 4, against which the shortlisted options should be compared. Note: The below presents an example with illustrative data of a potential return on investment of an intervention for palliative and end of life care. While the below does not adjust for discounting, a discount rate¹) should be ideally applied to convert all costs and benefits to 'present values'.

Category		Calculation	Assumptions (illustrative figures)	BAU	IMPaCT
Costs	Capital costs			-	£750k
	Revenue costs			-	£1m
	Risks			-	£50k
Benefits	Reduced bed days	Number of bed days saved x unit cost of palliative care	60-75k bed days saved p/a £50 unit cost of palliative care	-	£3m
	Reduced ED transport costs	Number of PEoLC patients transported via ambulance x unit cost of ambulance	25-30k ambulance conveyance £80 ambulance unit cost	-	£2m
Totals (non-	Total costs	Capital costs + revenue costs + risks	N/A	-	£1.8m
discounted)	Total benefits	CRB + NCRB + QB	N/A	-	£5m
	Net Present Social Value	Total benefits – Total costs	N/A	-	£3.2m
	Benefit Cost Ratio	Total benefits / Total costs	N/A	-	2.7

Notes

As per the current Green Book guidance: Rate of 3.5% should be applied to discount non-QALY related benefits, while 1.5% of rate should be applied to QALY related benefits

(essentially non-cash releasing benefits that impact quality-adjusted life year of patients). Given the above example, as the benefit is identified to be cash-releasing non-QALY, 3.5% rate should be used.

Worked Case Study 2 - IMPaCT: Cost and benefit quantification (...continued)

Modelling of costs and benefits over time

Let us say the preferred option requires £750k in upfront capital expenditure and £1 million per annum in revenue expenditure to realise benefits of £5 million per annum for the following 5 years (£3 million in reduced bed days and £2 million in reduced ambulance transport costs). Let's assume that the risk of demand exceeding supply is estimated to cost £500k per annum with a probability of the risk occurring at 10%.¹ The below calculation table shows what the discounted costs and benefits would be over time.

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Net present social value (undiscounted)



Net present social value (discounted)

Year	0	1	2	3	4	5
Total costs	£750k	£1m	£lm	£lm	£lm	£lm
Total risks	-	£50k	£50k	£50k	£50k	£50k
Total benefits	-	£5m	£5m	£5m	£5m	£5m
Net benefit	-£750k	£3.95m	£3.95m	£3.95m	£3.95m	£3.95m
Discounted net benefits (@3.5% discount rate)	-£750k	£3.81m	£3.68m	£3.55m	£3.43m	£3.31m



Qualitative benefit scoring and ranking

Using the 24/7 PEoLC single point of access hub intervention, the following table sets out the qualitative benefits identified

and an assessment of achievability of these benefits across the shortlisted options (incremental to the BAU option).

Qualitative benefit	BAU	IMPaCT
Improved coordination of care.	\bigcirc	
Increased operational data.	\bigcirc	
Improved reputation of ICS.	\bigcirc	

1ain menu





Appendix 1

Additional case studies





Appendix 1 – Additional case studies

24/7 Palliative Care Coordination Hub Case Study

The below case study for the Palliative Care Coordination Hub in Ipswich and East Suffolk illustrates how care can be co-ordinated in the community to reduce hospital admissions, ensure more patients are able to die at their place of choice and demand in the primary sector can be managed.

Summary of best practice initiative

The Palliative Care Coordination Hub was created from a long term ambition that was realised under the Covid pandemic to address the need to co-ordinate care and limit footfall through caring for people in their own homes and where possible allowing people to die in line with their wishes. The Palliative Care Coordination Hub works as an integrated part of health and social care providing specialist palliative care across the Ipswich and East Suffolk (IES) area. This service can be accessed via One Call – a 24-hour advice line – which provides essential support for patients and their families, and professionals caring for individuals nearing the end of life. Key aims of the service are to provide:

- Enhanced and expanded coordination of care through the hub
- Increased availability of palliative and end of life advice and support across the 24 hour period
- Patient choice in remaining at home (care homes included), if desired, reducing unwanted hospital admissions
- Increased resilience in the system to react to urgent and end of life episodes of careneed, making better use of resources
- A patient and family centred responsein the community that reduces the need to tell their story repeatedly
- · A central resource and support ofemotional and bereavement care
- A logistic resource for urgent deliveriessuch as small equipment.

The hub also provide a satellite clinic in Stowmarket to enable those who cannot access Ipswich to receive bereavement support closer to home.





Appendix 1 – Additional case studies (...continued)

24/7 Palliative Care Coordination Hub Case Study (...continued)

What outcomes has this achieved?

Patients, families and partners value this service as it supports choice to remain at home and supports others in symptom control. Some of the outcomes achieved includes:

- More home deaths than at the start of the Hub Majority of patients would like to die at home however when this service was set up the CCG was reporting a rate of 40%. It is now running at 35% (May 23 figures)
- Identification of patients at the end of their lives allow supporting advance care planning and joined up care
- Everyone in East Suffolk now has access to bereavement information via https://www.livinggriefeastsuffolk.co.uk/. Residents have a central point of contact for emotional and bereavement support via the LivingGrief Enquiry phone line. All referrals are triaged within three working days. NICE guidance recommends a three tier model of bereavement support which the LivingGrief service provides. This also helped to reduce demand on the primary sector.
- Often providing equipment to allow patients to remain at home instead of being admitted to hospital.
- Therapy provision on a Saturday and bank holidays reduces demand on the local healthcare teams.

Which aspects of the PEoLC Ambitions Framework does this example achieve?

Each person is seen as an individual

I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asking what matters most to me. Those who care for me know that and work with me to do what's possible.

Each person gets fair access to care

I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.

Care is coordinated



01

02

I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.





Appendix 1 – Additional case studies

PEoLC Data Dashboard in North East Essex

The below case study for the North East Essex Alliance shows how an End of Life Care dashboard can be used to understand and monitor end of life outcomes and drive targeted interventions. The dashboard provides a comprehensive view of outcomes (by condition, primary care network, deprivation etc) and can be accessed by a range of health and care professionals.

Summary of best practice initiative

The North East Essex Alliance have produced a dashboard to monitor outcomes in end of life care and provide targeted interventions where required to drive improvements. It seeks to provide a view on the outcomes for patients in their last 12 months of life and is available to clinicians and managers in the North East Essex area. This was built upon existing work to support primary care to identify people approaching the end of life. The dashboard was produced in consultation with patients to agree ten priorities for good end of life care and an associated metric to track whether these outcomes were being delivered. For example one of the ten priorities is patient identification and the associated metric captured on the dashboard to measure this is being on the My Care Choices Register.

The End of Life Care dashboard links quantitative data from four sources: Office of National Statistics, Hospital Episode Statistic, the local Electronic Palliative Care Coordination System called the My Care Choices Register and patient feedback. Metrics measured in the dashboard include: patients who died in their place of preference, hospital admissions, recurrent admissions, percentage of hospital deaths, percentage of patients who have a care plan in place within care homes, percentage who died who had an emergency admission in the last 90 days of life and the percentage who died who had 3 or more emergency admissions in the last 90 days of life. Data can be filtered by four main diagnostic condition groups (cancer, dementia, heart disease

and COPD), Primary Care Networks, Neighbourhoods, Deprivation, Ethnicity and Care homes.

What outcomes has this achieved?

The dashboard has supported system leaders to understand equity of access across demographic groups. During the Covid-19 pandemic there was an increased focus on reaching out to end of life patients to understand their end of life choices. An increase in the uptake of sharing end of life preferences was witnessed. However when reviewing deprivation data it showed that this had only increased for affluent areas and not for deprived areas. Knowing this, commissioners could make different choices about the interventions needed.

The dashboard has also been used to improve care coordination and symptom control across all the services within North East Essex for patients with advanced respiratory disease. Data from the dashboard has been used to increase early identification of people approaching the last phase of life, provide earlier advance care planning including access to the My Care Choices Register and the ReSPECT process. It is predicted that improved care coordination will improve outcomes and decrease unnecessary hospital admissions as has been shown on the North East Essex End of Life dashboard in relation to other conditions. It is known that people who have received advance care planning are less likely to have unplanned hospital admissions which reduces unnecessary costs to the system. The next page shows images of the dashboard.

What outcomes has this achieved?



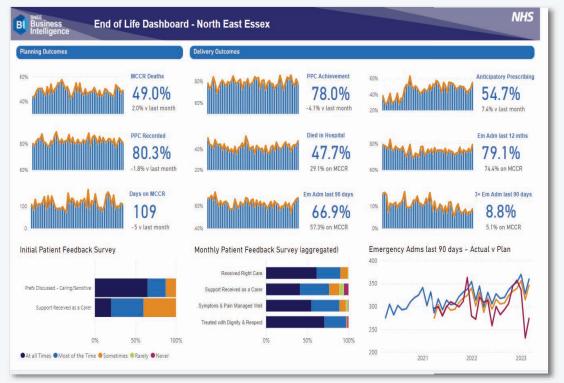
I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.



Appendix 1 – Additional case studies

PEoLC Data Dashboard in North East Essex

(...continued)













Patient personas and pathways





Appendix 2 – Patient personas and pathways

	POPULATION HEALTH MANAGEMENT	N	IDENTIFICATION AS END OF LIFE			
ase	NA		NA			
epointes			20	21	22	23
Anna	Lives independently at home	Attends regular GP appointments	Having an acute episode	Unable to access GP	Contacts 111	Attends A&E
e appening at each ti	Lives independently at home Phil lives at home and negulary feels lovely as he desirn have any support from friends, family or neighbours.	Attends regular GP appointments With no other support options. Phil regularly attends GP appointments to manage his weight issues, diabetes, angina and heart failure.	Having an acute episode Phil experiences severe breathlessness and dizziness after waiking up the starts.	Unable to access GP Phil is unable to access his GP as it is after closing hours, so he calls 111 for advice.	Contacts 111 111 advise that Phil attends A&E. He waits 5 hours for an ambulance.	Attends A&E After initial consultation in A&E, Phil is triaged and admitted for further investigations.
s / Providers and providers involved in	(New item	Primary care		Frimary care ① 111	 ④ A&E 	ABE
s from the experience		Regular engagement with primary care to monitor condition Phil values some face-to-face contact				 Staff supported PhI with investigations PhI feels relieved that he is in a place of safey and finds comfort in being connected with people
al Journey Journey of Phil	+10 Good 0	Cared for				
	Bad Isolated		Scared	Distressed	Confused	Hapeful
ges es and points of failure	No community support	 Phil's worsening mobility makes it difficult for him to attend the GP surgery As Phil lives in a rural area, it takes a long time to get to the GP surgery 	 Unable to do basic tasks 	(c) Unable to access GP	 Long ambulance wait times 	Further tests Phil does not have any of his personal items with him so has to use hospital gowns and tolletries where available
nibes Id we improve Phil's re?			Identification as end of life			
	Lives independently at home Social prescribing may help but this is difficult in rural areas - he could be part of social groups, friendship clubs etc.	Attends regular GP appointments Digital device used to track Phil virtually Virtual GP appointments Point of contact testing	Having an acute episode Access to a heart failure nurse	Unable to access GP 111 Having his full health history	Contacts 111 Digital device to monitor his health	Attends A&E Digital device used to Phil track vinually or being pa of a vinual ward



Appendix 2 – Patient personas and pathways (...continued)

Here we provide you with example personas to help you consider the needs of your diverse local population for PEoLC due to having one or multiple life-limiting conditions. For each persona, a summary is provided of their social characteristics, place, what matters most to them, and the journey they are making through services in all settings.We have also considered to a limited extent the needs of informal carers of people with life-limiting illness and it is important to recognise that some patients will not have any close friends or family to care for them.



Phil

Phil is 75 and has several underlying conditions. He has recently been diagnosed with heart failure. He lives in a rural area and has no family or friends to support him.



Ayesha

45 year old Ayesha is originally from Bangladesh, but now lives in Manchester with her husband and children. She has long been receiving treatment for rectal cancer, which is now considered terminal.



Margaret

Margaret is 91 and lives alone in one of the most deprived parts of Devon. She has dementia, which has progressively worsened. She moves in to a care home and passes away in a hospital.



Appendix 2 - Patient personas and pathways - Phil



Background information

Phil has long struggled with his weight, has mobility issues and is classed as obese. He has several underlying health conditions, such as diabetes and angina. Phil also has heart failure, which has recently deteriorated and his symptoms have become difficult to manage.

Phil lives on his own in a rural area and doesn't have any friends or family to rely on.

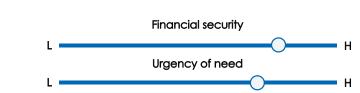
Personal Goals

- Simple access to help
- To build trust in local care services
- Limit the amount of pain he is in
- Maintain his independence in his own home

Key Attributes

Digital aptitude and access to technology





Age – Phil represents the 71.5% of people dving from CVD

Health – Phil has several health conditions and around 80% of

Nervous about engaging with the health and social care system

people with CVD have at least one other health condition

Location - Phil lives in a rural area, where adults have a

What does Phil need from the ICS (linked to Ambitions for Palliative and End of Life Care)?

Community support that provides a sense of belonging (ambition 6) A holistic and coordinated approach to care (ambition 4)

Empathetic communication that considers his personal circumstances (ambition 1) Local and accessible support within his community or home (ambition 2)

6 I don't have any family or friends left, so I often feel really isolated and lonely.

Why Phil?

Challenges

digitally

that are over 75 years old

higher risk of developing CVD

Feels isolated and lonely

In denial about the extent of his conditions

Worried about being put in a care home Regularly struggles with severe breathlessness

Phil



Occupation: **Retired**

Age:

75



Location: Rural Derbyshire



Interests: Watching sport, food and gardening



Appendix 2 - Patient personas and pathways - Ayesha



Background information

Ayesha is a Bangladeshi British woman and lives with her husband Hasan. She has no family here apart from her two children, Sara aged 9 and Omar aged 11.

Ayesha was diagnosed with early rectal cancer, which was successfully surgically removed. However, seven years later Ayesha has been experiencing persistent abdominal pain, which test results have confirmed is a reoccurrence of the rectal cancer. English is also not Ayesha's first language and she often finds it difficult to understand medical terms.

Goals

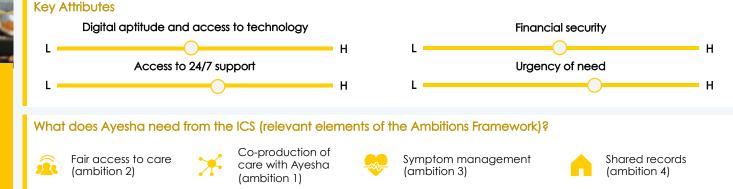
- Access to personalised, co-ordinated care and support, including translation services
- Medical history shared through a shared care record with all health and care professionals to prevent her having to share her story repeatedly
- Support for her family

Why Ayesha?

- Demographic Ayesha is from a minoritised ethnic group, like 18.3% of the population, and studies have shown there is a low uptake of PEoLC services for people from a minoritised ethnic group
- Geographic Ayesha lives in Manchester, which is an area of high deprivation
- Health Ayesha is suffering from rectal cancer, representing the 34% of adults in need of palliative care that have cancer

Challenges

- Looking after her children with little family support while managing her condition
- Trying to spend time with her family / friends with the limited time she may have
- Unable to fully understand the medical care she is being given, due to professionals not providing accessible interpreting services to account for English not being her first language



66 I'm having to attend a lot of appointments, which is making me feel more tired and confused and takes away from precious time with my family.

Ayesha



Occupation: **Home maker**

Age:

45



Location: Manchester



Interests: Cooking, stitching and poetry



Appendix 2 - Patient personas and pathways - Margaret



Margaret



Age: **91**



Occupation: **Retired**



Location: **Devon**



Interests: Reading, gardening and playing cards

Background information

Access to 24/7 support

To be close to her son

Goals

Margaret was born in one of the most deprived parts of Devon and has lived there all her life. Her husband passed away 2 years ago, so she lives alone but is sometimes visited by her son. Margaret has dementia and her symptoms have progressively worsened along with her becoming more frail. She moves in to a care home and eventually passes away in a hospital

To understand what to expect as her dementia worsens

To keep as much independence as possible

Challenges

Why Margaret?

dementia that are women

Starting to feel like a stranger in her own home because she regularly forgets where things are

Gender – Margaret represents the two thirds of people with

disadvantaged background, which studies have shown

increases an individual's risk of developing dementia. People

living in deprived areas typically have worse access to PEoLC

Demographic – Margaret is from an economically

- Feels isolated because she doesn't know anyone facing the same problems
- Scared of her dementia worsening

than people living in wealthier areas.

What does Margaret need from the ICS (linked to Ambitions for Palliative and End of Life Care)?

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Support writing an advance statement and advance decision (ambition 3) Social groups and community networks that help her feel less isolated (ambition 2)

Individualised support that considers things from her perspective (ambition 1)

A place in a care home, which is ideally close to her son (ambition 1)

66 My symptoms are worsening, I'd like to have some support for everyday tasks.



Appendix 2 – Patient personas and pathways: Example of current patient journey – Phil



CPJ_Phil.pdf

	Population Health Management	Identification as end of life	Advanced care planning	Progress and care delivery	Discharge
Summary of phase	 Phil lives at home independently and is alone Phil regularly attends GP appointments to manage his weight issues, diabetes, angina and heart 	 Experiences issues while walking up the stairs Tries to access GP due to pain but is unable to make contact with the GP. Experiences a long wait for the ambulance. In the hospital he is told that he is diagnosed with end stage heart failure 	 Development of advanced care plan including care package – there are delays in the care being put in place GP received discharge letter with minimal information. His first visit from the care worker is cancelled by the care worker Phil is referred to a district nursing team 	 Deterioration in condition – there are long ambulance waits Phil waits in the ambulance for 6 hours before being triaged. Phil's condition is deemed to have stabilised, so he does not require emergency treatment 	•The hospital follow up with the care plan – they find out the care support was cancelled due to the availability of support workers in the region. They are told to call in 24 hours for an update. The hospital are unable to discharge him yet •Phil's blood pressure increases and is difficult to stabilise which leads him to die a few hours later
Positive aspects of experience	•Regular engagement with primary care to monitor condition •Phil values some face-to-face contact	 Understands his diagnosis Once in hospital Phil feels relieved that he is in a place of safety 	•It reassures Phil to have a plan	•None	•None
Challenges	 No community support Difficulty in attending GP appointment due to rurality and mobility 	 Unable to do basic tasks Long ambulance wait times Further tests Diagnosis means he is unable to drive alone 	 Support is not provided immediately Appointment with district nurse is not for 2 weeks Discharge letter is not completed in enough detail 	 Long wait time for admission to triage Ambulance takes longer than expected wait time 	 Delay in care package being implemented Delay in discharge Preference was to die at home
Improvement opportunties	•Social prescribing •Virtual GP appointments •Point of Care Testing	•Digital device used to track Phil virtually •Offered transport support •Referred to hospice wellbeing service for relaxation, social support and wellbeing service or groups	 A key worker to lead on advanced care planning and co-ordinate services required including scenario planning Advanced care plan and discharge letter is shared more widely and is digital form An alarm pendant organised A Marie Curie Volunteer Companion allocated Access to PEoLC SPA (Single Point of Access) or 24/7 PEoLC hub with advice line. 	•An alarm pendant	•His ACP prompts a discharge home, just in case medications supply and MAR community prescription chart, urgent commencement of a hospice at home service and Marie Curie overnight service with a nurse staying overnight to provide care and support and Marie Curie Rapid Response service as needed. He is also part of a virtual ward team. Hospital transport is arranged swiftly to drop him off home



Appendix 2 – Patient personas and pathways: Example of current patient journey – Ayesha

the system



Ayesha

	Population Health Management	Identification as end of life	Advanced care planning	Progress and care delivery	Discharge
Summary of phase	 Ayesha has been recovering from cancer and has been receiving follow up care for almost 5 years After 7 years, Ayesha changes her GP and visits her GP due to abdominal pain. The GP is not able to access Ayesha's records. She has relevant tests carried out which reveal the tests are abnormal 	 Diagnosis of end of life received however the extent of this is not fully understood by Ayesha due to lack of interpreters She is referred to the palliative care team Ayesha's symptoms worsen and she is taken to the A&E. She stays here for a day due to the pain team being unavailable to see her immediately. She is discharged home. She has still not heard from the end of life care team 	•Development of care plan with a Care Coordinator (Thomas) from the palliative care team. The family ask for additional care support for Ayesha due to her mobility issues however Thomas is unclear of their request and no care package is put in place	 Deterioration in condition – In the early hours of the morning Ayesha has severe abdominal pain. Unable to access the specialist palliative care team she attends A&E. Here she is unable to access the suggested medication to relieve her pain so is suggested a substitute available at the hospital Her discharge is delayed due to the lack of sign off from the consultant on duty Follow up visit from Thomas 	 Ayesha experiences severe abdominal pain and visits A&E again The A&E staff realise she is dying but are unsure of her needs and contact the palliative care team to request the care plan. Her husband is also unable to fully explain what was outlined in the care plan Ayesha dies on the Sunday night
Positive aspects of experience	•Regular engagement with health and care professionals to monitor condition	•Clarity received on what was causing her symptoms	•It reassures Ayesha to have a plan	•None	•None
Challenges	•Unable to understand the language •Delays in GP access and arranging appointment •Explaining her medical history again	•Not being able to see the relevant heath and care professionals which delays her discharge •Delay in any contact from the palliative care team	 Paper based advanced care plan Her cultural / spiritual needs are not discussed Support for Hasan, as a carer, not discussed No care package received 	 Given substitute pain killers No specialist palliative care team available out of hours – generalist staff only No social care support for children Unable to access care plan 	•None
Improvement opportunties	 Electronic shared care record to allow the GP to access records Booking of appointment online / app to access her information and test results 	 Compassionate and trained staff Support with network groups she could get in touch with Interpreter to outline the full extent of the diagnosis The family could benefit from understanding what support is available to Ayesha's husband Hasan as a carer (including his young children).The GP should have the husband coded as a carer on 	 Digital care plan Carer support programme help and an explanation of all the support available Staff trained in patient needs (spiritual / language needs) who are able to have discussions on funeral care and dietary requirements 	 Digital care plan Care package support put in place more quickly 24/7 PEoLC hub Multi-lingual link workers Access to district nurses who have 24/7 access to medications 	 Ensuring quick release of the body by the services to meet any religious requirements Children being placed in to a beavered children's registry Bereavement support payment at enhanced rate for children could be made available



Appendix 2 – Patient personas and pathways: Example of current patient journey - Margaret



CPJ_Margaret.pdf

	Population Health Management	Identification as end of life	Discharge
Summary of phase	 Margaret lives at home with visits from her son Tom. Margaret is able to do most day to day tasks. However she has recently been feeling disorientated Margaret experiences a fall and is hurt. 111 are contacted. She is told to wait for an ambulance which has long waits. Due to this, Tom rushes from work and takes her to A&E A Mental Capacity assessment is not done 	 Margaret is bruised from her fall. The hospital decide a social worker referral is needed as it is unsafe to send her home. She is diagnosed with dementia. Due to the social assessment her discharge is delayed. After 1 week she is discharged with a care package and care plan put in place Margaret and Tom meet her GP a week after she is discharged to understand pain management medication. The GP hasn't received the discharge summary Margaret is struggling to swallow her food and is becoming more forgetful. She calls on the out of hours doctors. The doctor arrives at her home and provides medication. He is concerned about the unkept house and requests the social worker to visit Margaret again The social worker visits and conducts an assessment requesting a residential care home bed. Meanwhile, Margaret's care package is increased. She moves in to a care home shortly after A few weeks pass, Margaret begins to develop issues with swallowing and a severe cough again. Care home staff transport her to A&E With her deteriorating immune system she is told she has limited time to live due to severe pneumonia 	•Margaret has a dry mouth due to her issues with swallowing and is required to keep her mouth moist. In the early hours of the morning she dies
Positive aspects of experience	•Able to keep independent largely in her old age	•Care plan eventually put in place •Able to be in a care home	•None
Challenges	 Fed up of having to visit the A&E department each time she falls Long A&E waiting time 	•Delays in discharge •GP still unaware of Margaret's fall.	•Dying without saying goodbye to her son and is in pain
Improvement opportunties	 She would be referred to the frailty clinic and social worker for care package before Mental Capacity assessment is done Falls sensor Identified by data systems as a patient who is likely to die in the next 24 months from frailty Could be part of local community groups 	•Electronic shared care record •Use of VCSE to provide more support to enable Margaret to remain at home for longer more safely	•The staff being able to recognise Margaret might be dying and to call her son so they can spend time together and say goodbye



Appendix 2 – Patient personas and pathways: Example of future patient journey – Phil



	Population Health Management	Identification as end of life	Advanced care planning	Progress and care delivery	Discharge
Summary of phase	 Phil lives at home independently but is supported in his community through local services. He attends a local friendship group, attends swimming classes and receives calls from a befriender. A key worker visits him fortnightly Phil regularly attends GP appointments to manage his weight issues, diabetes, angina and heart failure. He is able to do Point of Care Testing when required too 	 Experiences issues while going upstairs 111 advise that Phil attends A&E. They are able to arrange his transport given he lives in a remote location and are able to access his previous health history. In the hospital he is told that he is diagnosed with end stage heart failure. He joins a virtual ward to manage his condition 	 The heart failure community nurse visits Phil with the key link worker to develop an electronic advanced care plan (ACP) and focuses on the escalation of care and DNACPR in a secondary care setting Discharge planning also organises a care package Phil's GP receives all this information through an electronic shared care record and is able to read the ACP. A Marie Curie Volunteer Companion visits weekly to provide social support The heart failure community nurse visits once a week, the key link worker visits Phil twice a week and he is able to receive support from his care worker. The key worker organises transport to the community activities he attends so Phil is able to continue enjoying these 	 Deterioration in condition - The virtual ward picks this up too and are able to send an ambulance immediately Phil's condition is deemed to have stabilised, so he does not require emergency treatment His ACP prompts a discharge home, just in case medications supply and MAR community prescription chart, urgent commencement of a hospice at home service and Marie Curie(MC) overnight service with a nurse staying overnight to provide care and support and Marie Curie Rapid Response service as needed. He is also part of a virtual ward team. Hospital transport is arranged swiftly to drop him off home He is visited by his key link worker the next day to re-assess his plan However, not every area has a MC service and some may be delivering similar services by another hospice or provider 	•The virtual ward team track Phil's health and begin to notice his blood pressure increases. The local ambulance is notified and arrive swiftly at Phil's home. Within 10 minutes from there arrival Phil's heart completely fails and he dies at home
Improvement opportunties incorporated	 Social prescribing – Referred to hospice wellbeing service for relaxation, social support and wellbeing service or groups Virtual GP appointments if he requires these Point of Care Testing Key worker assigned 	•Offered transport support •Provided a heart failure community nurse •Virtual ward	•Development of an electronic ACP and electronic shared care record •A Marie Curie Volunteer Companion provided •Key worker leading ACP	•Virtual ward •ACP followed	•His ACP prompts an urgent discharge home with DN, just in case medications supply and MAR community prescription chart, urgent commencement of a hospice at home service and MC overnight service with trained HCA/RN staying overnight to provide care and support and MC Rapid Response service as needed



Appendix 2 – Patient personas and pathways: Example of future patient journey – Ayesha



	Population Health Management	Identification as end of life	Advanced care planning	Progress and care delivery	Discharge
Summary of phase - Future	 Ayesha has been recovering from cancer and has been receiving follow up care for almost 5 years An interpreter is able to accompany her in most of her appointments and the need for an interpreter is noted in her electronic record After 7 years, Ayesha changes her GP and visits her GP due to abdominal pain. She schedule's an appointment with her GP on the NHS app and is triaged online for an urgent appointment. Her GP can access her records electronically The GP refers Ayesha under a 2 week straight to test referral for a colonoscopy and books a blood test Further tests are carried out 	 Diagnosis of end of life received and the interpreter is able to facilitate the discussion on this She is referred to the 24/7 palliative care hub and is assigned a specialist palliative care nurse 	 Ayesha and her husband work with the Care Coordinator from the palliative care team, Thomas and the interpreter who develops an electronic based advanced care plan. A care package is in place Ayesha's holistic needs are discussed. Spiritual and dietary needs are assessed e.g. requiring visits from a Muslim priest, ensuring at time of death her bed is faced towards Mecca. A carer programme is also put in place for the Hasan her husband. A discussion is also had on extra support for the children 	 Thomas and the specialist palliative care nurse receive a notification of the deterioration in condition and visit Ayesha with the interpreter. They discuss her condition and options. Further care support is put in place The family are able to receive Ayesha's medication through a prescription online delivery service Ayesha has been experiencing more severe episodes of abdominal pain. The end of life care team review pain management plan and it has been decided she needs an increased level of morphine to provide additional comfort to avoid hospital admission and maintain wishes to die at home. Her care support is increased for feeding and washing of Ayesha They call the priest and ensure her bed is facing Mecca 	•Ayesha dies on the Sunday night with minimal pain •A quick release of the body occurs in line with Ayesha's wishes
Improvement opportunties incorporated	 The ability to have an interpreter in most appointments Electronic shared care record Access to appointments via NHS app 2 week straight to test referral 	•The ability to have an interpreter in the appointment •Referral to the 24/7 palliative care hub and assignment of a specialist palliative care nurse	•Electronic advanced care plan •Holistic care planning •Interpreter involved	 Receiving medication via online service Follow up by relevant staff involved in her care – allowing her to stay outside of hospital Priest called and spiritual needs implemented as per the advanced care plan 	•Ensuring quick release of the body by the services to meet any religious requirements

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Appendix 2 – Patient personas and pathways: Example of future patient journey – Margaret



	Population Health Management	Identification as end of life	Discharge
Summary of phase - Future	 Margaret lives at home with visits from her son Tom. Margaret is able to do most day to day tasks. However she has recently been feeling disorientated. She receives fortnightly calls from her GP (as she has been identified by data systems as a patient who is likely to die in the next 24 months from frailty) to check in with her. He refers her to the frailty clinic, a social worker and signposts her to a local charity for Maintenance Cognitive Stimulation Therapy The social worker visits and puts in place an electronic advanced care plan Tom and Margaret visit the frailty clinic and Margaret explains how she is feeling disorientated and weaker. The frailty nurse identifies Margaret as being an individual at high risk of falls and gives a fall monitor to wear. The nurse notes this down in Margaret's shared electronic record Margaret has a fall which is detected by the response team connected to the falls device who then alert her local ambulance service. The response team are able to understand information about the intensity of her fall and are able to let the A&E team know about the urgency of this 	 Ambulance medics visit Margaret at home within 2 hours of the fall. They assess the fall is not serious and provide mild pain killers. The medics record the incident in her single shared electronic record. She is asked to contact the GP regarding next steps. Tom arranges for an appointment through the NHS app Margaret and Tom meet the GP and further painkillers are prescribed. A mental capacity assessment is done. She is diagnosed with dementia The social worker visits, provided by Council services, to discuss the results of the assessment and puts in place additional care support, letting Margaret know she is also eligible for a care home. The social worker also refers Tom to a carers support programme run by their local charity Margaret is struggling to swallow her food and is becoming more forgetful. It is late at night and she is feeling pain in her throat – she calls on the out of hours doctors as she does not want to go to A&E. She receives pain medication and her GP is asked to contact the following day. The doctor arrives at her home and provides medication. He is concerned about the unkept house and requests the social worker to visit Margaret again The social worker visits and conducts an assessment to be placed in a residential care home bed including sharing the financial aspects of this assessment. Meanwhile, Margaret's care package is increased. She moves in to a care home shortly after She is moved to a care home and the care home are able to review her electronic advanced care plan. Her family is provided with a bereavement booklet A week later Margaret begins to deteriorate. Two Community-based Dementia Support Workers (DSWs) specialising in end of life care provide advice, development sessions and support to the care home staff. The staff also have access to a 24/7 PEoLC hub A few weeks later, Margaret begins to develop issues with swallowing and a severe cough again. Care home staff transport her to A&E. With her deterior	•Margaret has a dry mouth due to her issues with swallowing and is required to keep her mouth moist. The nurse is able to keep her hydrated using a mouth swab. The nurse recognises this might also be a sign of her dying and calls Tom who is on her electronic care record. He arrives to be by the side of Margaret. In the early hours of the morning she dies
Improvement opportunties incorporated	 Identified by data systems as a patient who is likely to die in the next 24 months from frailty Fortnightly calls from the GP Attends for Maintenance Cognitive Stimulation Therapy Referred to the frailty clinic and social worker Falls sensor – Falls information shared with A&E team 	•Electronic shared care record •Mental capacity assessment done •Opportunity provided for Tom to join carers support programme •Bereavement booklet provided to family •Care home staff trained by Community-based Dementia Support Workers (DSWs) •Access to a 24/7 PEoLC hub for advice, guidance and support	•Trained staff •Electronic shared care record





Appendix 3

Additional KPIs to consider





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Appendix 3 – Main KPIs

КРІ туре	Sub-type	KPI name	
Operational KPIs	Demand for services	 % deaths in ethnicity groups % deaths by socioeconomic group % deaths split for people with learning disabilities % deaths split by homeless people % of deaths in hospital / in a care home / at home % deaths by specific causes 	
	Supply to deliver services	 Average caseload of a care coordinator in a given year Data on achieved PPC and PPD and on anticipatory meds Number of people on a supportive palliative care GP register/local palliative care support line, as a % of total deaths in a given timeframe and geography Number and capacity of existing specialist palliative care units/ community-based PEoLC services Number of carers known to LA and % having had a carers assessment 	



Appendix 3 – Additional KPIs in case of specific focus at certain part of the pathway

KPIs and datapoints across the pathway are listed below that are typically collected by healthcare organisations.

(Potentially other specific ones can be added to this list).

	Population Health Management	Identification as end of life	Advanced care planning	Progress and care delivery	Discharge
Demand	 Number of GP consultations prior to diagnosis in a given year Number of avoidable A&E admissions in admissions in a given year 	•Number of patients diagnosed as end of life in a given year	•Number of GP consultations post-diagnosis while waiting for care plan in a given year	•Number of patients arrive to hospice by conveyance	•Number of deaths in hospital vs other settings
Supply	•Number of patients waiting to access GP in a given year	 Number of diagnostic tests supplied Number of clinical FTE staff in a given year 	•Number of nursing visits required on average per week	 Average caseload of a care coordinator Number of nursing visits at residential home vs alternative setting 	•Number of beds available/ occupied in care home
Productivity and efficiency	•Average length of time from referral to admission	•Number of diagnostic tests per FTE •Average length of stay in hospital	•Lapse of time until care plan in place •Average length of time to put care plan in place	•Average length of time from referral to admission in care home •Average length of stay in palliative care unit	•Number of delayed discharges •Reason for delayed discharge
Cost	•Cost of GP consultation •Cost of pharmacy consultation •A&E attendance tariff cost	•Cost of diagnostic tests	•Cost of palliative care unit	•Cost of palliative care unit	•Inpatient admission bed day cost •Cost of care home
Quality of care	•Number of patients who felt supported by their GP	•Number of medical misdiagnoses in a given year	•Number of infections acquired in hospital vs other care settings (patient safety)	•Number of families who feel supported during their loved one's end of life	 Number of families who feel supported after their loved one's end of life % of people who die in their preferred place of care

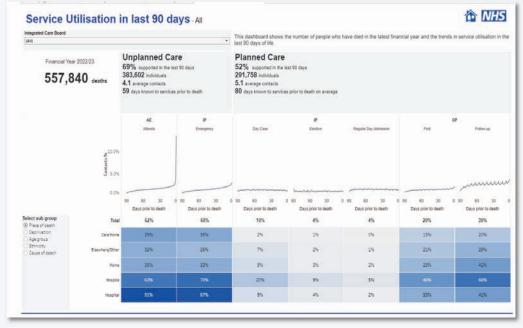


Appendix 3 - Additional KPIs, visualised

Data and KPIs could serve as basis for intervention and pathway assessment as explained in the main body of the guide.

The below dashboard based KPIs are:

- Data is available at each system level
- Given their importance for decision making, these KPIs are included on national dashboards





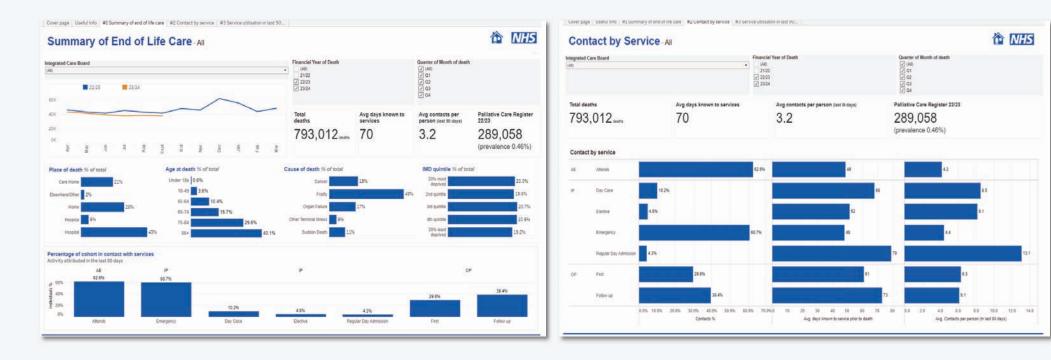


Appendix 3 – Additional KPIs, visualised (...continued)

Data and KPIs could serve as basis for intervention and pathway assessment as explained in the main body of the guide.

The below dashboard based KPIs are:

- Data is available at each system level
- Given their importance for decision making, these KPIs are included on national dashboards









Additional resources and guidance

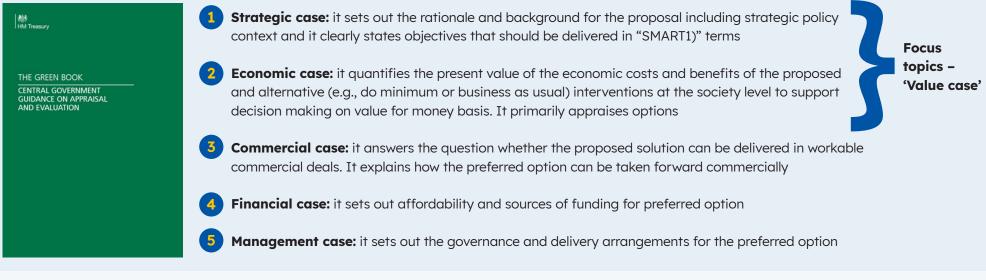




Appendix 4 – Additional resources and guidance: HM Treasury Green Book

Green Book approach for business case development in the broader public sector The Green Book is guidance issued by HM Treasury on how to appraise (public value focused) programmes and projects.

The five case model is the means of developing proposals in a holistic way that optimises the social / public value produced by the use of public resources. The guidance describes several types of business case for relatively smaller and relatively larger spends, and the work and detail should be scaled to the situation at hand.



Value (business) case development process:

Notes

- Value case and business case development is quite often an iterative process, which includes the development of an outline value case (and potentially business case as well),as well as the future pathway design
- Then the outline case can (in certain cases should) be put forward for external stakeholder consultation
- Keep in mind that regardless of whether you hold an external consultation, you should socialise the value case and future pathway changes with your internal stakeholders, early on, to gather their buy-in. Success of the implementation of change often depends on it

¹ Specific, Measurable, Achievable, Relevant and Time constrained goals.



Appendix 4 – Additional resources and guidance: HM Treasury Green Book (...continued)

Description of resource	Link to resource or embedded document
Green Book This is HM Treasury guidance on how to appraise and evaluate policies, projects and programmes.	https://www.gov.uk/government/publications/the-green- book-appraisal-and-evaluation-in-central-governent
Guide to developing the project business case This is HM Treasury guidance on how to develop project business cases.	https://assets.publishing.service.gov.uk/government/ uploads/system/uploads/attachment_data/file/749086/ Project_Business_Case_2018.pdf
Planning, assuring and delivering service change for patients This guidance is designed to be used by those considering, and involved in, substantial service change to navigate a clear path from inception to implementation.	https://www.england.nhs.uk/publication/planning- assuring-and-delivering-service-change-for-patients/
Major service change interactive handbook The aim of this handbook is to provide advice, information, and support to those with responsibilities related to service change and reconfiguration.	https://future.nhs.uk/system/login?nextURL=%2Fconnect% 2Eti%2Freconfiguration%2Fview%3FobjectID%3D126724229
Health Equity Assessment Tool This tool helps in assessing and driving action on health inequalities among multiple stakeholders across the system.	Health Equity Assessment Tool (HEAT): executive summary - GOV.UK (www.gov.uk)



Appendix 4 – Additional resources and guidance: Palliative and end of life care

The below captures other resources which outline PEoLC guidance and other good practice resources.

Description of resource	Link to resource or embedded document
Health and Care Act 2022 This is the link to the legislation introduced in regards to PEoLC.	Health and Care Act 2022 (legislation.gov.uk)
Palliative and end of life care: Statutory guidance ICB This guidance has been developed by NHS England to support ICBs with their duty to commission palliative care services within integrated care systems (ICSs).	NHS England » Palliative and end of life care: Statutory guidance for integrated care boards (ICBs)
PEoLC Handbook for ICBs This accompanies the statutory guidance and provides practical advice on implementing PEoLC.	https://www.england.nhs.uk/publication/palliative-and- end-of-life-care-statutory-guidance-for-integrated-care- boards-icbs/
Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026 This framework sets out the vision to improve end of life care through partnership and collaborative action between organisations at local level throughout England.	https://www.england.nhs.uk/publication/ambitions-for- palliative-and-end-of-life-care-a-national-framework-for- local-action-2021-2026/
Service specifications for palliative and end of life care: Adults This document provides the adult service model for delivering specialist level palliative care services from identification of need through to end of life.	https://www.england.nhs.uk/wp-content/uploads/2023/01/ B1674-specialist-palliative-and-end-of-life-care-services- adult-service-specification.pdf
Service specifications for palliative and end of life care: Children and young people This document provides a children and young people service model for delivering specialist level palliative care services from identification of need through to end of life.	https://www.england.nhs.uk/publication/service- specifications-for-palliative-and-end-of-life-care-children- and-young-people-cyp/
Guidance on developing the joint forward plan This guidance supports the development of the first 5-year joint forward plans (JFPs) with system partners.	https://www.england.nhs.uk/wp-content/uploads/2022/12/ B1940-guidance-on-developing-the-joint-forward-plan- december-2022.pdf
Functions to support the strategic governance of Palliative and end of life care at Integrated Care Board level This sets out recommendations for effective partnership working for strategic development.	https://www.england.nhs.uk/wp-content/uploads/2023/01/ B1674-specialist-palliative-and-end-of-life-care-services- adult-service-specification.pdf



Appendix 4 – Additional resources and guidance: Palliative and end of life care (...continued)

The below captures other resources which outline PEoLC guidance and other good practice resources.

Name of Resource	Aim of resource	Web or FutureNHS Palliative Care Network link
PEoLC Funding and Contracting Approaches Guidance	Approaches for funding PEoLC including an explanation of the blended payment model. Includes 3 phases of activities to assist ICBs in the journey to improving quality and sustainability.	PEoLC Funding & Contracting Approaches LIVE Draft - Palliative and End of Life Care Network - FutureNHS Collaboration Platform
RightCare costed case studies for PEoLC	These case studies were developed as part of the Right Care programme. They track the economic costs of a not atypical care journey and compare that to an optimal journey with earlier involvement of palliative care. These were published in 2018 but there is still relevant learning for those who wish to develop services.	Right Care Palliative Case Studies - Palliative and End of Life Care Network - FutureNHS Collaboration Platform
Specialist Palliative Care cost-effectiveness review	Nuffield Trust literature review of the cost effectiveness of specialist palliative care.	Specialist palliative care - Review of the evidence for cost- effectiveness - Palliative and End of Life Care Network - FutureNHS Collaboration Platform
Service specification self-assessment tool	A tool to support the self-assessment of current provision against the national specifications.	Assessment tool for PEoLC service specifications - Palliative and End of Life Care Network - FutureNHS Collaboration Platform
Anticipatory Care: Interventions Framework	A framework to help clinicians and other professionals plan and deliver services and supports for those eligible for AC.	Anticipatory-Care-Interventions-Framework-1 - Palliative and End of Life Care Network - FutureNHS Collaboration Platform
Palliative and End of Life Care Strategic Clinical Networks Core Metrics and Technical Guidance	The introduction and adoption of four core metrics will support colleagues in monitoring the impact of the PEoLC programme against the three key strategic priorities – improving access, quality and sustainability.	PEoLC Core Metrics and Technical Guidance - Palliative and End of Life Care Network - FutureNHS Collaboration Platform
A guide to commissioning bereavement services in England - National Bereavement Alliance	This document aims to help commissioners prepare tender specifications for area-based bereavement services for expected and unexpected deaths and help providers to respond to those tenders.	A guide to commissioning bereavement support in England – National Bereavement Alliance
Cruse Bereavement Care Service Standards	The Bereavement Care Service Standards were launched in 2013. The standards set out what organisations need to do to be safe and effective when offering services to bereaved people . They provide a vital tool for anyone who wants to help bereaved people across all sectors.	Bereavement Care Service Standards - Cruse Bereavement Support
Adults SPC Workforce Mapping Template v3 CYP SPC Workforce Mapping Template v3	Templates for local use.	Adults SPC Workforce Mapping Template v3 - Palliative and End of Life Care Network - FutureNHS Collaboration Platform CYP SPC Workforce Mapping Template v3 - Palliative and End of Life Care Network - FutureNHS Collaboration Platform
Specialist Service Descriptors for PEoLC	Guidance prepared by the Cheshire & Merseyside Palliative & End of Life Care Clinical Network to support the commissioning and provision of specialist palliative care and is aligned with national recommendations.	Specialist Service Descriptors for PEoLC - Palliative and End of Life Care Network - FutureNHS Collaboration Platform
Key enablers for end-of-life care	Commissioning advice and guidance for PEoLC - developed by Sue Ryder.	Key enablers for end-of-life care SueRyder - Palliative and End of Life Care Network - FutureNHS Collaboration Platform



Appendix 4 – Additional resources and guidance: Palliative and end of life care (...continued)

Description of resource	Link to resource
PEoLC Contract Specification Requirements This provides wording to assist those responsible for specifying best practice in service pathways.	https://www.england.nhs.uk/wp-content/uploads/2022/07/Palliative-and- End-of-Life-Care-Statutory-Guidance-for-Integrated-Care-Boards-ICBs- September-2022.pdf
PEoLC Commissioning Investment Framework This aims to support ICBs as they identify and address any gaps in commissioning arrangements for PEoLC and in meeting their legal duties.	If you would like a copy of these documents please email: england.palliativeandendoflife@nhs.net
Ambitions Self-Assessment Tool and Ambitions Self-Assessment Guidance This is to support localities to determine their current level of delivery of services against the Ambitions Framework to identify areas for improvement.	
PEoLC Quality measures in the home setting This provides metrics for consideration that can be employed for analysing care quality at home.	
24/7 Care and Specialist Advice for PEoLC: Commissioner's good practice guide This aims to support commissioners by providing the key principles of effective 24/7 care and advice services.	
Shared care records for PEoLC This sets out principles for implementing good practice around shared care records.	



Appendix 4 – Additional resources and guidance: Social investment in health and social care

Description of resource	Link to resource
Health and Social Care Investment Hub This is a resource hub aiming to demystify social investment in health and social care. It includes a recent webinar hosted by Social Finance, which gives readers a chance to listen to partners that have been involved in bringing some of the ideas to life.	<u>Health and Social Care Social Investment Hub Social Finance</u>
NHSE guidance on Social Investment Model Social Finance supported the development of NHSE guidance as an alternative approach to funding palliative and end of life care.	https://www.socialfinance.org.uk/insights/social-investment-funding-a- lifeline-for-the-nhs



Search: Marie Curie ICB Toolkit

Contact local@mariecurie.org.uk

X @MarieCurieEOLC

About Marie Curie

Marie Curie works hard to support dying people and their families. We offer expert care across the UK in people's own homes and in our nine hospices. Last year, we supported more than 50,000 people across the UK at the end of their lives. Our free information and support services give guidance and support to families. We're the largest charitable funder of palliative and end of life care research in the UK and campaign for the policy changes needed to deliver the best possible end of life experience for all.

Charity reg no. 207994 (England & Wales), SC038731 (Scotland).