Palliative and End of Life Care in Lincolnshire

High Level Design

Operating Model for Palliative & End of life Services

Document changes and version control

Version	Date produced	Changes from last version	Completed by	Reviewed by
V1.0	14 March 2022		PEOL Core grp	PEOL Delivery Grp
V2.0	21 March 2022	*Feedback from Delivery Group and Core Pro Team*	D Reed	PEOL Core Group
V2.0	24 March 2022	*Further feedback from Delivery Group and Core Team - reworked 'as is' and 'to be' maps, reworked demand flow and critical interventions slide*	D Reed	PEOL Core Group
v2.1	31 March 2022	Feedback on Design Principles from LF	D Reed	PEOL Core Group
v2.3	07 April 2022	Feedback on HLD from LF & others	D Reed	PEOL Core Group
v2.4	11/04	Feedback from LF / KH and others	D Reed	PEOL Core group
v2.5	12/04	Review by PEOL Delivery Group - and Feedback provided	D Reed	PEOL Delivery Group
V2.6	13/04		D Reed	PEOL Core Group
V2.8	19/04	Feedback from Core group	D Reed	PEOL Core Group
v2.9	20/04	Processing feedback	D Reed	PEOL Core group
v2.10	22/04	Initial Feedback from Critical Friend Reviews	D Reed	PEOL Core Group
V2.11	27/04	Feedback from Critical Friend Reviews	D Reed	PEOL Corre group
V3.1	29/04	Final Feedback from Critical Review sessions	D Reed	PEOL Core group
V3.2	10/05/22	Feedback from PEOL Core Group	D Reed	PEOL Core Group
v4.0	19/05/22	Feedback from Core Group	D Reed	PEOL Core Group
V5.0	20/05/22	Feedback from Core group	D Reed	PEOL Core Group

Operating Model Overview

Introduction

This pack provides a high level overview of the proposed Palliative and End of Life operating model for Lincolnshire. It works through the proposed operating model in 4 sections:

- **Section 1** sets out the **Strategic Context (s4)** of palliative and end of life care in Lincolnshire and the **current operating model (s5).** It then describes the **Scope** of the PEOL programme **(s6)**. the challenges that have been identified with it - both qualitatively **(s7)** and an assessment of how **demand currently flows** through PEOL services **(S7, 8 & 9)**. The pack summarises the current **Challenges** involved in providing PEOL services **(s9,10)**

- **Section 2** sets out the **Vision and objectives (S11)** and **Design Principles (s12)** that will inform work on the future model of care. The view of Patients and their families is reflected in a co-produced **Palliative Pledge (s 13)**

- **Section 3** describes the **'To be' model** is then described **(s14)** - along with a description of **service definitions (s15)**, our approach to **co-ordination (s16)** and the **Care Functions (s17, 18)** that underpin our work. It provides an insight into **Infrastructure** required to support the model and an **Overview** of how the model operates **(S19) .**

- **Section 4,** the final section describes the **Critical Interventions** need to deliver the new model of care **(S20,21,22,23).** The pack then outlines the proposed **Benefits (s24).** The final slides map out **Dependencies (s25)** conclude by articulating the key **Strategic Choices** that exist **(s29)** and by setting out proposed **Principles for Implementation (s 30)**

Palliative & End of Life Care: High Level Design

Changing patterns of demand

The current population in Lincolnshire is 751,200, but this figure is predicted to grow by 10% by 2041, with 30% of the population expected to be over 65. Our population is on average older than the population of England. It also has a higher proportion of adults over the age of 75 and the number in this age range is expected to double over the next 20 years. By 2026 it is estimated that the number of people dying each year who could have benefitted from PEOL care will have risen by 6.3%. But those who have more complex care needs will have increased by 7.5%
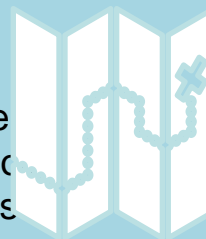
Variation in wealth and deprivation

Urban areas and particularly the coast suffer higher deprivation, although there are pockets of deprivation across the county, including in rural areas which frequently suffer from issues of accessibility.

Geography of Lincolnshire

Lincolnshire is predominately rural, with no motorways, little dual carriageway and 80km of North Sea coastline. 48% of people live rural areas - compared with the national average of 18%. It has p developed road networks, mainly of single carriage A and B roads impacting on ability of people to access services including healthcare. The coast has the largest concentration of static caravans in Europe leading to large seasonal variations in population.

Population Demographics

'In' migration of older people and 'out' migration of younger people is causing a significant imbalance. The East coast is a destination for retirees - often with lower income employment and reduced access to social and family networks. In East Lindsey, 28% are over 65 - whereas the national average is 16%

The diversity of the population has increased in recent years as a result of new and emerging communities. As of the 2011 Census, 93% of residents identify themselves as White British with a significant 4% identifying as White Other. This 4% is primarily made of Eastern European communities

Public Expectations

There are increasing expectations about the support that should be offered to people at the end of life - as set out in the National '**Ambitions for Palliative and End of Life care**". We want to put people and those who matter to them (family, friends and carers) at the heart of everything that we do.

Economic pressures

Lincolnshire has strong agriculture, manufacturing, food and tourism sectors, however these tend to provide lower paid and lower skilled employment than the national average. Unemployment in Lincolnshire is below national rates, however there is significant seasonal employment in relation to the strong horticulture and tourism sectors, particularly in the east and south of the county

Lincolnshire has one of the fastest growing rates of carers in the UK. Between 2001 and 2015, the county experienced a 27.5% increase in the number of carers, compared to the general rate of population growth of 6.2%.There are estimated to be over 84,000 unpaid carers in the county
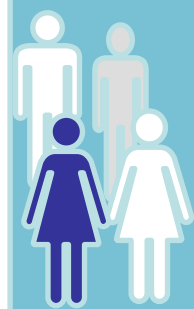
Advancing technology

With internet, telephone, and video consultations up and running in all of our PCNs, our G Tech is evolving. Some GP practices are dealing with about 80-90% of all patient contacts remotely without patients having to attend a face to face assessment.

The combination of an ageing population, a rural geography and areas of high socioeconomic deprivation defines the specific challenge of delivering high-quality and effective services in Lincolnshire.

Section 1:   Our Current operating model

Key features
(as at Jan 21)

- **Organisation**: Primary Care

- **Organisation:** Lincolnshire County Council

- **Organisation**: Lincolnshire Community Health Services

- **Organisation:** St Barnabas

- **Organisation:** Marie Curie

- **Organisation**: United Lincolnshire Hospitals Trust

Operating model delivers services through individual organisations and is coupled with variation developed through different processes and approaches to co-ordination in different localities (both by practice and PCN)

Each organisation provides several services with different pathways connecting services within individual organisations to others

The Lincolnshire CCG provides formal oversight of individual organisations and service provision - but there is no similar formal operational co-ordination across Lincolnshire.

Palliative & End of Life Care – High Level Functions
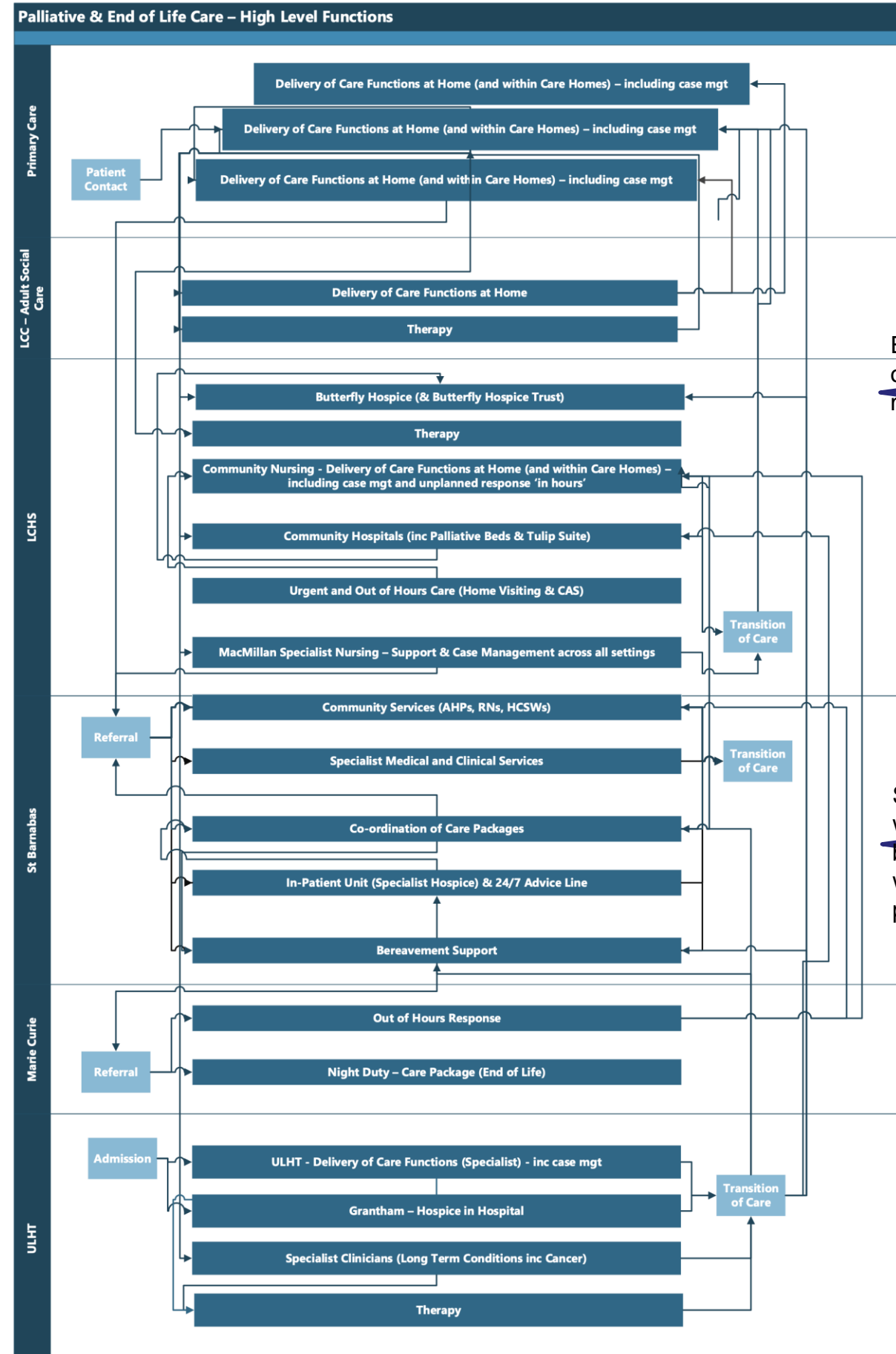
A range of different processes in Primary Care with variable timing and frequency of meetings operating within each locality. Locally developed - with some approaches being best practice - but creating challenges with wider co-ordination

Essential services delivered through different organisations - each with individual resource models, policy, referral and transition systems .

Important to recognise that in some areas provision is of a high quality with sufficient capacity but in others less so - with staff under significant pressure.

Services have developed incrementally without yet being able to maximise the benefits that can be obtained from system working and advances in technology - particularly digital technology

Lack of a system approach has led to complexity and inconsistency - and has tied up local resources in the additional work required to negotiate services and duplication

The scope of Palliative and end of Life Care is:

People
- All people, their carers, families and those important to them who require Palliative and End of Life (PEOL) care
- This includes adults and those transitioning from services for children and young people

Services
- All PEOL services that are provided by health and care professionals who provide direct care for those who are recognised as PEOL
- All structures, systems and processes that are needed to provide, communicate and co-ordinate PEOL services - including referral, admission and discharge processes, case management, operational management, triage and requests for unplanned care and support
- Emergency Care services - including 111 and EMAS

Health and Care staff
- All these who deliver PEOL services - including core health and care staff - ranging from ward and community based clinicians (such as Health care Support workers) to carers working in care & nursing homes and other professional carers and social workers. This also includes specialist health and social care staff who deal with more complex needs and where the needs of people cannot be met through the capability of the core team alone.
- Enhanced health and care services including social prescribers, the third sector, and community groups who are providing care and support to PEOL people
- People, their families and carers who are self-managing their condition or providing other personal care and support.

The size and scale of this programme is:

- In the last 12 months, 10,374 people in Lincs benefitted from PEOL care
- The number of people (and families) currently managing a palliative condition, based on the Palliative Register is 5373 (March 22)

The category of:
- Specialist staff includes:
  - 5.5 x Consultants, 34 Specialist Palliative Nurses / Clinical Nurse Specialists, 74 Registered Nurses, 53 Health Care Workers, 14.3 Allied Health Professionals

- (Pay costs for Specialist Palliative Care services, commissioned by the CCG, are around £10m per year)

- Core health and social care staff include;
  - 626 Community Nurses, 456 Nurses in Care Homes, 6670 Care workers and 2230 Non-Care workers in Care Homes
  - In Primary Care there are. 414 GPs, 313 other roles providing direct patient care and 1080 Admin / Non-clinical staff
  - Others include Adult Social Care (Social workers), community and acute therapists and Domiciliary Care

A total of *12,380* health and social care staff provide palliative care either for part or all of their working day

In-patient Beds
- In 2021/22, the CCG commissioned 13 Beds in Hospitals and up to 47 beds in various Hospices (includes in and out of area)

Strategic Pressures

The population of Lincolnshire is changing and, over the next 5 years, pressures are likely to grow. By 2026 it is estimated that the number of people dying who could have benefited from PEOL Care will have increased from 6169 (in 2020) to 6557, a 6.3% increase. However people are also likely to have more complex needs - with those who are frail rising from 4460 (in 2020) to 4795 - a 7.5% increase - and those who have a single long term condition rising from 893 to 957, a 7.2% increase.

This is an underlying pressure that, for specialist services alone, may represent an additional £700k in staff costs to maintain the existing level of service.

Patient Flow

Analysis of existing data suggests a series of points at which the level of PEOL care is not of consistent and equitable high quality - with consequences for patients and their families but also other areas of health and social care.

- **Palliative Register and Care Planning**: Using data from the PEOL Objectives Dashboard, in Mar 22, 5,373 patients were registered as Palliative with10,473 receiving PEOL care in the last 12 months. Of these patients,
  - ⊙ 0.73% of the population is identified on the PEOL, It is estimated that around 1-2% of the population should be recognised as palliative.
  - ⊙ Currently around 50% (51.6%) of overall number patients of palliative patients are also on cancer register, suggesting low recognition of other diagnoses. Nationally, around 1 in 4 deaths are cancer related.
  - ⊙ 74.3% had a GSF stage recorded (Year Plus 31.6%, Months 34.6%, Weeks 6.2%, Days 1.9%, Other 7.9%, Not recorded 17.8%)
  - ⊙ 35.6% had an ACP in place or had had a conversation about an ACP
  - ⊙ 15.8% had Anticipatory Care Meds
  - ⊙ 47.6% had a ReSPECT form
  - ⊙ 38.9% had recorded a preferred place of death (PPoD) - and 94.8% of those who provided a PPoD recorded it as home.
  - ⊙ For patients on PEOL Register who have died since 2019 43.3% (3726) were added to the PEOL within 4 weeks of death.

- **Hospital Admissions:** this data indicates that PEOL patients have a disproportionate impact on the capacity of the health system to manage care. Whilst the number of PEOL patients who attend A&E are relatively small, they are disproportionately more likely to attend A&E, be admitted and, once admitted, they are likely to stay, on average, for longer than any other patient group.
  - ⊙ 0.5% (1,695) patients who have PEOL as an identified health need accounted for 5% (2,142) of all NEL admissions, 3% of A&E attendances but 10% (29,561) OBD of occupied bed days;
  - ⊙ 79% conversion rates to admission after an A&E attendance
  - ⊙ 2.4% attended A&E more than 3 times, 9.8% more than 5 times
  - ⊙ 27.4% died on admission, 2.1% died within 48 hours (of all PEOL Admission), 7.6% of all those that died with 48 hours
  - ⊙ Average admission is 1.26 per person, maximum 12 per person
  - ⊙ 62.5% of admitted patients have a LOS > 8, and the average LOS was14 days.
  - ⊙ Activity in the prior 6 months to coding as PEOL indicates more activity for that cohort – (49.7% NEL Admissions and 28.6% OBD)
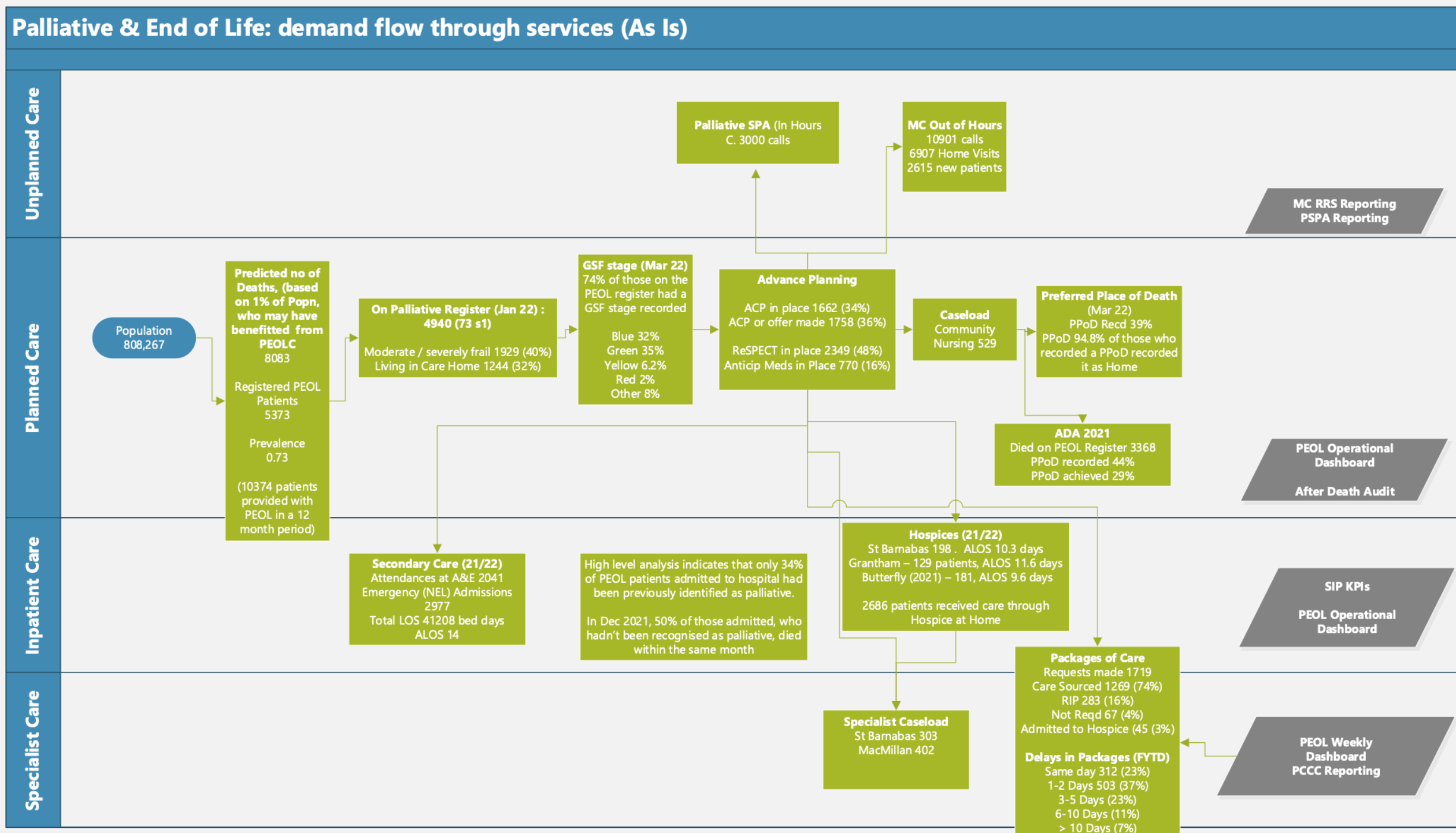
- **After Death Audits (ADA)**: Using the most recent available data (After Death Audit (March 22),
  - ⊙ 41.6% of patient who died were not on the PEOL register, but died of conditions where palliative care would have been expected
  - ⊙ 29.9% of all Deaths for were not on the PEOL or the LTC Register
  - ⊙ Using a Quality Indicator (0% High >80%, 22.2% Average between 60% and 80% ,77.8% Low < 60%)
  - ⊙ 66.7% (of those who recorded it Preferred Place of Death) managed to achieve their Preferred Place of Death (although only 66.7% place of death recorded)
  - ⊙ It is worth noting that the situation is different for those receiving specialist care. Data on MacMillan caseloads for 2019/20 indicated that 95% of patients had their PPD documented and 89% achieved this. However, given its obvious significance, low achievement of the preferred place for a person to die should be a cause for reflection

- **Care Packages:** for those cared for at home, 60% of care packages (FYTD) are sourced within 2 days and 40% commence within 2 days. These delays can occur as part of the process of being discharged from hospital (with a knock on impact on secondary care) and there is also an impact on families waiting for more than 2 days in their own home (especially if they live alone). However 16% of patients die before the package is provided - which may reflect challenges in sourcing care but which may also indicated late referrals.

- **Unplanned Need:** in the course of 2021, there were 10,901 calls for unplanned needs during the out of hours period - resulting in 6907 home visits. During the day, the newly implemented Palliative Single Point of Access now deals with around 250 patients a month - an estimated 3000 patients a year. The 24/7 service is therefore dealing with around 14000 calls per year -with many of these calls being from patties who are close to the end of life. Given the numbers who receive PEOL care each year, this volume of calls suggests that this is a critically important service to people and their families and there is no dedicated response service during "in hours", placing pressure on those delivery planned care.

- **Equalities Impact Data**: A review of data sources has included Age, Sex, Ethnicity and Deprivation has identified
  - ⊙ Around 43% of people have been placed on the palliative register in the last 4 weeks of their life –this late recognition is higher in areas of higher deprivation.
  - ⊙ Across all ages, locally around 54.9% of females are being identified as palliative, compared to 45.1% males, whilst the population distribution is 50.5% and 49.5% respectively. This suggests inequality in the services received by men.
  - ⊙ 'White other' - disproportionately low recognition compared to White British – 2% only whilst constituting 6% of the population. This picture is similar in other ethnicities
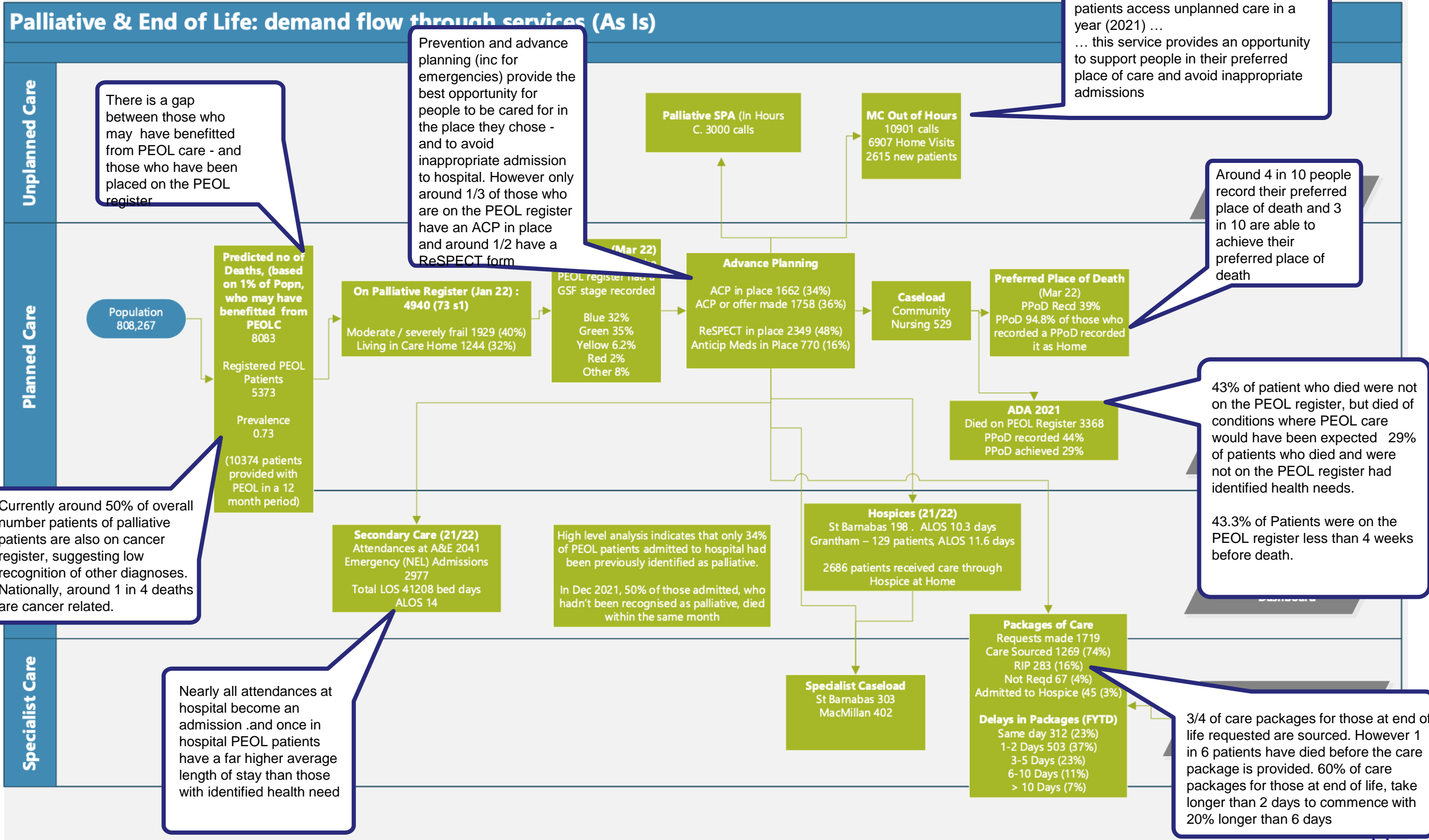
When we have looked at how demand flows through the PEOL system - and what the data tells us

Palliative & End of Life: demand flow through services (As Is)

Unplanned Care

Palliative SPA (In Hours C. 3000 calls

MC Out of Hours
10901 calls
6907 Home Visits
2615 new patients

MC RRS Reporting
PSPA Reporting

Planned Care

Population 808,267

Predicted no of Deaths, (based on 1% of Popn, who may have benefitted from PEOLC
8083

Registered PEOL Patients
5373

Prevalence
0.73

(10374 patients provided with PEOL in a 12 month period)

On Palliative Register (Jan 22) :
4940 (73 s1)

Moderate / severely frail 1929 (40%)
Living in Care Home 1244 (32%)

GSF stage (Mar 22)
74% of those on the PEOL register had a GSF stage recorded

Blue 32%
Green 35%
Yellow 6.2%
Red 2%
Other 8%

Advance Planning

ACP in place 1662 (34%)
ACP or offer made 1758 (36%)

ReSPECT in place 2349 (48%)
Anticip Meds in Place 770 (16%)

Caseload
Community Nursing 529

Preferred Place of Death
(Mar 22)
PPoD Recd 39%
PPoD 94.8% of those who recorded a PPoD recorded it as Home

ADA 2021
Died on PEOL Register 3368
PPoD recorded 44%
PPoD achieved 29%

PEOL Operational Dashboard

After Death Audit

Inpatient Care

Secondary Care (21/22)
Attendances at A&E 2041
Emergency (NEL) Admissions 2977
Total LOS 41208 bed days
ALOS 14

High level analysis indicates that only 34% of PEOL patients admitted to hospital had been previously identified as palliative.

In Dec 2021, 50% of those admitted, who hadn't been recognised as palliative, died within the same month

Hospices (21/22)
St Barnabas 198 . ALOS 10.3 days
Grantham – 129 patients, ALOS 11.6 days
Butterfly (2021) – 181, ALOS 9.6 days

2686 patients received care through Hospice at Home

Packages of Care
Requests made 1719
Care Sourced 1269 (74%)
RIP 283 (16%)
Not Reqd 67 (4%)
Admitted to Hospice (45 (3%)

SIP KPIs

PEOL Operational Dashboard

Specialist Care

Specialist Caseload
St Barnabas 303
MacMillan 402

Delays in Packages (FYTD)
Same day 312 (23%)
1-2 Days 503 (37%)
3-5 Days 23%
6-10 Days (11%)
> 10 Days (7%)

PEOL Weekly Dashboard
PCCC Reporting

When we have looked at how demand flows through the PEOL system - and what the data tells us

Palliative & End of Life: demand flow through services (As Is)

Unplanned Care

Planned Care

Specialist Care

There is a gap between those who may have benefitted from PEOL care - and those who have been placed on the PEOL register

Prevention and advance planning (inc for emergencies) provide the best opportunity for people to be cared for in the place they chose - and to avoid inappropriate admission to hospital. However only around 1/3 of those who are on the PEOL register have an ACP in place and around 1/2 have a ReSPECT form

Around 1/2 of all PEOL registered patients access unplanned care in a year (2021) …
… this service provides an opportunity to support people in their preferred place of care and avoid inappropriate admissions

Palliative SPA (In Hours) C. 3000 calls

MC Out of Hours
10901 calls
6907 Home Visits
2615 new patients

Around 4 in 10 people record their preferred place of death and 3 in 10 are able to achieve their preferred place of death

Population 808,267

Predicted no of Deaths, (based on 1% of Popn, who may have benefitted from PEOLC 8083

Registered PEOL Patients 5373

Prevalence 0.73

(10374 patients provided with PEOL in a 12 month period)

On Palliative Register (Jan 22) : 4940 (73 s1)

Moderate / severely frail 1929 (40%)
Living in Care Home 1244 (32%)

(Mar 22)
PEOL register had a GSF stage recorded

Blue 32%
Green 35%
Yellow 6.2%
Red 2%
Other 8%

Advance Planning

ACP in place 1662 (34%)
ACP or offer made 1758 (36%)

ReSPECT in place 2349 (48%)
Anticip Meds in Place 770 (16%)

Caseload
Community Nursing 529

Preferred Place of Death (Mar 22)
PPoD Recd 39%
PPoD 94.8% of those who recorded a PPoD recorded it as Home

ADA 2021
Died on PEOL Register 3368
PPoD recorded 44%
PPoD achieved 29%

43% of patient who died were not on the PEOL register, but died of conditions where PEOL care would have been expected 29% of patients who died and were not on the PEOL register had identified health needs.

43.3% of Patients were on the PEOL register less than 4 weeks before death.

Currently around 50% of overall number patients of palliative patients are also on cancer register, suggesting low recognition of other diagnoses. Nationally, around 1 in 4 deaths are cancer related.

Secondary Care (21/22)
Attendances at A&E 2041
Emergency (NEL) Admissions 2977
Total LOS 41208 bed days
ALOS 14

High level analysis indicates that only 34% of PEOL patients admitted to hospital had been previously identified as palliative.

In Dec 2021, 50% of those admitted, who hadn't been recognised as palliative, died within the same month

Hospices (21/22)
St Barnabas 198 . ALOS 10.3 days
Grantham – 129 patients, ALOS 11.6 days

2686 patients received care through Hospice at Home

Packages of Care
Requests made 1719
Care Sourced 1269 (74%)
RIP 283 (16%)
Not Reqd 67 (4%)
Admitted to Hospice (45 (3%)

Delays in Packages (FYTD)
Same day 312 (23%)
1-2 Days 503 (37%)
3-5 Days (23%)
6-10 Days (11%)
> 10 Days (7%)

Specialist Caseload
St Barnabas 303
MacMillan 402

Nearly all attendances at hospital become an admission .and once in hospital PEOL patients have a far higher average length of stay than those with identified health need

3/4 of care packages for those at end of life requested are sourced. However 1 in 6 patients have died before the care package is provided. 60% of care packages for those at end of life, take longer than 2 days to commence with 20% longer than 6 days

In addition to data analysis, the PEOL programme has paid close attention to the experience of people, family and carers who have experienced Palliative and End of Life Care in Lincolnshire. Given the nature of PEOL care, it has been noticeable that many health and care staff have had similar experiences - despite their knowledge of the 'system'. This applies to both the less than positive experiences as well as the occasions when there has been overwhelmingly positive feedback about the care provided.

In 2020, two pieces of work were commissioned from Whole Systems Partnership (WSP) and Healthwatch Lincs (HwL) to provide an Independent view of patient experience. WSP and the Core PEOL Programme Team undertook 34 detailed interviews and held 4 workshops with 87stakeholders. HwL Lincs surveyed 113 members of the public and 40 professionals.

- **Complexity**: several carers reported having 'to fight for their family to get the care' that mattered to them whilst trying to navigate complicated processes and being passed from one service to another. Professionals noted that it took " too many people to get anything done" and that "referral and triage processes are confusing and clunky" - and with much duplication involved. It was felt that teams were often fragmented and lacking in resilience.

- **Communication & Co-ordination**: 65% of professionals felt that the services delivered were variable and of a mixed standard, citing possible causes as lack of coordination, training, and knowledge of other services. There were several references to duplication of roles, services & pathways (leading to confusion for users and staff) and there was a constant theme of poor communication - with the patient as well as communication within and across teams and with several instances of repeated re-telling of patient stories to professionals.

- **Personalisation and Patient Focus:** there was evidence of a disconnect between patient and professionals, with expectations not being managed or services not being delivered as expected. WSP noted a perception that service user feedback was not often sought or acted on. It was also felt that the services were overly focussed on clinical aspects of care and on physical symptom management rather than on all 4 pillars of care. There was felt to be no or limited timely services available to support psychological needs - including bereavement. Some people reported a sense of being 'dropped' when their curative care was halted - but they still felt clinically well.

- **Skills Development:** education provision was felt to be poor and, associated with this, there appeared to be a poor understanding in some cases of important palliative ? tools. The use of systems and processes such as Discharge processes, the CD1 form and ReSPECT form appeared to be either underutilised, incomplete, missing or misunderstood. It was felt, in particular, that there was a lack of capability to recognise palliative need and subsequent deterioration - with action only occurring at a point of crisis (often on admission to hospital)

- **24/7 Response:** HwL noted, strongly, that there was a need for practical recognition that palliative and end of life care is a 24/7, 365 day requirement and aspects such training, information, access to services and support, need to be made available in a timely manner at the point of need.

- **Leadership and Specialist Services**: it was felt that, across PEOL services, there was a lack of co-ordinated clinical leadership and inconsistent access to specialist palliative care services

- **Resources & Capacity:** both reports noted challenges with workload and capacity. HwL went further and observed that some of the feedback was, in their view, associated with 'care giver burnout and compassion fatigue". A key issue is the wider resilience and sustainability of the workforce, particularly following COVID.

- **Care for carers:** of additional note was a strong sense of a lack of support for carers and families with ongoing implications for those who have not had support during a period of crisis and with a consequent impact, down the line, on other health and care agencies

Conclusions

- **Palliative Flow**: the data describes a situation in which there appear to be several opportunities to both recognise and then proactively support individuals who would benefit from being well supported in their own home. This includes both improved Recognition, personalised 'what matters to me' conversations and opportunities to complete Advance Care Planning. Improved and proactive management of palliative care would provide an opportunity for better anticipatory planning, to avoid inappropriate admission to hospital and, above all, to allow a person to remain in their preferred place of care and death.

- **Complexity and Co-ordination**: the existing care model is overly complex, with many small teams and organisations involved in providing care. Processes are different in different localities - which adds to the complexity - and there is duplication of roles and responsibilities which adds to the difficulty of getting things done. A service (rather than organisation) based approach would provide opportunity to simplify and standardise processes as well as ensuring greater consistency of service delivery across the County. Improving consistency of services will also help address health inequalities across the county.

- **Specialist Services**: an area in which resilience and consistency of service are critical is the provision of Specialist Services. A single service would assist in both providing the necessary sustainability and resilience but also improve consistency in which these services are made available

- **Demand Resource Management:** within the financial constraints that the service operates in, there must be a sustained focus on ensuring that there is sufficient capacity within the system to provide care and the co-ordination of care. This should include consideration of all opportunities to reduce unnecessary workloads and to providing effective triage arrangements that assist health and care staff to prioritise their workload.

- **24/7 PEOL support:** there is a continuing need for 24/7 response (both urgent and planned) and support. This needs to be both efficient and resilient to deal with potential increase in demand over the next 5 years.

- **Skills & Development**: there is a need for systematic support for and development of staff engaged in delivering PEOL care. This should be based on a set of clear expectations and competencies as to what each role should be able to provide.

- **Clinical Leadership:** several aspects of this assessment indicate the need for a more systematic, population health management approach to PEOL care - and it is essential to support this with a stronger framework of system -wide leadership. This would support the management immediate operational challenges but also provide the best opportunity to deliver continuous improvements in the quality of care provided.

- **Personalisation:** there is a desire and a need for PEOL care in Lincs to become more personalised and centred on the needs of the patient. These needs are not solely clinical and should included consideration of the holistic needs of the person, his family and carers. Personalised approaches should consider all ways in which an individual can be supported - including approaches based on self management that may provide valuable support when an individual is first diagnosed as palliative.

Palliative & End of Life Care: High Level Design

Vision

We will improve the quality of palliative and end of life care in Lincolnshire and make better use of all health, social care, neighbourhood and voluntary sector resources to support these improvements.

Health and Care agencies will work, together with communities, to identify all patients deteriorating from a life-limiting condition at the earliest possible stage. They will then provide the highest quality of care, communication and support to those patients and those who are important to them.

Palliative care services will be co-ordinated and delivered within Primary Care Networks, at Locality and County levels to provide the best possible support for patients and their families. These services will operate within a consistent framework and at the most appropriate level and setting to meet population health needs and provide equity of access to high quality care across all parts of the County.

The provision of Palliative and End of Life care will form an important part of a wider framework of person centred, integrated care across Lincolnshire, designed to meet the needs of the local population.

The changes in palliative and end of life care will have been delivered in a way that engages, involves and builds the confidence of staff and communities across the County. This will pave the way for future change across the health and care system

Objectives

A.   To increase our recognition of people deteriorating from a life limiting condition

B.   To increase the proportion of those on the Palliative register who have had high quality and timely conversations about dying

C.   To increase the proportion of patients who have had advance care planning and robust care assessments

D.   To increase the proportion of people who have had high quality care in the last days of their lives

E.   To increase the quality of our patient centred care

F.   To increase the resilience and sustainability of Palliative and End of Life services

Design Principles: Palliative and End of Life Care in Lincolnshire

We have worked with stakeholders to establish the principles to guide our new model of care.

By 2025, across Lincolnshire, there will be:

1	A PEOL care service that will focus, above all else, on delivering what is important to the person, their family and their carers.
2	Proactive identification of all those people who would benefit from palliative and supportive care including, after their death, for their families and carers.
3	A PEOL care service that works as a multi-disciplinary team, 24/7, to ensure patients receive the support, care and treatment required irrespective of their care setting.
4	A PEOL care service that operates in local, integrated teams to provide competent, confident and compassionate care.
5	In the last weeks and days of life there will, where needed, be access to personal care at home within 24 hours
6	A single Specialist Palliative Care Service (SPCS) that directly supports people and their families with complex needs and that provides advice, guidance, education and training for all core health and social care teams who provide direct PEOL care
7	A single point of access and a timely response for all requests for planned and unplanned care, advice & guidance.
8	Care Co-ordination that links local teams to Specialist Palliative Care, other system level support and ensures seamless transitions of care that takes into account any existing personalised care and support plans
9	A digital record of care that is shared, accessible and can be updated by all organisations providing PEOL care
10	A culture of continuous improvement that drives ongoing development in the quality and efficiency of palliative and end of life care

We have also worked with our Palliative Co-Production group to develop a 'Palliative Pledge'. This is being used to help define what our services need to deliver and how they should support people with palliative needs, their families and those they love.

Our Lincolnshire Palliative and End of Life Pledge

1st April 2022
Developed by Lincolnshire PEOL Co-production Group

You should experience support that is right for you to ensure you are living well and dying well.
We want people who are palliative or at the end of their life to have the best care and support possible to live as well as they can, with those important to them, for as long as they can.

I should:

…have my voice and those important to me, heard and listened to, and our individual needs and preferences respected and acted on sensitively

…be supported as a whole person and what matters to me is at the heart of my care

…be supported and cared for competently with compassion, care, commitment, courage, clear communication

…be helped to have the skills, knowledge, confidence and support to stay as in control as I can for as long as I can

…know that my family and / or the people who are important to me are considered, supported and they are involved as much as I want them to be and that they have a voice

…receive seamless care provided by people who work together so I only need to communicate information once. I can expect that the right people have access to up to date and accurate information about me when they need it

…have the opportunity to be actively engaged in the planning of my end of life care as much as I want to be

We pledge to:

…listen to your wishes, answer any questions and provide information in a way that is accessible to you

…help you think and plan ahead to ensure that your wishes are fulfilled, wherever possible, by all those who offer you care and support

… do our best to ensure you are as comfortable and pain free as possible and your physical, emotional, social, cultural, and spiritual needs are supported

…actively involve you in your care planning as much as you want to be and ensure it is regularly reviewed

…honour any wishes you have to involve those important to you in planning for your care and treatment

…support you and those important to you to have meaningful conversations with each other and to live through this together

…do all we can to help you protect your independence, dignity and sense of personal control

…continue to compassionately support and respect you and those important to you throughout your care and onto their bereavement

…value your experience and views, and also of those important to you and learn from this to continually improve

Throughout the design process - and in line with our design principles - we have maintained a focus on the needs of the patient and their families. To do this we have used our co-production group and a series of patient journeys to test our thinking and ensure we have kept on track.

The following is an example of one of the patient journey's used - "Gosia". These journeys were used to explore clinical requirement at each step of their journey, but also their likely needs/ concerns and the holistic response required.

Background	Concerns/ worries
Gosia is 35yrs old and has breast cancer with bone metastases in her spine. Polish is her first language but she speaks good English. She is having palliative chemotherapy.	Gosia does worry that in the future her cancer may spread further but does not want to worry Bartek or her children.
Physical	**Social**
Apart from some side effects from chemo she remains fairly active. She has some mild back pain which is controlled with medication.	Gosia is a mother of 3 children, aged 13yrs,9yrs and 5yrs. She lives with Bartek, the father of her youngest child. The father of the eldest 2 children lives in Poland but remains in contact.
Psychological	**Spiritual**
Gosia is determined to remain positive. Although she is aware her cancer is incurable she has an unrealistic view of her life expectancy.	Gosia finds thinking about a future for her children that she may not be part of too distressing to contemplate.

Bartek
Bartek is worried about how he will support the family now Gosia is not well enough to work. His English is limited.
He is concerned about the children and whether they will be able to remain together if Gosia dies.

Oliwia (13yrs)
Is worried her Mum is going to die and then what will happen to her?

Jakub (9yrs)
Knows his Mum has cancer but believes she will get better

Zofia (5yrs)
Knows Mummy sometimes feels poorly and is having medicine to make her better.

The table (below) illustrates how the patient journey were used to set a requirement for the overall design of the PEOL preparing model.

Patient Story (2): John

JOHN - Background and role: John is 62 yrs old and lives with his wife Norma. He took early retirement due to worsening of his chronic obstructive airways disease (COPD).

Goals and motivations: Prefers to be treated at home and avoid hospital. Wants to put some future plans in place for himself and Norma

Physical: Breathless on exertion and uses intermittent oxygen. Walks short distances around home.

Social Norma has arthritis. John helps her with her personal care. She walks with a zimmer frame but is Prone to falls. They have a supportive son Peter who lives nearby. They are estranged from their daughter Jane.

Psychological John is worried about his increased breathlessness is getting worse and how he and Norma will manage. He does not want to "let Norma down" or burden Pete

Spiritual John regrets past events and would like to make amends with Jane

NORMA Norma is worried, she has noticed that John is finding it more difficult to help her as his breathlessness is worse. She feels like a burden. She does not know who to talk to.

	Step 1	Step 2	Step 3	Step 4	Step 5	Step 6
Situation	John speaks to his GP about early retirement through ill health	John gets a chest infection	Norma has a fall and attends A&E - no fractures and she is discharge	John now needs constant oxygen and is unable to help norma	John doesn't respond to antibiotics for a chest infection and becomes	John dies at home a few days later
Needs / Concerns	•Loss of role / see of purpose •Becoming a burden •Financial pressures •Understanding what is	•Fear about future •Concern about Norma •Concern about coping •Guilt that they cannot help each other	•Increasing fear and possible denial •Difficulty coping	•Increasing difficulty in coping •Fear of dying and impact on family •Unresolved issues	• Helplessness •Agitated & confused •Difficulty in coping •Fear / anger	• Grief •Difficulty coping and managing practical affairs
Response	•Start the conversation about dying (John & Norma together) •Find out what matters most •Holistic assessment (inc finance & carers)	•Assess understanding & expectations •Develop ACP •Develop contingency/ escalation plans •Personalised care & support plans	•Recognise frailty •Consider housing / support arrangements • Jt Care Plans •Advance care planning inc wills and power of attorney	• Review / refresh ACP Care plans & ReSPECTin light of circs •Conversation re EOL •Therapy and palliative rehab •Pre-bereavem't support	•MDT review •Capacity assessm't/LPA / best interest decision •24/7 Response service •Move to EOL support •Psychologicall support •Manage symptoms	•Support cultural rqmts •Post-bereavement support inc check ins (immediately but also 6 months later) • Individual and group support
Care Functions	• Recognition (F/C) •Assessment (F/C) •Planning Ahead (C) •Enhanced Care & Support (C/E) •Care closer to death C	• Recognition (C) •Assessment (C) •Planning Ahead (C •Enhanced Care & Support (C/E)	• Recognition (C) •Assessment (C/E) •Planning Ahead (C/E) •Enhanced Care & Support (F/C/E) •Bereavement (F/C/E/A)	• Recognition © •Assessment (C) •Planning Ahead (C/E) •Enhanced Care & Support (C/E) •Bereavement (F/C/E)	• Recognition (C) •Assessment (E) •Planning Ahead (E/A) •Enh'd Care & Support (C/E) •Care Clser Death (F/C/E) •Bereavement (F/C/E)	•Recognition (F/C) •Assessment (C/E) •Planning Ahead (C) •Enhanced Care & Support (C) •Care Closer to Death (E) •Bereavement (F/C/E)
Delivery	• Placed on Practice / PCN GSF Register •Initial assessment by PCN/ community resource •Case co-ordination by PCN Co-ordinator	•Monthly review of GSF patients •PCN/ Community resource to review, develop ACP & plans •Continuing co-ordination by PCN Co-ordinatotr	•PCN Co-ordinator confirms Carers assessment & planning •PCN/ Community resource to review plans • PCN Co-ord initiés social prescribing for support	• GSF review - moved to Virtual ward for EOL • PCN Co-ord ensures therapy / pool referrals made and actioned •PCN / Community resource to initiate pre-bereavement support	• PCN/ Community resource to initiate Fast Track referral • PCN / Community resource to link care & support •PCN Co-ord to ensure co-ord of care • Continuing GSF oversight	• PCN / Community resource to undertake initial bereavement support and onward referrals •PCN Co-ord to track care and ensure co-ord across agencies for Norma • Social prescribing to provide additional support for Norma

Palliative & End of Life Care: High Level Design

Section 3	Slide
To Be' Operating model	22
Service Definitions	24
Co-ordination of Care	25
People: Care Functions and Skill levels	26
Infrastructure (IT, Estate, Finance, HR)	28
Overview	32

Key features

- **Service**: Unplanned Care

- **Service**: Planned Care

- **Service**: Inpatient Care

- **Service:** Specialist Care

To deliver our Vision, and in line with our Design Principles and the Palliative Pledge, we will move from an approach based on the capability of individual organisations to a Population Health Management approach. This re-orientates PEOL service delivery to provide individualised care at scale through the different PEOL services.
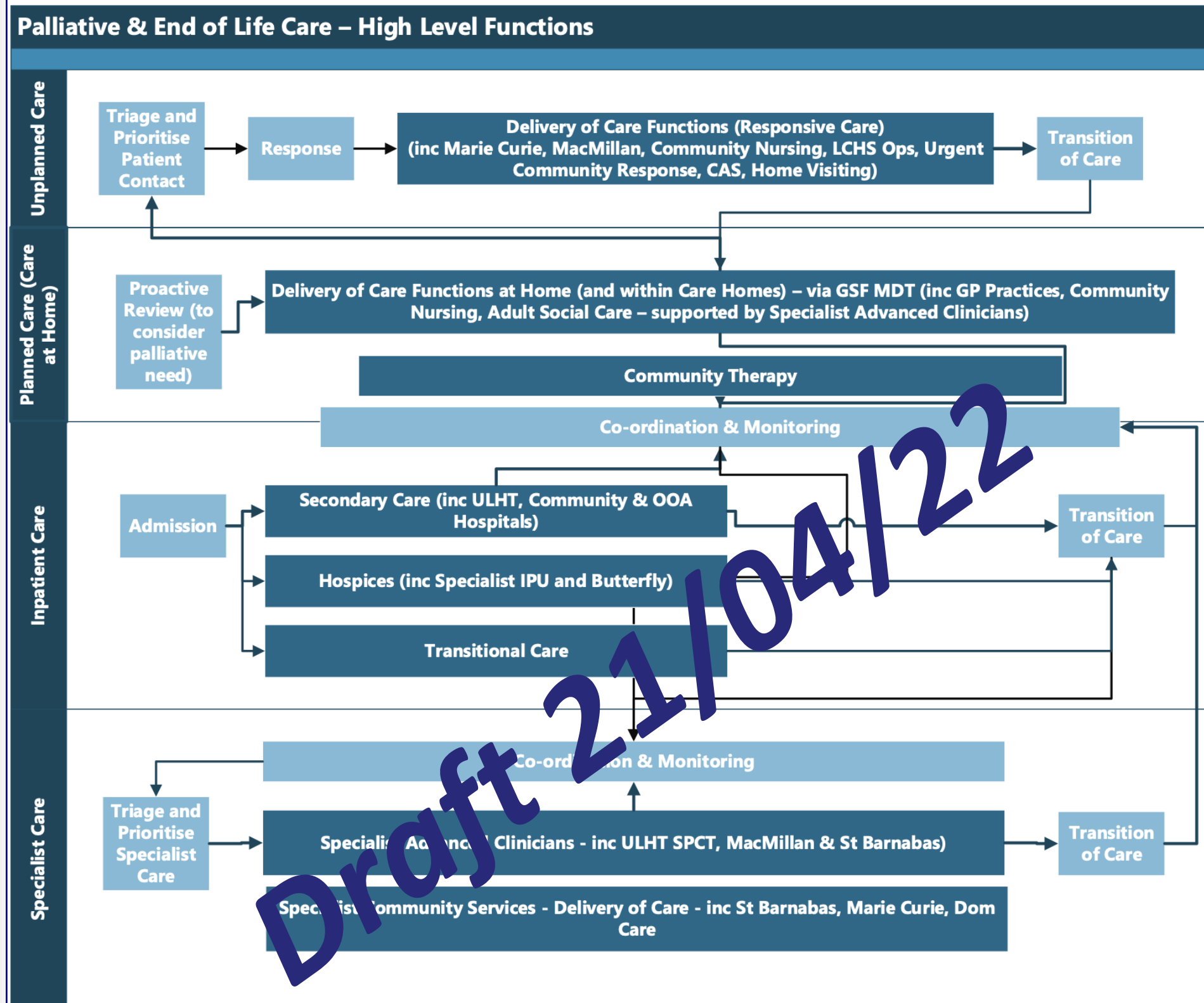
We know that a person's level of involvement with each service will fluctuate as they move towards death. This is therefore an intentionally flexible model, supported by improved co-ordination, which will respond to changing needs with seamless transitions of care.

This model is a whole system approach in which consistent use of structures, systems and IT will improve co-ordination and communication between service providers and support seamless, high quality care. It will minimise any gaps in service and health inequalities and ensure that specialist care is targeted where needed most.

The foundation for this approach will be a PEOL MDT in every PCN, which will use the Gold Standards Framework (GSF). PCN MDTs will be supported by Specialist services with escalation to Specialist care for more complex cases.

Future care planning, facilitated through the GSF framework, will include personalised care and support planning and supported self management. This will reduce unnecessary Inpatient admissions and Unplanned need
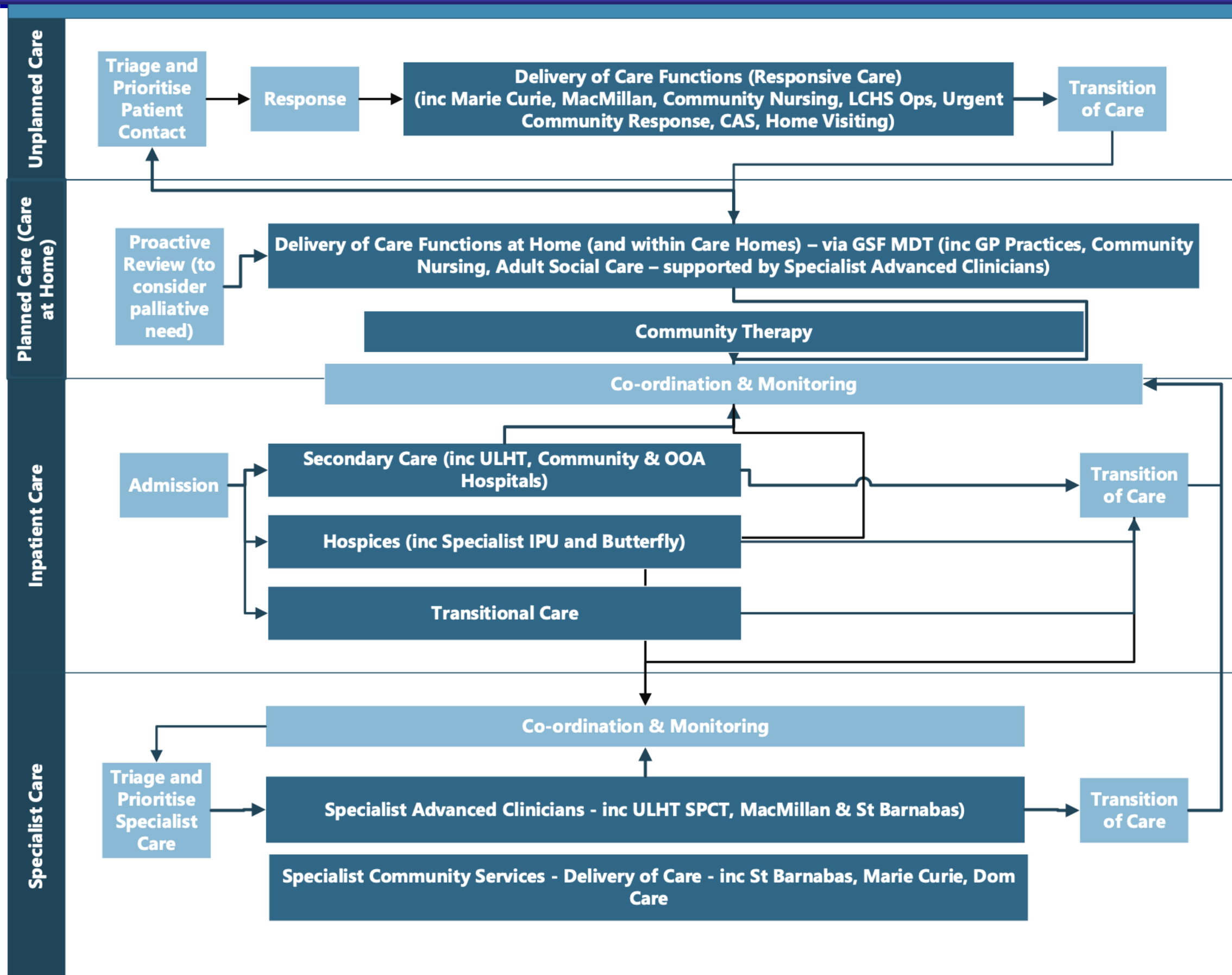
A specialist service, supporting unplanned community response, to deal with unplanned PEOL and provide a 24/7 safety net for care,

Palliative & End of Life Care – High Level Functions

Unplanned Care: Triage and Prioritise Patient Contact → Response → Delivery of Care Functions (Responsive Care) (inc Marie Curie, MacMillan, Community Nursing, LCHS Ops, Urgent Community Response, CAS, Home Visiting) → Transition of Care

Planned Care (Care at Home): Proactive Review (to consider palliative need) → Delivery of Care Functions at Home (and within Care Homes) – via GSF MDT (inc GP Practices, Community Nursing, Adult Social Care – supported by Specialist Advanced Clinicians); Community Therapy; Co-ordination & Monitoring

Inpatient Care: Admission → Secondary Care (inc ULHT, Community & OOA Hospitals); Hospices (inc Specialist IPU and Butterfly); Transitional Care → Transition of Care

Specialist Care: Triage and Prioritise Specialist Care → Co-ordination & Monitoring; Specialist Advanced Clinicians - inc ULHT SPCT, MacMillan & St Barnabas) → Transition of Care; Specialist Community Services - Delivery of Care - inc St Barnabas, Marie Curie, Dom Care

Draft 21/04/22

Section 3: Our 'To Be' Operating Model

Our proposed end-state model works on the basis that the focus will be on the delivery of Palliative and End of Life services. The definitions we are using for these services are as follows:
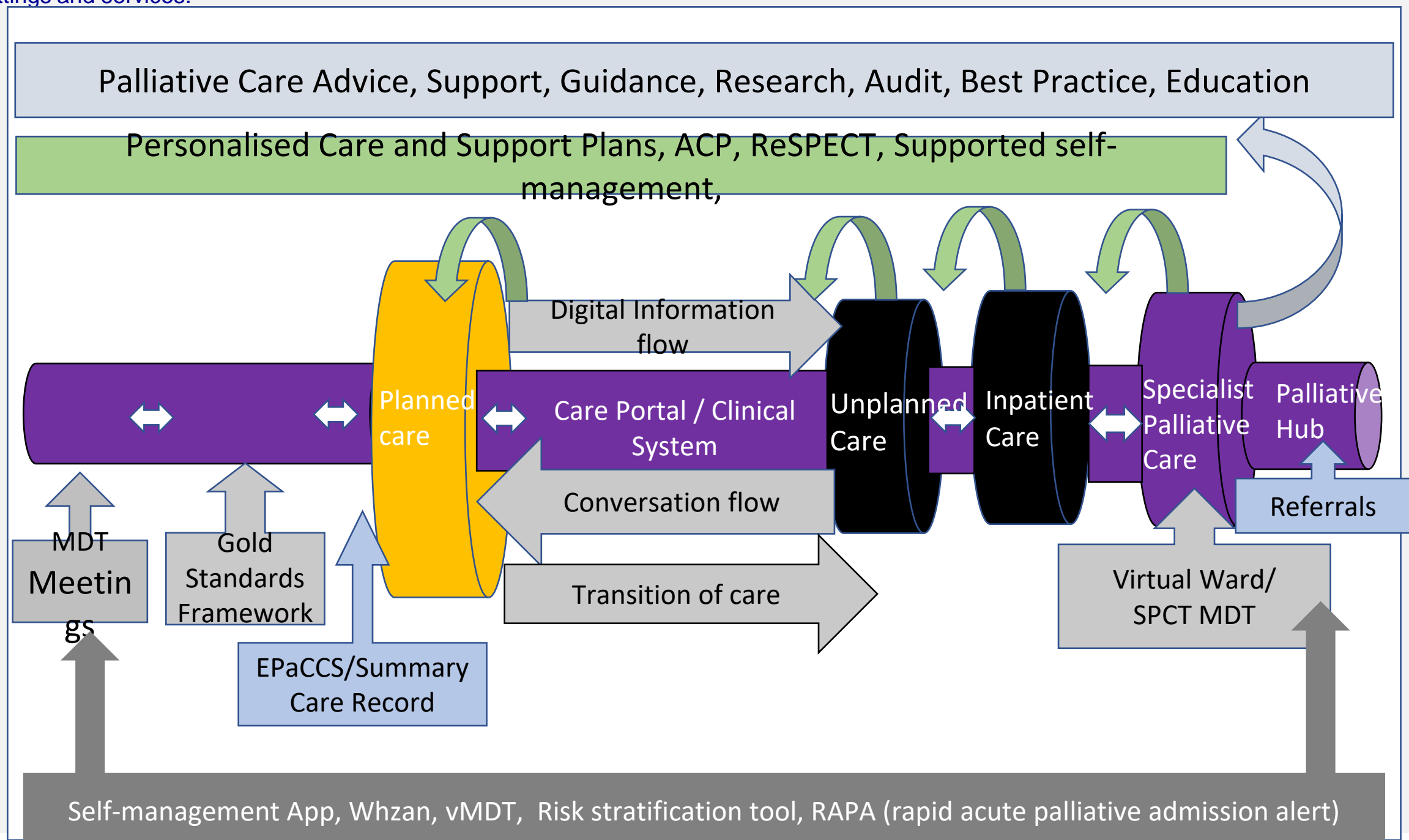
- **Planned Care:** Providing effective home based support services. Straightforward access to PEOL services with opportunities identified to improve recognition of palliative needs. This involves all essential core, non-specialist services, including but not limited to GPs, district nursing, community pharmacy, care homes etc that underpin specialist level palliative care. This service will be the primary point of access into social prescribing and third sector support for PEOL patients and their families.

- **Unplanned Care:** Provide 24/7 advice, guidance and support with patient access to Urgent Responsive care - and the team providing that responsive care have easy access to specialists so that presenting needs are met.

- **Specialist Care:** Provision of Specialist palliative care services for people (adults and those transitioning from services for children and young people) who are living with a condition that is life threatening and where there is complexity. The needs of this group cannot be met by the capability of the core, non-specialist team alone. This care requires, as a minimum;

  - ▸ in depth specialist knowledge (specialist consultant and specialist nursing services as a minimum) to undertake assessment and management of physical, psychological and spiritual symptoms to reduce symptoms, suffering and distress and maximise quality of life.
  - ▸ supporting analysis of complex clinical decisions-making challenges where medical and personal interests are finely balanced by applying relevant ethical and legal reasoning alongside clinical assessment
  - ▸ Provision of specialist advice, education and support to the wider care team which is providing direct core level palliative care
  - ▸ This includes all dedicated specialist services including domiciliary care for those in the last days and weeks of life
  - ▸ Provision of clinical leadership, audit and quality improvement capability

- **In-patient care:** Provision of a stay in hospital (or other establishment) for 1 night or more for tests, medical treatment or surgery. For PEOL care this involves
  - ▸ Beds in acute secondary care
  - ▸ Beds in Community hospitals
  - ▸ Beds in Specialist Hospices (IPU)
  - ▸ Beds in Hospices
  - ▸ Beds for Transitional care ("step down" from secondary care)
  - ▸ Beds for Interim Care (short term care to prevent inappropriate admission to secondary care)

A critical element of our whole system approach is more effective communication and co-ordination within and across the different PEOL Care services. The infographic (below) describes key features of how co-ordination will operate.

We will establish a Palliative Hub to provide the link between different services - and the means by which individual services can manage and prioritise their work. This hub is both digital (supporting the management and exchange of information) and physical (providing advice, guidance and support for all who need it).

Each service (planned, unplanned, inpatient and specialist care) will have its own co-ordination and MDT arrangements - but drawing on the same patient information (based on a digital health record). Escalation and Discharge processes will support the movement of patients between different settings and services.

Palliative Care Advice, Support, Guidance, Research, Audit, Best Practice, Education

Personalised Care and Support Plans, ACP, ReSPECT, Supported self-management,

Digital Information flow

Planned care

Care Portal / Clinical System

Unplanned Care

Inpatient Care

Specialist Palliative Care

Palliative Hub

Conversation flow

MDT Meetings

Gold Standards Framework

Transition of care

Virtual Ward/ SPCT MDT

Referrals

EPaCCS/Summary Care Record

Self-management App, Whzan, vMDT, Risk stratification tool, RAPA (rapid acute palliative admission alert)

25

In our end state model we expect all those who deliver palliative and end of life services to be able to deliver the following care functions as appropriate to their role and setting:

- o **Recognition:** the process of recognising those who are in their last year or stage of life

- o **Assessment:** the process of assessing, actioning, sharing and reviewing the needs of all individuals and those important to them who are entering the last year of life

- o **Planning Ahead:** provide ongoing opportunities and clear process for all individuals if / when they wish to discuss what's important to them enabling them to document their preferences including Advance Care Planning, ReSPECT which includes Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR), Advanced Decisions to Refuse Treatment (ADRT) and share as they wish Care & Support

- o **Enhanced Care and Support:** the provision of the necessary services and support for those who are in the last year of life and those important to them to help meet their informational, emotional, spiritual, social, and physical needs

- o **Care Closer to Death:** to recognise that an individual is in the last days or hours, to communicate and provide the care and support needed including immediate care after death.

- o **Bereavement:** to assess need and provide care and support to bereaved individuals

This care is delivered at 4 levels

- o **Foundation:** This level of skill requires staff to have an understanding and awareness of work procedures which staff would be expected to have after induction + on-the-job training

- o **Core:** An understanding and knowledge of work procedures that requires a level of theoretical knowledge normally acquired through formal training or equivalent experience

- o **Enhanced:** Understanding a range of work procedures and practices that require a higher level of theoretical knowledge and practical experience normally acquired through formal training or equivalent experience applied in a specific area of need such as a single health condition

- o **Advanced:** Knowledge across a range of work procedures underpinned by advanced theoretical knowledge acquired through extended formal education, training and practical experience

These functions and levels are clinical - however it is expected that work in individual roles will have additional non-clinical elements and also that roles may sometimes may sometimes deliver the care functions across a range of skills levels

The Lincolnshire Care Functions started to be developed in 2020. They represent work across all Lincolnshire organisations - both core clinical and medical services and Specialist Palliative and End of Life Services. These Prime Care Functions are a summary of the Lincolnshire palliative and end of life (PEOL) care functions matrix. The purpose is to draw out and articulate the main activities carried out at each skills level. The Care Functions relate to contact with or discussions about a specific named patient and can be direct or indirect.

Direct care functions are face to face or virtual contact with a named patient or their significant other. Indirect care functions are person specific and includes discussions or advice given about a named individual.

There is an acknowledgement that Specialist Palliative Care (SPC) has a wider role than the care functions described in the care function matrix. The following will be provided and accessible to support the delivery of the direct and indirect care functions at each of the four levels described (ie. foundation, core, enhanced and advanced): clinical leadership - leading and developing best practice; quality improvement and service development; training and education supervision and support; research & audit.

PEOL MASTER CARE FUNCTION MATRIX

PRIME CARE FUNCTION:	Foundation	Core	Enhanced	Advanced
Description of skill mix level	This level of skill requires staff to have an understanding and awareness of work procedures which staff would be expected to have after induction plus on-the-job training.	An understanding and knowledge of work procedures that requires a level of theoretical knowledge normally acquired through formal training or equivalent experience.	Understanding a range of work procedures and practices that require a higher level of theoretical knowledge and practical experience normally acquired through formal training or equivalent experience applied in a specific area of need such as a single health condition.	Knowledge across a range of work procedures underpinned by advanced theoretical knowledge acquired through extended formal education, training and practical experience.
Summary of prime care function	**Using recognised tools, delivers delegated and planned care, accessing support and escalating where needed.**	**Supported by the use of agreed tools and guidance, holisitically assesses, plans, delivers (or delegates) and reviews care. Accesses support where required, makes onward referrals and escalates unmet needs or complexity when needed.**	**Accessing and escalating to the Specialist Palliative Care MDT, liaises, influences and supports others where there is complexity or unresolved needs. Advices on, devises or makes recommendations and where appropriate delivers direct care where there is complexity.**	**Where there is uncertainty, contention, legal or ethical dilemmas or contention, high complexity, unmet need, unpredictability, uncertainty, unplanned, unpredicted needs and reactions, worsening or unresolved symptoms -and as a result these cannot be managed by others.**
Recognition	Uses recognised tools to support recognition of actual deterioration and escalates.	Supported by the use of agreed tools recognises risk of, as well as actual deterioration where planned care is not meeting needs and initiates a conversation.	Influences and supports others to recognise risk of deterioration and actual deterioration. Initiates a conversation recognising and triaging complexity.	Influences and supports others to recognise risk of deterioration and actual deterioration. Initiates a conversation recognising and triaging complexity. Delivers direct care and supports decision making where there is contention or ethical dilemmas.
Assessment	Recognises deterioration and refers to others for assessment, review of care planning and "what matters to you conversations".	Completes an holistic assessment (physical, psychological, spiritual and social), reviews care planning, initiates and continues "what matters to you" conversations.	Supports others to, or directly, completes an holistic assessment where there is complexity, reviews care planning, initiates and continues "what matters to you" conversations.	Where there is complex unmet need, completes detailed holistic assessment considering causes and interpreting information to identify and instigate plan of action with the patient.
Planning Ahead	Continues "what matters to you" conversations with onward referral for palliative care assessment.	Accessing support where required, case manages and co-ordinates care. Initiates, maintains and reviews personalised care and support plan (PCSP).Instigates review of medication and anticipatory prescribing.	Accessing support from SPC MDT where required, case manages and co-ordinates care where there is complexity. Initiates, maintains and reviews personalised care and support plan (PCSP). Makes recommendations and instigates review of medication and anticipatory prescribing.	Provides leadership, advice and support to others, or directly case manages and co-ordinates care where there is high complexity. Assimilates information to predict future risks and facilitates difficult conversations relating to palliative care emergencies, complex ethical and safeguarding issues.
Enhanced Care and Support	Provide support and deliver planned and delegated care, contributing to care planning through escalation and liaison with others.	Liaising with others plan, organise, review and where appropriate deliver fundamental care and support to meet needs. Assess mental capacity, encourage informed choice or facilitate best interest decisions. Support patient and informal carer to retain, regain or develop skills to manage their life. Manage medications within agreed plan and escalate needs.	Liaising with others, and accessing support form SPC MDT plan, organise, review and deliver care managing unpredictability where there is complexity. Assess mental capacity encouraging and empowering informed choice or facilitating best interest decisions where there is complexity. Devise a plan of care to support patient and informal carer to retain, regain and develop skills to manage their lives. Manage medications to achieve optimum outcomes.	Provides leadership, specialist support and advice to others, as well as developing and delivering complex palliative and end of life care plans. Manages unpredictability, assesses and triages unplanned needs and reactions. Empower informed choice and support decision making where there is an ethical dilemma or contention. Provide specialist skill to support patients and informal carer to retain, regain and develop skills to manage their lives. Advocate for patients and professionally challenge others. Advises other professionals on symptom management for 2nd and 3rd line interventions / or "off licence" prescribing.
Care Closer to Death	Deliver planned care and delegated symptom management, providing immediate physical and psychological support. Review plan of care recognising worsening symptoms and escalate appropriately.	Review and deliver planned care (including physical, psychological, social and spiritual support) and liaise with others. Recognises worsening symptoms, monitors, and/or delivers medications for symptom management seeking support / advice as necessary.	Review and deliver planned care and liaise with others. Recognises worsening symptoms, monitors, and/or delivers medications for symptom management seeking support / advice and escalating as necessary. Provide physical, psychological, social and spiritual support recognising complexity requiring escalation.	Review of planned care, advising others on symptom management and prescribing. Provide physical, psychological, social and spiritual support to patients and families.
Bereavement	Provide immediate care and psychological support and signpost to others.	Provide fundamental care and psychological support, referring to others as needed.	Assesses and recognises complex needs needing onward referral. Supports other staff.	Liaises with other services for ongoing support and provides specialist bereavement expertise. Supervision and wellbeing support for the wider MDT.

Information Technology

Improvements in co-ordination of care, self-management and more efficient systems to manage demand will rely on digital development

What is the business issue/problem to solve?	• **Establishing an Enterprise Architecture for PEOL care** 　▸ PEOL Care is delivered by more than 10000 staff and deals with more than 10000 patients in the course of a year. This staffing is distributed over a large number of specialist and non-specialist services and local teams. The need for effective co-ordination means that there is a high pressure for an effective digital infrastructure that supports this care. Work has been initiated on this through the development of EPaCCs and the Care Portal and this now needs to be completed (taking into account the different needs of System1 and EMIS users.) This needs to be linked with local and Specialist MDT meetings - with consideration of the benefits of establishing Virtual Wards. 　▸ Wide access to shared care records and the ability to update these records is an additional requirement • **Extending Online Services:** 　▸ existing technology in LCHS Ops Centre provide an infrastructure for the management of calls for urgent unplanned need. This needs to be integrated with 24/7 provision for PEOL but supplemented with a online services (eg chat functions) that can be used to provide advice and guidance to both public and professionals. • **Self-Management App** 　▸ A gap in existing PEOL Care is service provision for those identified as being at an early Palliative stage. Self-management - facilitated through a self-management app - is a potential solution to address this gap. • **Mobile Technology:** 　▸ Access to relevant patient data and the ambition to reduce workload (eg double keying) will require a consistent use of mobile technology across the PEOL workforce - particularly the Specialist workforce. Detailed requirements are not known at this stage
What technology services will be impacted?	• Existing Projects - including EPaCCs and Care Portal • Core clinical systems - Systm1 and EMIS • Command & Control systems • New technology - MDT systems and Self Mgt App

Section 3:   Infrastructure Requirements

Estate

Provision to meet patient need, locally based teams and establishment of a palliative hub may all have implications for the existing estate

What is the business issue/problem to solve?	**Inpatient provision** ▸ The location and quantity of in-patient beds will rely on an accurate assessment of demand and the extent to which care is delivered at home rather than in inpatient facilities. This is unlikely to be ready to be scoped in the course of 22/23 and will be scheduled for the next tranche of programme activity (23/24). In the interim, it is proposed to maintain existing provision. **Accommodation for locally based PEOL teams:** ▸ An assessment of accommodation requirements may be required - however this should form part of existing proposals for the establishment of PCNs and will not be progressed separately. **Palliative Hub** ▸ It is unclear at this point whether the Palliative hub could be entirely virtual . This will be dependent on the development of suitable digital technology. In the event that a physical location is required, co-location with existing services (such as the LCHS Ops Centre or St Barnabas PCCC) is likely to be preferable.
What existing services will be impacted?	- Organisational Estates Strategy - ICS Programme and PCN estates

Finance

Provision of appropriate finance, contract and commissioning arrangements to support a new service model

What is the business issue/problem to solve?	• **Commissioning and Contracting:** the Operating Model will develop a new Specialist Palliative Service Specification to contract organisations to provide palliative and end of life services. Refreshed contract / commissioning arrangements need to be established with these and other organisations to deliver these services and maintain them during the transition to new ways of working. • **Investment and Benefits Realisation**: the new operating model requires investment and there will be a challenge in realising the cashable benefits that the new operating model is intended to deliver to enable this investment to take place. For example, the model should deliver reduction in admissions and overall bed days and this reduction in costs within ULHT needs to be translated into the necessary investment in community services or in expanding provision within ULHT to provide 7 day cover. Funding may also become available from other external sources or programmes eg Virtual Ward, Ageing Well, NHSE/I Initiatives. • **Dependency Management:** given the nature of the Palliative & End of Life services, costs are spread across different organisations and programmes. Future services may change where these costs sit. For example, the developments within PCN are likely to involve investment to support non-clinical care co-ordination roles
What existing services will be impacted?	• LCCG Finance, Contract and Commissioning services • Financial services in providers (eg LCHS, ULHT, St Barnabas and Marie Curie) • Continuing Health care (CHC) • Linked programmes (eg CHC, SDP, Care Closer to Home programmes, UEC, Patient Flow)

Human Resources

Management of any changes required in delivery of new model - including recruitment to new clinical and non-clinical roles as well as the management of people during transition.

What is the business issue/problem to solve?	• **Recruitment**: the new operating model requires investment in clinical and non-clinical resources. Advice will be required to support role development, banding, recruitment and induction of staff into these roles. • **Transitional Support:** discussion on desired competencies of individual roles will require consideration as to whether these represent minor or significant changes to existing roles and may also require suitable support fr individuals affected. • **Shift Planning**: some developments involve a potential move to 7 day or 24/7 working. • **Single Specialist Palliative Service:** a potential challenge within this service is the existence of different roles & responsibilities and banding structures within individual organisations.
What existing services will be impacted?	• Existing provider organisations during the transition period (eg PCNs) • HR Depts in any affected organisations (eg ULHT, LCHS, St Barnabas and Marie Curie)

How it will work

Our 'To Be' way of working is emphatically focussed on the needs of individual patients and will be rooted within their GP Practices and PCNs.

GP practices will use risk stratification to proactively identify individuals who are likely to benefit from palliative care. Once identified, people will be assessed and then placed on the Palliative Register and Gold Standards Framework (GSF). They will be offered a conversation about what matters to them and an opportunity to discuss Advance Care Planning, including considering personalised recommendations for clinical care in emergency situations (ReSPECT).

The condition and plans of palliative people will be monitored in line with their GSF stage and Phase of illness. These meetings will take place at either practice or PCN level and be supported by local, integrated PEOL teams and a GSF MDT. They will be supported so that, wherever they take place, there will be an identified cohort of palliative patients at every PCN.

The GSF MDT will be supported by Core and Specialist Palliative resources. A specialist input will be provided for patients at a local level and will identify patients with more complex PEOL needs who require consideration by the Specialist MDT. These Specialist MDTs will be locality or Cluster PCN based - and will provide the required support from specialist services.

A Palliative Hub (PHub) will support co-ordination and communication across these services by supporting and maintaining a shared data template (EPaCCs) accessible via clinical systems and the care portal. It will also support systems and structures that link unplanned, planned, specialist and in-patient care. As part of its role, the Phub will co-ordinate personal care packages for people in their own home who have unmet needs and are in their last days or weeks of life.

All patients who would benefit from a palliative and supportive approach, including those not previously identified as palliative will have access to care and support, 24/7, through a single point of access. The Palliative hub will provide advice, guidance and will also support Specialist Services by co-ordinating referrals for specialist support

Where an individual's needs cannot be met at home or in a care home, there will be a consistent process to enable them to be provided with an appropriate level of care and clinical treatment in an inpatient bed. Provision of these beds will be as equitable as possible across Lincolnshire in order to reduce the distance that patients and their families travel to be with each other.

Each service will have a responsibility to co-ordinate care to support seamless transitions. This includes using shared care records to underpin effective communication. The PCN GSF will retain a co-ordination role where any patient is required to move to or from their home or in-patient bed plus access to specialist resources.

PEOL services will be supported by health and social care staff who provide direct PEOL care in line with a competency framework. These will be based on the agreed Lincolnshire PEOL care functions. All staff will be supported by training and education provision, delivered primarily by specialist services, that will support them to attain and maintain expected standards and then to maintain their skills and capability.

Specialist Palliative Care will have a wider role than providing direct care. They will identify best practice and be responsible for quality improvement and service development. They will also undertake research and audit as necessary. However, a key role will be the provision of clinical leadership for PEOL care across Lincolnshire.

Palliative & End of Life Care: High Level Design

To address the challenges identified and to deliver our proposed operating model, we have identified the following critical interventions:

• **To increase our recognition of people deteriorating from a life limiting condition,** we will establish

    1. Proactive risk stratification to identify those with unrecognised palliative need

• **To increase the proportion of those on the palliative register who have had high quality and timely conversations about dying,** we will establish

    2. A specialist and core PEOL workforce with clearly defined competencies and skill levels for their roles

    3. *Support for the self-management of palliative care (including a Self-Management App)*

    4. Specialist roles with the capability and capacity to support ongoing PEOL training and education

    5. A learning network for specialist and core PEOL staff

• **To increase the proportion of patients who have had advance care planning and robust care assessments** we will establish

    6. The capacity to deliver specialist and core care to an agreed standard in all settings *(to include 7 day working in ULHT and integrated teams around PCNs*

• **To increase the quality of patient-centred care**

    7. Enhanced personalised advance care planning practices and documentation *(including ReSPECT)*

    8. Improve the consistency and access to pre- and post-bereavement services for people, families, carers and professionals

• **To increase the proportion of people who have had high quality care in the last days of their lives,** we will establish

    9. A Palliative Hub, operating 24/7, through which patients, carers and professionals will be able to access support and care can be co-ordinated

    10. An enhanced 24/7 response and re-ablement provision for PEOL patients with urgent need

    11. Efficient contracting arrangements that provide personal care at the end of life, where necessary, within 24 hours of referral

• **To increase the resilience and sustainability of Palliative and End of life Services,** we will establish

    12. A single Specialist Palliative Care team

    13. A Specialist MDT and operating practices to co-ordinate and manage specialist support

    14. In-patient provision that is accessible, meets demand and admits people 7/7

    15. A Multi-Disciplinary PEOL Team and operating practice in every PCN *(using the Gold Standards Framework)*

    16. The capacity to support the co-ordination and transition of PEOL care in every PCN

    17. A digital infrastructure that supports the co-ordination and transition of PEOL care *(inc shared care records, a care portal, virtual wards and MDT)*

Key features

- **Function**: Unplanned Care

- **Function**: Planned Care (Care at Home)

- **Function**: Inpatient Care

- **Function:** Specialist Care

The graphic shows the primary point of impact of our proposed interventions.

From the top:

Interventions 2, 5, 6, 8 & 17 generate change across the PEOL system

Interventions 9 & 10 focus on Unplanned Care but also the development of the Palliative Hub and the associated advice, guidance and support services

Interventions 1, 3, 7, 15 & 16 focus on planned and primary care

Intervention 14 examines inpatient capability and capacity

Intervention 4, 11, 12 & 13 come together to define the new single specialist service

Palliative & End of Life Care – High Level Functions

Unplanned Care: Triage and Prioritise Patient Contact → Response → Delivery of Care Functions (Responsive Care) (inc Marie Curie, MacMillan, Community Nursing, LCHS Ops, CAS, Home Visiting) → Transition of Care

Interventions: 2, 5, 6, 8, 17, 9, 10

Planned Care (Care at Home): Proactive Review (to consider palliative needs) → Delivery of Care Functions at Home (and within Care Homes) – via GSF MDT (inc Primary Care, Community Nursing, Adult Social Care – supported by Specialist Advanced Clinicians), Community Therapy

Interventions: 1, 3, 7, 15, 16

Co-ordination & Monitoring

Inpatient Care: Admission → (Secondary Care – ULHT & Community Hospitals), Specialist In Patient Unit – Hospice, Hospices (inc Butterfly) → Transition of Care

Intervention: 14

Co-ordination & Monitoring

Specialist Care: Triage and Prioritise Specialist Care → Specialist Advanced Clinicians - inc ULHT SPCT, MacMillan & St Barnabas), Specialist Community Services - Delivery of Care - inc St Barnabas, Marie Curie, Dom Care → Transition of Care

Interventions: 4, 11, 12, 13

	Interventions	Description
1	**Proactive risk stratification to identify those with unrecognised palliative need**	• Establish a framework to identify, in each GP practice, those patients with single or multiple long term conditions who should be assessed for palliative need. Those identified should be placed on the PEOL Register and the Gold Standards Framework (GSF) • Establish a monitoring and assessment framework within the GSF to identify and track any subsequent deterioration and change in palliative needs
2	**A specialist and core PEOL workforce with clearly defined competencies and skill levels for they roles**	• Review specialist and non-specialist roles to define the competencies and skill level expected in each role - using the Lincolnshire Care Function matrix. • Preparation of a Training Needs Analysis and a Delivery plan to support all staff to achieve and the maintain expected levels of skill and competence
3	***Support for the self-management of palliative care (including a Self-Management App)***	• Develop and then deliver an approach to supported palliative self-management (including Patient Activation Measures) • Establish a Self-Management App or other appropriate on-line technologies to link individuals with the appropriate member of an MDT to enable the provision of appropriate support for the individual. • Demand / Resource modelling to provide capacity to deliver this service (and realisation of associated benefits)
4	**Specialist roles with the capability and capacity to support ongoing PEOL training and education**	• Realise service efficiencies (eg through reduction in duplicated activity) and obtain any necessary investment to create the capacity for specialist advanced PEOL clinicians to invest 20% of their time in Education and Development support for all specialist and core health and social care staff who deliver direct PEOL care.
5	**A learning network for specialist and core PEOL staff**	• Build on existing ECHO network to provide a learning network for all specialist and core staff who are engaged in providing PEOL care • This network will also operate as a Change Network to facilitate the development of the PEOL programme. • These learning networks will operate around PCN footprints and build local communities of practice, remaining connected to a whole system approach.
6	**The capacity to deliver specialist and core care to an agreed standard in all settings *(to include 7 day working in ULHT)***	• Delivery and realisation of benefits of improved triage, referral and co-ordination to release capacity from existing staff • Develop case for targeted investment in specific areas that would support resilience and sustainability of the wider system - specifically in the provision of staff to enable 7 day working in ULHT.

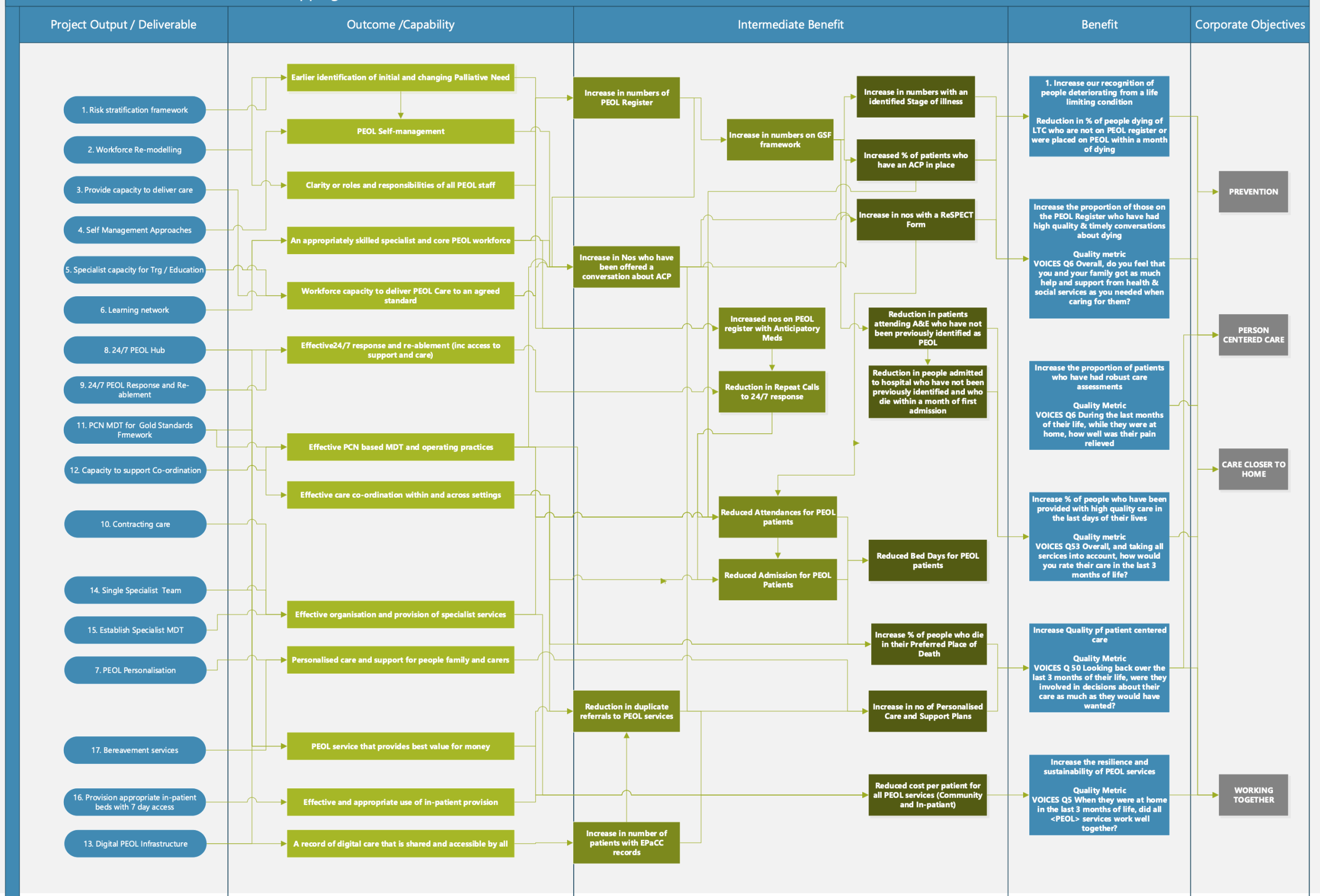| Interventions	Description
7 **Enhanced personalised advance care planning practices and documentation** *(including ReSPECT)*	• Review existing Advance Care Planning and ReSPECT documentations to ensure that they reflect ambition for personalised care and support planning • Establish education / training provision within TNA and Delivery plan to support staff • Review MDT and operating practices to focus on personalisation of care at scale
8 **Improved pre- and post-bereavement services to support people, families, carers and professionals**	• Review existing provision and then establish process to improve access to this provision and proactively identify those who may benefits from this support. • Identify and deal with any identified gaps in provision.
9 **A Palliative Hub, operating 24/7, through which patients, carers and professionals will be able to access support and care can be co-ordinated**	• Review, in detail, existing 24/7 advice, support and referral processes • Establish a 'hub' for 24/7 system level activity and a single, easily accessible point of support for care and guidance • In principle the hub will be virtual and digital, using online technologies
10 **An enhanced 24/7 urgent response and re-ablement provision for PEOL patients with urgent need**	• Development of existing in-hours and out of hours services to provide an efficient 24/7 response to urgent need. This is already in motion and will involve the establishment of a single number for patients to call - supported by call handling within LCHS Ops Centre. • This service will be integrated with the 2 Hour Urgent care Response - channels to provide support for PEOL patients through the use of both specialist PEOL resources as well as other core health and care staff
11 **Efficient contracting arrangements that provide personal care at the end of life, where necessary, within 24 hours of referral**	• To establish contracting arrangements that will provide the current 'fast track' care packages in an efficient and timely way

Interventions	Description
12 A single Specialist Palliative Care (SPC) team	• This involves the creation of a Specialist Palliative and End of Life Service Specification (based on this operating model) and then refreshing the relevant contracting and finance arrangements to deliver these services. • The SPC team will cross all providers - including LCHS (MacMillan), ULHT, St Barnabas and Marie Curie. Leadership and operational arrangements will be developed across organisations and around PCN teams. • This work involves the confirmation of a Specialist MDT - including those who are specialist in other settings but who are able to assist with the management of a single caseload of complex cases
13 A Specialist MDT and operating practices to co-ordinate and manage specialist support	• Specialist MDT meetings will be held on a locality basis - and an agreed Terms of reference. • This will enable escalation of suitable cases from PCN MDTs as well as the co-ordination of specialist support
14 In-patient provision that is accessible, meets demand and admits people 7/7	• Demand for inpatient provision will be assessed in the light of changes within the operating model that may affect the bed requirements. • This provision will be informed by the development of an In-Patient strategy. This will define the requirement in terms of the type of beds required in the County and the admission criteria.
15 A Multi-Disciplinary PEOL Team and operating practice in every PCN *(using the Gold Standards Framework)*	• A MDT will be established in every PCN and will provide consistent and equitable access to the range of palliative services required. There will be a minimum standard of operation and provision in all PCNs - with additional services supplied with each PCN according to local need • PCNs will operate using the Gold Standards Framework and will be supported by a digital infrastructure that will provide access for specialist and core staff to digital care records
16 The capacity to support the co-ordination and transition of PEOL care in every PCN	• Co-ordination at PCN level requires resources to maintain and provide support for delivery of the Gold Standards framework and consistent monitoring of all on the Palliative register. • To make best use of clinician resources, non-clinical care co-ordinators operate on every PCN to deliver the agreed model.
17 A digital infrastructure that supports the co-ordination and transition of PEOL care *(inc shared care records, a care portal, virtual wards and MDT arrangements)*	• A critical enabler of care co-ordination is a digital architecture that supports PEOL care. This includes the ongoing development of EPaCCs and skills development to optimise its use. It also includes sharing via a portal with access/ update rights to all who deliver direct PEOL care. • This work includes the identification and provision of suitable hardware / mobile technology to supports the effective use of digital technologies in the community • Digital PEOL will also include the creation of a Virtual Wards and MDT systems - aimed at supporting co-ordination

The PEOL benefits map illustrates the movement from critical interventions (or project outputs) to the realisation of the desired capability. Delivery of these capabilities is designed to have an impact on measurable 'intermediate outcomes" and then on higher level 'outcomes. These Outcomes are designed, in turn, to impact on the programme benefits. Intermediate Outcomes & Outcomes can be measured on using existing data on After Death Audits or the PEOL Operational Dashboard or SIP data. It should be noted that 5 of the Benefits are qualitative measures to be drawn from the forthcoming Lincs Voices survey

Palliative & End of Life Care – Benefits Mapping

Project Output / Deliverable	Outcome /Capability	Intermediate Benefit	Benefit	Corporate Objectives

Project Output / Deliverable
- 1. Risk stratification framework
- 2. Workforce Re-modelling
- 3. Provide capacity to deliver care
- 4. Self Management Approaches
- 5. Specialist capacity for Trg / Education
- 6. Learning network
- 8. 24/7 PEOL Hub
- 9. 24/7 PEOL Response and Re-ablement
- 11. PCN MDT for Gold Standards Frmework
- 12. Capacity to support Co-ordination
- 10. Contracting care
- 14. Single Specialist Team
- 15. Establish Specialist MDT
- 7. PEOL Personalisation
- 17. Bereavement services
- 16. Provision appropriate in-patient beds with 7 day access
- 13. Digital PEOL Infrastructure

Outcome /Capability
- Earlier identification of initial and changing Palliative Need
- PEOL Self-management
- Clarity or roles and responsibilities of all PEOL staff
- An appropriately skilled specialist and core PEOL workforce
- Workforce capacity to deliver PEOL Care to an agreed standard
- Effective24/7 response and re-ablement (inc access to support and care)
- Effective PCN based MDT and operating practices
- Effective care co-ordination within and across settings
- Effective organisation and provision of specialist services
- Personalised care and support for people family and carers
- PEOL service that provides best value for money
- Effective and appropriate use of in-patient provision
- A record of digital care that is shared and accessible by all

Intermediate Benefit
- Increase in numbers of PEOL Register
- Increase in numbers on GSF framework
- Increase in Nos who have been offered a conversation about ACP
- Increased nos on PEOL register with Anticipatory Meds
- Reduction in Repeat Calls to 24/7 response
- Reduced Attendances for PEOL patients
- Reduced Admission for PEOL Patients
- Reduction in duplicate referrals to PEOL services
- Increase in number of patients with EPaCC records
- Increase in numbers with an identified Stage of illness
- Increased % of patients who have an ACP in place
- Increase in nos with a ReSPECT Form
- Reduction in patients attending A&E who have not been previously identified as PEOL
- Reduction in people admitted to hospital who have not been previously identified and who die within a month of first admission
- Reduced Bed Days for PEOL patients
- Increase % of people who die in their Preferred Place of Death
- Increase in no of Personalised Care and Support Plans
- Reduced cost per patient for all PEOL services (Community and In-patient)

Benefit
- 1. Increase our recognition of people deteriorating from a life limiting condition
- Reduction in % of people dying of LTC who are not on PEOL register or were placed on PEOL within a month of dying
- Increase the proportion of those on the PEOL Register who have had high quality & timely conversations about dying
  - Quality metric VOICES Q6 Overall, do you feel that you and your family got as much help and support from health & social services as you needed when caring for them?
- Increase the proportion of patients who have had robust care assessments
  - Quality Metric VOICES Q6 During the last months of their life, while they were at home, how well was their pain relieved
- Increase % of people who have been provided with high quality care in the last days of their lives
  - Quality metric VOICES Q53 Overall, and taking all sercices into account, how would you rate their care in the last 3 months of life?
- Increase Quality pf patient centered care
  - Quality Metric VOICES Q 50 Looking back over the last 3 months of their life, were they involved in decisions about their care as much as they would have wanted?
- Increase the resilience and sustainability of PEOL services
  - Quality Metric VOICES Q5 When they were at home in the last 3 months of life, did all <PEOL> services work well together?

Corporate Objectives
- PREVENTION
- PERSON CENTERED CARE
- CARE CLOSER TO HOME
- WORKING TOGETHER

The complexity of the operating environment means that Dependency Management is a critically important aspect of taking forward this operating model. The mix of inbound and outbound dependencies will require a sensitive approach to ensure that the PEOL Operating model retains coherence in its own right but is also an effective part of the wider health and social care system. This will involve both managing the requirements of other programmes and setting minimum requirements for individual elements of work that sits more naturally within another programme.

	Programme / Organisation	High level dependency
1	Urgent Care (2 Hour Community Response)	• The requirement for a specialist PEOL response will remain - however the receipt of initial calls and the co-ordination of a response will require co-ordination. • A 24/7 response function is likely be considerably more effective and efficient when combined with wider response resources (eg for a response to calls in which the issue can be resolved through a skilled core clinician rather than a specialist)
2	Patient flow	• The flow of PEOL patients into hospital - and resulting admissions and length of stay - is a critical challenge to the Lincs system. The role of the ULHT SPCT in supporting patients in hospital and subsequent discharge and the role of Planned Care in supporting a patient at home once discharged are key elements of both programmes of work. • Effective Advance Care planning in Planned Care services - coupled with responsive and effective 24/7 PEOL response - are considered likely to have the quickest impact on wider system challenges being addressed through Patient Flow
3	Personalisation	• Both programmes are focussing on the personalisation of Advance Care Planning and on the development supporting tools (eg the development of Patient Activation measures (PAM)). Clarity on responsibilities for development of associated templates, tools and working practices is essential to avoid any duplication of effort.
4	Ageing Well (Frailty)	• This programme is addressing the needs of a population cohort that are also central to PEOL. Of particular note is that it is individuals within this cohort who are often considered to have unrecognised PEOL need and who are therefore likely to be most impacted by increased recognition of PEOL need. • Work in this area links with other activity to manage Long Term Conditions (LTC) eg Respiratory, Heart Failure, Diabetes and Cancer. They key challenge being the consistent recognition of the point at which an individual would benefit from palliative care. • A direct dependency is likely to exist re Benefits - in that increased effort to recognise individuals as palliative may impact on the benefits of frailty (positively) and PEOL (as a dis-benefit)
5	PCN Development	• The focus on PCN developments with the PEOL operating model make this a strong dependency - with a particular challenge in maintaining both local control and devolution balanced by the PEOL need for a wider framework to provide consistency of service supported by 24/7 response and a Palliative Hub. • Early involvement in PCN development and testing is an essential mechanism to manage this dependency
6	Living with Cancer	• Approx 50% of those on the Palliative Register have cancer as their primary condition. The co-ordination of the move from active cancer treatment into palliative care is an identified gap in service provision - and is also an area where the operating model needs to reach into specialist services for specific conditions. It should be noted that this will also apply to other conditions (eg Dementia, Parkinsons, MND) and the development of an appropriate clinical pathway into palliative service provision will be required to deliver a personalised and seamless service
7	Clinical Re-Design of Nursing and Other Services (LCHS, ULHT)	• PEOL services are provided by a mix of specialist PEOL and community nursing providers. The extent to which resources are occupied delivering PEOL care varies but can be large (eg estimates of the % of time that PEOL takes up for community nurses varies between 25 and 40%). Clinical re-design of these wider services creates a significant dependency with PEOL and provides both opportunities and risks for service delivery (eg by increasing or reducing the time for PEOL in the context of other demands)
8	Digital Programmes	• The proposed operating model is heavily dependent on an effective digital infrastructure to support effective co-ordination. Whilst some of the work required is already under way (eg EPaCCs and Shared Care Portal) there are others which require further development (eg vMDT and Self-Management App).

41

Palliative and End of Life Care in Lincolnshire

To provide feedback or obtain further information please contact: **lisa.foyster@nhs.net** , **kay.howard@nhs.net** ,

magda.krupczak@nhs.net or **david.reed7@nhs.net**