



Palliative and end of life care in Integrated Care Systems

Survey Report

**Exploring how Integrated Care Systems are
responding to the Health and Care Act 2022**

November 2023

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Foreword

At Marie Curie, we were very encouraged by the inclusion in the Health and Care Act 2022 of a statutory duty for Integrated Care Boards (ICBs) to commission palliative and end of life care services that meet the needs of their populations.

We understand the immense pressures on the health and care system at the present time and want to work closely with ICBs across the country to understand the support they need to act on this new duty - one which we believe has the potential to reduce pressures on the wider system, in addition to improving end of life experience for all.

This is why we wrote to ICBs recently and asked them about their work on palliative and end of life care for adults. The survey findings provide a timely insight into how systems are responding to the new legal duty and the opportunities and barriers they are experiencing when seeking to meet this duty.

We are incredibly grateful to ICBs for taking the time to complete the survey on which this report is based. Suffolk & North East Essex and Birmingham & Solihull ICBs in particular have been very generous with their time, allowing for a detailed exploration of their experiences in a 'deep dive' analysis.

The survey findings provide some grounds for optimism. ICB respondents feel they are performing strongly in delivery of services, collaboration and engagement across providers, governance and accountability, and use of data to drive improvements.

The survey findings also point to areas requiring further work to ensure improved outcomes for people at the end of life.

Only a minority of ICB respondents feel they have properly understood population need, and a majority report significant challenges in addressing inequalities in palliative and end of life care. Workforce and funding are seen as key barriers to improving services and ICBs also report significant gaps in some of the core components of commissioned palliative and end of life care services in the Ambitions framework.

At Marie Curie, we are keen to support ICBs on this journey. Our report proposes seven priority actions ICBs should take to ensure the best possible experience for everyone facing death, dying and bereavement in their local area.

We also recommend further action at national level to ensure that ICBs have all the support they need to be able to deliver in full on the requirements of the Health & Care Act.

“We look forward to continuing to work with ICBs across the country to ensure everyone has the best possible end of life experience, both now and in the future.”

Yours sincerely,

Matthew

Matthew Reed, Chief Executive, Marie Curie

Context

Why Palliative and End of Life Care should be a priority

Marie Curie welcomes the introduction of the new legal duty for ICBs to commission palliative care services in the Health & Social Care Act because it is a positive opportunity to make the changes needed to improve end of life experience for everyone.

This is a critical moment for action to improve Palliative and End of Life Care (PEoLC). Our ageing population and the growing number of people living with multiple and major health conditions is resulting in a significant rise in need for PEoLC.

Demand for palliative care is projected to increase by 13% over the next ten years. Although as many as 90% of the people who die each year could benefit from palliative care¹, many are currently struggling to access that care. People whose PEoLC needs are least likely to be met include: those living with conditions other than cancer; aged over 85; living in poverty and deprivation; with learning disabilities; racialised and LGBTQ+ communities; people living in rural and more deprived areas; and people in prison.²

Improving PEoLC brings benefits not just for patients and carers, but also for the wider health and care system. Each year more than 650,000 out-of-hours visits are made in the UK to emergency departments by people at the end of life, and the number of visits is highest for people living in deprived areas.³ Ambulance conveyancing of people in the last year of their lives to emergency departments is also extremely high.

When integrated PEoLC services are provided in community settings, they can improve outcomes for patients and carers, and also reduce system pressures by lowering rates of A&E admissions, ambulance conveyancing, and emergency hospital admissions of people who are reaching the end of their lives.

The new legal duty

Integrated Care Boards were placed on a statutory footing on 1 July 2022, replacing Clinical Commissioning Groups and taking on a new and expanded remit.

This new remit includes a legal duty for all 42 ICBs to commission palliative care services that meet the needs of their local populations, set out in the Health and Care Act 2022.

In September 2022, NHS England published its **Statutory Guidance ('Palliative and End of Life Care Statutory Guidance for Integrated Care Boards')** to support ICBs to deliver on this duty. In January 2023, further guidance was published by NHS England through a **Handbook for Integrated Care Boards ('Palliative and End of Life Care Handbook for Integrated Care Boards')**.

The guidance and handbook are both based on the **'Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026'**.

This framework was co-designed by 34 statutory and voluntary sector organisations including Marie Curie. It sets out how to achieve high quality PEoLC around six key ambitions.

(1) Marie Curie (2023) How many people need palliative care?

(2) Boland J, Johnson MJ. End-of-life care for non-cancer patients. *BMJ Support Palliative Care* (2013); Dixon J, King D, Matosevic T, et al. Equity in the provision of palliative care in the UK: review of evidence (2015); CQC. A different ending: addressing inequalities in end of life care (2016); Bristowe K, Hodson M, Wee B, et al. Recommendations to reduce inequalities for LGBT people facing advanced illness. *Palliative Med* (2018); Gattrell AC, Wood DJ. Variation in geographic access to specialist inpatient hospices in England and Wales. *Health & place* (2012); Hospice UK. *Dying Behind Bars: How can we better support people in prison at the end of life* (2021).

(3) Pask et al (2022), *Better end of life report 2022: Mind the gaps – understanding and improving out-of-hours care for people with advanced illness and their informal carers.*

Ambitions for Palliative and End of Life Care

1
Each person is seen as an individual

2
Each person gets fair access to care

3
Maximise comfort and wellbeing

4
Care is co-ordinated

5
All staff are prepared to care

6
Each community is prepared to care

The statutory guidance outlines key considerations for ICBs to meet their legal duty for a whole system approach including:

- access to out-of-hours PEO LC
- ensuring access to a wide variety of non-specialist palliative care delivered by primary, community, acute and urgent care services, as well as specialist-level palliative care services
- a clear vision of how the package of services they commission locally deliver against the Ambitions Framework having the right workforce in place to deliver those services.

The statutory guidance states that in order to realise this duty, ICB commissioners should take a number of steps including: action an Ambitions for Palliative and End of Life Care self-assessment; develop and implement a PEO LC service specification; work to ensure that there are sufficient providers available to deliver this; ensure access to general medical and nursing services, out of hours services and rapid response; and complete an equalities and health inequalities impact assessment and action plan focused on PEO LC.

The statutory guidance also sets out some core components for commissioning PEO LC services that meet people's needs, aligned to those in the Ambitions Framework.

Marie Curie support for ICBs

Over the last year, Marie Curie has been engaging with ICBs to provide support to them in meeting this new legal duty to provide palliative care to adults in their local populations.

In June 2023, a survey was sent to all 42 ICBs in England to understand how they are responding to the new legal duty, alongside a 'deep dive' analysis with two ICBs – Suffolk & North East Essex and Birmingham & Solihull.

The aim of the survey was to understand:

- how ICBs are responding to their statutory duty in respect of PEO LC and what barriers they are experiencing
- what support ICBs would benefit from to overcome challenges and meet the statutory duty.

“This report summarises the survey findings related to how ICBs are responding and what barriers they are experiencing.”

It is intended to strengthen and inform work to realise the new legal duty to commission PEO LC in ICB areas and at national level.

A second Marie Curie publication to follow this one will respond to the support requested from ICBs in the survey to help them address the challenges they are facing.

Survey findings

To gather insights on how ICBs are meeting the new statutory requirement to commission PEO LC services that meet the needs of their population, a survey was sent to all 42 ICBs in England. The survey asked 23 questions. A full list of questions and analysis of responses to individual questions is provided in the accompanying appendices.

The survey went live on 1 June 2023 and closed on 14 July 2023, with a response rate of 62% (26 ICBs). The map below shows the geographical breakdown of respondents. Respondents generally held roles specialising in PEO LC (e.g. System Clinical Lead for End of Life) or senior roles such as Medical Directors.

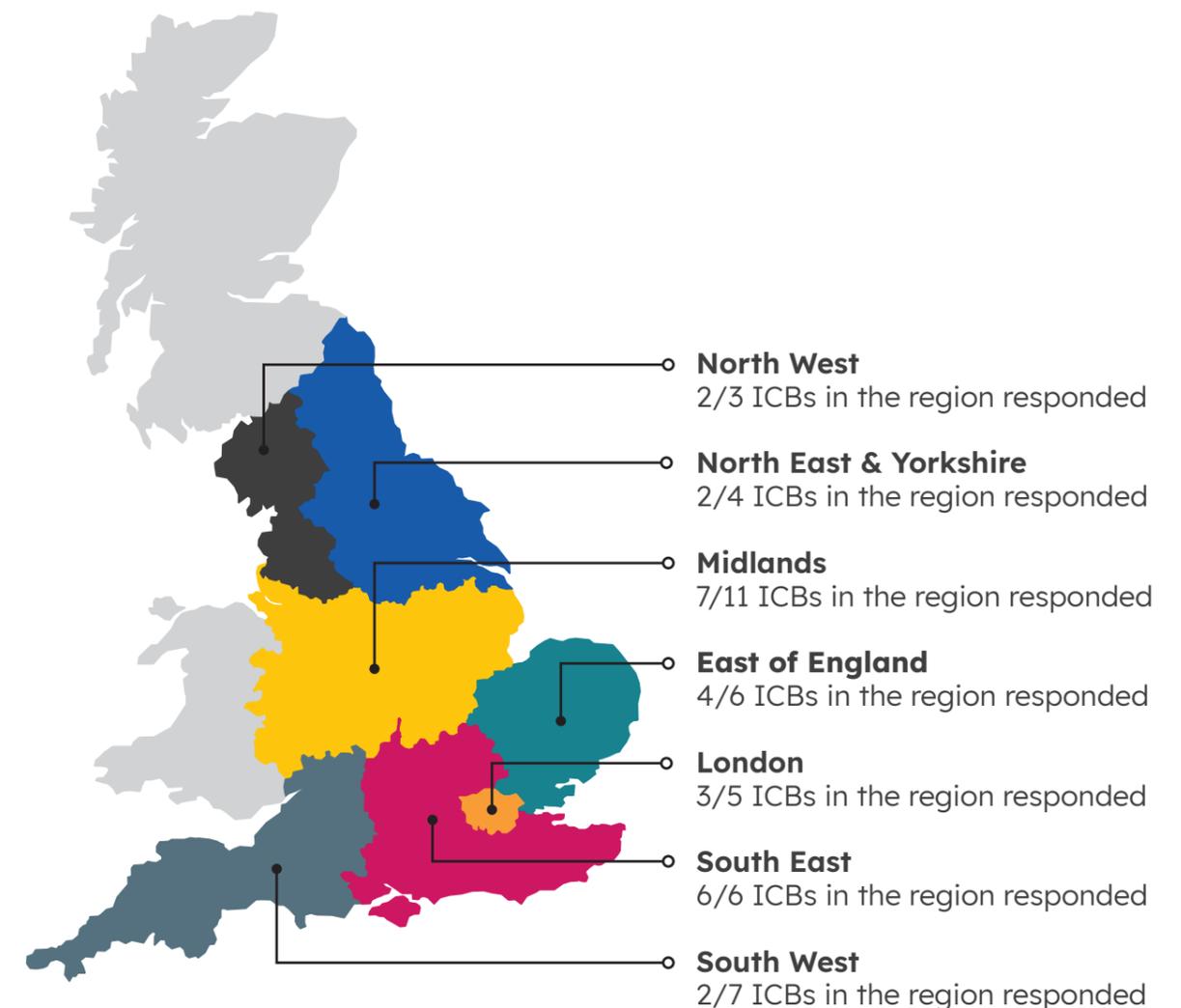


Fig 1. Geographical breakdown of respondents

Key findings

The survey of ICBs across England highlighted the following key themes in relation to palliative and end of life care (PEoLC):



1. Lack of a consistent strategic focus on PEoLC services

More than a quarter of ICBs in our survey told us their Integrated Care Strategy does not cover PEoLC and almost one in five told us their Joint Forward Plan does not do this.



2. Improvements required to fully understand population health need

Whilst the vast majority of systems (92%) feel they have at least moderately understood the PEoLC needs of their population, only 35% of systems report having a significant or full understanding of population health need.



3. Significant gap in understanding and addressing PEoLC inequalities

Understanding and addressing inequalities in access to and experience of PEoLC is a major gap for most systems, with two thirds of respondents yet to complete an Equalities and Health Inequalities Impact Assessment, as required in NHS England's statutory guidance on the new legal duty.



4. Workforce and funding are key barriers to PEoLC service improvement

Workforce and funding issues are considered the most significant barriers to effectively delivering and improving PEoLC services. Only 3% of ICB respondents have fully or significantly assessed the required workforce to deliver services effectively.



5. Appetite for additional support to demonstrate the benefits of PEoLC investment

Most systems would welcome additional resources and support to demonstrate the potential value of additional investment in PEoLC services.

Quantitative responses

Leading and shaping PEoLC services



Of ICBs responded that their Integrated Care Strategy covers PEoLC



ICBs engage with a range of stakeholders including people with lived experience, specialist palliative care providers e.g. charitable hospices, VCSEs and local authorities to develop PEoLC services

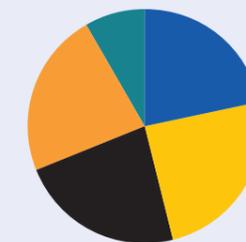


Of ICBs responded that their Joint Forward Plan covers PEoLC

Do you engage with the following to define PEoLC strategies and commissioning needs?



Types of support ICBs feel they could benefit from to meet the PEoLC legislation include evidence on value case (76%) and good practice case studies (36%)



- People with lived experience
- Specialist palliative care providers
- VCSE
- Local authorities
- Other

Commissioning PEoLC services



Understanding Population Health Need

92%

Of ICBs reported that they understand the PEoLC needs of their local population to at least a moderate extent.

However, only 35% reported that they significantly or fully understand PEoLC population health needs.

Meeting Population Health Needs

100%

Of ICBs reported that local PEoLC services meet local population need to at least a moderate extent.

However, only 38% reported that local services significantly or fully meet population needs.

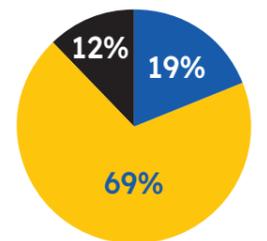


77%

Of ICBs have conducted a self assessment against the PEoLC Ambitions.

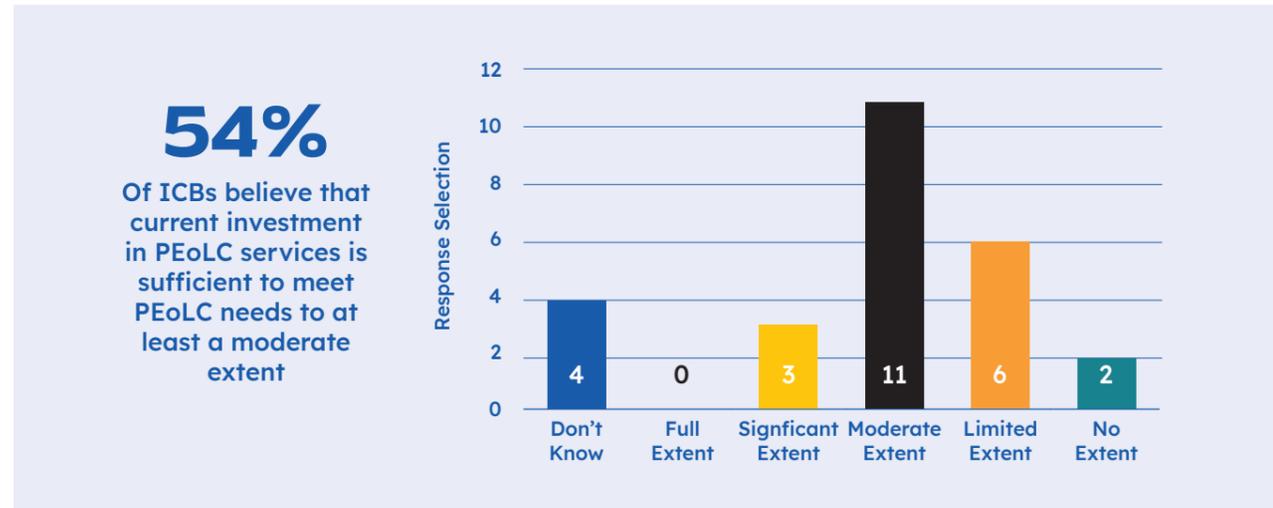
69%

Of ICBs have not completed an Equalities and Health inequalities impact assessment and action plan on PEoLC.



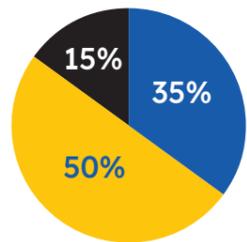
■ Yes ■ No ■ Dont Know

Enabling the delivery of PEOLC services



50%

Of ICBs have not made or do not plan to make significant capital investment in PEOLC



■ Yes ■ No ■ Don't Know



62%

Of ICBs are using joint funding arrangements across health & care for the delivery of PEOLC services



58%

Of ICBs have only assessed the required workforce to deliver PEOLC services effectively to a limited extent

Qualitative responses



ICBs feel they are performing particularly strongly in the following areas:

58%

Delivery of PEOLC services

46%

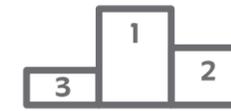
Collaboration & engagement across providers

29%

Governance & accountability structures

25%

Use of data to support PEOLC improvement



ICBs top priorities for PEOLC services include:

38%

Early identification of end of life care patients

35%

Equity of PEOLC services (including between cancer and non-cancer patients)

35%

Enhanced 24/7 access to PEOLC services

35%

Enhanced co-ordination of patients services

23%

PEoLC workforce education & training

19%

Supporting carers



Key barriers ICBs face in planning, recruiting and retaining a skilled workforce to deliver PEOLC services:

74%

Shortage of health & care professionals

61%

Funding and wage pressures

17%

Career pathways for PEOLC staff



Ways of working with the VCSE sector:

40%

VCSE representation on PEOLC governance groups

24%

Working with a broad range of partners

9%

Providing financial support to VCSE partners

Alignment with the Ambitions Framework

In the survey, we asked ICBs to what extent some of the core components of commissioned services set out in the Ambitions Framework are in place in their ICB.

Only 3 ICB respondents rated themselves as having these core components in place to a 'significant' or 'full' extent.

Core components that ICBs reported having in place significantly or to a full extent include:

- 56%** • joined up and coordinated PEOLC services with NHS, primary care, hospices and local authorities
- 48%** • ensuring quality of personalised care and support planning

Core components that ICBs reported having in place to a moderate extent include:

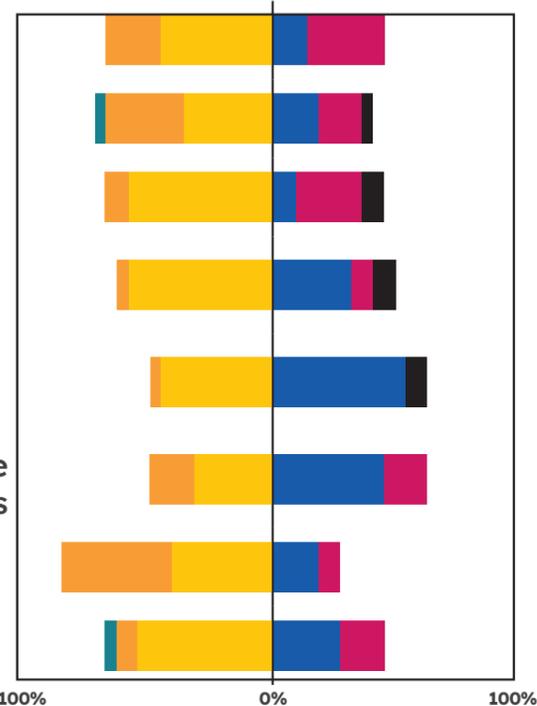
- 48%** • bereavement support service
- 42%** • ability to identify, assess and support family, carers and those important to the dying person

Areas which ICBs report having in place to a limited extent include:

- 40%** • electronic shared care records
- 28%** • 24/7 access to medicines
- 20%** • 24/7 access to care, advice, and support

Core components of commissioned services

- 24/7 access to care, advice, and support
- 24/7 access to medicines
- Access to equipment for PEOLC
- Ability to identify, assess and support family, carers and those important to the dying person
- Ensuring quality of personalised care and support planning
- Joined up and coordinated PEOLC services with the NHS, primary care, hospices and local authorities
- Access to electronic shared care records
- Bereavement support service



1 - No extent 2 - Limited extent 3 - Moderate extent 4 - Significant extent 5 - Full extent Don't know

Please see the accompanying appendices for more information on this and other questions.

Core components of commissioned services in the statutory guidance

- 1 Personalised care and support planning**
- 2 Shared care records**
- 3 Evidence and information**
- 4 Involving, supporting and caring for those important to the person**
- 5 Education and training**
- 6 24/7 access, co-design and integration**

Deep dive findings

Alongside our survey sent to all 42 ICBs in England, we also conducted a ‘deep dive’ discovery exercise with two ICBs – Suffolk & North East Essex (SNEE) and Birmingham & Solihull (BSol) to allow for a more in depth exploration of both strengths/areas of good practice and challenges/barriers. The deep dives took the form of interviews with a range of stakeholders across the systems. Further detail is provided in the appendices.

“Suffolk & North East Essex (SNEE) and Birmingham & Solihull (BSol) were selected as two systems that would provide insight from areas with varying characteristics, including significantly different levels of rurality, population demographics and density.”

Suffolk and North East Essex (SNEE)

SNEE context

Local population characteristics

There are over 1 million people registered with GPs across SNEE (with Ipswich and East Suffolk being the largest population, home to more than 40% of the total population). The majority of the population are white (95%), which is significantly higher than the national average of 87%. SNEE is spread across a mix of urban, rural and coastal areas, with pockets of significant deprivation. There is a life expectancy gap between individuals born in the most deprived communities in SNEE and those in the least deprived of 7.4 years in men and 5.9 years in women.

About the Integrated Care System (ICS)

SNEE ICS brings together the organisations responsible for planning and delivering health and care across the area to ensure shared leadership and joint action to improve the health and wellbeing of the population. Organisations represented within the ICS include the ICB, local authorities, social care providers, voluntary and community organisations, social enterprises, and other key stakeholders. There are three place-based alliances within SNEE: North East Essex, West Suffolk and Ipswich & East Suffolk.

These form part of the ICS along with two health and wellbeing boards, primary care networks, the ICB and the Integrated Care Partnership (ICP) among others. The ICB brings together its three predecessor Clinical Commissioning Groups – North East Essex CCG, West Suffolk CCG and Ipswich & East Suffolk CCG.

Challenges

Some of the challenges faced by SNEE include rising service demand, financial constraints, rising costs, and inequalities across the different geographical areas. As in many parts of the country, engagement with patients and the public has shown that in particular there is concern with accessing primary care services and waiting for diagnosis, treatment and support.

Priorities

SNEE’s Integrated Care Strategy outlines four ambitions: ‘making the best health and wellbeing a genuine reality for all’; ‘the opportunity of health equality for everyone’; ‘Live Well (everyone able to Start Well, Be Well, Stay Well, Feel Well, Age Well, Die Well)’; and, ‘Can Do Health & Care System that people can trust’. Key to the Die Well area is ensuring timely identification of the people who are approaching the end of their lives and communicating this with them and those who are important to them with sensitivity and honesty.

Suffolk and North East Essex (SNEE)

SNEE deep dive insights – strengths and areas of good practice

Strategic focus and prioritisation

SNEE have a clear strategic focus on and commitment to PEOLC. ‘Die well’ is one of the six strategic themes within the system’s Joint Forward Plan. This strategic focus and explicit recognition of the importance of PEOLC services within core system strategies and plans, whilst not unique, is not universal across all systems.

Strength of relationships and joint governance arrangements

Interviews with stakeholders across the SNEE system consistently highlighted the strength of relationships that underpin the commissioning, management and delivery of palliative and end of life care services. It was clearly evident through our interviews that hospice providers are recognised as critical partners, and there is a range of governance forums and working groups in place to support and facilitate collaboration and joint working.

Use of data to manage and improve quality and performance

North-East Essex (one of the three “places” within SNEE) have implemented a PEOLC dashboard to support outcome-based commissioning. This allows the system to understand a range of metrics including the number of PEOLC patients on their ‘My Care Choices Register’,

the number of emergency admissions of PEOLC patients in the last 90 days of life, the conditions PEOLC patients have been identified as dying from and patients in a care home who have a care plan. The dashboard also supports an understanding of inequalities through data on deprivation and ethnicity and enables targeted PEOLC interventions.

Specific good practice initiatives, including a 24/7 Palliative Care Hub

Multiple stakeholders interviewed across SNEE were able to give specific examples of good practice projects and initiatives that are contributing to improving PEOLC services across the system. One particular example, referred to by multiple stakeholders, was the implementation of a palliative care “hub” that provides 24/7 access to specialised PEOLC support to those in need.

“This was universally recognised by stakeholders as a major intervention that has improved PEOLC in the area.”

Suffolk and North East Essex (SNEE)

SNEE deep dive insights – challenges and barriers

Variability between places and legacy models

Our deep dive interviews with stakeholders from across the SNEE system consistently highlighted the variability in approach, and in particular funding arrangements, between the three “places” in SNEE (referred to locally as “alliances”). This was described as the most significant issue impacting their ability to more effectively commission, manage and deliver PEOLC services.

There are very significant variances in the funding of PEOLC services across the three alliances. The ICB still relies on and utilises many legacy arrangements for the commissioning of PEOLC services, with each alliance managing services somewhat independently based on historic Clinical Commissioning Group footprints.

Discussions with stakeholders highlighted significant uncertainty regarding the implications of these arrangements in relation to the legal requirement to commission palliative care services that meet the needs of their population. Some stakeholders took the view that to meet the requirement in the Health & Care Act and truly commission PEOLC services that meet the needs of the population, then as commissioner they should fully pay for these services. However, this is clearly a major challenge in the context of no additional funding available to ICBs, alongside the already significant expectations for ICBs to reduce their cost base.

Assessing and quantifying value

Interviews with stakeholders across SNEE consistently highlighted that the system would value additional support in assessing and quantifying the benefits of investment in PEOLC services.

Long term planning and transformation

Several stakeholders we engaged with raised concerns over the system’s ability to plan for the longer term and deliver long-term transformation of services. The nature of the NHS planning cycle makes it difficult to invest in and/or fund initiatives in the longer term. This concern was also linked to the need to assess and quantify value.

“The Palliative Care Hub, for example, is considered a huge asset locally but further work is needed to quantify value in order to confirm longer term funding beyond the current year.”

Birmingham and Solihull (BSol)

SNEE context

Local population characteristics

BSol has a population of 1.36 million people, with more than 1.14 million people living in Birmingham and 217,000 in Solihull. The ICS area includes pockets of significant levels of deprivation, with one in three children in Birmingham living in poverty. Parts of BSol experience lower life expectancy than the UK average life expectancy.

About the ICS

The ICS is formed of health and care partners including the ICB, Birmingham and Solihull Mental Health NHS Foundation Trust, Birmingham Community Healthcare NHS Foundation Trust, Birmingham Women's and Children's NHS Foundation Trust, The Royal Orthopaedic Hospital, University Hospitals Birmingham, West Midlands Ambulance Service, Birmingham City Council, Solihull Metropolitan Borough Council, and members from the voluntary sector.

Challenges

There are significant disparities in income across the area, with people in Birmingham earning £49 per week less than the national average, compared to Solihull where people earn £80 more than the national average. As is the case in many parts of the country, some of the challenges faced by BSol include long waiting times for procedures, large numbers of people dying from causes that are potentially preventable and

people living for long periods in poor health.

Priorities

BSol's 10 year Integrated Care Strategy outlines the following shared objectives to drive improvements in health and social care: 'Reduce inequalities'; 'Deliver integration for people'; 'Protect people from harm'; 'Be there across the life-course'; 'Build a thriving inclusive workforce'; and 'Address the wider determinants of health'.

“The Health and Wellbeing Board Strategy priorities for Birmingham and Solihull include ‘ageing well’ and ‘healthy life expectancy at 65 years old’.”

Birmingham and Solihull (BSol)

BSol deep dive insights - areas of good practice

Strong governance arrangements

BSol have strong governance arrangements in place in relation to PEOLC. This includes an End of Life (EoL) Collaboration System Steering Group. There is also an EoL Operational Group, EoL Ambitions Action Plan Workstream Review Groups and an EoL Staff Engagement Group. The Operational Group, which feeds into a senior steering group, meets monthly with 40 representatives across the acute, voluntary and private sectors.

Improving equity

BSol have introduced Personal Health Budgets to help address health inequalities and deliver personalised care. This has allowed end of life patients to receive funds for items / services which can better support their health needs, for example, this can apply to cleaning services or funds for grocery shopping in certain specific circumstances. Patient feedback has shown that this has made a significant positive impact.

Single point of access

Patients, carers or professionals can receive support on end of life care through a telephone helpline available from 8am – 8pm (though not on a 24/7 basis). To support this further there are daily calls between the hospice and local hospitals in BSol to manage bed capacity for end of life care patients.

BSol deep dive insights - challenges and barriers

Data driven PEOLC insights

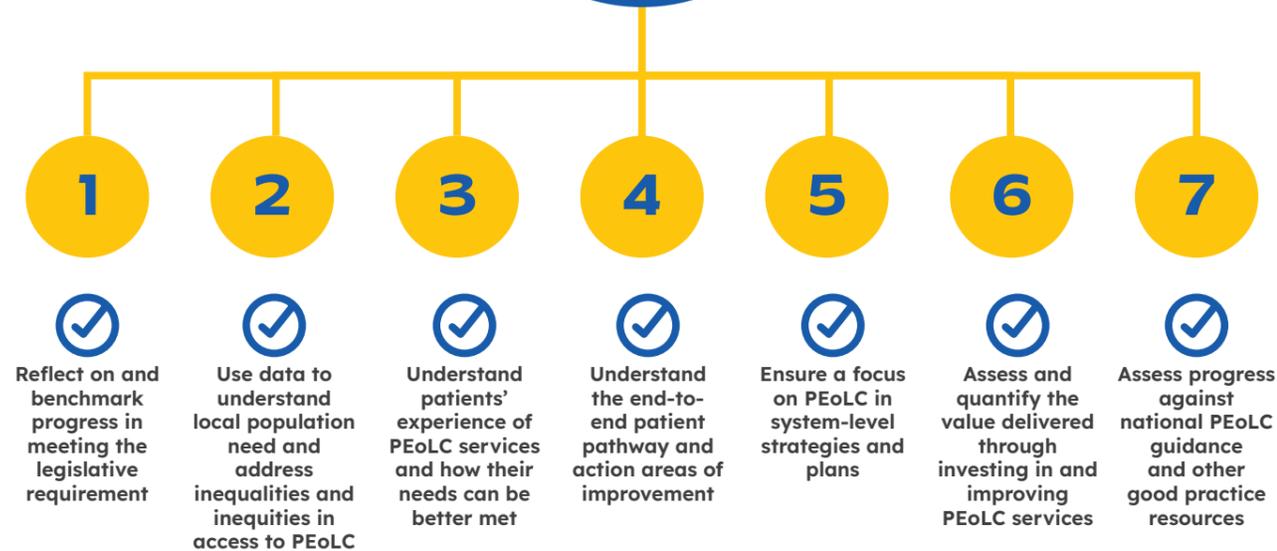
BSol have limited data on PEOLC outcomes and recognise this as an area for improvement. Some work has been undertaken with hospices on modelling bed capacity for end of life patients.

Investment and funding

Stakeholders felt there was a need for increased funding in palliative and end of life care, whilst noting the difficulty of making this happen in the context of wider funding pressures.

Recommendations for Integrated Care Boards

ICB Checklist Key Points for Consideration



Conclusions

Removing key barriers and enabling further progress on PEOLC will require action not only at a local level by individual ICBs, but also at a national level.

An important first step towards strengthening systems' strategic focus on PEOLC is to **update the statutory guidance on Integrated Care Strategies and Joint Forward plans to ensure proper coverage of PEOLC**. At the time of writing, the current versions of both sets of guidance do not make any reference to the new legal duty to commission palliative care and we are hopeful the current reviews of both sets of guidance will address this gap.

We also recommend that the **forthcoming Major Conditions Strategy (MCS) prioritises enabling early access to integrated PEOLC services in community settings** so that people can be supported to manage their life-limiting conditions effectively. We welcome the inclusion of palliative care in the MCS strategic framework and recommend that the full strategy includes specific policy proposals to address the gaps in core PEOLC services that ICBs have identified here.

To support systems to better understand and measure population need for palliative care, we recommend **developing an evidence-based approach for measuring population need for palliative care at ICS level for use by all ICBs**. ICBs would use this alongside other measures to fully understand the needs of their local population such as involvement of people with lived experience and under-served and marginalised communities.

Addressing the funding barriers that systems face requires **significant additional funding for all parts of the health and care system that play a role in PEOLC provision, including charitable hospices**. Charitable hospices are key providers of specialist PEOLC for adults, but on average they receive just over one third of their income from statutory sources, with the remainder raised largely through charitable fundraising.

Addressing the workforce barriers that systems face will require **planning a health and care workforce that is capable of responding to future need for PEOLC**. The new NHS Long Term Workforce Plan does not account for the workforce needs of charitable hospices and other VCS and CIC providers of health and social care. Future workforce plans should ensure parity of esteem for NHS and charitable hospice workers doing similar roles. We also recommend that PEOLC is made a compulsory part of initial training and continuing professional development for all health and care workers so they are equipped to respond to the rising demand for PEOLC.

At Marie Curie, we look forward to working with both our national and ICB partners to ensure that everyone has the best possible end of life experience, both now and in the future. It is what all of us would hope and wish for at the end of our own lives.

More information

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About Marie Curie

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