



Hampshire  
County Council

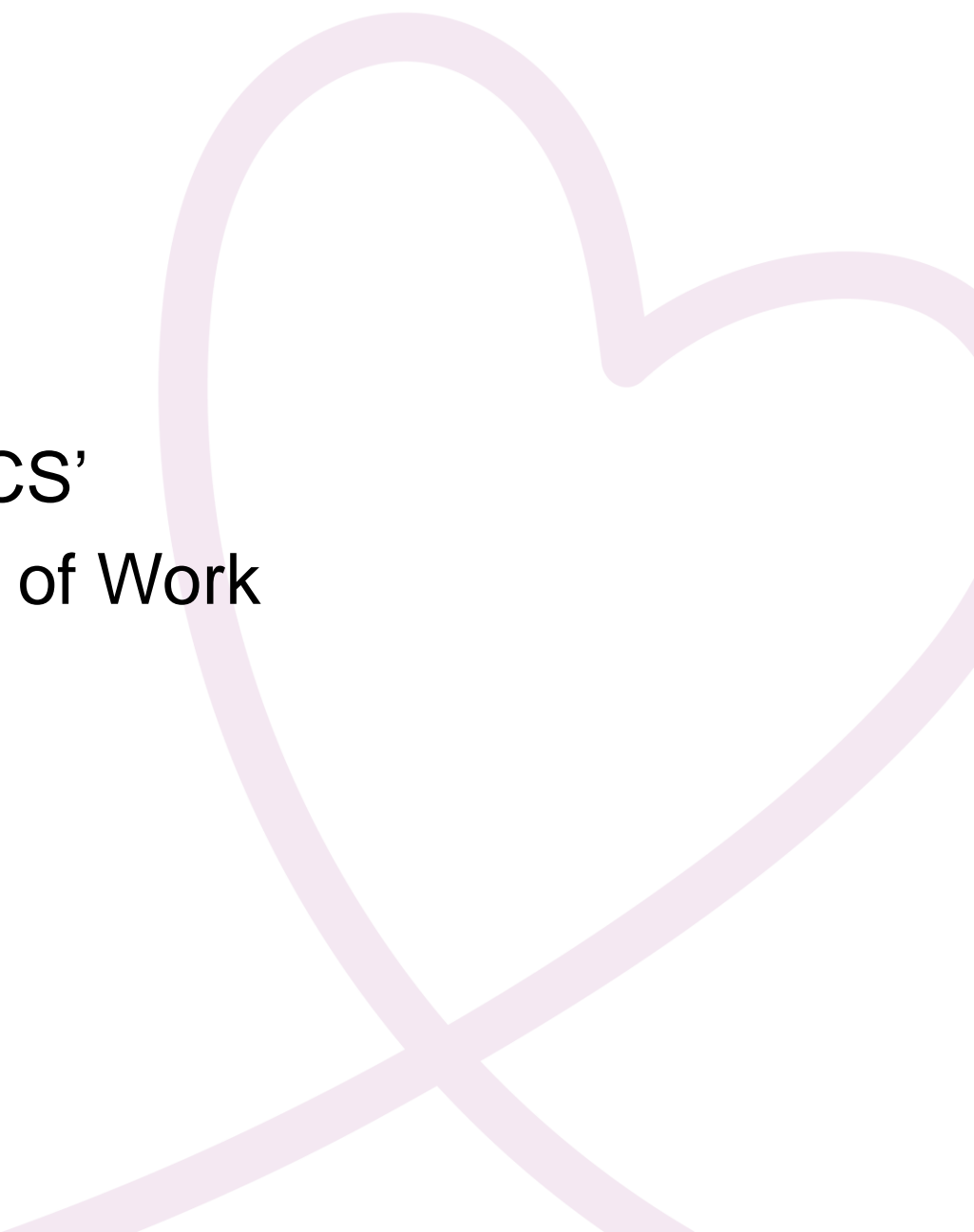
# Health and Wellbeing Strategy Dying Well Update

15 June 2023

Hampshire  
**Health and  
Wellbeing**  
Board



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# Dying Well Key Priorities (2019 – 2024)

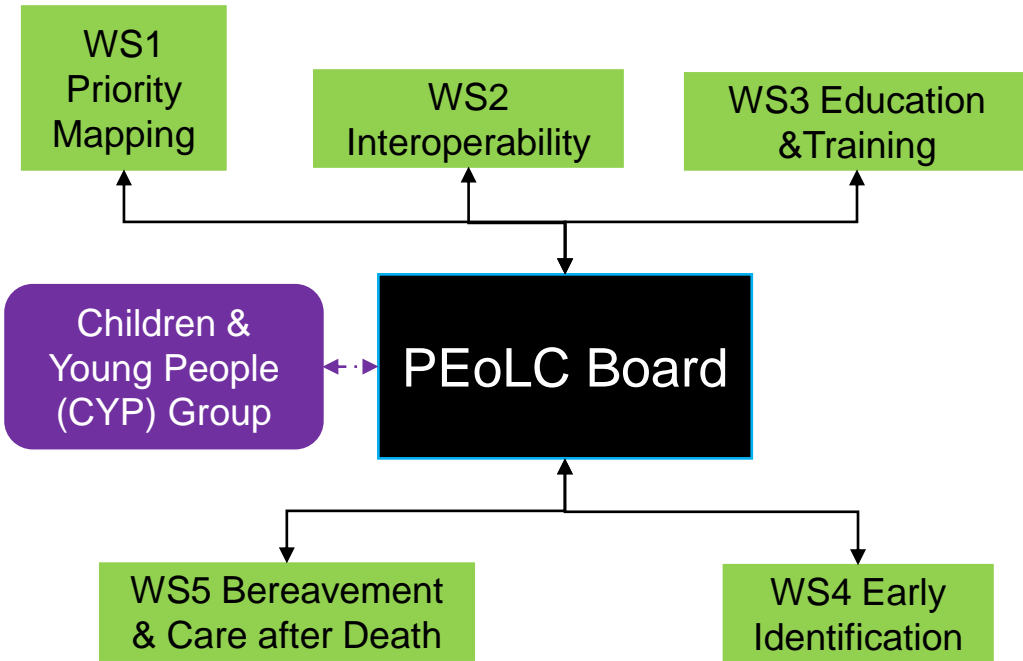
- Ensure person-centred care, choice and control is consistently in place across Hampshire to help people live well with life-limiting conditions
- Support people at end of life to return to or remain in their preferred setting in the last days and hours of life
- Improve skills and capacity across Hampshire to ensure people are encouraged and supported to have early and timely conversations about end of life wishes and choices. This will help individuals and their families to plan and prepare in advance.
- Work together effectively across organisations to provide well integrated care and consistent palliative care, building on a shared care plan irrespective of organisational or funding boundaries
- Improve access to bereavement support and services locally, for all age groups, especially for parents, families and educational communities following the death of a child, for children experiencing the loss of a parent, and for long-term carers who may also need support when their caring role ceases.

# Partnership Working across Frimley & HLOW

- Full engagement now established with the PEOLC South-East Regional Team within NHS England
  - Representation from both HLOW & Frimley ICS'
- Working together strengthened between Children and Young Adults (CYA) & Adults Palliative and End of Life Care (PEOLC) leads.
- Hospice Collaborative established – further focus needed on bringing together independent and trust-based hospices.
- New Leadership within HLOW further strengthened PEOLC voice within ICB.

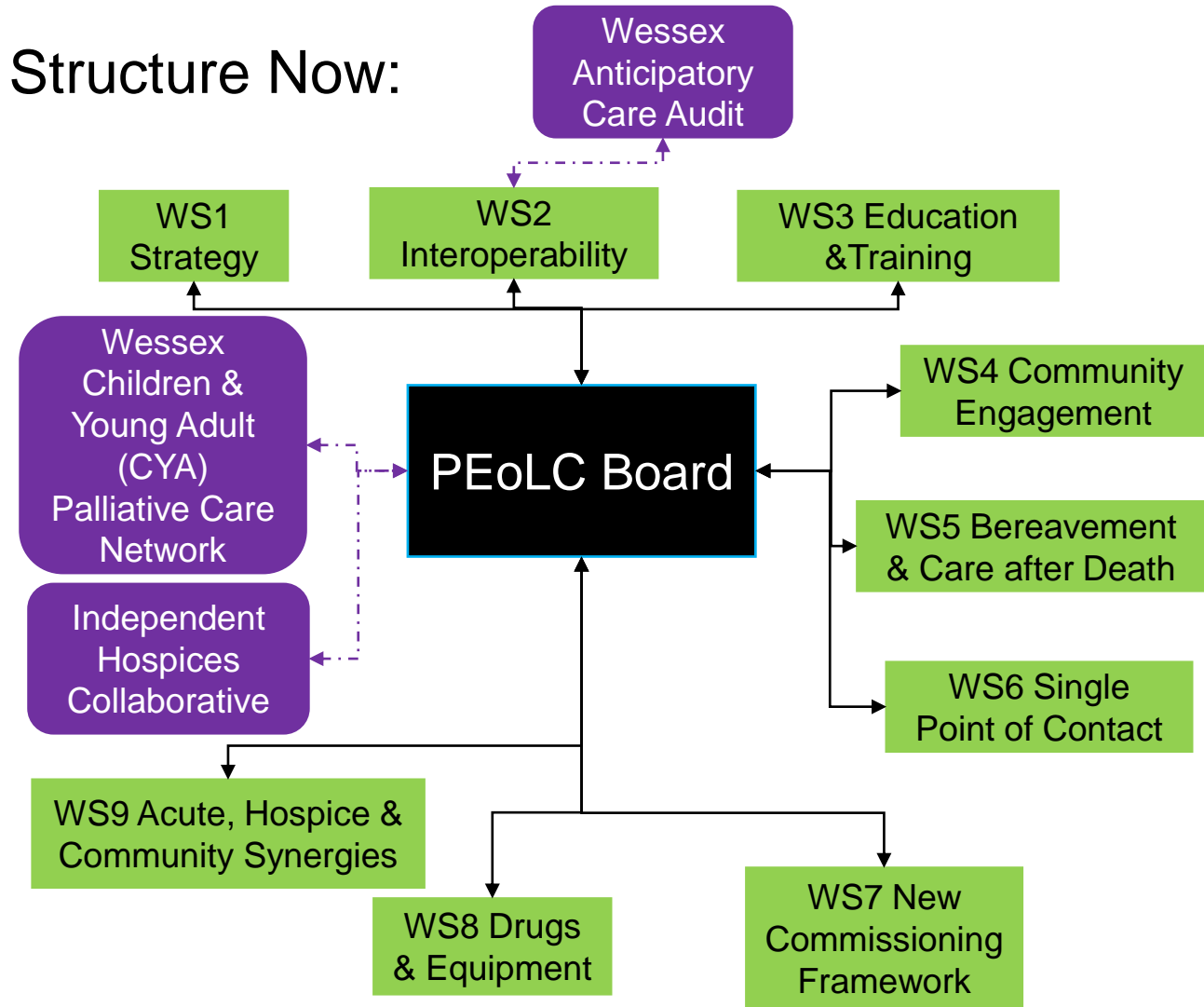
# Palliative and End of Life Care Board & Workstreams

## Initial Structure:



Please note: CYA previously CYP. Wessex covers wider than H&IOW IC as includes Dorset, part of Wiltshire whilst CYA covers Channel Island and UHS is a Tertiary referral centre, covering across the country. Wessex Anticipatory Care Audit is also wider than ICB geography and covers Dorset, part of Wiltshire

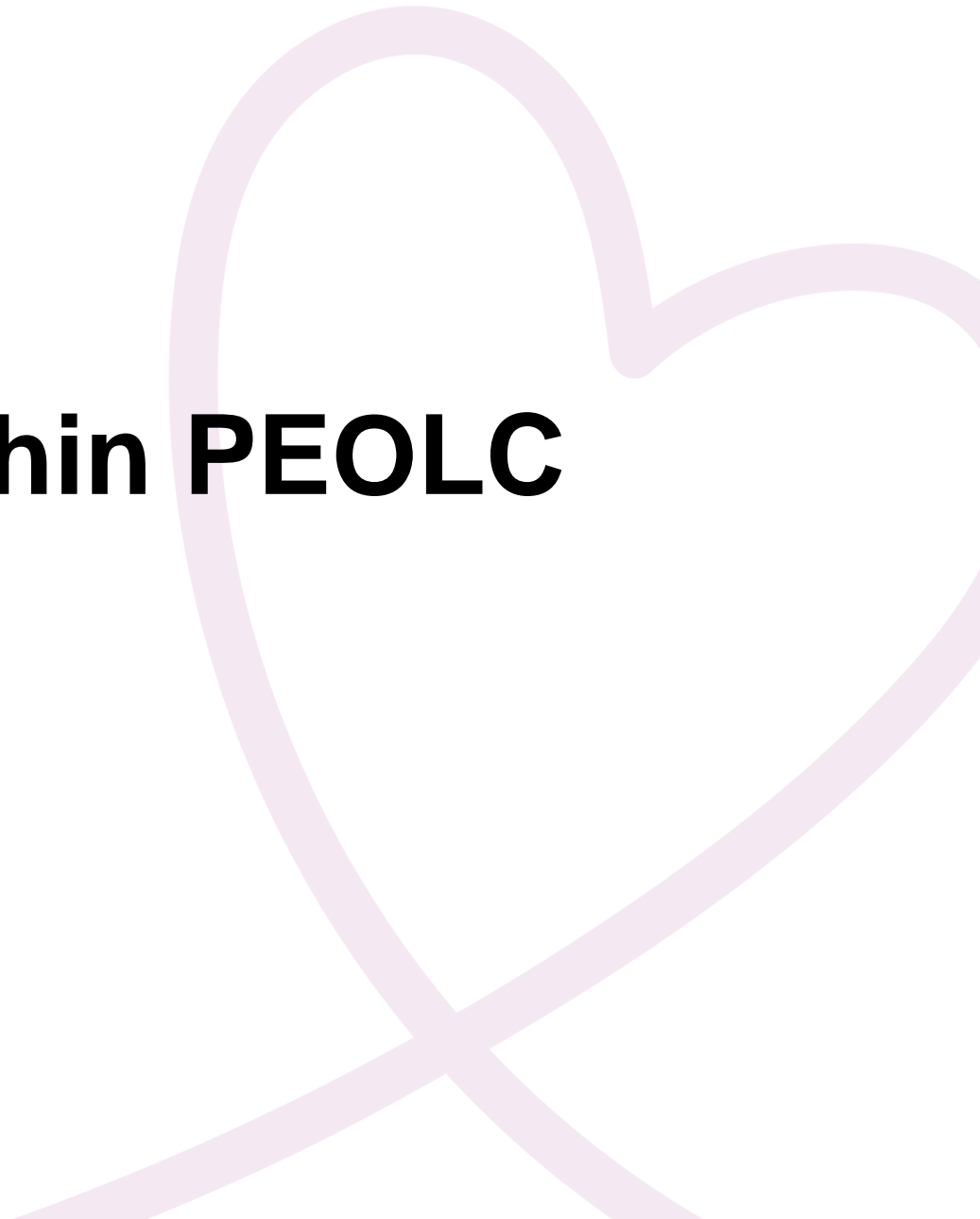
## Structure Now:



# Overview of Work Programmes (2022/23)

Area of Work	Details
<b>EOL Interoperability</b>	<b>Focussed on developing a technical solution to sharing information concerning PEOLC.</b> Wessex AHSN Proactive Care Audit & BA Mapping. Community Conversations held.
<b>Education and Training</b>	<b>Focussed on developing a Training and Education Model across ICS – targeted at specific bands initially.</b> Working with HEE to build into existing platform and establish within <b>HEE Learning Pathways</b>
<b>Community Engagement</b>	Several Community Conversations held, commencing Summer 2021, recommendation being to focus on <b>people with a learning disability and those who support them</b> to design the solutions.
<b>Bereavement and Care After Death</b>	<b>Focussed on strengthening co-ordination and support for bereavement and care after death.</b> Outcomes to date include designing series of death fairs & Community Chaplains booklet.
<b>Health and Care Bill – EOL Commissioning</b>	Following news of pending Health and Care Bill, transformation leads are working together to develop an <b>EOL methodology for initial mapping of core/specialist services delivered, gaps and areas for collaboration.</b>
<b>Single Point of Contact</b>	Models being developed across HIOW and group established to share learning to inform HIOW wide model.
<b>ICS PEOLC All Ages Strategy</b>	Work now underway. All ages strategy drafted and shared with stakeholders for comment. Shared with our community for comment and aim to complete initial draft June 23, final Sept 23.
<b>Data Dashboard</b>	National team core metrics mandate issued. Plans to produce data in June via Population Health Management pulling on primary care dataset.

# **Examples of Delivery within PEOLC**



# PEOLC Interoperability: Anticipatory Care - Community Perspective & Audit

We spoke with 130 people across communities in HIOW to find out their understanding and experiences with anticipatory care

Overall, communities have limited understanding of anticipatory care and how to access support.

Staff raised concerns with regard to interoperability and accountability, and it's direct impact on patient experience.

Key challenges expressed by communities with prior anticipatory care experience include needing to:

repeat your wishes multiple times, needing additional support to make informed decisions about care, lack of cultural and religious understandings amongst staff, and anticipatory care plans not being followed through.

Communities and staff both shared frustrations on the current stigma around death and dying as well as anticipatory care discussions occurring too late in a person's life.

Communities with prior anticipatory care experience were all able to recognise the potential benefits.



What improvements would communities like to see in the future?

Increased awareness and discussions on anticipatory care, increased challenge towards the stigma surrounding death and dying and additional support to individuals in an unpaid caring role were key themes discussed by communities.

Staff expressed benefiting from additional education and training to ensure they are confident and empowered to have difficult discussions as well as increased and innovative ways of communicating with colleagues internal and external to their organisation.



**ANTICIPATORY CARE**  
A COMMUNITY PERSPECTIVE

SOLENT NHS TRUST  
Community Engagement  
& Experience team  
March 2023





# WS2 - Wessex Anticipatory Care Planning (ACP) Audit

The audit aims to understand the existing Anticipatory Care processes and systems in place, how these are shared and accessed alongside existing examples of best practice and operational challenges.

## What has gone well

58 responses – covering all settings  
 2 ICSs involved – able to share knowledge and learning  
 Great community response – seeking to understand more.  
 Community engagement approach to meet communities needs – 1:1, groups, in person, on line

## Key challenges

Differing levels of engagement across professional groups within the ICSs  
 Unknown staff knowledge level outside those completing audit

## Involvement, awareness, impacted

Staff that completed audit aware/involved  
 Community engagement sessions currently being run - outcome paper due imminently

## Aspirations & recommendations for 2023/24 and beyond

Outcome of Community Engagement sessions – paper drafted March 23  
 Anticipatory Care Feedback event – 29 March 2023. Report due May 23  
 Need to agree how do we take the learning forward – together  
 Anticipate recommendations and community feedback will feed into PEOLC Strategy



Please note: ACP is wider than PEOLC, covers all older people. Wessex also covers wider than ICB as include Dorset and part of Wiltshire.

# Future Planning

- Future Planning Resource in place in multiple locations across HIOW
- Further work underway to operationalise in services across HIOW (alongside other alternatives)
- Site is for patients, families, general practitioners, community nurses and anyone else experiencing or involved in caring for patients with chronic conditions, life shortening illness or frailty with organisational leads from across Solent NHS Trust, Southern Health NHS Foundation Trust, Wessex LMC, Oakhaven Hospice, St Michaels Hospice and The Rowans Hospice.
- <https://www.futureplanning.org.uk/>

# Death and Bereavement Public Mental Wellbeing Campaign

To be shaped by insight from professionals, volunteers and residents during Summer 2023, but aims are proposed as:

- Destigmatise talking about death, dying and bereavement and normalising grief
- Know how to prepare yourself/someone else for dying / a death
- Know where to seek/provide support following a bereavement
- Workforce/volunteers and community leaders know where to signpost for appropriate bereavement support
- Culturally appropriate messaging



Bereavement and End of Life

# Campaign Call To Action

Talk about death and bereavement • Find the emotional support you need to prepare for a death • Find the emotional support available following a bereavement • Signpost people to appropriate bereavement support.

Launch date proposed September 2023. Print and online.

Campaign will **signpost to:**

- [Mental Wellbeing Hampshire: Bereavement and End of Life](#). This page will be further developed ahead of the campaign to include a richer range of information and resources.
- [Connect to Support Hampshire](#) (for the practical elements)

## Key Campaign Partners

- HCC Death Positive Libraries
- HCC Adults Health and Care
- HCC Registration Services
- Hospices
- Hospitals and ICBs
- Funeral care organisations
- Community and voluntary sector
- Faith groups and community leaders

# WS4 - Community Engagement

## Initial focus - how we work with our community to support development of PEO LC

### What has gone well

2<sup>nd</sup> community conversation resulted in focus on people with a learning disability  
Opportunity to share their story  
Genuinely getting underneath and not just touching the surface  
Greater connections with those non-statutory groups not known to statutory organisations, so connecting with the hidden members, those most likely to have a late diagnosis.

### Key challenges

Takes time and resources  
Full change pending outcomes of conversations which continue, relationships and connections made.  
  
Told by communities to shrink down what we are trying to do, as too big

### Involvement, awareness, impacted

Everything this group does is about utilising alongside communities approach to engaging our communities, which include our staff, patients, carers and their loved ones  
Always looking for more avenues to share and especially the hidden groups  
What else to explore:  

1. What will make the most difference to the most people
2. Identify the best of what we do
3. Share and spread

## Aspirations & recommendations for 2023/24 and beyond

Key focus on people with a learning disability moving towards the end of their life, agreeing 1 – 3 key focus areas with our community – Q1 23/24

Develop & run Community Conversations through ambition and aspirations, broader conversations regarding learning community -Jun 23

Work with Consultants on supporting community conversation approach – Q1/2 23/24

PEoLC Solent Approach & Audit write up, to share with colleagues across the ICB – Q1 23/24

All workstreams are also including working with people and communities and when reviewing actions, members will ask themselves:

- Where is the voice of the community in informing our knowledge of where we are now?
- How will we actively involve communities in the development, design, and delivery of this “product”?
- What is our process to ensure our community participates in the monitoring of progress?

# Developing our Palliative and End of Life Care Strategy

Information and people involved in shaping the strategy

Our patients, carers and loved ones, community and staff have shared what is important to them and/or impact positively on Palliative & End of Life Care.

Utilising an engagement and inclusion approach, cocreated with people from our local communities

Palliative and End of Life Care Leads reviewed outcomes, workstreams, strategies and directives in line with Nationally identified priorities and recommended adjustments for local need.

Initial thoughts tested with wider group ahead of further community engagement

Baseline information gathered. Further evidence needed to support robust multi-factorial /system conversations.

Plans to strengthen local statistics to further support clinical early thoughts

1. We reviewed the national information on Palliative and End of Life Care direction of travel.
2. We mapped the national requirements alongside the current Palliative and End of Life Care workstreams, clinical feedback and feedback organisations had received from patients, their loved ones & carers
3. We sought, through community conversations with our patients, their loved ones, carers, our communities and staff, their feedback, experiences, and priorities in relation to palliative and end of life care.
4. We drafted an outline strategy which will, once reviewed by the Palliative and End of Life Board, go back to our community for further community conversations to ensure we have interpreted what they shared and ask for their ongoing support to check in to ensure effective delivery and keeping it live.

## This strategy:

- ✓ builds on work already completed/in progress, including work by the Palliative and End of Life Care Board and Workstreams
- ✓ sets out the priorities for developing & delivering Palliative and End of Life Care 2023 and beyond
- ✓ incorporates feedback that our patients, their loved ones, carers, community and staff have shared
- ✓ builds on the trusting & resilient relationship build
- ✓ uses the national Palliative and End of Life Care framework as the basis for its development
- ✓ will be a living document, being updated and adjusted to reflect the changing needs and feedback from our patients, their loved ones, carers, our community and staff and opportunities to work even more closely together

# PEOLC Strategic Priorities 2023 - 2026



Priority	Aim
<b>Identification &amp; Personalised Care and Support Planning</b>	Our ICB will strengthen the ways in which we identify people in their last hours, days, weeks, months and years of life, enabling early and meaningful conversations around what matters most to them, their loved ones and those important to them, to drive the care received.
<b>Shared Care Records</b>	Our ICB will work with an agreed set of information to guide discussions around what matters most you or your loved one in meeting your or their needs, sharing the outcome of these discussions as needed to enable a more co-ordinated, effective approach in the planning of your care for the future. Ultimately, we aim to develop a digital solution in the sharing of information, to strengthen the effectiveness of how we share information to inform you and your care.
<b>Evidence and Information</b>	Our ICB will have access to detailed and timely evidence and information, creating an accurate picture of palliative and end of life care across Hampshire and Isle of Wight. This information will drive and inform our approach to the future development and commissioning of services which remain responsive to your needs.
<b>Involving, Supporting &amp; Caring for those important to the you</b>	Our ICB understands the importance of caring and supporting those important to you, ensuring they receive the advice and care they need during the care of a loved one and/or following a bereavement.
<b>Workforce, Education and Training</b>	Our ICB recognises the value of our workforce in the delivery of high quality PEOLC. We will work to ensure our workforce and wider partners have both the specialist and generalist skills required to support you and your loved ones when receiving PEOLC.
<b>24/7 access</b>	Our ICB will develop services which work together to deliver consistency of access to PEOLC advice and support 24 hours a day, 7 days a week (in line with need).
<b>Co-production</b>	Our ICB will work alongside our patients, carers and communities in equal partnership, seeking to engage at the earliest stage to inform development and evaluation of PEOLC.
<b>Leadership</b>	Our ICS invests in PEOLC leadership, creating the necessary leadership for ongoing delivery of high quality PEOLC.
<b>Integration, Quality and Sustainability</b>	Our ICB will work with partners across the HIOW patch to ensure delivery of integrated PEOLC services, delivered in line with patient need irrespective of organisational boundaries.

# PEOLC Strategic Outcomes

People across Hampshire & Isle of Wight who need palliative and /or end of life care will:

- Be seen and treated as individuals who are encouraged to make and share proactive care plans and be involved in decisions regarding their care and wishes or in their best interests if they are unable to articulate their needs for themselves
- Receive care that is well-coordinated, shared effectively and told once
- Be supported to live well as long as possible, taking account of their expressed wishes and maximising their comfort and wellbeing
- Be assured that their loved ones, carers and those close to them are well supported during and after their care, and that they are kept involved and informed throughout
- Have their care provided by people who are well trained to do so and who have access to the necessary resources
- Have their needs and conditions recognised quickly and be given fair access to services regardless of their background or characteristics
- Be part of communities that talk about death and dying, and that are ready, willing, and able to provide the support needed
- Be part of a community that recognises the value of compassionate leadership to enable effective delivery of palliative and end of life care
- Receive care that is well-coordinated






# What's next for us.....

- **Strengthen Governance Structure:** Formally establish revised reporting and governance structure to further strengthen voice of PEOLC within ICB.
- **Finalise PEOLC All Ages Strategy:** including building in clear outcomes and resource requirements & taking steps to align with the ICB Joint Forward Plan. Target finalise September 2023.
- **Programme Overview:** Work with the ICB PMO office to outline clear deliverables and outcomes for delivery of PEOLC strategy during 2023 – 2026
- **Co-production of an ICS PEOLC Webpage:** which will hold what is important to our patients, their loved ones, carers, staff and communities.
- **Pull in Specialist Expertise:** to inform, support and enable delivery of the PEOLC Strategy e.g. comms, finance, BI etc.
- **Quality Data Oversight:** To strengthen oversight of quality triangulated data via PEOLC ICB wide review – promote shared learning and links with wider programme of work.
- **Strengthen our engagement with our Communities:** Seek to underpin all of our work with the expectation that it will be done working with people and communities and asking each workgroup to ask:
  1. Where is the voice of the community in informing our knowledge of where we are now?
  2. How will we actively involve communities in the development, design and delivery of this “product”?
  3. What is our process to ensure our community participates in the monitoring of progress?



# Challenges going forward (23/24)

1. Understanding and navigating the newly formed ICB infrastructure
  2. Securing project resources and clinical leadership into second half of 2023/24 (including specialist resources)
  3. Embedding and maintaining pace of delivery following launch of the PEOLC Strategy
  4. Enabling meaningful access to PEOLC data which represents the successes and challenges within our area.
  5. Wider linkages with other ICB programmes of work to support successful delivery e.g. EOL Interoperability
  6. Ensuring PEOLC voice remains strong within ICB and wider programmes of work.
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# Recommendations for Board

## HWB Board are asked to:

- Note the progress on Dying Well through partnership working over the last year.
- Acknowledge and support the plans to continue working together on programmes of work outlined.
- To support our projects including:
  - **HIOW ICS Palliative and End of Life Care Strategy:** Support focussed feedback from stakeholders within H&W Board noting links with priorities of the Dying Well Strategy.
  - Ongoing Community Conversations planned.
  - Ongoing development and implementation of PEOLC Single Point of Contacts for ICS.
  - Mapping of PEOLC provision in line with the National Commissioning Framework.
  - Support the launch of the Death and Bereavement Campaign in Autumn 2023
  - Development of a PEOLC data dashboard following the first cut of data in June 2023.
  - Consider H&W Representative to support recent developments with Bereavement Alliance

# Additional Information: Signposting and Resources

In the workplace/for employers:

[Bereavement resources for the social care workforce - GOV.UK \(www.gov.uk\)](https://www.gov.uk)

[Terminal illness and wellbeing: supporting people in the workplace - OpenLearn - Open University](#)

[The Dying to Work Campaign | Dying to Work](#)

[Workplace Wellbeing Support | Compassionate Employers Workplace Support | Hospice UK \(paid for\) and Compassionate Employers Webinars | Hospice UK- free webinars](#)

[Dying well: work and terminal illness webinar slides - What Works Wellbeing](#)

[Understanding Grief & Loss \(March 2023\) v2.mp4 \(sharepoint.com\)](#) – HCC internal workshop video recording

[Planning for your future :: Southern Health NHS Foundation Trust](#)

# Contact Details (for information)

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